

## Patient Suffering and Caregiver Compassion: New Opportunities for Research, Practice, and Policy

Richard Schulz, PhD,<sup>1</sup> Randy S. Hebert, MD,<sup>2</sup> Mary Amanda Dew, PhD,<sup>3</sup>  
Stephanie L. Brown, PhD,<sup>4</sup> Michael F. Scheier, PhD,<sup>5</sup> Scott R. Beach, PhD,<sup>1</sup>  
Sara J. Czaja, PhD,<sup>6</sup> Lynn M. Martire, PhD,<sup>1</sup> David Coon, PhD,<sup>7</sup>  
Kenneth M. Langa, MD, PhD,<sup>8</sup> Laura N. Gitlin, PhD,<sup>9</sup>  
Alan B. Stevens, PhD,<sup>10</sup> and Linda Nichols, PhD<sup>11</sup>

The purpose of this article is to stimulate discussion and research about patient suffering and caregiver compassion. It is our view that these constructs are central to understanding phenomena such as family caregiving, and that recognizing their unique role in the caregiving experience provides new directions for intervention research, clinical practices, and social policy. We first define and characterize these

constructs, review empirical evidence supporting the distinct role of suffering and compassion in the context of caregiving, and then present a conceptual model linking patient suffering with caregiver compassion. We conclude with a discussion of implications and future directions for clinical intervention, research, and policy.

*Key Words: Caregiving, Suffering, Compassion, Health, Well-being*

---

Preparation of this article was supported in part by grants from the National Institute on Aging (AG024827, AG13305, AG015321, AG20677, AG19180), the National Institute on Nursing Research (NR08272), the National Institute on Mental Health (MH071944), the National Center on Minority Health and Health Disparities (MD000207), and the National Heart, Lung, and Blood Institute (HL076852, HL076858).

Address correspondence to Richard Schulz, University Center for Social and Urban Research, 121 University Place, Pittsburgh, PA 15260. E-mail: schulz@pitt.edu

<sup>1</sup>University Center for Social and Urban Research, University of Pittsburgh, PA.

<sup>2</sup>Division of General Internal Medicine, University of Pittsburgh, PA.

<sup>3</sup>Department of Psychiatry, University of Pittsburgh, PA.

<sup>4</sup>Institute for Social Research, University of Michigan, Ann Arbor.

<sup>5</sup>Department of Psychology, Carnegie Mellon University, Pittsburgh, PA.

<sup>6</sup>Center on Adult Development and Aging, University of Miami, FL.

<sup>7</sup>Arizona State University, Department of Social and Behavioral Sciences, West Campus, Glendale.

<sup>8</sup>Health Services Research and Development Center of Excellence, Veterans Affairs Ann Arbor Healthcare System, and Division of General Medicine, University of Michigan, Ann Arbor.

<sup>9</sup>Center for Applied Research on Aging and Health, Thomas Jefferson University, Philadelphia, PA.

<sup>10</sup>Scott & White Memorial Hospital, Temple, TX.

<sup>11</sup>VA Medical Center (11H), University of Tennessee at Memphis.

For several decades, researchers have documented the nature of patient illness and disability and their impact on the health and well-being of patients and their families. Experts have compiled a vast array of evidence showing how the illness or disability of a close relative causes distress in family members and compromises caregiver health and survival. Whether it is a parent caring for a sick child, a child caring for an elderly parent, or a wife or husband caring for a spouse, emotional distress, burden, impaired self-care, and increased biological vulnerabilities are commonplace among caregivers. Although there is considerable individual variability in response to these illness-related challenges, researchers have consistently linked the generally negative consequences of caregiving to a variety of factors including

patient physical disability, cognitive impairment and confusion, disruptive behaviors, and the caregiving demands engendered by these disabilities.

Researchers and clinicians would readily acknowledge that patient suffering and caregiver compassion play a role in this process as well, but authors have paid relatively little attention to these constructs in the empirical or clinical literature on family caregiving. Scores of published studies support the general conclusion that illness and disability have negative effects on the emotional and physical well-being of family caregivers, and although the notion of suffering may be implicit in existing conceptualizations of illness and disability, the empirical research has not focused on patient suffering as a unique and independent contributor to caregiver outcomes. This article is motivated in part by our view that caregiving research to date has ignored some key components of the caregiving experience, perhaps in part because these components are not well described or understood. The purpose of this article is to show that focusing on the concepts of suffering and compassion enriches researchers' views of caregiving and, more broadly, the effects of illness and disability in a familial context. We hope to stimulate discussion and research about patient suffering and caregiver compassion as two distinct concepts that pervade everyday life. It is our view that these constructs are central to understanding phenomena such as family caregiving, and that they explain findings that are difficult to explain using existing caregiving perspectives. For example, current caregiving perspectives do not easily explain why family members not involved in care provision experience similar levels of distress or why helping others can improve health and well-being as well as diminish it (Amirkhanyan & Wolf, 2003; Post, 2005).

This article is organized into four sections. We first define and characterize suffering and compassion and present examples of measurement strategies for operationalizing these constructs. Next, we review empirical evidence that supports the distinct role of suffering and compassion in the context of caregiving. We follow this with a preliminary conceptual model that links patient suffering with caregiver compassion and health. We conclude with suggestions for future directions for research, clinical intervention, and social policy.

## Suffering

The nature of and reasons for human suffering have been the subject of scholarly writings for millennia. Suffering is a focal point for many of the religions of the world. For our purposes, however, we limit our discussion to suffering as it is commonly viewed in the context of illness and disability. Indeed, the origin of the word *patient* means *sufferer* (Byock, 1996). Thus, *suffering* is defined as the bearing or undergoing of pain or distress, or tribula-

tion (Oxford English Dictionary, 1989); at extreme levels, suffering can threaten the intactness of the person as a complex social and psychological entity (Cassell, 1982, 1999, 2004). To further limit the scope of this discussion, our primary interest is on manifestation of suffering in others and ways it impacts on the perceiver. Equally important, but not discussed in this article, are the specific ways in which illness experiences lead to the experience of suffering.

