



Published in final edited form as:

*Psychol Aging*. 2009 September ; 24(3): 681–695. doi:10.1037/a0016355.

## Interpersonal Effects of Suffering in Older Adult Caregiving Relationships

**Joan K. Monin, Ph.D. and Richard Schulz, Ph.D.**

Department of Psychiatry and University Center for Social and Urban Research, University of Pittsburgh, Pittsburgh, PA 15213

### Abstract

Examining the interpersonal effects of suffering in the context of family caregiving is an important step to a broader understanding of how exposure to suffering affects humans. In this review article, we first describe existing evidence that being exposed to the suffering of a care recipient (conceptualized as psychological distress, physical symptoms, and existential/spiritual distress) directly influences caregivers' emotional experiences. Drawing from past theory and research, we propose that caregivers experience similar, complementary, and/or defensive emotions in response to care recipient suffering through mechanisms such as cognitive empathy, mimicry, and conditioned learning, placing caregivers at risk for psychological and physical morbidity. We then describe how gender, relationship closeness, caregiving efficacy, and individual differences in emotion regulation moderate these processes. Finally, we provide directions for future research to deepen our understanding of interpersonal phenomena among older adults, and we discuss implications for clinical interventions to alleviate the suffering of both caregivers and care recipients.

### Keywords

Caregiving; Suffering; Emotion

---

Caring for a close relative with a chronic disease or disability can have a negative impact on family caregivers' physical and psychological well-being. Family caregivers often experience personal distress, burden, impaired self-care, and increased psychological and physical morbidity (Burton, Zdaniuk, Schulz, Jackson, & Hirsch, 2003; Christakis & Allison, 2006; Pinquart & Sörensen, 2003a, 2003b; Schulz & Beach, 1999; Vitaliano, Zhang & Scanlan, 2003). The family caregiving literature suggests that these detrimental health effects are primarily due to care recipients' functional disabilities, such as level of physical and cognitive impairment and behavior problems, and the associated caregiving demands, such as providing assistance and staying vigilant to care recipients' needs (Pinquart & Sörensen, 2003a). However, another common feature of the caregiving experience is that caregivers are frequently exposed to the physical and psychological suffering of a loved one, which may also directly influence caregivers' emotional experiences and subsequent psychological and physical health. Theory and empirical evidence suggest that individuals are vigilant to relationship partners'

---

Corresponding author contact information: Richard Schulz, 121 University Place, Pittsburgh PA 15260, Phone: 412-624-2311; schulz@pitt.edu.

**Publisher's Disclaimer:** The following manuscript is the final accepted manuscript. It has not been subjected to the final copyediting, fact-checking, and proofreading required for formal publication. It is not the definitive, publisher-authenticated version. The American Psychological Association and its Council of Editors disclaim any responsibility or liabilities for errors or omissions of this manuscript version, any version derived from this manuscript by NIH, or other third parties. The published version is available at [www.apa.org/journals/pag](http://www.apa.org/journals/pag).

physical and emotional distress and often experience similar emotions (e.g. anxiety in response to anxiety) and/or complementary emotions (e.g. love in response to anxiety) in response to this distress (Hatfield, Cacioppo & Rapson, 1994; Hatfield, Rapson, & Le, 2008; Keltner & Kring, 1998). There is also evidence that people respond to relationship partners' vulnerability defensively (e.g. anger in response to anxiety; Rholes, Simpson, & Orina, 1999).

From an evolutionary perspective, it has been theorized that vigilance to others' emotional and physical distress is adaptive because distress provides important information about threats to survival (Frijda, 1988), and in the caregiving context it signals the need and desire for care and support (Clark, Fitness, & Brissette, 2001; Graham, Huang, Clark, & Helgeson, 2008). However, constant exposure to a loved one's suffering may take a toll on caregivers.

Based on previous research on family caregiving and the interpersonal effects of emotion, we make the case that exposure to suffering is an important and understudied pathway that may explain some of the psychological and physical consequences of caregiving. To support our argument we synthesize diverse literatures to address four key issues.

First, we provide a working definition of suffering as a holistic construct defined by three measurable dimensions: psychological distress, physical symptoms, and existential/spiritual distress. The advantage of bundling the three dimensions under the rubric of "suffering" is that it allows us to capture the holistic state of a person which is missing when individual physical and psychological symptoms are measured in isolation (Cassel, 2004; Cherny, 1996; Heath, 1989; Kleinman, 1988). This is particularly true when suffering is viewed in an interpersonal context where the focus is on understanding the effects of suffering in one person on another. Our view is that people automatically make appraisals about the magnitude of suffering in another person based on a learned algorithm that incorporates the three key dimensions of suffering. This holistic appraisal is an important final pathway to understanding the interpersonal effects of suffering and is different from approaches which treat factors such as psychological distress and pain separately. This has important implications for the development of treatments and interventions to improve the lives of people with chronic disease and disabilities and their caregivers. Clinical practice that focuses on the treatment of human suffering in a general, as opposed to the fragmentation and decontextualization of the person that often occurs in health care practice, is likely to be more effective (Cassell, 2004).

Second, we review research that supports the claim that the perception of care recipient suffering can directly affect caregivers' emotions, while also acknowledging methodological issues that limit the extent to which we can draw conclusions about this direct link. Although our review examines the impact of each constituent dimension of suffering on caregiver outcomes, we also show that high levels of suffering on all three dimensions uniquely contribute to caregiver outcomes.

Third, we propose a model through which care recipients' suffering behaviors influence caregivers' emotions through three pathways: cognitive empathy, mimicry and feedback, and conditioned responding. We then discuss how gender, relationship closeness, caregiver efficacy, and individual differences in emotion regulation may affect caregivers' emotional reactions to care recipients' suffering.

Finally, we discuss implications for future research and interventions, emphasizing the importance of assessing the unique effects of care recipient suffering on caregiver outcomes, moderators of this effect, and developing new interventions that help caregivers minimize their loved ones' suffering as well as helping them cope with those aspects of suffering that are not under their control.

## What is Suffering and How is It Measured?

The nature of and reasons for human suffering have been the subject of scholarly writings for millennia. Many important questions can be asked about suffering, including why do people suffer, how is it experienced and expressed by individuals, and how is it perceived and responded to by individuals exposed to suffering. Our emphasis in this paper is limited to the interpersonal aspects of suffering, how the experience of suffering in one individual is perceived by and affects the well being of the observer. Thus, our conceptual focus is on defining and measuring the experience and perception of suffering, recognizing that what an individual experiences may sometimes be at odds with what is perceived.

The experience of patient suffering has received increasing attention in the medical and health care literature (Cassell, 2004; Ferrell & Coyle, 2008; Schulz et al., 2007). Eric Cassell, a physician and leading contributor to discourse on this topic, stated that suffering is “experienced by persons, not merely bodies, and has its source in challenges that threaten the intactness of a person as a complex and social entity” (Cassell, 1982, 2004). He explained that suffering may include pain, but is not limited to it. Laural Copp defined suffering as “a state of anguish in one who bears pain, injury, or loss” (Copp, 1990); and in a recent book on the nature of suffering and the goals of nursing, Ferrell and Coyle (2008) summarized definitions of suffering that included the following qualities: multidimensional distress/pain/discomfort, loss of control, helplessness, inability to cope, anxiety, and depression.

Although some researchers believe that attempting to measure suffering is inappropriately reductionistic because the experience of suffering is unique to the individual and is inherently inaccessible to scientific inquiry (Black & Rubenstein, 2004), researchers interested in end-of-life care have been at the forefront in developing methods to assess various components of suffering. Notable examples include simple, direct questions such as “Are you suffering?” (Cassell, 1999) and scales that emphasize physical symptoms, such as the Edmonton Symptom Assessment system (Bruera, Kuehn, Miller, Selmser, & Macmillan, 1991), and measures of pain behavior (Keefe et al., 2003; Wilson et al., 2004). Other researchers have included psychological, spiritual, and social feelings with measurement of the physical symptoms (e.g., Ferrell, Grant, Dean, Funk, & Ly, 1996; Idler et al., 2003; McClain, Rosenfeld, & Breitbart, 2003). Still others have taken a more clinical approach, asking health care providers to rate attributes such as calmness, screaming, pain, and stability of general medical condition, and the impression of medical staff and family regarding the patient’s level of suffering (Aminoff & Adunsky, 2004).

The conceptual and measurement literature on suffering suggest consensus around four common themes. First, suffering is a holistic construct with multiple dimensions. Second, suffering includes psychological distress, such as depression and anxiety, along with feelings of lack of control, which reflect the individual’s appraisal of their condition. Third, physical symptoms, such as pain, nausea, and difficulty breathing, are a key feature of suffering. Fourth, suffering has an existential/spiritual dimension which includes loss or impairment of inner harmony, meaning and purpose of life, and comfort and strength in religious beliefs. Thus, our recommendation for measuring suffering would include a simple direct question assessing suffering, as suggested by Cassell, in conjunction with scales that capture each of the three dimensions.

Both the experience of suffering and perception of suffering by others can be measured. In the present paper we primarily focus on the effects of caregivers’ perceptions of care recipients’ suffering and suggest that perceptions of suffering should be most predictive of caregivers’ emotional reactions. Although we would expect the experience, expression, and perception of suffering to be correlated, one can also imagine situations where they might be at odds with

one another. For example, an observer might over- or under-estimate the suffering of their partner (compared to their partner's own report of suffering) if they thought that their partner tended to inhibit expressions of suffering or dramatize their suffering.

How is our conceptualization and suggested measurement of suffering different from existing multidimensional measures such as quality of life? Although there is some overlap between quality of life (QOL) and suffering measures in that they both include assessments of emotional well-being, there are important differences. QOL scales typically do not assess a variety of physical symptoms or existential/spiritual aspects of suffering, and they assess only a subset of the psychological suffering items we deem important (see Carr & Higginson, 2001 for a review of domains captured by well known QOL measures). Moreover, most of the QOL scales measure such a broad array of domains that they have limited utility in guiding interventions that would benefit the person who is suffering.

