Published in final edited form as:

Ageing Int. 2010 June 1; 35(2): 85–95. doi:10.1007/s12126-010-9061-4.

The Multiverse of Inquiry: Introduction to the Special Issue on “Dementia Care and Chinese Culture”

Hongtu Chen and

Department of Psychiatry, Harvard Medical School, Boston, MA, USA

Sue E. Levkoff

College of Social Work, University of South Carolina, Columbia, SC, USA

Hongtu Chen: hongtuchen@hotmail.com

We organized this special issue for several reasons. Among them are two alarming facts: China has the largest aging population in the world and providing care to its more than ten million elders suffering from Alzheimer’s disease is becoming a significant public health threat and challenge. But we also find “Dementia Care and Chinese Culture” an intriguing topic because it reinforces a common view that the Chinese case challenges what we believe we already know. Moreover, no doubt what we learn will soon change our current understanding.

We know for sure, based on research in the past 30 years, that dementia caregiving, regardless of geographical, educational, and socioeconomic differences, causes physical, emotional, and financial burdens to many caregiving families. What we do not know is how dementia care is and should be provided in a transitioning society. During this transition, traditional, family-based care for elders with chronic health problems and functional limitations is being tremendously challenged by a new, rapidly urbanizing and market-centered society; emerging institution-based care remains limited due to various financial, cultural, and social constraints. We also do not know how to connect what we have learned mainly from Western societies with Chinese culture. How do we blend dementia caregiver burdens, theories and measures of psychological distress, and intervention strategies and models with the emerging understanding of Chinese values, coping styles, and resources with which people influenced by Chinese cultures engage in dementia care tasks?

Perhaps, a simple way to enter a quest for the unknown is to sort through what we believe we already know.

Theoretical Models of Dementia Caregiver Burden

Our understanding of dementia care in general, especially the processes and mechanisms that lead to emotional distress of dementia caregivers, has improved tremendously in the past two to three decades. The theoretical framework that initially influenced our thinking on this topic originated from the **Cognitive Stress and Coping Model** proposed by Lazarus and Folkman (1984). From the perspective of this model, facing stressors or a stressful situation, an individual may experience stress, a psychological state of anxiety, if “the relationship between the person and the situation is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being.” Specifically, this model posits that it is the cognitive appraisal of the stressful situation that one is involved in

(primary appraisal) and the appraisal of one's coping capacity (secondary appraisal) that determine whether one will experience psychological stress. In other words, our perception and thoughts of what is at stake in a situation and what can be done about it determine our experience of psychological stress (Fig. 1).

Others soon applied the model to the studies of psychological distress of caregivers of patients with dementia (Haley et al. 1987), and it continued to influence empirical works on this topic thereafter (e.g., Gonzalez 1997; Beauchamp et al. 2005).

The key strength of the Stress and Coping model is its emphasis on the importance of cognitive appraisal in determining the emotional responses to a situation with perceived, imagined, or actual threat to one's well-being. By using cognitive processes that are heuristically meaningful and relevant to our experiences, the model provides a general framework for explaining individual differences in emotional experiences when they are faced with the same stressful situation.

While being applied to the complex situations of dementia caregiving, the basic principles of the Cognitive Stress and Coping model have remained the same, though some modifications or additions have been made, particularly concerning two aspects that seem crucial for understanding of the dementia caregiving processes. First, the stress and coping model does not acknowledge the unique interaction and changing relationship between the caregiver and the individual with dementia. Second, the model does not specify the role of social and cultural factors in the caregiving processes.

The most pronounced attempt to elucidate the interaction between caregiver and care receiver is the **Stress Process Model** proposed by Pearlin et al. (1990). The model was originally developed based on the stress of caring for a community-dwelling individual with Alzheimer's disease. It was later adapted to consider the stress of caring for older adults with other chronic diseases in long-term care (Pearlin et al. 1997; Turner et al. 1998). In addition to the primary stressors (e.g., stressors directly related to caregiving activities such as problem behavior of the patient and caregiver perception of overload), the Stress Process Model also includes a set of secondary stressors (e.g., strains due to conflict between caregiving responsibilities and non-caregiving roles such as managing family financial problems or because of the caregiver's self-concept and self-identity) as main determinants of caregiver health outcomes (Pearlin et al. 1990).