One can generally view suffering as having three components—physical, emotional, and existential or spiritual—and as being distinct from illness and disability in that (a) not all illnesses necessarily entail suffering, and (b) there is considerable individual variability in how persons respond to illnesses and disabilities (Cassell, 1999, 2004; Chimich & Neko-laichuk, 2004; Gallagher, Wagenfeld, Baro, & Haepers, 1994; Ganzini, Johnston, & Hoffman, 1999; Kleinman, Eisenberg, & Good, 1978; Pelletier, Verhoef, Khatri, & Hagen, 2002; Strang, 1998). Even if two patients have identical symptoms, their suffering is likely to be different; what causes suffering in one person may not do so in another (Cassell, 1999, 2004). Because individual tolerance for pain, discomfort, and disability varies widely, and because the expression and perception of disease-related symptomatology is shaped by factors such as culture and religion (Morris, 1998), the extent to which someone is perceived to be suffering will vary widely as well. We conclude from this that it should be possible to assess the effects of perceived patient suffering on involved family members independent of the effects of illness and disability.

Researchers interested in end-of-life care have been at the forefront in developing measures to assess various components of suffering. Notable examples include the work of Cassell (1999), who advocated asking simple, direct questions such as “Are you suffering?”; and Bruera, Kuehn, Miller, Selmser, and Macmillan (1991), who developed the Edmonton Symptom Assessment system, a simple rating scale used to assess symptoms of pain, fatigue, nausea, depression, anxiety, drowsiness, appetite, feelings of well-being, and shortness of breath. Experts have further elaborated measures of pain to include pain behavior checklists that include non-verbal (e.g., grimacing, limping) and audible (e.g., grunting, groaning) expressions of distress (Keefe et al., 2003; Wilson et al., 2004). Researchers also have developed measures of spiritual well-being and despair (e.g., Idler et al., 2003; McClain, Rosenfeld, & Breitbart, 2003). For example, McClain and colleagues assessed spiritual well-being with two subscales: the meaning subscale measures the extent to which individuals feel inner harmony and are at peace with themselves, whereas the faith subscale measures the extent to which individuals find comfort and strength in their religious beliefs. Despair, on the other hand, is thought of as a triad consisting

of pessimism and hopelessness, desire for a hastened death, and suicidal ideation (McClain-Jacobson et al., 2004). Researchers interested in characterizing the quality of life of dementia patients have identified several additional affective dimensions such as fear, loneliness, frustration, and embarrassment, as well as feelings of usefulness (Brod, Stewart, Sands, & Walton, 1999; Logsdon, Gibbons, McCurry, & Teri, 2002). Finally, we add to this list measures of depression and anxiety or fear to the extent that they reflect patient distress about one's condition.

We propose that these existing measures serve as a starting point for the assessment of suffering. These measures have three things in common: (a) They can be administered either as patient self-report or caregiver rating measures, (b) they can be reliably completed by patients with mild to moderate cognitive impairment, and (c) they are rarely administered in caregiving studies. We do not advocate substituting these measures for existing approaches to assess patient status in areas such as physical functioning or cognitive status, but we think it is important to supplement functional status measures with more direct indicators of suffering. We also argue, however, that none of these measures fully assesses the construct of suffering as we have defined it and that there is a need for further refinement of measures to assess patient suffering along with parallel measures of caregiver perception of such suffering within the caregiving context.

Having good measures of suffering is a critical first step toward addressing important questions about the experience, expression, and perception of suffering. For example, under what circumstances do individuals inhibit or exaggerate overt signs of suffering, and under what circumstances do perceivers over- or underestimate the level of suffering in others? One can imagine situations in which individuals are perceived to be suffering in silence because they show few overt signs of distress under circumstances in which high distress levels might be expected and because the sufferer is viewed as someone who inhibits or suppresses outward expression of discomfort and emotions.

Ultimately, measures of the suffering construct should focus on (a) patient experience (degree and type) of suffering, typically based on patient self-report; (b) patient direct (verbal) and indirect (nonverbal) expressions of suffering, based on observed patient behavior and/or patient self-report; (c) caregiver perceptions of the patient's degree of suffering (i.e., how much and on which dimensions he or she is suffering); and (d) caregiver perceptions of whether the patient's expression of suffering is an accurate reflection of his or her actual degree of suffering (i.e., is he or she suffering in silence or overdramatizing?). Ideally, researchers would collect data from both patient and caregiver, which would not only allow them to explore issues of concordance, but also enable an examination of which aspects of

suffering are most strongly related to caregiver outcomes. Of course, some patient populations, such as individuals with advanced Alzheimer's disease or other dementias, may not be able to provide such reports, in which case only caregiver perceptions or nonverbal assessments of suffering would be available.

## Compassion

*Compassion* is defined as a sense of shared suffering, combined with a desire to alleviate or reduce such suffering (American Heritage Dictionary, 2000), or the sympathetic consciousness of others' distress along with a desire to alleviate it, or the feeling or emotion when a person is moved by the suffering or distress of another (Oxford English Dictionary, 1989). One generally considers a person to be compassionate if he takes into account the suffering of others and attempts to alleviate that suffering as if it were his own. Thus, compassion has cognitive, emotional, and motivational components: The compassionate individual must be able to recognize and empathize with the person in distress, feel some connection toward the sufferer, experience both positive (e.g., love, concern) and negative (e.g., upset, distress about the suffering of another) affect, and be motivated to reduce or diminish that suffering. This definition of compassion is very similar to the construct of empathic concern, which is defined as a feeling of sympathy and concern for the sufferings of another coupled with the desire to relieve this suffering (Gleitman, Fridlund, & Reisberg, 2000).

Although compassion has been the province of philosophical and religious scholars for centuries, it also has a basis in the empirical literature. For example, researchers use the term *compassion fatigue* to refer to the stress, strain, and weariness of caring for others who are suffering from a medical illness or a psychological problem (Thomas & Wilson, 2004). Clinicians also have coined the phrase *vicarious traumatization* or *secondary traumatization* to characterize the distress and inner transformation experienced by health professionals resulting from empathic engagement with a client's trauma experience (Sabin-Farrell & Turpin, 2003). Other related constructs include emotional or affective contagion, a phenomenon in which an individual's mood seems to spread to those in close proximity (Bookwala & Schulz, 1996; Joiner & Katz, 1999), and reciprocal suffering (Sherman, 1998). In general, people in close relationships are especially susceptible to experiencing their partner's emotions, because they are likely to be highly invested in each other's physical and emotional welfare and are likely to be closely attuned to their partners' moods and symptoms (Brown & Brown, 2006; Hatfield, Cacioppo, & Rapson, 1994).

Some of the examples provided here suggest that compassion involves the experience of identical or similar emotions to those of the person who is suffering, but this need not always be the case. For example, an individual might respond emotionally one way (e.g., anxiety, fear, sadness) to physical signs of suffering (such as pain in a loved one who has sustained an injury) even though that individual expresses very different emotions (e.g., anger) in response to the pain.