## **Existing Evidence for the Link between Care Recipients' Suffering and Caregivers' Emotions**

Although a vast number of studies have examined the influence of care recipients' impairment (e.g. physical, cognitive, and behavioral problems) and the associated demands on caregivers' psychological and physical morbidity (see Pinquart & Sörensen, 2003a, 2003b; Schulz, O'Brien, Bookwala, & Fleissner, 1995), few studies have examined the role of care recipients' suffering on caregiver emotions (Schulz, et al., 2009; Schulz, et al., 2008). There are, however, studies that have examined associations between individual components of suffering (psychological distress, physical symptoms, and existential/spiritual distress) and caregivers' emotions. Here we review these studies, while discussing methodological issues that limit the extent to which we can make claims about the direct link between care recipients' suffering and caregivers' emotions. In our review of the effects of physical suffering on caregivers' emotions, we limit our discussion to pain expression, because it has received the most research attention. Little is known about the interpersonal effects of other physical symptoms.

Most of the research in this review focuses on the effects of individual components of suffering on caregivers' emotions; however, we also describe studies that examine multiple components of suffering (e.g. Kornblith, Herr, Ofman, Scher, & Holland, 1994; Schulz et al., 2009; Schulz et al., 2008). Although studies that investigate the combined effects of the multiple components of suffering are likely to give us a more accurate view of how human suffering affects others, a first step is to understand the contribution of each component.

### **Effects of Psychological Suffering**

A number of studies show significant positive associations between care recipients' psychological distress and caregivers' emotional experiences. In these studies, psychological distress and emotional experiences are operationalized as depression, anxiety, negative mood, presence of a psychiatric disorder, and/or symptoms of distress measured with a variety of instruments including the Beck Depression Inventory (BDI; Beck, Rial, & Rickets, 1974), the State Trait Anxiety Inventory (STAI; Spielberger, Gorsuch, Lushene, Vagg, & Jacobs, 1983), the Profile of Moods Scale (POMS; McNair, Lorr, & Droppleman, 1981), the Minnesota Multiphasic Personality Inventory (MMPI; Hathaway & McKinley, 1967), and/or the Brief Symptom Inventory (BSI; Derogatis & Melisaratos, 1983). Positive associations between care recipients' distress and caregivers' emotional experiences have been found in situations involving patients with cancer (e.g. Bambauer et al., 2006; Breitbart, Gibson, & Tremblay, 2002; Matthews, Baker, & Spillers, 2003; Northouse, Templin, & Mood, 2001), rheumatoid arthritis (Revenson & Majerovitz, 1990), osteoarthritis (Druley, Stephens, Martire, Ennis, & Wojno, 2003), chronic pain (Ahern, Adams, & Follick, 1985; Kerns & Turk, 1984; Leonard,

Cano, & Johansen, 2006), dementia (Drinka, Smith, & Drinka, 1987; Yeatman et al., 1992), amyotrophic lateral sclerosis (Rabkin, Glenn, & Del Bene, 2000), and individuals on dialysis (Soskolne & Kaplan De-Nour, 1989).

In many of these studies, the extent to which the care recipient's distress influences the caregiver's emotional experience is not the primary focus. Typically researchers examine the effects of disease characteristics, such as the level of care recipient disability, and caregiving demands on caregiver outcomes such as stress, burden, psychiatric morbidity, and physical health. They may report the correlation between care recipient and caregiver distress in their descriptive statistics, but they rarely analyze the underlying cause of the observed co-variation. However, significant independent links between partners' distress have been reported in studies that control for demographic and social variables (e.g. age, gender, race, education, financial strain; Bookwala & Schulz, 1996; Goodman & Shippy, 2002; Tower & Kasl, 1995, 1996), care recipient and caregiver lifetime psychiatric diagnosis (depression, anxiety, and panic disorders; Bambauer et al., 2006), and various care recipient health and disability variables (e.g. cognitive impairment, dependencies in activities of daily living; Goodman & Shippy, 2002; Northouse, Dorris, & Charron-Moore, 1995).

Other researchers have found direct links between care recipient and caregiver distress with path analyses, controlling for patient dependency (but not care provision) in their models (Given et al, 1993; Kurtz, Kurtz, Given, & Given, 1995; Northouse et al., 2001). For example, using structural equation modeling, Kurtz and colleagues (1995) found in a sample of cancer patients and their family caregivers that patient symptoms, and to a lesser degree patient immobility, were strong predictors of patient depression, which in turn predicted caregiver depression. Similarly, in a sample of cancer patients and their caregivers, Given and colleagues (1993) found that caregivers' depression was dependent on patient depression to a greater extent than patients' dependencies with activities of daily living. Also, using structural equation modeling that controlled for variables such as gender, age, disease severity, marital satisfaction, and appraisals such as hopelessness and uncertainty, Northouse and colleagues (2001) found in a study of breast cancer patients and their husbands, that partners' emotional distress was significantly linked.

Not only have researchers found direct associations between care recipient and caregiver distress concurrently, there are several longitudinal studies indicating changes over time. For example, Revenson and Majerovitz (1990) found that spouses of patients with rheumatoid arthritis whose wives or husbands became more depressed reported greater perceived stress with current life circumstances. Also, in a study of patients with multiple sclerosis and their caregivers, Pakenham (2001) found that patients' distress was strongly related to caregiver distress 12 months later, but patients' disability was not strongly related to caregivers' adjustment concurrently or longitudinally. In both of these studies, amount of care provision was not associated with caregiver adjustment.

Further evidence for the association between care recipient and caregiver emotional distress can be found in studies of the effects on caregivers of placement of spouses in institutional care or bereavement. Although caregivers have less caregiving responsibilities after the transition to institutionalization of their loved ones, they often still experience impaired health and well-being (The Canadian Study of Health and Aging Working Group, 2002). This suggests that the physical burden associated with taking care of a loved one is not the only source of caregiver distress. Thoughts about or actual exposure to care recipient suffering during visitation is likely to be a stressor for caregivers even after the care recipient's institutionalization. For example, research has shown that institutionalization of a loved one can result in relief from the primary effects of caregiving (e.g. feelings of overload and tension) and improved well-being, but other indicators of stress remain unchanged (e.g. negative affect, changes in how they view the self,

and competency; Zarit & Whitlatch, 1992). Also, caregivers who visit their loved one more frequently in the institution are more likely to experience increased depression and anxiety than those who visit less frequently, controlling for care recipients' cognitive and functional disability (Schulz et al., 2004). However, it is important to note that exposure to suffering may not be the only predictor of caregivers' distress in this case. Changes in financial situations, reduced control over care provision, and guilt over abandonment have also been theorized to be related to continued caregiver depression after institutionalization of a loved one (Schulz et al., 2004). Despite these alternative explanations, the role of caregivers' continued perceptions of care recipient suffering should not be overlooked as a determinant of caregiver emotional distress.

Although bereavement in the elderly is generally associated with increased depression (Mendes de Leon, Kasl, & Jacobs, 1994) and weight loss (Rosenbloom & Whittington, 1993), in some cases caregivers' health improves after the death of a care recipient (Kurtz, Kurtz, Given & Given, 1997; Mullan, 1992; Schulz et al., 2001). Specifically, Schulz and colleagues (2001) found in a prospective study that the impact of bereavement varied according to the level of caregiving involvement preceding the death. Among caregivers who were strained prior to the death of their spouse, the death itself did not increase the level of distress. By comparison, non-strained caregivers or non-caregivers who experienced the death of their spouse had increased depression after their partner's death. In another prospective study of bereavement among Alzheimer's disease caregivers, Schulz and colleagues (2003) showed that depression levels quickly declined to near normal levels after the death of their loved ones. Caregivers also reported relief after death, because death marked the end of suffering for their relatives and themselves. Caregivers may benefit when they feel their loved ones are no longer suffering, even if it means they have died.

Taken together, this research suggests that there is a significant link between care recipient psychological suffering and caregivers' emotional distress in relationships between older adults where one person has a disease or disability. Not only do caregivers experience distress because of the support-related demands of caregiving, exposure to a loved one's psychological suffering is also an important predictor.

### Effects of Physical Suffering (Pain)

Only a few studies have examined the emotional effects of care recipient pain expression on caregivers of older adults with a chronic disease or disability (Dar, Beach, Barden, & Cleeland, 1992; Redinbaugh, Baum, DeMoss, Fello, & Arnold, 2002; Schwartz, Slater, Birchler, & Atkinsons, 1991; Stephens, Martire, Cremeans-Smith, Druley, & Wojno, 2006), and only one study reporting physiological indicators of caregivers' emotional responses (Block, 1981). In general, these studies suggest that being exposed to expressions of pain in a loved one is distressing for caregivers and can often be more distressing for caregivers than for the care recipients themselves (Yeager, Miaskowski, Dibble, & Wallhagen, 1995). For example, Schwartz and colleagues (1991) found that for patients with chronic pain and their spousal caregivers, patient pain intensity was the strongest predictor of caregiver depression. Similarly, Dar and colleagues (1987) found that spousal caregivers' mood was dependent on patient pain (and less on patients' mood) in couples coping with cancer. Furthermore, Redinbaugh and colleagues (2002) found that caregivers' perceptions of end-stage cancer patients' pain were associated with caregiver distress beyond the effects of the patients' level of physical disability.

The importance of expressed pain as opposed to patients' reports of the experience of pain was demonstrated in a study by Stephens and colleagues (2006). They found that disclosure of pain was more important than experienced pain intensity in predicting spouses' distress in couples dealing with osteoarthritis. Specifically, husbands whose wives had the most severe osteoarthritis pain and who verbally disclosed their pain to a greater degree experienced

increases in depressive symptoms over the course of 6 months. In contrast, husbands whose wives experienced similar levels of pain but disclosed their pain to a lesser degree did not show such increases. Also, they found that husbands of women who engaged in more nonverbal pain behavior became less satisfied with life, regardless of the initial levels of wives' pain. Thus, caregivers' exposure to expressions of pain is an important determinant of their emotional distress. Caregivers who have more expressive partners are more likely to perceive that their partner is in pain and respond emotionally to this exposure.

Research also suggests that people react physiologically to others' pain expression (Bandura & Rosenthal, 1966; Berger, 1962; Block, 1981; Craig & Lowery, 1969; Craig & Weinstein, 1965; Craig & Wood, 1970). In one experiment specific to the context of caregiving spouses watched videotapes of "painful" and "neutral" facial expressions emitted by spouses with a chronic pain condition (Block, 1981). Results indicated that spouses showed greater increases in skin conductance to painful than to neutral displays.