Compared with Lazarus and Folkman's Cognitive Stress and Coping Model, the key conceptual advance in Pearlin's framework is its inclusion of the caregiver role, its conflict with other roles that one normally needs to play as a family or social member, and its resulting challenge, at a more profound level, to one's self-concept and identity. The overall approach relies on cognitive processes to explain caregiver health outcomes and is consistent with that of Lazarus's cognitive mediation theory of psychological stress (from which the Cognitive Stress and Coping Model was derived). However, the specificity of how perceived conflicts between the caregiver role and other socially and culturally defined roles—rather than coping capability and resources—serve as a major source of one's psychological distress and associated mental and physical health problems is undoubtedly a conceptual progress.

This very notion of conflict between caregiving role/responsibility and non-caregiving roles is of critical importance for caregivers living in a family setting. Shyu and colleagues approached the issue with a focus on competing needs. They proposed the **Finding a Balance Point Model**, which highlighted the importance of recognizing competing needs, weighing and making judgments about them, and choosing and implementing balancing strategies (Shyu 2002; Shyu et al. 1998). They found in their Taiwanese samples of

dementia caregivers that those who balanced their competing needs would not only accurately predict the effects that caregiving had on them, but could also plan ahead and be flexible in using various coping strategies. By balancing their needs, these individuals managed to provide care without jeopardizing their emotional or physical health. This conceptual advance around the issues of psychological demands associated with caregiving tasks, needs, and role expectations and how they compete with resources necessary for handling other aspects of the caregiver's life has greatly enriched our understanding of the coping processes of a dementia caregiver.

Another major conceptual thrust, the **Sociocultural Stress and Coping Model** (Aranda and Knight 1997; Knight and Sayegh 2010), originates from the Cognitive Stress and Coping model but continues to enhance and expand it with increasing evidence from cross-cultural studies of dementia caregiving processes. Recognizing that culture or ethnicity is much more than a demographic or structural variable, a number of researchers interested in cross-cultural dementia caregiving have developed a nuanced socio-cultural model to specify the role of cultural factors in influencing stress and coping processes (Knight and Sayegh 2010; Aranda and Knight 1997; Knight et al. 2000; Montoro-Rodriguez and Gallagher-Thompson 2009).

Aranda and Knight (1997) first proposed a model of stress and coping in which cultural values operate through the caregiver's *cognitive appraisals* of the stressful caregiving situation in affecting the caregiver burden. In a recent revision of this earlier socio-cultural model of stress and coping, Knight and Sayegh (2010) suggest that cultural differences in the stress and coping model also result in differences in the *care resources* available to caregivers, including social support, coping styles, and perceived self-efficacy for caregiving. Research with ethnic Korean caregivers (Knight and Sayegh 2010) emphasized that cultural values (e.g., familism) directly influence coping style and social support behavior, but not appraisals of caregiving stress or burden. This updated socio-cultural model of stress and coping is consistent with other early qualitative research that suggested that cultural values about caregiving may be best regarded as "resources" that become salient for caregivers when a family member experiences dementia (Levkoff et al. 1999; Hinton et al. 1999).

Some Research Evidence Relevant to Chinese Culture

In addition to these general theoretical models that focus on explaining the dementia caregiver's experience of distress and burden based on cognitive processes, our thinking and understanding of the caregiving processes have also been expanded and deepened by evidence generated from several major research initiatives. In particular, studies focusing on the borderland of psychiatry, dementia caregiving, and Chinese culture have influenced investigators' work.

Since 1968 and throughout the two following decades, for instance, Kleinman conducted research in Chinese societies (both Taiwan and China) on various mental illnesses as defined in Western terms. One of his discoveries—now a classic case in medical anthropology textbooks—demonstrates that mental distress is much more likely to be expressed by Chinese patients in somatic forms, such as bodily ailments, than as psychological distress, such as sad feelings or loss of interest, as commonly presented in the West (Kleinman 1988). Despite the finding, first published at least three decades ago (Kleinman et al. 1978), we still do not know to what extent the Chinese dementia caregivers tend to experience or express their psychological distress in somatic forms, as opposed to emotional or interpersonal symptoms.