In sum, the experience of compassion occurs when (a) there are affectional ties between two individuals, (b) there is an awareness of suffering, (c) this awareness generates distress and negative affect in the observer, and (d) the observer is motivated to reduce or eliminate the observed suffering. The strong emphasis on motivation to reduce suffering is a key element of compassion and distinguishes this construct from related concepts such as emotional contagion or vicarious distress, which do not necessarily include motivational components.

Why individuals engage in behavior to reduce suffering or help another, often with limited or no benefit to themselves, has been the subject of study and debate in the fields of social and developmental psychology, evolutionary neurobiology, economics, and sociology for several decades (Batson, 1998; Cialdini et al., 1987; Clark, 2000; Fehr & Rockenbach, 2004; Penner, Dovidio, Piliavin, & Schroeder, 2005; Schroeder, Dovidio, Penner, & Piliavin, 1994; Simmons, 1991; Stevens & Hauser, 2004). People may help others in order to alleviate their own distress, feel good about themselves, or look good to others. They may also be motivated to help because of reciprocity norms, and they may be motivated to preferentially help relatives so that genes held in common will survive. In addition, Batson has been a strong proponent of the idea that people's motives are sometimes purely altruistic in that their only goal is to help the other person, even if doing so involves some cost to themselves, and that altruism is likely to come into play when one person feels empathy and compassion for another person in distress. Although researchers still debate the existence of pure altruistic helping (Batson, 1998; Cialdini et al., 1987; Maner et al., 2002), they generally agree that helping can be simultaneously egoistically and altruistically based. Thus, caregivers who are altruistically motivated help because they feel love, concern, and responsibility for their relative and wish to reduce their suffering. Caregivers who are egoistically motivated provide care to obtain rewards such as praise and respect from others, avoid censure from others or feelings of guilt, or reduce their own distress. To varying degrees, one would expect both of these motives to operate in a caregiving context, with high levels of compassion being associated with stronger altruistic motives and low levels of compassion with stronger egoistic motives.

Family caregiving is characterized by multiple factors that converge to create strong motives for helping and, we argue, high levels of altruistic helping and compassion. These factors include kinship relations, affectional ties between caregiver and recipient, and the fact that caregivers typically do not perceive patients to be responsible for their suffering. In general, one would predict that the greater the suffering, the greater the compassion. Furthermore, one would expect factors such as the empathy of the observer; the amount of contact between patient and family member; the level of closeness, intimacy, and attachment between family member and patient (Lee, Brennan, & Daly, 2001); and the perceived responsibility for the occurrence of suffering to moderate the level of compassion. In contrast, one would expect little or no compassion for a stranger whose suffering is the result of voluntary action with foreseeable consequences. One would further expect that the level of compassion would affect the quality and intensity of care provided. In social psychological studies of young adults, caregivers motivated by love and concern for their partners are more responsive and less controlling in the help they provide when compared to individuals who are motivated primarily by self-benefit and obligation (Feeney & Collins, 2003). Finally, one would predict that the frequently reported negative health effects of caregiving are partially mediated through compassion, such that higher levels of compassion lead to greater negative health effects under circumstances in which the caregiver is unable to diminish the suffering of the patient. Conversely, successful helping should be uplifting to the caregiver and should increase his or her well-being.

Assessing compassion requires a focus on three interrelated components: (a) feelings of love, concern, and interdependence; (b) feelings of negative affect and distress; and (c) motivation to help. As suggested by Feeney and Collins (2003, pp. 956–957), items for assessing feelings of love and concern might include “I want my partner/relative to be happy; I can't stand to see him/her hurting; I love my partner/relative and am concerned about his/her well-being.” Measures of negative affect and distress should capture the negative emotions of upset, depression, sadness, and anxiety engendered by suffering and might include items such as “It's very upsetting for me to see my partner/relative suffer; Being around my partner/relative when he/she is suffering makes me very anxious; It saddens me to see what my partner/relative is going through” (pp. 956–957). Existing caregiving measures that focus on the benefits of caregiving and the quality of care provided reflect, to some extent, motivation to help (Tarlow et al., 2004) but rarely assess it directly. Candidate items for assessing motivation might include “It is important for me to do everything I can to help my partner/relative; I truly enjoy helping

my partner/relative; Knowing that I've helped makes me feel good" (Feeney & Collins, 2003, pp. 956–957). To date, motivational issues in caregiving are relatively unexplored. As is the case with measures for suffering, additional work is needed to refine instruments to assess emotional and motivational aspects of compassion.

## Supporting Evidence

Despite the vast literature on patient illness and disability and their effects on family members, there are relatively few published findings that directly bear on the propositions put forth in this article. Here we review several studies that provide indirect support for these propositions.

Scores of published studies support the general conclusion that illness and disability have negative effects on the emotional and physical well-being of family caregivers, but virtually none of these studies show that patient suffering uniquely and independently contributes to caregiver outcomes. In the prototypical study, caregiver outcomes are attributed to functional disability of the patient, patient symptoms and behaviors, the demands of care provision, and miscellaneous other sources of distress in the caregiving environment. As a result, the unique contribution of suffering is difficult to assess. However, several recently published studies provide at least indirect support for the role of suffering and compassion.

A recent study by Amirkhanyan and Wolf (2003) provides one approach to isolating the effects of care recipient suffering from factors such as the physical work of care. In a large sample of adult children, Amirkhanyan and Wolf found strong support for the hypothesis that parental care need—a marker for illness, disability, and presumably suffering—is associated with depressive symptoms even among children who are not involved in caregiving. By examining the effects of parental care need on both caregiving and noncaregiving children, the researchers were able to show that parental need is a distinct stressor that produces a greater negative effect than caregiving itself. One interpretation of these findings is that parental need serves as a proxy for suffering. Thus, children who are not involved in the physical care of their parents are still subject to their suffering and its effects.

These findings are consistent with research on the effects of placement in a long-term-care facility on the caregiver. Caregiver distress levels do not decrease, even though the caregiver often reduces his or her involvement in formal care provision. One possible explanation for the continued distress of the caregiver is the fact that care recipient suffering continues and possibly increases after placement (Schulz et al., 2004). In contrast, a caregiver whose relative dies shows improvement after the death, in

part because the pain and suffering of the care recipient ends with death (Schulz et al., 2003). Studies of bereaved siblings of bone marrow donors have reported similar results. Following bereavement, donors exhibit enhanced self-esteem, happiness, and life satisfaction compared to donors whose siblings are still alive and who must confront the continued suffering of their siblings on a daily basis (Switzer et al., 1998).