Together, these studies suggest that witnessing a loved one in pain can have negative consequences for caregivers' emotions and psychological and physical health. However, more research is needed on the acute and chronic effects of care recipients' pain expression and caregivers' perceptions of care recipients' pain in the caregiving context. Furthermore, pain expression is not the only physical symptom involved in suffering. Additional research is needed to examine the effect of other symptoms perceived by caregivers, such as fatigue, difficulty breathing, and nausea, on caregivers' emotions.

### **Effects of Existential/Spiritual Suffering**

There are several qualitative studies on family members' reflections of the existential and spiritual aspects of their loved one's suffering and how this affects family members' feelings (e.g. Coyle, 1996). For example, in Coyle's study, one nurse described her intense sadness in response to the loss of "something vital" in her loved one that had been eroded by drugs, pain, and illness. In the book *Soul Pain: The Meaning of Suffering in Later Life*, Black interviewed an elderly woman who explained that her son suffers because he has not fulfilled his life, further elaborating that he has never worked at a paying job, is presently on disability for mental problems and he is a loner (2006; pg. 77). This woman was emotionally distressed by her son's suffering as defined by his lack of fulfillment in life. Although this qualitative work provides important insights into the effects of existential/spiritual suffering on family members, more research, especially quantitative research, is needed linking caregivers' emotions with perceptions of negative changes in loved ones' existential and spiritual well-being. Perceiving that a loved one has lost his/her will to live or faith in religion is likely to be very distressing for caregivers. Witnessing a partner lose the desire for generativity, the engagement in life and work activities that outlive the self, may also be disheartening for caregivers (Black & Rubenstein, 2009; Kotre, 1984). Surprisingly, there is no quantitative research on this topic.

### **Additive Effects of Multiple Components of Suffering**

Researchers have only just begun to examine the simultaneous impact of multiple components of suffering—psychological distress, physical symptoms, and existential/spiritual distress-- on caregivers' emotional experiences using quantitative methods (Schulz, et al., 2009; Schulz, et al., 2008). For example, in a large multi-site sample of dementia patients and their family caregivers, Schulz and colleagues (2008) assessed the extent to which caregivers' perceptions of patient suffering affected caregiver depression. Suffering was assessed using the depression subscale of the Revised Memory and Behavior Problems Checklist (RMBPC; Teri et al., 1992). Three items assessed emotional distress (anxious, sad, crying), and six items assessed existential distress (worthless, failure, hopelessness, lonely, talking of death, threatened self). Importantly, they controlled for the effects of patient physical and cognitive disability, memory

problems, disruptive behaviors, the amount of care provided by the caregiver, and socio-demographic characteristics. Consistent with their predictions, they found that both emotional and existential suffering were independently associated with caregiver depression and antidepressant medication use cross-sectionally and longitudinally. It is important to note that one cannot make strong claims about directionality in this study because depression and medication use could just as well affect perceptions of partner suffering. In another recent study involving a large sample of elderly married couples, Schulz and colleagues (2009) found evidence that the combination of physical, psychological, and existential distress in a spouse predicts prevalent and incident depression and prevalent cardiovascular disease (CVD) in their partners, independent of known risk factors for depression or CVD. Physical distress was measured by the number of following symptoms reported by the respondent as occurring in the two weeks before the baseline of the study: shortness of breath, dizziness, fatigue, weakness, nausea, abdominal pain, fever, muscle aches, and diarrhea. Existential distress was measured with a single item asking respondents to rate satisfaction with the meaning and purpose of their life. Psychological distress was measured with the CES-D. The additive effects of spouses' exposure to the three different types of suffering was supported by findings demonstrating a dose-response relationship between the number of different types of suffering reported by the spouse and the odds of clinical depression in their partner.

Several additional studies show the combined impact of physical and psychological symptoms in care recipients as predictors of caregiver distress controlling for cognitive and physical impairments in the care recipient. For example, Kornblith, Herr, Ofman, Scher, and Holland (1994) found for prostate cancer patients, the sum of problems with physical symptoms, fatigue/malaise, psychological distress, sexual problems, and impact on the family, was positively related to the sum of these symptoms in spouses. Researchers have also used the Neuropsychiatric Inventory (NPI; Cummings, Mega, Rosenberg-Thompson, Carusi, & Gornbern, 1994) which assesses caregivers' perceptions of various care recipient physical and psychological symptoms of distress (sleep disturbance, agitation, depression, and delusions), to show that these symptoms are associated with caregiver distress beyond care recipients' cognitive and physical impairment (Aarsland, Larsen, Lim, & Tandberg, 1999; Craig, Mirakhor, Hart, McIlroy, & Passmore, 2005; Figved, Kjell-Morten, Larson, & Aarsland, 2007; Kaufer, et al., 1998).

Viewed as a whole, this literature suggests that care recipient suffering with its multiple components influence caregiver outcomes above and beyond the effects of care recipient physical and cognitive disability and amount of care provided. Furthermore, there is evidence that the effects of the multiple components of suffering are additive, as suggested by the dose-response relationships reported by Schulz et al. (2009).

## **The Proposed Model of the Link between Care Recipients' Suffering and Caregivers' Emotions and Psychological and Physical Morbidity**

As illustrated in Figure 1, there are multiple pathways to caregivers' psychological and physical morbidity. The traditional stress health model is illustrated in the top half of Figure 1. In this model, care recipient disease-related factors (operationalized as cognitive and physical disability and problem behaviors) and associated caregiving demands (assistance provided, vigilance demands, time spent caregiving) are viewed as primary sources of stress. These stressors can have direct effects on caregivers' health as well as generate secondary stressors such as family conflict which in turn also affects caregivers' psychological and physical morbidity. However, we believe that an important additional pathway to caregiver's psychological and physical morbidity is missing from the traditional stress-health model: caregivers' exposure to care recipient suffering.

As shown in the bottom half of the model, we propose that care recipient disease-related conditions directly affect care recipients' experience of suffering. Having a disease may cause the care recipient to exhibit suffering behaviors: psychological distress, physical symptoms, and existential/spiritual distress. In addition to having a direct effect on caregivers' stress (e.g. increased assistance, vigilance) the effects of suffering on the caregiver are mediated through three processes which generate similar, complementary, or defensive emotional responses in the caregiver. These processes include cognitive empathy, mimicry and feedback, and conditioned learning. Caregivers may respond to symptoms of suffering with similar or complementary emotions by consciously putting themselves in their partner's place (cognitive empathy). They may automatically experience emotions similar to those they observed (mimicry) or experience similar, complementary, or defensive emotions as a result of conditioned responses evoked by exposure to suffering. Although not illustrated in Figure 1, we also believe that caregiver responses are moderated by gender, relationship closeness, feelings of efficacy in relieving care recipients' suffering, and individual differences in emotion regulation.

## **Mediators of the Link between Care Recipient Suffering and Caregiver Emotions**

Caregivers may often feel similar emotions to those of the care recipients, such as anxiety in response to anxiety, a phenomenon that has been referred to as emotional contagion (Hatfield, et al., 1994; Hatfield et al., 2008). Caregivers may feel complementary emotions such as love in response to care recipient anxiety; complementary emotions are thought to "motivate important social behaviors, including helping, soothing, and forgiveness (Keltner & Kring, 1998, p. 324)". Still others may experience defensive emotional reactions such as anger in response to anxiety, which are aimed at protecting the self against feelings of insecurity or vulnerability. The latter claim is supported by the substantial literature on "expressed emotion" that emphasizes the role of family members' hostile and critical attitudes toward care recipients (Croog, Burleson, Sudilovsky, & Baume, 2006; Wagner, Logsdon, & Pearson, 1997). The type and intensity of emotion elicited by exposure to suffering is determined by both mediators and moderators in our model. Here we explain the processes through which caregivers experience similar, complementary, and defensive emotions.

### **Cognitive Empathy**

Caring for a loved one is likely to influence caregivers' emotions because close relationship partners actively empathize with each other (Bandura, 1969; Stotland, 1969). Care recipients' emotion expression helps caregivers understand how to attend to care recipients' needs and understand whether or not care recipients are satisfied with the care they have received (Graham, et al., 2008; Keltner & Kring, 1998). An important feature of cognitive empathy is that it does not require caregivers to witness emotion expression from care recipients. Caregivers can empathize with care recipients' suffering through imagery, in addition to direct exposure to emotions (Hatfield et al., 1994). For example, people are psychologically and physiologically responsive to experimental conditions in which they are asked to imagine the emotions of others or to talk about emotional situations with others (Eisenberg et al., 1991; Vitaliano, Russo, Bailey, Young, & McCann, 1993). Cognitive empathy may result in the experience of similar emotions to the care recipient, such as personal distress, as well as complementary emotions, such as love, empathic sadness, or concern in response to care recipient distress (Eisenberg et al., 1991; Omdahl & O'Donnel, 1999).

### **Mimicry and Feedback**

Research also suggests that innate mimicry mechanisms can generate similar emotions to those observed in others. Two types of mechanisms have been proposed for generating similar

emotions. One focuses on afferent feedback from facial, verbal, and body movement. The other argues that a cortical neural network is activated by merely observing emotion in another person.

There is evidence that in conversation people tend automatically and continuously to mimic the facial expressions (Adelmann & Zajonc, 1989), voices (Capella & Planalp, 1981), and body movements (Bavelas, Black, Chovil, Lemery, & Mullett, 1988) of others. It has been proposed that subjective emotional experiences are affected, moment to moment, by the activation and/or feedback from such mimicry (Niedenthal, 2007). For example, according to the “facial feedback hypothesis”, when facial muscles move, they produce afferent feedback, which plays a primary causal role in generating and shaping emotions (e.g. Buck, 1980; Izard, 1971; Laird, 1974; Lanzetta, Cartwright-Smith & Kleck, 1976; Tomkins, 1984). People can experience emotions consistent with the configuration of their facial muscles, without being consciously aware of the face they are making. For example, Strack, Martin, and Stepper (1988) had students hold pens between their teeth (activating the zygomatic smile muscles) and showed that these students rated a series of cartoons as funnier when the pen was between their teeth than between their lips (forming a “pout”) or in their hands. Similarly, Levenson, Ekman, and Friesen (1990) gave muscle by muscle instructions to participants, some of which produced prototypical emotional expressions. They found that participants who received these instructions reported feeling the emotion associated with the combination of the facial movements at greater than chance levels. Also, the associated emotion was reported most often when the instructed movements were produced most accurately (i.e., the resulting expression was closest to the emotion prototype). In addition to emotional experience, there were also autonomic nervous system changes appropriate to the associated emotion (e.g. increased heart rate when making an angry expression), and these autonomic changes were pronounced when the facial movements most closely resembled the emotion prototype.