A separate line of research, which started in the late 1990s, first addressed a general question: Do dementia caregivers with Chinese cultural background experience more or less burden and distress than their Western counterparts? Several researchers first speculated that Chinese caregivers would experience less burden and distress, because they would be more likely to accept the caregiver role because of a number of culturally relevant reasons. These reasons include (a) Chinese families traditionally place more emphasis on harmony and interdependence among family members than Westerners; (b) Chinese children expect to care for their frail elders out of filial piety; and (c) Chinese tend to view memory and behavioral problems of dementia as part of normal aging (e.g., Nilchaikovit et al. 1993). Lee and Sung (1998) did observe lower levels of distress among Korean caregivers whose cultural background presumably overlapped with the Chinese Confucian values. Ikels (1998), based on her qualitative research, also reported that dementia caregiving in China did not seem to evoke the kind of dread that is common among Americans. However, further cross-cultural comparative studies that included larger Chinese samples revealed no significant differences in overall burden in Chinese caregivers compared with the American counterpart (Patterson et al. 1998).

Despite the methodological issues in the studies (e.g., inconsistent use of measures and non-probability samples) that raised concerns (Janevic and Connell 2001; Dilworth-Anderson et al. 2002), recent multinational reviews and meta-analyses of dementia caregiver burdens lean toward a general conclusion that Asian (e.g., Chinese and Korean) dementia caregivers experience a similar or even higher level of depression and burden compared to those in Western societies. Asian female caregivers bear a particularly heavy burden that is often heightened by certain non-cognitive, behavioral disturbances of patients with dementia (Torti et al. 2004; Pinquart and Sörensen 2005; Pang et al. 2002).

The Current Approach and Its Challenges

The major efforts of scientific inquiries over the past two to three decades about dementia caregivers' experiences can be illustratively summarized in the following meta-model (see Fig. 2). On the one hand, researchers strive to understand the psychological processes and mechanisms through which the individual caregiver's health outcomes can be determined and explained. Much of the theoretical contributions in this aspect have focused on elaboration of cognitive processes through which the caregiver makes sense of the stressful demands of caregiving situations and the coping resources available for managing the situation. Derived from these understandings, researchers developed various kinds of interventions aimed at reducing the caregivers' burden by changing the actual as well as their view of the caregiving situation. The interventions include providing educational information and improving the caregiver's sense of coping resources, whether through skill training for solving problems or by obtaining social support or increasing a sense of self-efficacy (e.g., Steffen et al. 2002). On the other hand, the cultural variability as revealed at various levels of observations provides a fascinating challenge. It provides opportunities for expanding and deepening our understanding of not only particular ethnic groups of caregivers but also the overall conceptual framework that will help formulate our research questions as well as the operationalization of our measurements.

In hindsight, this overall approach to the investigation of the nature and determinants of the dementia caregiver's burden and suffering is somewhat limited. Much of the research centers on caregiver experiences. As a result, we know disproportionally much more about the *quality of life* of a caregiver than the *quality of caregiving* delivered by the caregiver. We have learned so much about the primary caregiver's experience while knowing so little about the main caregiver's relationships to other members of the caregiving family or the hosting institution. Our measures of individual coping strategies become increasingly

sophisticated, while we know very little about how to measure different patterns of family-based or community-based collective coping that seem to play a crucial role in many ethnic cultural groups. We have developed numerous studies to test various interventions for helping individual caregivers (Selwood et al. 2007; Kennet et al. 2000; Schulz 2000; Bourgeois et al. 1996), but we have done much less to help develop a coordinated, community-based care system in which the caregiving family is only an organic part of the whole that provides a social and cultural safety net for the dementia-affected individuals and families.

Related to this caregiver-centeredness, this current approach, as summarized in Fig. 2, also is challenged by several methodological issues.

Methodological Challenges

First, over-reliance on subjective measures may fundamentally limit our research capability in verifying or falsifying the cognitive stress and coping model. Although appraisal theorists such as Richard Lazarus agree that part of the appraisal processes are beyond consciousness (e.g., Scherer et al. 2001), the popular use of subjective measures such as self-report in favor of appraisal theories has introduced an intrinsic limit in accessing the appraisal processes beyond the reporter's awareness (McNally 2001). For instance, by relying on self-report data, it would be a methodological challenge to determine if an under-reporting of emotional distress by an Asian female caregiver is an indication of her true experience of the situation. Rather, it may only reflect the tip of the iceberg that is culturally, morally, and emotionally appropriate—and therefore allowed to be experienced by her.