These examples are suggestive of the role of suffering in that they show that care provision per se is not necessary in order to feel distress, but they leave open other explanations for the observed effects. In order to more precisely assess the effects of suffering, we recently analyzed data from two different dementia caregiver/patient samples ( $n_s = 1,222$  and  $642$ , respectively; Schulz, Belle et al., 2003; Belle et al., 2006). Direct measures of suffering were not available in this study, but we were able to use the depression subscale of the Revised Memory and Behavior Problem Checklist (Teri et al., 1992) as an indicator of patients' distress about their condition, and we used this as a proxy measure for suffering. Emotional aspects of patient suffering were assessed by asking caregivers to rate the extent to which patients appeared sad or depressed, expressed feelings of hopelessness or sadness about the future, made comments about feeling worthless or being a burden to others, during the last week. In multivariate linear regression models, we were able to show that perceived patient suffering uniquely contributes to caregiver depression and burden above and beyond the effects of patient cognitive and physical disability, memory problems, disruptive behaviors, and time spent caregiving. Furthermore, in longitudinal multivariate models based on these data, we were able to show that change in suffering is strongly associated with change in caregiver depression and burden, controlling for changes in other caregiving-related factors. Similar findings have been reported in the literature on spousal caregiving for arthritis patients: Verbal and non-verbal communications about their pain, especially severe pain and suffering, are associated with lower psychological well-being of their caregiving spouses (Stephens, Martire, Cremeans-Smith, Druley, & Wojno, 2006), even after controlling for level of patient disability.

Findings from the cancer caregiving literature also report positive associations between the well-being of cancer patients and their family caregivers (Cassileth et al., 1985; Hodges, Humphris, & Macfarlane, 2005; Hodgson, Higginson, McDonnell, & Butters, 1997; Kristjanson, Sloan, Dudgeon, & Adaskin, 1996). For example, Miaskowski, Kragness, Dibble, and Wallhagen (1997) compared mood states, health status, and caregiver strain between family caregivers of oncology patients with and without cancer-related pain. The results indicated that caregivers of patients with pain had greater

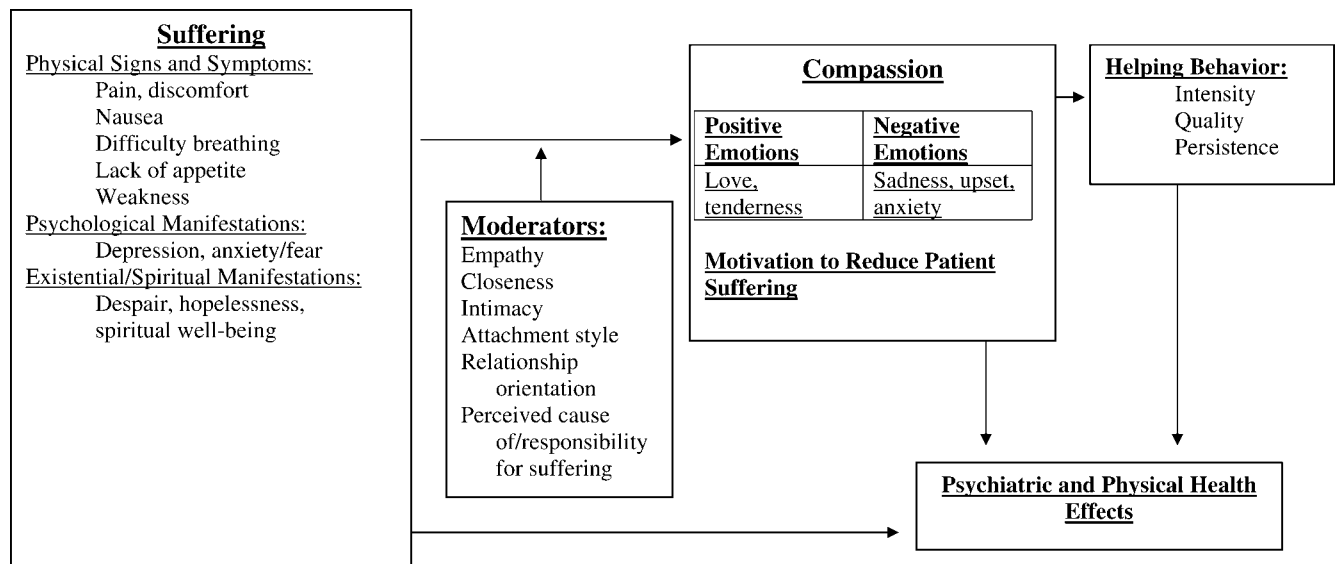


Figure 1. Conceptual model of perceived suffering, caregiver compassion, and their relation to caregiver helping and health.

mood disturbances, particularly anxiety and depression, than did caregivers of patients without pain. Riley-Doucet (2005) found, in a sample of family dyads that consisted of adult cancer patients and their family caregivers, that caregivers who believed that pain was controllable reported less subjective burden. Ferrell, Rhiner, Cohen, and Grant (1991) found that family caregivers who reported feelings of helplessness in being unable to provide patients with relief from pain and suffering also rated their own distress with the pain as high. Unfortunately, these studies did not report the independent contributions of patient distress to caregiver outcomes, leaving open the possibility that other factors, such as physical care provision, account for these associations.

Research on emotional, affective contagion, or mood convergence, a phenomenon wherein one individual's mood seems to spread to those in close proximity (Joiner & Katz, 1999), is also consistent with our view. Numerous studies have shown strong associations between husbands' and wives' emotional statuses, even after controlling for the effects of sociodemographic factors, the functional and health statuses of both members of the dyad, and shared life events (Bookwala & Schulz, 1996; Fultz et al., 2005; Gaugler et al., 2005; Kurtz, Kurtz, Given, & Given, 1995; Tower & Kasl, 1995, 1996). Experimental studies have shown that viewing faces with sad or happy expressions specifically evokes the expressed feelings in the viewer (Wild, Erb, & Bartels, 2001). Stronger expressions evoke stronger emotions. The fact that this process occurs rapidly, repeatedly, and almost automatically suggests that it may be biologically wired in the neural system of humans (Hatfield, Cacioppo, & Rapson, 1992). Recent findings suggest that humans may be hard-wired through a mirror neuron system located in

visceromotor centers to experience and understand the emotions of others (Gallese, Keysers, & Rizzolatti, 2004). Overall, these data suggest that humans are programmed to respond affectively to the distress of others, and the nature and magnitude of response is proportional to the expressed affect of the stimulus person.