Neuroscientists have recently proposed a direct neural mechanism through which people experience the emotions of others. This proposal was based on the discovery in macaque monkeys that a set of neurons (called “mirror neurons”) representing a particular goal-oriented action responded when they observed another individual performing a similar action (Gallese, Fadiga, Fogassi, & Rizzolatti, 1996; Rizzolatti, Fadiga, Gallese, & Fogassi, 1996). Several studies using different methodologies have shown the same effects with humans (see Rizzolatti, Fogassi, & Gallese, 2001 for a review). The core of this proposition is that the observation of a particular action leads to the activation of parts of the same cortical neural network that is active during its execution. Gallese, Keysers, and Rizzolatti (2004) proposed that a similar mechanism is involved in the capacity to understand and experience the emotional states of others. Consistent with this proposition, Carr, Iacoboni, Dubeau, Mazziotta, and Lenzi (2003) have shown activation of the anterior insula, an area associated with the formation and experience of one’s own emotions during the observation and imitation of facial expressions of basic emotions (happy, sad, angry, surprise, fear). There is also evidence that this occurs for the experience of others’ pain. Singer and colleagues (2004) found that the anterior insula and rostral anterior cingulate cortex activate in response to both the direct experience of a painful stimulus and when observing a loved one in pain. Thus, there is increasing evidence that people experience the emotions and pain they observe in others in a similar manner to the way they experience their own emotions and pain. We suggest that this has important implications for emotional lives of caregivers because they are likely to witness expressions of suffering on a daily basis.

### **Conditioned Emotional Responses**

Caregivers may experience emotions in reaction to care recipients’ suffering behaviors because of past experiences and memories associated with those behaviors (Aronfreed, 1970; Klinnert,

Campos, Sorce, Emde, & Sveida, 1983). In other words, a care recipient's suffering may be paired with negative consequences for both him/herself as well as a caregiver. In subsequent interactions this may condition the viewer to feel distressed when the other person is suffering. In the context of caregiving, witnessing a loved one suffer may bring up memories and feelings from past experiences that were painful or frightening for caregivers, such as the loss of another close family member or a bad experience at the hospital. Not only are caregivers likely to be conditioned to feel similar emotions to their loved one, such as anxiety in response to anxiety, they may also be conditioned to feel complementary emotions, such as love or empathic concern, or more defensive emotions, such as anger in response to distress. These different emotional reactions to care recipient suffering may stem from caregivers' attachment history, or the extent to which others have been responsive to the caregivers' needs and own emotion expression over time (Bowlby, 1969/1982). Some caregivers feel the need to protect the self when witnessing care recipients' negative emotions; whereas others feel more secure in their caregiving role and better able to focus on the needs of the care recipients (Rholes et al., 1999). However, as evidenced by the results of the numerous studies showing a positive association between care recipient and caregiver psychological distress, caregivers' experience of complementary emotions may be a less frequent or secondary response to care recipient suffering than the experience of similar emotions.

## **Moderators of the Link between Care Recipients' Suffering and Caregivers' Emotions**

Numerous factors may influence the extent to which one person's suffering impacts another person's emotions. Here we highlight factors that are likely to be relevant in the context of caregiving. These include (1) the gender of the caregiver, (2) the closeness of the relationship, (3) the caregivers' efficacy of relieving care recipient suffering, and (4) individual differences in the caregiver's emotion regulation. Considering these moderators may help researchers identify those who are at a greater risk for negative emotional reactions and psychological and physical morbidity.

### **Gender**

Female caregivers may be affected more by care recipients' suffering than male caregivers for several reasons. First, women pay more attention to others. From birth, girls seem to be much better at decoding emotions than boys are (Haviland & Malatesta, 1981), they are more likely to maintain eye contact with others (Haviland & Malatesta, 1981; Hittelman & Dickes, 1979), and at age four years and older, they are better at processing, storing, and retrieving social stimuli such as faces, names, and voices (Feldstein, 1976; Haviland & Malatesta, 1981). In a review of 125 studies, Hall (1978) found that at all ages, women are better than men at reading nonverbal expressions of emotion. Second, women are more likely to mimic others' facial expressions and posture than men are (Eisenberg & Lennon, 1983), and are more likely to experience the emotion of others (Doherty, Orimoto, Singelis, Hebb, & Hatfield, 1995). Robles and Kiecolt-Glaser (2003) conclude in a review of multiple studies that women are more physiologically responsive to marital conflict than men are, and women show more cardiovascular reactivity than men in response to relational events in general (Bloor, Uchino, Hicks, & Smith, 2004; Nealy, Smith, & Uchino, 2002).

The differences between male and female caregivers' sensitivity to their partners' emotions are important to take into account because it suggests that female caregivers are at a higher risk for suffering the negative consequences of providing care to their loved ones. Indeed caregiving studies show that female caregivers are more distressed than male caregivers (Lutzky & Knight, 1994; Yee & Schulz, 2000).

## Closeness of the Relationship

People, and even non-primate mammals, are more likely to converge emotionally, or empathize, with those with whom they have a close relationship. Langford and colleagues (2006) found that mice who were exposed to cage-mates in pain also displayed pain behaviors themselves, but this did not occur for mice that were not their cage-mates. And, although these effects were marginally enhanced in same-sex siblings living together, a separate experiment confirmed that close genetic relatedness was not required. Thus, it seems that closeness or familiarity, (operationalized as being a cage-mate), but not necessarily genetic similarity moderated emotional contagion.

But what about humans? Batson, Turk, Shaw, and Klein (1995) theorized that empathic feelings arise when a person values another's welfare and perceives the other to be in need. Consistent with their theory, they found that a similarity manipulation led to increased valuing of a similar person's welfare and, in turn, to increased empathy when this person was in need. Direct manipulations of empathy (perspective-taking instructions, or false physiological arousal feedback) led to increased self-reported empathy and, in turn, to increased valuing of the welfare of the person in need. Also, Block (1981) found that marital satisfaction, which is related to closeness, had an effect on emotional contagion, such that spouses who were more satisfied with their marriages, showed greater increases in skin conductance to painful displays of their mates than did unsatisfied spouses. Tower and Kasl (1995, 1996) also demonstrated that greater marital closeness was associated with greater emotional contagion of depressive symptoms among elderly, community-dwelling spouses. Thus, research suggests that caregivers who feel close to their partners share their partner's experience of suffering more intensely.

## Efficacy of Relieving Care Recipient Suffering

The extent to which a caregiver is able to alleviate his or her loved one's suffering is likely to affect the caregiver's emotions. If a caregiver feels that he/she is not able to help his or her partner alleviate adverse physical and psychological symptoms or help the partner feel at peace with his/her condition, because of the nature of the partners' disease or because of other uncontrollable circumstances, the caregiver may feel helpless and distressed or become clinically depressed. Consistent with this idea is the finding that beliefs about uncontrollability of pain among cancer patients and their family caregivers are associated with more symptoms of distress and more caregiver burden (Riley-Doucet, 2005). Furthermore, caregivers vary considerably in their perceptions of their own abilities to help cancer patients manage pain (Blood, Simpson, Dineen, Kauffman, & Raimondi, 1994; Carey, Oberst, McCubbin, & Hughes, 1991; Danielson, Hamel-Bissell, & Winstead-Fry, 1992), and caregivers' perceptions of low self-efficacy of helping partners manage pain is associated with more caregiving strain as well as increased negative mood and decreased positive mood (Keefe et al., 2003; Zeiss, Gallagher-Thompson, Lovett, Rose, & McKibbin, 1999). Hagedoorn, Sanderman, Buunk, and Wobbles (2002) showed similar findings, but only for women. They argue that self efficacy of caregiving abilities is particularly important for women because caregiving is a more identity relevant stressor for them than it is for men.

If caregivers are able to relieve their partners' suffering, this is likely to increase feelings of competency and mastery while also increasing their partners' well-being and positive emotions. This can, in turn, feed back to the caregiver (Monin, Martire, Schulz, & Clark, 2009). A large literature shows that caregiving has negative consequences for caregivers, but there is increasing evidence that helping a care recipient, under some circumstances, can have positive effects on caregiver well-being (Beach, Schulz, Yee & Jackson, 2000; Brown & Brown, 2006; Brown, Nesse, Vinokur, & Smith, 2003; Brown et al., in press). From our

perspective, the benefits of helping should be maximized when they effectively relieve the suffering of another person.

### Caregivers' Emotion Regulation

Although it is theorized that normatively people feel some amount of personal distress when watching or imagining a loved one suffer, not everyone is able to regulate this distress equally well. For example, in research with children and adults, Eisenberg and colleagues emphasized the distinction between sympathy (a concern for the other person's well-being) and personal distress (preoccupation with one's own negative feelings) reactions to empathy-eliciting situations (Eisenberg et al., 1988; Eisenberg et al., 1989; Shortt & Pennebaker, 1992; Wiesenfeld, Whitman, & Malatesta, 1984). They found that participants' self reports and facial expressions of sympathy are linked to a specific pattern of physiological activity, heart rate deceleration (which indicates attention to external stimuli) and high heart rate variability (which has been associated with positive psychological and physical health outcomes); whereas personal distress is linked with a heightened cardiac stress response. This has implications not only for family caregivers' well-being, but also for professional caregivers such as nurses, social workers, and clinical psychologists. Research indicates that personal distress is associated with caregiver burnout in nurses, whereas empathic concern is not (Omdahl & O'Donnell, 1999). There is also an emerging literature that suggests that psychotherapists who work with chronically ill individuals often experience "compassion fatigue" from caring for, empathizing with, and emotionally investing in the suffering of their clients. Figley (2002) argues that empathy and emotional energy are the driving force in effective work with those who are suffering. However, noticing and responding to the pain of the client (often achieved through projecting the self into the client's position) can result in stress that can be relieved through successful treatment of or distancing the self from the client between sessions or exacerbated by prolonged exposure to the client, traumatic recollections from other experiences, and life disruption caused from outside sources.