Recent efforts to use objective measures such as stress biomarkers to evaluate caregiver distress (e.g., Goldman et al. 2005; Kim and Knight 2008) are hopeful attempts to move beyond the limit of the subjective measures. These efforts, however, also pose a theoretical challenge in developing coherent explanatory models that can encompass speculated pathways based on different levels of data sources. Similarly, the attempt to differentiate perceived social support and received (actual) social support is another example of trying to incorporate objective measures, even though it may introduce new theoretical challenges (Tang 2008).

Second, in almost all of the theoretical models concerning dementia caregiver distress, the relationships among the precursor, outcome, mediating, and moderating variables included in these models are essentially causal and often bi-directionally causal, no matter whether the model refers to an intra-psychic or an inter-personal relationship. However, much of the published research only uses the models as a general conceptual framework, rather than striving to test the causal relations in the model. Any sustaining progress in testing and challenging a theoretical model that describes the causal pathways will have to be based on rigorous experimental designs such as randomized, controlled intervention trials. Even then, we are typically unable to examine bi-directionality of any causal relationship that we often include in our preferred theoretical models.

Third, the overall emphasis on caregivers and the intention to reduce caregiver burden through better management of the stress and coping processes is essentially a reactive approach to the problem of dementia. While we continue to identify interventions that may achieve visible effect sizes, the dementia caregiving community may benefit more if we also explore more proactive research strategies. Such strategies might include ways of preventing dementia or certain symptoms of dementia from occurring, delaying its onset, or at least reducing its magnitude or severity. Recent research into prevention of Alzheimer's disease, based centrally on promising evidence of promoting brain health (Hendrie et al. 2006), also

fundamentally challenges the existing models that essentially are based on cognitive processes.

Fourth, another methodological challenge occurs when these models guide research in a population of a cultural background known to be different from the culture or subculture that originally formed the basis for developing the measures of the variables included in the theoretical model. For instance, measures of coping-related variables, such as emotional coping or self-efficacy, are often culturally situated and may not reflect or represent the experience that is meant to be measured in the specific sociocultural context. Furthermore, the measures employed by investigators may fail to capture the culture-specific factors (e.g., cultural values) that are of importance to the caregivers, but which the researchers, who operate within a particular theoretical framework, may have not included in the measurement design. Standard quantitative strategies—such as examining content and concurrent validity of a translated instrument in a sample representing a new cultural group or testing cross-cultural validation of measurements by identifying common construct across cultures (e.g., Beckstead et al. 2008)—have made laudable contributions. However, our knowledge of the cultural relevance of these instruments will be tremendously improved if these research efforts for psychometric validation are complemented by other qualitative research strategies, such as cognitive interviews for pretesting instruments. Such efforts support researchers' ability to verify cultural relevance of existing instruments and identify items beyond the existing pool of knowledge.

Fifth, while the general approach based on the cognitive stress and coping model has helped develop various intervention programs to reduce caregiver burdens (e.g., Beauchamp), we are confronted with a new challenge when we stand on the borderland of two cultures. That is, how do we address the gap between the large body of evidence-based knowledge about interventions for dementia caregivers accumulated in the past three decades in the Western sphere and the local needs for having cost-effective and, most importantly, culturally appropriate intervention programs to help people in a different region, such as China? The current model cannot provide specific guidance for a culturally competent translation or adaptation of an intervention based on robust evidence, even when collected from different cultural settings.

While pointing out the limitations of the current research approach to the study of caregiver burden as illustrated in Fig. 2, we should acknowledge both the value and function of the current model. With regard to the function of the model, we are reminded of the insightful words written by Pearlin and colleagues about 20 years ago. They stated that a scientific model “should be regarded as a heuristic device rather than as a literal reflection of realities,” and “as something to be built upon rather than something to be followed or perpetuated” (Pearlin et al. 1990, p. 591).

The Future as a Multiverse

It is more likely that the foreseeable future will be a multiverse, rather than a coherent, well-integrated universe. A little over 100 years ago, William James, who initially coined the word *multiverse*, wrote, “The value of a multiverse, as compared with a universe, lies in this, that where there are cross-currents and warring forces our own strength and will may count and help decide the issue; it is a world where nothing is irrevocably settled, and all action matters.”