### Conceptual Model Linking Suffering and Compassion

Figure 1 presents a preliminary conceptual framework linking patient suffering and caregiver compassion. We do not intend this model to be a comprehensive presentation of the many complexities inherent in this topic, but rather we hope it provides a broad heuristic framework that might serve as a basis for further discussion and development.

Beginning with the left panel and moving right, patient suffering is manifest by three related and measurable constructs: (a) physical signs and symptoms, which include pain, nausea, fatigue, poor appetite, and difficulty breathing; (b) psychological symptoms of distress, such as depression and anxiety/fear; and (c) existential factors, such as spiritual well-being and despair. Earlier in this article we identified examples of specific instruments and items useful in assessing these constructs.

Based on both the descriptive literature on caregiving and the experimental literature on helping, one would expect the experience of compassion to be moderated by the amount of contact between patient and caregiver; the quality of the relationship between caregiver and patient; as well as the empathy, attachment style, and relationship orientation of the caregiver (e.g., communal vs exchange;

Davis et al., 1999; Mikulincer & Shaver, 2005; Williamson & Schulz, 1995; Williamson, Shaffer, & Schulz, 1998). Contextual factors, such as the perceived cause of suffering as well as attributions of responsibility for suffering, are likely to play a role as well; compassion may be reduced when the perceived cause of suffering is temporary (e.g., pregnancy) as opposed to permanent and possibly life threatening (e.g., cancer). Similarly, when caregivers judge the patient to be directly responsible for his or her condition (e.g., attribute the underlying condition to character flaws or bad behavior), compassion may also be diminished.

The perception or knowledge of patient suffering generates varying degrees of compassion in the caregiver that has both an emotional and motivational component. Feelings of love and concern for the patient, feelings of distress, and a strong motivation to reduce patient suffering characterize high levels of compassion. At low levels of compassion, positive and negative emotions generated by patient suffering diminish, and the motivation to help is weak. Behaviorally, one would expect better quality and higher intensity of care to be provided by a highly compassionate caregiver compared to a less compassionate one. Successful attempts to decrease patient suffering should be particularly uplifting to the highly compassionate caregiver and may explain why helping under some circumstances leads to psychological well-being and better health (Post, 2005), whereas failed attempts to reduce patient suffering should be particularly distressing. Over time, the intensity of emotional and motivational components of compassion will shift as a function of the intensity and duration of patient suffering. A worst case scenario would be a situation in which suffering is chronic and intense with low perceived ability to affect its course. Under these circumstances, negative affect would become the dominant feature of compassion, and this in turn would lead to depression, hopelessness, and fatigue in the caregiver.

Although the model emphasizes the directional effects of suffering on compassion, over time the relation between these variables is likely to be bidirectional. To the extent that a patient perceives that his or her suffering causes negative affect and distress in the caregiver, suffering may increase, fueling a downward spiral for both patient and caregiver. Alternatively, patients' awareness of the link between their suffering and caregiver distress may inhibit expressions of suffering in order to spare the caregiver.

The final component of the model shows that suffering is directly linked to psychiatric and physical morbidity as well as being mediated through compassion. To the extent that humans are hard-wired to respond emotionally or viscerally to at least some components of suffering, one would expect the emotional health of the observer to reflect these

effects (e.g., Hatfield et al., 1994). Compassion and helping also mediate the effects of suffering on health. One can think of compassion as a filter that, under most circumstances, intensifies the effects of suffering on health. The act of helping may further diminish health through personal self-neglect, for example, but may also be salutary. For example, the highly compassionate caregiver who effectively improves patient suffering may experience strong positive affect and improved physical health.

We do not intend this model to provide a complete or comprehensive view of the caregiving experience but rather to highlight some key features that have received little attention in the literature. For example, experts are well aware that caregivers provide help for reasons other than compassion (such as having no choice or feeling obligated to do so). Similarly, many other factors—including the work and frustration of providing care, disruptions in desired routines, and inability to care for oneself—determine the health effects of caregiving. Finally, Figure 1 also neglects the cultural context within which suffering and compassion occur. Several recent qualitative studies show that the experience of suffering and the manner in which it is described is shaped by the cultural and religious experiences of the individual (Black & Moss, 2005; de Medeiros, 2005; DeMichele & Rubinstein, 2005; Rubinstein, 2005).

It is important to ask what researchers gain from the suffering–compassion approach to caregiving when compared to existing models of caregiving that are based primarily on stress–coping. First, we do not intend for our model to compete with or serve as a substitute for existing stress–coping models. A major goal of this article is to make the point that some of the variance in caregiver outcomes is attributable to patient suffering, independent of other illness and caregiving-related factors. Thus, we argue for the inclusion of suffering as an independent stressor in stress–coping models along with compassion as a mediator of the effects of suffering on health. It is important to note that our model emphasizes that one can observe the effects of suffering in individuals who are not involved in care provision and helps explain why siblings of care providers can experience distress even though they are not involved in care. Family members with strong motives to help who are unable to do so because of conflicting demands, geographic separation, lack of knowledge or skills, or family conflict may be at particularly high risk of negative health outcomes, even though a traditional caregiving perspective would view them as noncaregivers. Second, the model identifies a number of moderators of the suffering–compassion relationship that researchers have infrequently studied in the caregiving literature. Issues of empathy, attachment style, and relationship orientation in the caregiver and patient become more central in this view of caregiving.

Third, our concept of compassion emphasizes factors that contribute to variability in compassion and its measurement, as well as the behavioral consequences of that variability. Caregivers motivated by high levels of compassion should provide more help of higher quality and persist longer than individuals with low levels of compassion. One would also predict greater psychological and physical health benefits to compassionate helpers when their efforts result in the reduction of suffering of the patient when compared to less compassionate helpers. However, compassionate helpers may be at greater risk for negative health consequences when their efforts are unable to diminish the suffering of another. Testing these hypotheses requires that researchers go beyond traditional caregiving measurement strategies and assess suffering, compassion, the quality and intensity of help provided, and the success or failure of help provision in reducing suffering of the patient. To facilitate these goals, we have identified a variety of measurement options that can serve as a starting point for this enterprise.

### Research and Policy Implications

No one would disagree with the idea that suffering and compassion are defining characteristics of human existence. That makes it all the more surprising that they receive relatively little attention in health and social service policy and in research focused on illness and disability.