Empathic concern or personal distress may not be caregivers' only reactions to their loved ones' suffering. Caregivers may be non-reactive or angry as a result of defensive strategies, such as motivated cognition. One example of this is the tendency for people to believe in a "just world" which leads to a number of strategies to reduce threats in the environment (Lerner, 1980). Lerner and Simmons (1966) found that when presented with a victim who suffered through little fault of her own (i.e., an innocent victim), people recognized the unfairness of the situation and were motivated to respond with compassion. However, when faced with the expectation that the victim would continue to suffer, people derogated the victim's character, suggesting that the victim deserved the punishment she received. In line with this thinking, some caregivers may protect themselves from feeling distress by finding fault with the partner. For example, one could imagine a caregiver saying, "He knows he shouldn't be lifting such heavy things. He is just being stubborn. It is his own fault he is in pain."

Caregivers may not only protect themselves through "just world" beliefs. Research suggests that people have the capacity to make overly positive self evaluations, exaggerating perceptions of control and mastery, and to be unrealistically optimistic (Taylor & Brown, 1988). The extent to which unrealistic optimism actually benefits caregivers is not clear however. For example, Martire and colleagues (2006) found that spouses who were more accurate in their perceptions of their partners' level of pain during a pain eliciting log-carrying task reported less stress from providing support and assistance.

### Future Research and Implications for Interventions

First and foremost, future research on the health effects of caregiving should not only examine the effects of care recipient functional impairment and behavioral problems (and the associated

caregiver demands), but the effects of care recipient suffering on the caregivers' emotions and health. In doing so, it will be important for researchers to show that care recipient suffering contributes to caregiver outcomes, above and beyond the effects of demographic characteristics (e.g., age, gender, race, SES) and health-related factors (e.g., cognitive and physical impairment, dependencies with activities of daily living). A related goal should be to demonstrate the independent effects of different components of suffering. Although we would expect the three components of suffering to be moderately correlated, it will nevertheless be important to assess the additive or synergistic effects of the three discrete components of suffering (psychological distress, physical symptoms, and existential/spiritual distress) on caregiver emotions and associated morbidity, as demonstrated by Schulz and colleagues (2009). Addressing these questions will require additional research on the conceptualization and measurement of suffering. There is still considerable debate about what elements are necessary and common to most people's experiences, expressions, and perceptions of suffering. For example, are features such as controllability, responsibility, and fairness central to suffering, or should they be viewed as moderators of suffering?

Second, future research should explore the role of key moderators of the effects of suffering on caregiver outcomes, including the gender of the caregiver, the closeness of the relationship, caregiving efficacy, and individual differences in the ability of caregivers to regulate their emotions effectively. This will help researchers and clinicians identify who is at increased risk for experiencing the negative effects of their partners' suffering.

Third, it is important to explore the role of suffering when measured from both care recipient and caregivers' perspectives. A central question to address concerns the concordance between care recipients' and caregivers' assessment of care recipient suffering and how this affects caregiver and care recipient outcomes. As suggested by Schulz and colleagues (2007), 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 may be expected. Alternatively, there might be situations in which individuals are considered to be exaggerating or dramatizing their suffering for secondary gains. These scenarios are likely to have different implications for the type and quality of support that caregivers provide.

Fourth, in order to better understand the interpersonal effects of suffering, it is important to view this construct from an adult developmental perspective. For example, according to socioemotional selectivity theory, older individuals selectively prune their relationships and maintain those that are emotionally meaningful to them, resulting in smaller social networks (Carstensen, 1994). Emotionally meaningful relationships are thought to be conducive to positive emotional experiences; however, according to our view, a small network of emotionally close individuals also has greater potential for generating distress or negative affect when those network members experience suffering. Investing in emotionally meaningful relationships is a double-edged sword; it increases opportunities for both positive and negative emotions. As long as network members are healthy and happy they should generate positive emotional experiences, but when illness-related suffering increases, the pendulum swings more toward negative emotional experiences. In addition, a homogeneous constrained social network may limit access to information and resources that might help an older individual cope with the suffering of a close relative. Predictions that follow from this analysis are that over time the potential for negative emotional experiences increases among older individuals and that small homogeneous networks are likely to be less adaptive than larger diverse networks in coping with negative emotional experiences.

Research on age-related identity and stereotypes also has implications for interpersonal effects of suffering. It is generally believed that disease and disability are a normative part of the aging process. For example, older adults are more likely to define the self in terms of the status of

their health (Hooker, 1992), and older adults are generally viewed as less healthy than younger adults (Gekoski & Knox, 1990). Frazier and Hooker (2006) suggest that the acknowledgement of health for one's identity helps older adults adapt to and cope with disease and disability because it reflects acceptance of their condition. By extension, older individuals may view suffering as normative when it occurs in the context of late life disease and disability. This may in turn diminish the interpersonal effects of being exposed to suffering. Although young adults also view aging as being associated with declining health, they lack the first-hand experience of health decline and suffering and may therefore find it more difficult to cope with exposure to suffering in others.

What might control theory (Heckhausen & Schulz, 1993,1995; Schulz & Heckhausen, 1996) say about how aging influences caregivers' reactions to care recipients' suffering? The lifespan theory of control claims that striving for primary control -- achieving effects in the external environment (White, 1995) -- is a constant and universal motivational drive throughout the life course. However, as individuals' capacity for primary control declines in old age, they increasingly resort to secondary control strategies of adjusting expectations, values, and attributions to cope with threats to their ability to exert primary control. For older caregivers exposed to their partners' suffering, the initial response is to control or alleviate the symptoms of suffering in their relative; if this fails, secondary control strategies such as blaming the victim or diminishing the perceived intensity of suffering may be invoked. However, these strategies are difficult to apply under circumstances where suffering is the result of normative age-related conditions. As a result, we would predict that the inability to have an impact on symptoms of suffering represents a fundamental erosion of primary control for the caregiver and should be associated with intense and lasting negative affect.

Our views on suffering also point toward new approaches to interventions for family caregivers. A wide variety of caregiver intervention programs have been developed and implemented to provide respite care, home alterations, and skills training to the caregiver, often based on the assumption that caregiver psychological and physical morbidity is due to the pragmatics of providing physical care to relatives with functional impairment (National Caregiver Support Program, 2006). However, equal emphasis should be placed on helping caregivers minimize their loved ones' suffering as well as helping them cope with those aspects of suffering that are not under their control.

For example, Problem Solving Therapy (PST; D'Zurilla & Chang, 1995; Nezu, Nezu, & Perri, 1989) may be particularly effective in diminishing caregivers' distress by allowing caregivers the opportunity to: (a) identify specific behaviors or symptoms that lead to the perception that the care recipient is suffering, (b) determine which suffering symptoms caregivers can help minimize or alleviate, and (c) come to terms with those aspects of care recipients' suffering that are out of caregivers' control. Identifying specific suffering behaviors, rather than focusing on suffering as a global and uncontrollable fact of life may make it easier for caregivers to help their partners in concrete ways (e.g. reminding their partner to take their pain medication or engaging their partner in activities that elevate their mood). By helping their partners, caregivers are likely to receive benefits not only because the care recipient's well-being is improved (thus decreasing the effects of negative emotional contagion), but also because the act of helping a loved one is fulfilling in its own right. Recent findings suggest that supporting or helping others may be just as beneficial to health as receiving support (Beach et al., 2000; Brown & Brown, 2006; Brown et al., 2003; Brown et al., in press).

In cases where caregivers are not able to fully alleviate the care recipient's suffering, other therapeutic strategies may be useful. For example, increasing attention has been given to therapies that induce mindfulness, which involves (1) the self-regulation of attention maintained on the immediate experience that allows for increased recognition of mental events

in the present moment and (2) an orientation toward one's experience in the present moment that is characterized by curiosity, openness, and acceptance (Bishop et al., 2004). Instead of suppressing or ruminating on one's emotional experience, both of which can be harmful to a person's psychological and physical health (Hayes & Feldman, 2004), mindfulness meditation is hypothesized to develop a distanced or "decentered" relationship with one's internal and external experiences, to decrease emotional reactivity, and to facilitate a return to baseline after reactivity. This approach stems from Buddhist traditions developed as a path leading to the cessation of personal suffering (Thera, 1962; Silananda, 1990), and it has been found to be effective in reducing psychological morbidity associated with medical illness (e.g. Reibel, Greenson, Brainard & Rosenzweig, 2001; Specia, Carlson, Goodey & Angen, 2001) and the mitigation of stress and enhanced emotional well-being in non-clinical samples (e.g. Astin, 1997). This type of therapy may be particularly useful for caregivers in helping them distance themselves from, but not avoiding or suppressing feelings of distress in reaction to the partner's suffering. Mindfulness training may help foster empathic concern or sympathy in caregivers rather than rumination or inner conflict with one's own personal distress. As suggested by Eisenberg and colleagues (e.g. Eisenberg et al., 1988) and nursing researchers (e.g. Omdahl & O'Donnell, 1999), feeling personal distress is associated with increased caregiver stress and burnout; whereas, empathic concern (concern for the well-being of the other person without sharing the other person's emotional state) is associated with feelings of personal accomplishment and prosocial behavior. Thus, therapies that allow caregivers to acknowledge their negative feelings but not become overwhelmed by them are likely to have positive outcomes for both caregivers and their partners.

Mindfulness therapy may also help caregivers who are dealing with suffering that is not being experienced in the "here and now", for example, bereaved spouses experiencing traumatic grief (Prigerson et al, 1999). For some people, the death of a loved one can be particularly difficult, causing them to experience a pathological form of grief that includes intrusive thoughts about the suffering of their loved one. Because it is no longer an option for the bereaved individual to alleviate the partner's suffering, the individual must come to terms with negative emotions he or she is experiencing. Mindfulness therapy may be an effective coping tool in this situation.

For those dealing with suffering in ongoing caregiving relationships, interventions that simultaneously focus on both caregivers and care recipients may be more effective than interventions that focus on the caregiver only. Two recent meta-analyses show that dyadic approaches that include both patients and their spouses in a psycho-social interventions for chronic disease are more effective than interventions solely focused on patients (Martire, 2005) or typical medical care (Martire, Lustig, Schulz, Miller, & Helgeson, 2004). Couple interventions have also been effective in disease involving pain (Keefe et al., 1996, 1999). Berg and Upchurch (2007) suggest that interventions situated within the dyadic coping perspective (Bodenmann, Charvoz, Cina, & Widmer, 2003; Widmer, Cina, Charvoz, Shantinah, & Bodemann, 2005) that focus on understanding the other person's perspective regarding stress, couple communication, mutual problem-solving skills, and coordination and collaboration regarding daily management tasks will help both care receivers and caregivers with their distress.