Using the metaphor of multiverse, as suggested by James, our inquiry of dementia caregiving may soon enter a world where multilayered modeling and analyses at biological, psychological, sociological, and anthropological levels will co-exist. These analyses, as performed at different levels, will inevitably cross their disciplinary borders to vigorously

seek connections with each other, rather than existing side by side in separate parallel tracks. Ultimately, any progress toward conceptual advances in our understanding of this complex subject depends on thoughtful and active research initiatives that aim to construct and deconstruct the theoretical coherence recognized in the course of the inquiry.

It is in this context we welcome this special issue. It includes a set of articles contributed by some of the most active investigators and thinkers of dementia care and Chinese culture. Arthur Kleinman, after briefly examining the situation of caregiving in China for dementia and other severe illnesses, concludes that “caregiving is at best inadequately taught and supported among students and physicians, and at worst is a hollow skill that has been emptied of content, commitment and competence.” He puts dementia caregiving in the larger context of our time, where discrepancies are common between mainstream moral claims and local, individual moral conditions; between progress made in medical care for mainstream groups and neglect in medical research and services for rural and migrating groups; and where heroism-based moral thinking and drug-based treatment have considerably removed the meaning and value of suffering from our culture. He is calling for a true reform of medical practice and education in both China and the U.S., where we will rediscover the ethical roots and common moral ground on which we may expect to see biomedicine remarry with caregiving. The significance and meaning of this thought-provoking article is definitely beyond the scope of this special issue.

Jason M. Holland and colleagues, including Dolores Thompson-Gallagher—some of the most creative and productive researchers in the field of dementia care—have presented an exemplary analysis of both self-report and biomarker data collected from Chinese women caring for older relatives with dementia in the San Francisco Bay Area. They demonstrate a profile of “resilience” among Chinese-American caregivers, who show significant levels of emotional distress, but also quite high levels of self-efficacy, positive caregiving experiences, and problem-solving coping style. Their data further show that Chinese culture seems to contribute to this psychological resilience, as those having stronger beliefs in Asian values tend to have more normal salivary cortisol patterns (i.e., a biomarker for chronic stress), less depressive symptoms, and greater self-efficacy. The analysis, using both subjective and objective data, is a perfect example of using cross-sectional analysis to explore possible mediating and moderating processes, as well as roles of culture, in contributing to caregiver distress.

The other three articles provide analysis and perspective on how dementia care systems have been and should be organized for people of Chinese cultural backgrounds in both China and the US. Bei Wu and colleagues provide a qualitative review of development of dementia caregiving models for Chinese Americans in the U.S. Based on some existing programs and interventions for Chinese dementia caregivers provided by service organizations and academic institutions, they point out that only limited intervention programs and services are currently available for Chinese Americans. They further offer a set of recommendations for developing dementia care models to fit in the cultural and social situation of the Chinese-American community.

Dan Cui and colleagues examine the situation of dementia care in China and provide their perspectives on how it should develop based on the special cultural and social resources available in the local setting of China. They contend that China remains in the exploratory phase in forming a long-term care model based on its own culture and argue that China should build an indigenous “family-based, community-oriented, and social worker-supported” (three-pronged) dementia care model.

Huali Wang and colleagues examine the actual hours and associated costs needed for providing care to people with dementia in China. Using cross-sectional analysis of a group of community-dwelling dementia caregivers in Beijing, they found that as the severity of the cognitive impairment increases with time, the family caregivers spend increasing amounts of time providing both direct care to address patient personal issues (e.g., toileting, eating, dressing, grooming, walking, and bathing) and supervision to other helpers. Using average salary levels to convert the caregiving time to costs, the estimated annual cost for home care ranges from 5,916 USD for mild cases to 20,076 USD for severe cases, which is quite substantial for families in China.

We believe that the articles in this special issue will open up a wide range of discussion on topics related to dementia care for people with Chinese cultural backgrounds. We hope they stimulate further work to support the ultimate goal of better understanding and support for Chinese dementia caregivers living all over the world.