The observation that suffering plays a unique and independent role in affecting caregiver compassion and caregiver health has a number of important implications. First, developing interventions that directly address patient suffering should receive high priority among both policy makers and researchers. Current health and social service policy focused on family caregiving places a strong emphasis on interventions designed to facilitate care provision. Although valuable, programs such as respite care, home alterations, and caregiver skills training are unlikely to address an underlying source of caregiver distress if they have little impact on patient suffering. Because patient suffering and caregiver compassion are closely intertwined, and because together they impact caregiver health, reducing suffering should at the same time improve caregiver outcomes. Interventions that enable the caregiver to effectively address patient suffering are particularly important because of their dual impact on the patient and caregiver. Second, researchers need to know more about what contributes to suffering in patients, variability in its display to others, and factors that contribute to accurate and inaccurate assessment of patient suffering by caregivers. Third, experts need to better understand moderating factors that contribute to patient suffering and caregiver compassion. For example, one

would expect the experience of compassion to be moderated by the amount of contact between patient and caregiver; their proximity to each other; as well as the level of intimacy, closeness, and attachment between the family member and patient. Fourth, even when little can be done to alleviate patient suffering, it may nevertheless be possible to minimize caregiver distress through interventions that enable caregivers to come to terms with the limits of their ability to control suffering. In this regard, cognitive reframing methods advocated by cognitive behavior therapy or strategies used in the hospice approach to palliative care may be useful intervention strategies.

Experts also need to develop methods for assessing suffering and compassion more directly. In particular, researchers need to sharpen the conceptual distinction between illness-related suffering from generalized affective states such as depression and anxiety, as well as distinctions between markers of compassion and psychiatric morbidity. We have identified a number of candidate instruments that could serve as useful starting points in this effort. Measures should also distinguish between suffering as reported by the patient and suffering as perceived by the family caregiver. Existing data suggest good agreement between caregivers and patients in some domains (e.g., pain) but not others (e.g., depression, weariness; Adelman et al., 2004). Additional research is needed to identify factors associated with discordant ratings of suffering among patients and caregivers. Understanding under what circumstances caregivers either over- or underestimate suffering or why patients dramatize or inhibit signs of suffering will be important in designing interventions for caregivers and patients.

### Conclusion

We have placed this discussion of suffering and compassion in the context of family caregiving because there is a large empirical base from which to derive relevant examples. However, the principles articulated here have much broader applications. They apply to any situation in which one individual is exposed to the suffering of another. For example, people clearly feel compassion for strangers suffering because of natural disasters, famine, or war and other forms of violence and victimization throughout the world, although this compassion may be attenuated by factors such as great distances and low levels of attachment between the victim and the observer.

Discussions of suffering and compassion will undoubtedly continue to be a central feature of religious and philosophical dialogue. Our goal is to promote an empirical approach to this topic with the idea that this perspective will not only enrich researchers' understanding of these phenomena but also lead to new strategies for improving the human condition.