In sum, we support existing interventions strategies that emphasize providing assistance with the pragmatics of caregiving, but at the same time argue that these approaches be augmented with strategies that address issues of care recipient suffering and its impact on caregiver emotions. Existing therapeutic interventions such as problem solving therapy and mindfulness interventions could be adapted to address specific symptoms of suffering as well as help the caregiver come to terms with the limits of their ability to impact the suffering of others. A dyadic or couples-oriented approach to implementing these strategies might be particularly effective in achieving positive effects for both care recipient and caregiver.

## Conclusion

The expression of suffering can be adaptive in that it communicates a need for support and enables others to attend to and respond to a person's needs (Clark & Finkel, 2004; Clark, et al., 2001; Graham, et al., 2008; Martire, et al., 2006; Monin et al., 2009). However, in this paper we have made the case and presented evidence that chronic exposure to the suffering of others can also take a toll on a caregiver. Specifically, we draw from existing theory to propose that caregivers often experience negative emotions in reaction to care recipient suffering. Importantly, we believe that this direct spread of suffering from one person to another is an understudied pathway that can shed light on the widespread phenomenon that caregiving is deleterious for the caregivers' psychological and physical health. This paper takes an important step by applying diverse perspectives on emotion to understand the effects of suffering in an interpersonal context. It addresses Hatfield and colleagues (2008) suggestion that researchers pay attention to which *people* and in what kinds of *relationships* people are most vulnerable to emotional contagion. We suggest that caregivers are particularly vulnerable to emotional contagion because of chronic exposure to the suffering of a loved one. By enhancing our understanding about processes that lead to similar, complementary and defensive emotions within caregiving relationships, we are likely to identify strategies for improving caregiver and care recipient outcomes. The ultimate goal of this research is to reduce suffering and its effects on family members.

## Acknowledgments

Preparation of this article was supported in part by grants from the Alzheimer's Association, the National Institute of Nursing Research (NR08272, NR0009573), the National Institute of Mental Health (MH071944), the National Heart, Lung, and Blood Institute (HL076852, HL076858), the National Science Foundation (EEEC-0540865), and the National Institute on Aging (F32 AG031635-01A2). We would like to thank Martin Greenberg and Lynn Martire for comments on an earlier draft and Jennifer Morse for her insight concerning clinical implications.

## References

- Aarsland D, Larsen JP, Lim NG, Tandberg E. Mental symptoms in Parkinson's disease are important contributors to caregiver distress. *International Journal of Geriatric Psychiatry* 1999;14:866–874. [PubMed: 10521886]
- Adelmann PK, Zajonc RB. Facial efference and the experience of emotion. *Annual Review of Psychology* 1989;40:249–280.
- Ahern DK, Adams AE, Follick MJ. Emotional and marital disturbance in spouses of chronic low back pain patients. *The Clinical Journal of Pain* 1985;1:69–74.
- Aminoff BZ, Adunsky A. Measuring the suffering of end-stage dementia: Reliability and validity of the Mini-Suffering State Examination. *Archives of Gerontology and Geriatrics* 2004;38(2):123–130. [PubMed: 14698490]
- Aronfreed, J. The socialization of altruistic and sympathetic behavior: Some theoretical and experimental analyses. In: Macauly, J.; Berkowitz, L., editors. *Altruism and helping behavior*. New York: Academic Press; 1970. p. 103-126.
- Astin J. Stress reduction through mindfulness meditation: Effects on psychological symptomatology, sense of control, and spiritual experiences. *Psychotherapy and Psychosomatics* 1997;66:97–106. [PubMed: 9097338]
- Bambauer KZ, Zhang B, Maciejewski PK, Sahay N, Pirl WE, Block SD, et al. Mutuality and specificity of mental disorders in advanced cancer patients and caregivers. *Social Psychiatry and Epidemiology* 2006;41:819–824.
- Bandura, A. *Principles of behavior modification*. New York: Holt, Rinehart & Winston; 1969.
- Bandura A, Rosenthal TL. Vicarious classical conditioning as a function of arousal level. *Journal of Personality and Social Psychology* 1966;3:54–62. [PubMed: 5902077]

- Batson CD, Turk CL, Shaw LL, Klein TR. Information function of empathic emotion: Learning that we value the other's welfare. *Journal of Personality and Social Psychology* 1995;68:300–313.
- Bavelas JB, Blak A, Chovil N, Lemery CR, Mullett J. Form and function in motor mimicry: Topographic evidence that the primary function is communication. *Human Communication Research* 1981;14:275–299.
- Beach SR, Schulz R, Yee JL, Jackson S. Negative and positive health effects of caring for a disabled spouse: Longitudinal findings from the Caregiver Health Effects Study. *Psychology and Aging* 2000;15:259–271. [PubMed: 10879581]
- Beck AT, Rial WY, Ricketts K. Short form of Depression Inventory: Cross-validation. *Psychological Reports* 1974;34:1184–1186. [PubMed: 4424377]
- Berg CA, Upchurch R. A developmental-contextual model of couples coping with chronic illness across the adult life span. *Psychological Bulletin* 2007;133(6):920–954. [PubMed: 17967089]
- Berger SM. Conditioning through vicarious instigation. *Psychological Review* 1962;69:450–466. [PubMed: 13867454]
- Bishop SR, Lau M, Shapiro S, Carlson L, Anderson ND, Carmody J, et al. Mindfulness: A proposed operational definition. *Clinical Psychology: Science and Practice* 2004;11:230–241.
- Black, HK. *Soul Pain: The meaning of suffering in later life*. New York: Baywood; 2006.
- Black HK, Rubinstein RL. Themes of suffering in later life. *Journal of Gerontology: Social Sciences* 2004;59B(1):S17–S24.
- Black HK, Rubinstein RL. The effect of suffering on generativity: Accounts of elderly African American men. *Journal of Gerontology: Social Sciences* 2009;64(2):296–303.
- Block AR. Investigation of the response of the spouse to chronic pain behavior. *Psychosomatic Medicine* 1981;43:415–422. [PubMed: 7313033]
- Blood GW, Simpson KC, Dineen M, Kauffman SM, Raimondi SC. Caregivers of individuals with laryngeal cancer: caregiver strain and burden. *Journal of Communication Disorders* 1994;27:19–35. [PubMed: 8006204]
- Bloor LE, Uchino BN, Hicks A, Smith TW. Social relationships and physiological function: The effects of recalling social relationships on cardiovascular reactivity. *Annals of Behavioral Medicine* 2004;28(1):29–38. [PubMed: 15249257]
- Bodenmann G, Charvoz L, Cina A, Widmer K. Prevention of marital distress by enhancing the coping skills of couples: 1 year follow-up study. *Swiss Journal of Psychology* 2003;60:3–10.
- Bookwala J, Schulz R. Spousal similarity in subjective well-being: The Cardiovascular Health Study. *Psychology and Aging* 1996;11(4):582–590. [PubMed: 9000291]
- Bowlby J. Attachment and loss: Retrospect and prospect. *American Journal of Orthopsychiatry* 1982/1969;52(4):664–678. [PubMed: 7148988]
- Breitbart W, Gibson C, Tremblay A. The delirium experience: Delirium recall and delirium-related distress in hospitalized patients with cancer, their spouses/caregivers, and their nurses. *Psychosomatics* 2002;43:183–194. [PubMed: 12075033]
- Brown SL, Brown RM. Selective investment theory: Recasting the functional significance of close relationships. *Psychological Inquiry* 2006;17:1–29.
- Brown SL, Nesse RM, Vinokur AD, Smith DM. Providing support may be more beneficial than receiving it: results from a prospective study of mortality. *Psychological Science* 2003;14(4):320–327. [PubMed: 12807404]
- Brown SL, Smith DM, Schulz R, Kabeto MU, Ubel PA, Poulin M, Yee J, Kim C, Langa KM. Caregiving behavior is associated with decreased mortality risk. *Psychological Science*. (in press).
- Bruera E, Kuehn N, Miller MJ, Selmsler P, Macmillan K. The Edmonton Symptom Assessment System (ESAS): A simple method for the assessment of palliative care patients. *Journal of Palliative Care* 1991;1:6–9. [PubMed: 1714502]
- Buck R. Nonverbal behavior and the theory of emotion: The facial feedback hypothesis. *Journal of Personality and Social Psychology* 1980;38:811–824. [PubMed: 7381683]
- Burton L, Zdaniuk B, Schulz R, Jackson S, Hirsch C. Transitions in spousal caregiving. *The Gerontologist* 2003;43:230–241. [PubMed: 12677080]