References

- Aranda MP, Knight BG. The influences of ethnicity and culture on the caregiver stress and coping process: a sociocultural review and analysis. *The Gerontologist*. 1997; 37:342–354. [PubMed: 9203758]
- Beauchamp N, Irvine AB, Seeley J, Johnson B. Worksite-based internet multimedia program for family caregivers of persons with dementia. *The Gerontologist*. 2005; 45(6):793–801. [PubMed: 16326661]
- Beckstead JW, Yang CY, Lengacher CA. Assessing cross-cultural validity of scales: a methodological review and illustrative example. *International Journal of Nursing Studies*. 2008; 45(1):110–119. [PubMed: 17081547]
- Bourgeois MS, Schulz R, Burzio L. Interventions for caregivers of patients with Alzheimer's disease: a review and analysis of content, process, and outcomes. *Journal of Aging and Human Development*. 1996; 43(1):35–92.
- Dilworth-Anderson P, Williams IC, Gibson BE. Issues of race, ethnicity, and culture in caregiving research: a 20-year review (1980–2000). *The Gerontologist*. 2002; 42(2):237–272. [PubMed: 11914467]
- Goldman N, Gleit DA, Seplaki C, Liu I-W, Weinstein M. Perceived stress and physiological dysregulation in older adults. *Stress*. 2005; 8(2):95–105. [PubMed: 16019601]
- Gonzalez EW. Resourcefulness, appraisals, and coping efforts of family caregivers. *Issues in Mental Health*. 1997; 18(3):209–227.
- Haley WE, Levine EG, Brown SL, Bartolucci AA. Stress, appraisal, coping, and social support as predictors of adaptational outcome among dementia caregivers. *Psychology and Aging*. 1987; 2:323–330. [PubMed: 3268224]
- Hendrie HC, Albert MS, Butters MA, et al. The NIH cognitive and emotional health project: report of the critical evaluation study committee. *Alzheimer's & Dementia: The Journal of the Alzheimer's Association*. 2006; 2(1):12–32.
- Hinton WL, Fox K, Levkoff S. Introduction: exploring the relationships among aging, ethnicity, and family dementia caregiving. *Culture, Medicine and Psychiatry*. 1999; 23(4):403–413.
- Ikels C. The experience of dementia in China. *Culture, Medicine and Psychiatry*. 1998; 22(4):257–283.
- Janevic MR, Connell CM. Racial, ethnic, and cultural differences in the dementia caregiving experience: recent findings. *The Gerontologist*. 2001; 41:334–347. [PubMed: 11405431]
- Kennet, J.; Burzio, L.; Schulz, R. Interventions for in-home caregivers: A review of research 1990 to present. In: Schulz, R., editor. *Handbook of dementia caregiving*. New York: Springer; 2000. p. 61–125.
- Kim J, Knight BG. Effects of caregiver status, coping styles, and social support on the physical health of Korean American caregivers. *The Gerontologist*. 2008; 48:287–299. [PubMed: 18591354]
- Kleinman, A. *Social origins of distress and disease: Depression, neurasthenia, and pain in modern China*. Yale University Press; 1988.