## References

- Adelman, E. E., Albert, S. M., Rabkin, J. G., Del Bene, M. L., Tider, T., & O'Sullivan, I. (2004). Disparities in perceptions of distress and burden in ALS patients and family caregivers. *Neurology*, *62*, 1766-1770.
- American heritage dictionary of the English language* (4th ed.). (2000). Boston, MA: Houghton Mifflin.
- Amirkhanyan, A. A., & Wolf, D. A. (2003). Caregiver stress and noncaregiver stress: Exploring the pathways of psychiatric morbidity. *The Gerontologist*, *43*, 817-827.
- Batson, C. D. (1998). Altruism and prosocial behavior. In D. Gilbert, S. Fiske, & G. Lindzey (Eds.), *The handbook of social psychology* (4th ed., Vol. 2, pp. 282-316). New York: McGraw-Hill.
- Belle, S. H., Burgio, L., Burns, R., Coon, D., Czaja, S. J., Gallagher-Thompson, D., et al. (2006). Enhancing the quality of life of dementia caregivers from different ethnic or racial groups. *Annals of Internal Medicine*, *145*(10), 727-738.
- Black, H. K., & Moss, M. (2005, November). *Who is the self that suffers?* Presentation at the 58th Annual Scientific Meeting of The Gerontological Society of America, Orlando, FL.
- Bookwala, J., & Schulz, R. (1996). Spousal similarity in subjective well-being: The Cardiovascular Health Study. *Psychology and Aging*, *11*, 582-590.
- Brod, M., Stewart, A. L., Sands, L., & Walton, P. (1999). Conceptualization and measurement of quality of life in dementia: The dementia quality of life instrument (DQoL). *The Gerontologist*, *39*, 25-35.
- Brown, S. L., & Brown, R. M. (2006). Selective investment theory: Recasting the functional significance of close relationships. *Psychological Inquiry*, *17*(1), 1-29.
- Bruera, E., Kuehn, N., Miller, M. J., Selmsler, P., & Macmillan, K. (1991). The Edmonton Symptom Assessment System (ESAS): A simple method for the assessment of palliative care patients. *Journal of Palliative Care*, *7*(2), 6-9.
- Byock, I. R. (1996). The nature of suffering and the nature of opportunity at the end of life. *Clinics in Geriatric Medicine*, *12*, 237-252.
- Cassell, E. J. (1982). The nature of suffering and the goals of medicine. *New England Journal of Medicine*, *306*, 639-645.
- Cassell, E. J. (1999). Diagnosing suffering: A perspective. *Annals of Internal Medicine*, *131*, 531-534.
- Cassell, E. J. (2004). *The nature of suffering and the goals of medicine* (2<sup>nd</sup> ed). New York: Oxford University Press.
- Cassileth, B. R., Lusk, E. J., Strouse, T. B., Miller, D. S., Brown, L. L., & Cross, P. A. (1985). A psychological analysis of cancer patients and their next-of-kin. *Cancer*, *55*(1), 72-76.
- Chimich, W. T., & Nekolaichuk, C. L. (2004). Exploring the links between depression, integrity, and hope in the elderly. *Canadian Journal of Psychiatry*, *49*, 428-433.
- Cialdini, R. B., Schaller, M., Houlihan, D., Arps, K., Fultz, J., & Beaman, A. L. (1987). Empathy-based helping: Is it selflessly or selfishly motivated? *Journal of Personality and Social Psychology*, *52*, 749-758.
- Clark, M. S. (2000). Altruism. In A. E. Kazdin (Ed.), *Encyclopedia of psychology* (Vol. 1, pp. 127-130). New York: Oxford University Press.
- Davis, M. H., Mitchell, K. V., Hall, J. A., Lothert, J., Snapp, T., & Meyer, M. (1999). Empathy, expectations, and situational preferences: Personality influences on the decision to participate in volunteer helping behaviors. *Journal of Personality*, *67*, 469-503.
- de Medeiros, K. (2005, November). *Suffering and metaphor: Verbal images of the imagined "other."* Presentation at the 58th Annual Scientific Meeting of The Gerontological Society of America, Orlando, FL.
- DeMichele, K., & Rubinstein, R. L. (2005, November). *The cultural basis of suffering in later life.* Presentation at the 58th Annual Scientific Meeting of The Gerontological Society of America, Orlando, FL.
- Feeney, B. C., & Collins, N. L. (2003). Motivations for caregiving in adult intimate relationships: Influences on caregiving behavior and relationship functioning. *Personality and Social Psychology Bulletin*, *29*, 950-968.
- Fehr, E., & Rockenbach, B. (2004). Human altruism: Economic, neural, and evolutionary perspectives. *Current Opinion in Neurobiology*, *14*, 784-790.
- Ferrell, B. R., Rhiner, M., Cohen, M. Z., Grant, M. (1991). Pain as a metaphor for illness. Part I: Impact of cancer pain on family caregivers. *Oncology Nursing Forum*, *18*, 1303-1309.
- Fultz, N. H., Rahrig Jenkins, K., Ostbye, T., Taylor, D. H., Jr., Kabeto, M. U., & Langa, K. M. (2005). The impact of own and spouse's urinary incontinence on depressive symptoms. *Social Science & Medicine*, *60*, 2537-2548.
- Gallagher, T. J., Wagenfeld, M. O., Baro, F., & Haepers, K. (1994). Sense of coherence, coping and caregiver role overload. *Social Science & Medicine*, *39*, 1615-1622.
- Gallese, V., Keysers, C., & Rizzolatti, G. (2004). A unifying view of the basis of social cognition. *Trends in Cognitive Sciences*, *8*, 396-403.
- Ganzini, L., Johnston, W. S., & Hoffman, W. F. (1999). Correlates of suffering in amyotrophic lateral sclerosis. *Neurology*, *52*, 1434-1440.
- Gaugler, J. E., Hanna, N., Linder, J., Given, C. W., Tolbert, V., Kataria, R., et al. (2005). Cancer caregiving and subjective stress: A multi-site, multi-dimensional analysis. *Psycho-oncology*, *14*, 771-785.
- Gleitman, H., Fridlund, A. J., & Reisberg, D. (2000). *Basic psychology* (5th ed.). New York: Norton.
- Hatfield, E., Cacioppo, J., & Rapson, R. L. (1994). *Emotional contagion*. New York: Cambridge University Press.
- Hatfield, E., Cacioppo, J. T., & Rapson, R. L. (1992). Primitive emotional contagion. In S. C. Margaret (Ed.), *Emotion and social behavior: Review of personality and social psychology* (Vol. 14, pp. 151-177). Newbury Park, CA: Sage Publications.
- Hodges, L. J., Humphris, G. M., & Macfarlane, G. (2005). A meta-analytic investigation of the relationship between the psychological distress of cancer patients and their carers. *Social Science & Medicine*, *60*, 1-12.
- Hodgson, C., Higginson, I., McDonnell, M., & Butters, E. (1997). Family anxiety in advanced cancer: A multicentre prospective study in Ireland. *British Journal of Cancer*, *76*, 1211-1214.
- Idler, E. L., Musick, M. A., Ellison, C. G., George, L. K., Drause, N., Ory, M. G., et al. (2003). Measuring multiple dimensions of religion and spirituality for health research. *Research on Aging*, *25*, 327-365.
- Joiner, T. E., Katz, J. (1999). Contagion of depressive symptoms and mood: Meta-analytic review and explanations from cognitive, behavioral, and interpersonal viewpoints. *Clinical Psychology: Science and Practice*, *6*, 149-164.
- Keefe, F. J., Lipkus, I., Lefebvre, J. C., Hurwitz, H., Clipp, E., Smith, J., et al. (2003). The social context of gastrointestinal cancer pain: A preliminary study examining the relation of patient pain catastrophizing to patient perceptions of social support and caregiver stress and negative responses. *Pain*, *103*(1/2), 151-156.
- Kleinman, A., Eisenberg, L., & Good, B. (1978). Culture, illness, and care: Clinical lessons from anthropologic and cross-cultural research. *Annals of Internal Medicine*, *88*, 251-258.
- Kristjanson, L. J., Sloan, J. A., Dudgeon, D., & Adaskin, E. (1996). Family members' perceptions of palliative cancer care: Predictors of family functioning and family members' health. *Journal of Palliative Care*, *12*(4), 10-20.
- Kurtz, M. E., Kurtz, J. C., Given, C. W., & Given, B. (1995). Relationship of caregiver reactions and depression to cancer patients' symptoms, functional states and depression: A longitudinal view. *Social Science & Medicine*, *40*, 837-846.
- Lee, H. S., Brennan, P. F., & Daly, B. J. (2001). Relationship of empathy to appraisal, depression, life satisfaction, and physical health in informal caregivers of older adults. *Research in Nursing and Health*, *24*(1), 44-56.
- Logsdon, R. G., Gibbons, L. E., McCurry, S. M., & Teri, L. (2002). Assessing quality of life in older adults with cognitive impairment. *Psychosomatic Medicine*, *64*, 510-519.
- Maner, J. K., Luce, C. L., Neuberger, S. L., Cialdini, R. B., Brown, S., & Sagarin, B. J. (2002). The effects of perspective taking on motivations for helping: Still no evidence for altruism. *Personality and Social Psychology Bulletin*, *28*, 1601-1610.
- McClain, C. S., Rosenfeld, B., & Breitbart, W. (2003). Effect of spiritual well-being on end-of-life despair in terminally ill cancer patients. *Lancet*, *361*, 1603-1607.
- McClain-Jacobson, C., Rosenfeld, B., Kosinski, A., Pessin, H., Cimino, J. E., & Breitbart, W. (2004). Belief in an afterlife, spiritual well-being, and end-of-life despair in patients with advanced cancer. *General Hospital Psychiatry*, *26*, 484-486.
- Miaskowski, C., Kragness, L., Dibble, S., & Wallhagen, M. (1997). Differences in mood states, health status, and caregiver strain between family caregivers of oncology outpatients with and without cancer-related pain. *Journal of Pain and Symptom Management*, *13*(3), 138-147.
- Mikulincer, M., & Shaver, P. R. (2005). Attachment security, compassion, and altruism. *Current Directions in Psychological Science*, *14*(1), 34-38.
- Morris, D. B. (1998). *Illness and culture in the postmodern age*. Berkeley: University of California Press.
- Oxford English dictionary* (2nd ed.). (1989). Available online at <http://digital.library.pitt.edu/>
- Pelletier, G., Verhoef, M. J., Khatri, N., & Hagen, N. (2002). Quality of life in brain tumor patients: The relative contributions of depression, fatigue, emotional distress, and existential issues. *Journal of Neuro-oncology*, *57*(1), 41-49.
- Penner, L. A., Dovidio, J. F., Piliavin, J. A., & Schroeder, D. A. (2005). Prosocial behavior: Multilevel perspectives. *Annual Review of Psychology*, *56*, 365-392.
- Post, S. G. (2005). Altruism, happiness, and health: It's good to be good. *International Journal of Behavioral Medicine*, *12*(2), 66-77.
- Riley-Doucet, C. (2005). Beliefs about the controllability of pain: Congruence between older adults with cancer and their family caregivers. *Journal of Family Nursing*, *11*, 225-241.