- Capella JN, Planalp S. Talk and silence sequences in informal conversations: III interspeaker influence. *Human Communication Research* 1981;7:117–132.
- Carey PJ, Oberst MT, McCubbin MA, Hughes SH. Appraisal and caregiving burden in family members caring for patients receiving chemotherapy. *Oncology Nursing Forum* 1991;18:1341–1348. [PubMed: 1762974]
- Carr AJ, Higginson IJ. Measuring quality of life: Are quality of life measures patient centred? *British Medical Journal* 2001;322:1357–1360. [PubMed: 11387189]
- Carr L, Iacoboni M, Dubeau MC, Mazziotta JC, Lenzi GL. Neural mechanisms of empathy in humans: a relay from neural systems for imitation to limbic areas. *Proceedings from the National Academy of Science, U. S. A* 2003;100:5497–5502.
- Carstensen LL. Social and emotional patterns in adulthood: support for socioemotional selectivity theory. *Psychology and Aging* 1992;7:331–338. [PubMed: 1388852]
- Cassell EJ. The nature of suffering and the goals of medicine. *New England Journal of Medicine* 1982;306:639–645. [PubMed: 7057823]
- Cassell EJ. Diagnosing suffering: A perspective. *Annals of Internal Medicine* 1999;131:531–534. [PubMed: 10507963]
- Cassell, EJ. *The nature of suffering and the goals of medicine*. 2nd ed.. New York: Oxford University Press; 2004.
- Cherny N. The problem of inadequately relieved suffering. *Journal of Social Issues* 1996;52:13–30. [PubMed: 15154422]
- Christakis N, Allison PD. Mortality after the hospitalization of a spouse. *New England Journal of Medicine* 2006;354:719–730. [PubMed: 16481639]
- Clark, MS.; Finkel, EJ. Does expressing emotion promote well-being? It depends on relationship context. In: Tiedens, LZ.; Leach, CW., editors. *The social life of emotions*. Cambridge University Press; 2004. p. 105-128.
- Clark, MS.; Fitness, J.; Brissette, I. Understanding people's perceptions of relationships is crucial to understanding their emotional lives. In: Brewer, MB.; Hewstone, M., editors. *Emotion and motivation*. Malden, MA: Blackwell Publishing; 2001. p. 21-46.
- Copp LA. The nature and prevention of suffering. *Journal of Professional Nursing* 1990;6:247–249. [PubMed: 2229712]
- Coyle, N. Suffering in the first person: Glimpses of suffering through patient and family narratives. In: Ferrel, BR., editor. *Suffering*. Sudbury, MA: Jones & Bartlett; 1996. p. 29-64.
- Craig KD, Lowery HJ. Heart-rate components of conditioned vicarious autonomic responses. *Journal of Personality and Social Psychology* 1969;11:381–387. [PubMed: 5787026]
- Craig D, Mirakhor A, Hart DJ, McIlroy SP, Passmore AP. A cross-sectional study of neuropsychiatric symptoms in 435 patients with Alzheimer's disease. *American Journal of Geriatric Psychiatry* 2005;13:460–468. [PubMed: 15956265]
- Craig KD, Weinstein MS. Conditioning vicarious affective arousal. *Psychological Reports* 1965;17:955–963. [PubMed: 5854280]
- Craig KD, Wood K. Physiological differentiation of direct and vicarious affective arousal. *Canadian Journal of Behavioral Science* 1970;1:98–105.
- Croog SH, Burlison JA, Sudilovsky A, Baume RM. Spouse caregivers of Alzheimer patients: Problem responses to caregiver burden. *Aging & Mental Health* 2006;10:87–100. [PubMed: 16517483]
- Cummings JL, Mega M, Rosenberg-Thompson S, Carusi DA, Gornbein J. The Neuropsychiatric Inventory: Comprehensive assessment of psychopathology in dementia. *Neurology* 1994;44:2308–2314. [PubMed: 7991117]
- Danielson, CB.; Hamel-Bissell, B.; Winstead-Fry, P. *Families, health, and illness*. St. Louis, MO: Mosby; 1992.
- Dar R, Beach CM, Barden PL, Cleeland CS. Cancer pain in the marital system: A study of patients and their spouses. *Journal of Pain and Symptom Management* 1992;7:87–93. [PubMed: 1573290]
- Derogatis LR, Melisaratos N. The brief symptom inventory: An introductory report. *Psychological Medicine* 1983;13:595–605. [PubMed: 6622612]

- Doherty RW, Orimoto L, Singelis TM, Hebb J, Hatfield E. Emotional contagion: Gender and occupational differences. *Women's Psychology Quarterly* 1995;18:355–371.
- Drinka TJK, Smith JC, Drinka PJ. Correlates of depression and burden for informal caregivers of patients in a geriatrics referral clinic. *Journal of the American Geriatrics Society* 1987;35:522–525. [PubMed: 3553288]
- Druley JA, Stephens MA, Martire LM, Ennis N, Wojno WC. Emotional congruence in older couples coping with wives' osteoarthritis: Exacerbating effects of pain behavior. *Psychology and Aging* 2003;18(3):406–414. [PubMed: 14518804]
- D'Zurilla TJ, Chang EC. The relations between social problem solving and coping. *Cognitive Therapy and Research* 1995;19(5):547–562.
- Eisenberg N, Fabes RA, Schaller M, Miller P, Carlo G, Poulin R, Shea C, Shell R. Personality and socialization correlates of vicarious emotional responding. *Journal of Personality and Social Psychology* 1991;61:459–470. [PubMed: 1941517]
- Eisenberg N, Lennon R. Sex differences in empathy and related capacities. *Psychological Bulletin* 1983;94:100–131.
- Eisenberg N, Fabes RA, Bustameante D, Mathy RM, Miller PA, Lindholm E. Differentiation of vicariously induced emotional reactions in children. *Developmental Psychology* 1988;24:237–246.
- Eisenberg N, Fabes RA, Miller PA, Fultz J, Shell R, Mathy RM, Reno RR. Relation of sympathy and personal distress to prosocial behavior: A multimethod study. *Journal of Personality and Social Psychology* 1989;57:55–66. [PubMed: 2754604]
- Feldstein JH. Sex differences in social memory among preschool children. *Sex Roles* 1976;2:75–79.
- Ferrell, B.; Coyle, N. *The nature of suffering and the goals of nursing*. New York: Oxford University Press; 2008.
- Ferrell BR, Grant M, Dean GE, Funk B, Ly J. "Bone Tired": The experience of fatigue and its impact on quality of life. *Oncology Nursing Forum* 1996;23:1539–1547.
- Figley CR. Compassion fatigue: Psychotherapists' chronic lack of self care. *Journal of Clinical Psychology* 2002;58:1433–1441. [PubMed: 12412153]
- Figved N, Kjell-Morten M, Larsen J, Aarsland D. Caregiver burden in multiple sclerosis: The impact of neuropsychiatric symptoms. *Journal of Neurology, Neurosurgery, and Psychiatry* 2007;78:1097–1102.
- Frazier, LD.; Hooker, K. Possible selves in adult development: Linking theory and research. In: Dunkel, C.; Kerpelman, J., editors. *Possible Selves: Theory, Research, and Applications*. Nova Science Publishers; 2006. p. 41-59.
- Frijda NH. The laws of emotion. *American Psychologist* 1988;43:349–358. [PubMed: 3389582]
- Gallagher TJ, Wagenfeld MO, Baro F, Haepers K. Sense of coherence, coping and caregiver role overload. *Social Science & Medicine* 1994;39:1615–1622. [PubMed: 7846558]
- Gallese V, Fadiga L, Fogassi L, Rizzolatti G. Action recognition in the premotor cortex. *Brain* 1996;119:593–609. [PubMed: 8800951]
- Gallese V, Keysers C, Rizzolatti G. A unifying view of the basis of social cognition. *Trends in Cognitive Sciences* 2004;8:396–403. [PubMed: 15350240]
- Gekoski WL, Knox VJ. Ageism or healthism? *Journal of Aging and Health* 1990;2(1):15–27.
- Given CW, Stommel M, Given B, Osuch J, Kurtz ME, Kurtz JC. The influence of cancer patients' symptoms and functional states on patients' depression and family caregivers' reaction and depression. *Health Psychology* 1993;12:277–285. [PubMed: 8404801]
- Goodman CR, Shippy RA. Is it contagious? Affect similarity among spouses. *Aging and Mental Health* 2002;6(3):266–274. [PubMed: 12217095]
- Graham SM, Huang J, Clark MS, Helgeson VS. The positives of negative emotion: Willingness to express negative emotions promotes relationships. *Personality and Social Psychology Bulletin* 2008;34:394–406. [PubMed: 18272807]
- Hagedoorn M, Sanderman R, Buunk BP, Wobbes T. Failing in spousal caregiving: The 'identity-relevant stress' hypothesis to explain sex differences in caregiver distress. *British Journal of Health Psychology* 2002;7:481–494. [PubMed: 12614498]
- Hall JA. Gender effects in decoding nonverbal cues. *Psychological Bulletin* 1978;85:845–857.