- Kleinman A, Kunstadler P, Alexander ER. Culture and healing in Asian societies: Anthropological psychiatric and public health studies. Transaction. 1978
- Knight BG, Sayegh P. Cultural values and caregiving: the updated sociocultural stress and coping model. *Journal of Gerontology: Psychological Sciences*. 2010; 65B(1):5–13.
- Knight BG, Silverstein M, McCallum TJ, Fox LS. A sociocultural stress and coping model for mental health outcomes among African American caregivers in South California. *The Journals of Gerontology. Series B: Psychological Sciences and Social Sciences*. 2000; 55(3):142–150.
- Lazarus, RS.; Folkman, S. Stress, appraisal, and coping. New York: Springer; 1984.
- Lee YR, Sung KT. Cultural differences on caregiving burden: cases of Korean and Americans. *International J. Aging and Human Development*. 1998; 46(2):125–141.
- Levkoff S, Levy B, Weitzman PF. The role of ethnicity and religion in the help seeking of family caregivers to dementia-affected elders. *Journal of Cross-Cultural Gerontology*. 1999; 14:335–356. [PubMed: 14618013]
- McNally RJ. On the scientific status of cognitive appraisal models of anxiety disorder. *Behaviour Research and Therapy*. 2001; 39(5):513–521. [PubMed: 11341248]
- Montoro-Rodriguez J, Gallagher-Thompson D. The role of resources and appraisals in predicting burden among Latina and non-Hispanic white female caregivers: a test of an expanded socio-cultural model of stress and coping. *Aging & Mental Health*. 2009; 13(5):648–658. [PubMed: 19882403]
- Nilchaikovit T, Hill JM, Halland JC. The effects of culture on illness behavior and medical care: Asian and American differences. *General Hospital Psychiatry*. 1993; 15(1):41–50. [PubMed: 8436284]
- Pang FC, Chow TW, Cummings JL, Leung VP, Chiu HF, Lam LC, et al. Effect of neuropsychiatric symptoms of Alzheimer's disease on Chinese and American caregivers. *International Journal of Geriatric Psychiatry*. 2002; 17(1):29–34. [PubMed: 11802227]
- Patterson TL, Semple SJ, Shaw WS, Yu E, He Y, Zhang MY, et al. The cultural context of caregiving: a comparison of Alzheimer's caregivers in Shanghai, China and San Diego, California. *Psychological Medicine*. 1998; 28(5):1071–1084. [PubMed: 9794014]
- Pearlin LJ, Mullan JT, Semple SJ, Skaff MM. Caregiving and the stress process: an overview of concepts and their measures. *The Gerontologist*. 1990; 30:583–591. [PubMed: 2276631]
- Pearlin, LI.; Aneshensel, CS.; Mullan, JT.; Whitlach, CJ. Caregiving and its social support. In: Binstock, RH.; George, LK., editors. *Handbook of aging and the social sciences*. 4th ed.. San Diego: Academic; 1997. p. 283-302.
- Pinquart M, Sörensen S. Ethnic differences in stressors, resources, and psychological outcomes of family caregiving: a meta-analysis. *The Gerontologist*. 2005; 45:90–106. [PubMed: 15695420]
- Scherer, KR.; Schorr, A.; Johnstone, T. Appraisal processes in emotion: Theory, methods, research. New York: Oxford University Press; 2001.
- Schulz, R. *Handbook on dementia caregiving: Evidence-based interventions for family caregivers*. Springer; 2000.
- Selwood A, Johnston K, Katona C, Lyketsos C, Livingston G. Systematic review of the effect of psychological interventions on family caregivers of people with dementia. *Journal of Affective Disorders*. 2007; 101(1–3):75–89. [PubMed: 17173977]
- Shyu YI. A conceptual framework for understanding family caregiving process to frail elders in Taiwan. *Research in Nursing & Health*. 2002; 25(2):111–121. [PubMed: 11933005]
- Shyu YI, Archbold P, Imle M. Finding a balance point: a process central to understanding family caregiving in Taiwanese Families. *Research in Nursing & Health*. 1998; 21(3):261–270. [PubMed: 9609511]
- Steffen AM, McKibbin C, Zeiss AM, Gallagher-Thompson D. *The Journals of Gerontology*; Jan 2002; 57B, 1; The revised scale for caregiving self-efficacy: Reliability and validity studies. *Research Library*. 2002:74–86.
- Tang Y. Social support of elderly caregivers. *International Journal of Business and Management*. 2008; 3(8):81–84.
- Torti FM Jr, Gwyther LP, Reed SD, Friedman JY, Schulman KA. A multinational review of recent trends and reports in dementia caregiver burden. *Alzheimer Disease and Associated Disorders*. 2004; 18(2):99–109. [PubMed: 15249854]

Turner H, Pearlin LI, Mullan JT. Sources and determinants of social support. *The Journal of Health and Social Behavior*. 1998; 39:137–151.

Biographies

Hongtu Chen, Ph.D. is an assistant professor in the Department of Psychiatry, Harvard Medical School, and a senior research scientist at Brigham and Women's Hospital. His research has focused on mental health care for elders from diverse cultural backgrounds. He served as project director, principal investigator, and consultant on numerous research projects aiming to improve care for elderly persons with mental disorders and neurodegenerative diseases.

Sue E. Levkoff, ScD, SM, MSW, is Professor in the College of Social Work, and the Endowed Chair in Community and Social Support at the SmartHome and SeniorSmart Center of Economic Excellence at the University of South Carolina (USC). Over the past 15 years, her research has focused on examining the impact on culture on dementia caregiving, the development of internet-based, online communities for dementia caregivers, and the integration of behavioral health services into primary care. She also remains Senior Lecturer in the Department of Global Health and Social Medicine at Harvard Medical School, as well as Adjunct Professor at St. Thomas University and the University of New Brunswick, both in Fredericton, New Brunswick, Canada, where she is consulting on the development of the Atlantic Institute on Aging Care. Her current research focuses on the development of new technologies that will enable older adults to live independent, safe, and fulfilling lives in their homes and communities.

Fig. 1.
The cognitive stress and coping model

Fig. 2.
The meta-model of dementia caregiver burden