- Rubinstein, R. L. (2005, November). *Suffering and the life-worlds of older people*. Presentation at the 58th Annual Scientific Meeting of The Gerontological Society of America, Orlando, FL.
- Sabin-Farrell, R., & Turpin, G. (2003). Vicarious traumatization: Implications for the mental health of health workers? *Clinical Psychology Review, 23*, 449–480.
- Schroeder, D. A., Dovidio, J. F., Penner, L. A., & Piliavin, J. A. (1994). *The social psychology of helping and altruism*. New York: McGraw-Hill.
- Schulz, R., Belle, S. H., Czaja, S. J., Gitlin, L., Wisniewski, S., & Ory, M. G. (2003). Introduction to the special section on Resources for Enhancing Alzheimer's Caregiver Health (REACH). *Psychology and Aging, 18*(3), 357–360.
- Schulz, R., Belle, S. H., Czaja, S. J., McGinnis, K. A., Stevens, A., & Zhang, S. (2004). Long-term care placement of dementia patients and caregiver health and well-being. *Journal of the American Medical Association, 292*, 961–967.
- Schulz, R., Mendelsohn, A. B., Haley, W. E., Mahoney, D., Allen, R. S., Zhang, S., et al. (2003). End of life care and the effects of bereavement on family caregivers of persons with dementia. *New England Journal of Medicine, 349*, 1936–1942.
- Sherman, D. W. (1998). Reciprocal suffering: The need to improve family caregivers' quality of life through palliative care. *Journal of Palliative Medicine, 1*, 357–366.
- Simmons, R. G. (1991). Presidential address on altruism and sociology. *Sociological Quarterly, 32*(1), 1–22.
- Stephens, M. A. P., Martire, L. M., Creameans-Smith, J. K., Druley, J. A., & Wojno, W. C. (2006). Older women with osteoarthritis and their caregiving husbands: Effects of pain and pain expression on husbands' well-being and support. *Rehabilitation Psychology, 51*(1), 3–12.
- Stevens, J. R., & Hauser, M. D. (2004). Why be nice? Psychological constraints on the evolution of cooperation. *Trends in Cognitive Sciences, 8*(2), 60–65.
- Strang, P. (1998). Cancer pain: A provoker of emotional, social and existential distress. *Acta Oncologica, 37*, 641–644.
- Switzer, G. E., Dew, M. A., Magistro, C. A., Goycoolea, J. M., Twillman, R. K., Alter, C., et al. (1998). The effects of bereavement on adult sibling bone marrow donors' psychological well-being and reactions to donation. *Bone Marrow Transplantation, 21*, 181–188.
- Tarlow, B. J., Wisniewski, S. R., Belle, S. H., Rubert, M., Ory, M. G., & Gallagher-Thompson, D. (2004). Positive aspects of caregiving. *Research on Aging, 26*, 429–453.
- Teri, L., Truax, P., Logsdon, R., Uomoto, J., Zarit, S., & Vitaliano, P. P. (1992). Assessment of behavioral problems in dementia: The Revised Memory and Behavior Problems Checklist. *Psychology and Aging, 7*, 622–631.
- Thomas, R. B., & Wilson, J. P. (2004). Issues and controversies in the understanding and diagnosis of compassion fatigue, vicarious traumatization, and secondary traumatic stress disorder. *International Journal of Emergency Mental Health, 6*(2), 81–92.
- Tower, R. B., & Kasl, S. V. (1995). Depressive symptoms across older spouses and the moderating effect of marital closeness. *Psychology and Aging, 10*, 625–638.
- Tower, R. B., & Kasl, S. V. (1996). Depressive symptoms across older spouses: Longitudinal influences. *Psychology and Aging, 11*, 683–697.
- Wild, B., Erb, M., & Bartels, M. (2001). Are emotions contagious? Evoked emotions while viewing emotionally expressive faces: Quality, quantity, time course and gender differences. *Psychiatry Research, 102*, 109–124.
- Williamson, G. M., & Schulz, R. (1995). Caring for a family member with cancer: Past communal behavior and affective reactions. *Journal of Applied Social Psychology, 25*, 93–116.
- Williamson, G. M., Shaffer, D. R., & Schulz, R. (1998). Activity restriction and prior relationship history as contributors to mental health outcomes among middle-aged and older spousal caregivers. *Health Psychology, 17*, 152–162.
- Wilson, K. G., Graham, I. D., Viola, R. A., Chater, S., de Faye, B. J., Weaver, L. A., et al. (2004). Structured interview assessment of symptoms and concerns in palliative care. *Canadian Journal of Psychiatry, 49*, 350–358.

Received December 19, 2005

Accepted July 20, 2006

Decision Editor: Linda S. Noelker, PhD

## Editor Nominations

### *Journal of Gerontology: Psychological Sciences*

The Gerontological Society of America's Publications Committee is seeking nominations for the position of Editor of the *Journal of Gerontology: Psychological Sciences*, the Society's journal on the psychological science of aging.

The position will become effective January 1, 2008. The Editor makes appointments to the journal's editorial board and develops policies in accordance with the scope statement prepared by the Publications Committee and approved by Council (see the journal's General Information and Instructions to Authors page). The Editor works with reviewers and has the final responsibility for the acceptance of articles for the journal. The editorship is a voluntary position. Candidates must be dedicated to developing a premier scientific journal.

Nominations and applications may be made by self or others, but must be accompanied by the candidate's curriculum vitae and a statement of willingness to accept the position. **All nominations and applications must be received by April 2, 2007.** Nominations and applications should be sent to the Publications Committee, Attn: Patricia Walker, The Gerontological Society of America, 1030 15th Street, NW, Suite 250, Washington, DC 20005-1503.