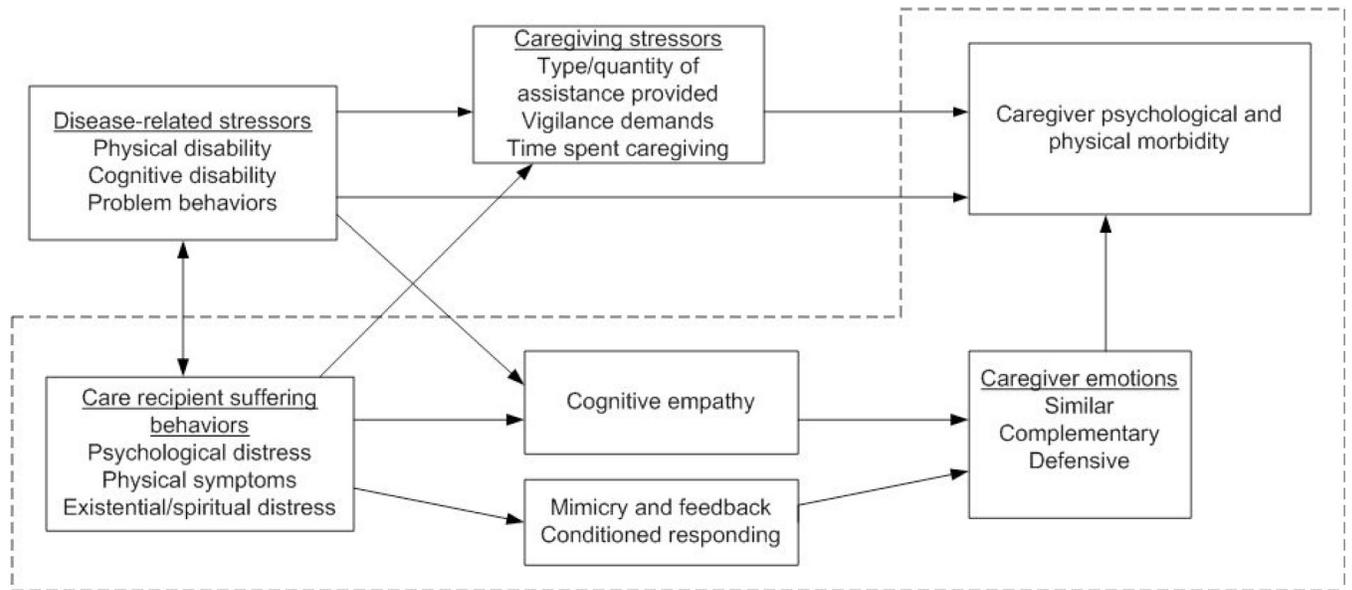
- Hall, JA. Baltimore: Johns Hopkins Press; 1984. Nonverbal sex differences: communication accuracy and expressive style.
- Hatfield, E.; Cacioppo, J.; Rapson, RL. Emotional Contagion. New York: Cambridge University Press; 1994.
- Hatfield, E.; Rapson, RL.; Le, YL. Decety, J.; Ickes, W. The social neuroscience of empathy. Boston, MA: MIT Press; 2008. Emotional contagion and empathy; p. 28-51.
- Hathaway, SR.; McKinley, JC. Minnesota Multiphasic Personality Inventory. Rev. ed.. New York: Psychological Corporation; 1967.
- Haviland, JM.; Malatesta, CZ. Mayo, C.; Henley, NM. Gender and nonverbal behavior. New York: Springer-Verlag; 1981. The development of sex differences in nonverbal signals: Fallacies, facts, and fantasies; p. 183-208.
- Hayes AM, Feldman G. Clarifying the construct of mindfulness in the context of emotion regulation and the process of change in therapy. *Clinical Psychology: Science and Practice* 2004;11:255–262.
- Heath C. Pain talk: the expression of suffering in medical consultation. *Social Psychological Quarterly* 1989;52:113–125.
- Heckhausen J, Schulz R. Optimization by selection and compensation: Balancing primary and secondary control in life-span development. *International Journal of Behavioral Development* 1993;16:287–303.
- Heckhausen J, Schulz R. A life-span theory of control. *Psychological Review* 1995;102(2):284–304. [PubMed: 7740091]
- Hittelman JH, Dickes R. Sex differences in neonatal eye contact time. *Merrill-Palmer Quarterly* 1979;25:171–184.
- Hooker K. Possible selves and perceived health in older adults and college students. *Journal of Gerontology: Psychological Sciences* 1992;47:85–95.
- Idler EL, Musick MA, Ellison CG, George LK, Drause N, Ory MG, et al. Measuring multiple dimensions of religion and spirituality for health research. *Research on Aging* 2003;25:327–365.
- Izard, CE. The face of emotion. New York: Appleton-Century-Crofts; 1971.
- Kaufner DI, Cummings JL, Christine D, Bray T, Castellon S, Masterman, et al. Assessing the impact of neuropsychiatric symptoms in Alzheimer's disease: the neuropsychiatric inventory caregiver distress scale. *Journal of the American Geriatrics Society* 1998;46:210–215. [PubMed: 9475452]
- Keefe FJ, Caldwell DS, Baucom D, Salley A, Robinson E, Timmons K, et al. Spouse-assisted coping skills training in the management of osteoarthritic knee pain. *Arthritis Care and Research* 1996;9:279–291. [PubMed: 8997917]
- Keefe FJ, Caldwell DS, Baucom D, Salley A, Robinson E, Timmons K, et al. Spouse-assisted coping skills training in the management of knee pain in osteoarthritis: Long-term followup results. *Arthritis Care and Research* 1999;12:101–111. [PubMed: 10513498]
- Keefe FJ, Lipkus I, Lefebvre JC, Hurwitz H, Clipp E, Smith J, et al. 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* 2003;103:151–156. [PubMed: 12749969]
- Kerns RD, Turk DC. Depression and chronic pain: The mediating role of the spouse. *Journal of Marriage and the Family* 1984;46:845–852.
- Kleinman, A. The illness narratives: Suffering, healing, and the human condition. New York: Basic Books; 1988.
- Klennert, MD.; Campos, JJ.; Sorce, JF.; Emde, RN.; Svejda, M. Emotions as behavior regulators: social referencing in infancy. In: Plutchik, R.; Kellerman, H., editors. *Emotion: Theory, research and experience*. Vol. 2. New York: Academic Press; 1983.
- Kornblith AB, Herr HW, Ofman US, Scher HI, Holland JC. Quality of life of patients with prostate cancer and their spouses: the values of a data base in clinical care. *Cancer* 1994;73:2791–2802. [PubMed: 8194021]
- Kotre, J. *Outliving the self: How we live on in future generations*. Baltimore: Johns Hopkins University Press; 1984.

- Kurtz ME, Kurtz JC, Given CW, Given B. Relationship of caregiver reactions and depression to cancer patients' symptoms, functional states and depression- a longitudinal view. *Social Science Medicine* 1995;40:837–846. [PubMed: 7747219]
- Kurtz ME, Kurtz JC, Given CC, Given B. Concordance of cancer patient and caregiver symptom reports. *Cancer Practice* 1997;4:185–190. [PubMed: 8900759]
- Laird JD. Self-attribution of emotion: The effects of expressive behavior on the quality of emotional experience. *Journal of Personality and Social Psychology* 1974;33:475–486. [PubMed: 4818323]
- Langford DJ, Cramer SE, Shehzad Z, Smith SB, Sotocinal SG, Levenstadt JS, Chanda ML, Levitin DJ, Mogil JS. Social modulation of pain as evidence for empathy in mice. *Science* 2006;312:1967–1970. [PubMed: 16809545]
- Lanzetta JT, Cartwright-Smith J, Kleck RE. Effects of nonverbal dissimulation on emotional experience and autonomic arousal. *Journal of Personality and Social Psychology* 1976;33:354–370. [PubMed: 1271216]
- Leonard MT, Cano A, Johansen AB. Chronic pain in a couples context: a review and integration of theoretical models and empirical evidences. *Journal of Pain* 2006;7(6):377–390. [PubMed: 16750794]
- Lerner, MJ. *The belief in a just world: a fundamental delusion*. New York: Plenum Press; 1980.
- Lerner MJ, Simmons CH. Observer's reaction to the "innocent victim": Compassion or rejection? *Journal of Personality and Social Psychology* 1966;4:203–210. [PubMed: 5969146]
- Levenson RW, Ekman P, Friesen WV. Voluntary facial action generates emotion-specific autonomic nervous system activity. *Psychophysiology* 1990;27:363–384. [PubMed: 2236440]
- Lutzky SM, Knight BG. Explaining gender differences in caregiver distress: The roles of emotional attentiveness and coping styles. *Psychology and Aging* 1994;9(4):513–519. [PubMed: 7893422]
- Martire LM. The "relative" efficacy of involving family in psychosocial interventions for chronic illness: Are there added benefits to patients and family members? *Families, Systems, & Health* 2005;23:312–328.
- Martire LM, Lustig AP, Schulz R, Miller GE, Helgeson VS. Is it beneficial to involve a family member? A meta-analysis of psychosocial interventions for chronic illness. *Health Psychology* 2004;23:599–611. [PubMed: 15546228]
- Martire LM, Keefe FJ, Schulz R, Ready R, Beach SR, Rudy TE, Starz TW. Older spouses' perceptions of partners' chronic arthritis pain: Implications for spousal responses, support provision, and caregiving experiences. *Psychology and Aging* 2006;21:222–230. [PubMed: 16768570]
- Matthews BA, Baker F, Spillers RL. Family caregivers and indicators of cancer-related distress. *Psychology, Health & Medicine* 2003;8:45–56.
- McClain CS, Rosenfeld B, Breitbart W. Effect of spiritual wellbeing on end-of-life despair in terminally ill cancer patients. *Lancet* 2003;361:1603–1607. [PubMed: 12747880]
- McNair, DM.; Lorr, M.; Droppleman, LF. *Profile of mood states*. San Diego, CA: Educational and Industrial Testing Service; 1981.
- Mendes de Leon CF, Kasl SV, Jacobs S. A prospective study of widowhood and changes in symptoms of depression in a community sample of the elderly. *Psychological Medicine* 1994;24:613–624. [PubMed: 7991743]
- Monin JK, Martire LM, Schulz R, Clark MS. Willingness to express emotion to older adult caregiving spouses. *Emotion* 2009;9(1):101–106. [PubMed: 19186921]
- Mullan JT. The bereaved caregiver: a prospective study of changes in well-being. *Gerontologist* 1992;32:673–683. [PubMed: 1427280]
- National Caregiver Support Program. 2006. Retrieved October 30, 2008 from <http://aoa.gov/PROF/aoaprogram/caregiver/careprof/resources/fcs.pdf>
- Nealy JB, Smith TW, Uchino BN. Cardiovascular responses to agency and communion stressors in young women. *Journal of Research in Personality* 2002;36:395–418.
- Nezu, AM.; Nezu, CM.; Perri, MG. *Problem solving therapy for depression: Theory, research, and clinical guideline*. New York: John Wiley & Sons, Inc; 1989.
- Niedenthal PM. Embodying emotion. *Science* 2007;316(5827):1002–1005. [PubMed: 17510358]

- Northouse LL, Dorris G, Charron-Moore C. Factors affecting couples' adjustment to recurrent breast cancer. *Social Science and Medicine* 1995;41:69–76. [PubMed: 7667674]
- Northouse L, Templin T, Mood D. Couples' adjustment to breast disease during the first year following diagnosis. *Journal of Behavioral Medicine* 2001;24:115–136. [PubMed: 11392915]
- Omdahl BL, O'Donnell C. Emotional contagion, empathic concern and communicative responsiveness as variables affecting nurses' stress and occupational commitment. *Journal of Advanced Nursing* 1999;29:1351–1359. [PubMed: 10354229]
- Pakenham KI. Application of a stress and coping model to caregiving in multiple sclerosis. *Psychology, Health, and Medicine* 2001;6(1):13–27.
- Pinquart M, Sörensen S. Predictors of caregiver burden and depressive mood: A meta-analysis. *Journal of Gerontology, Psychological Sciences* 2003a;58:112–128.
- Pinquart M, Sörensen S. Differences between caregivers and non-caregivers in psychological health: a meta-analysis. *Psychology and Aging* 2003b;18:250–267. [PubMed: 12825775]
- Prigerson HG, Shear MK, Jacobs SC, Reynolds CF, Maciejewski PK, Pilkonis PA, et al. *British Journal of Psychiatry* 1999;174:67–73. [PubMed: 10211154]
- Rabkin JG, Glenn JW, Del Bene M. Resilience and distress among amyotrophic lateral sclerosis patients and caregivers. *Psychosomatic Medicine* 2000;62:271–279. [PubMed: 10772408]
- Redinbaugh EM, Baum A, DeMoss C, Fello M, Arnold R. Factors associated with the accuracy of family caregiver estimates of patient pain. *Journal of Pain and Symptom Management* 2002;23:31–38. [PubMed: 11779666]
- Reibel DK, Greeson JM, Brainard GC, Rosenzweig S. Mindfulness-based stress reduction and health-related quality of life in a heterogeneous patient population. *General Hospital Psychiatry* 2001;23:183–192. [PubMed: 11543844]
- Revenson TA, Majerovitz SD. Spouses' support provision to chronically ill patients. *Journal of Social and Personal Relationships* 1990;7:575–586.
- Rholes WS, Simpson JA, Orina MM. Attachment and anger in an anxiety-provoking situation. *Journal of Personality and Social Psychology* 1999;76(6):940–957. [PubMed: 10402680]
- Riley-Doucet C. Beliefs about the controllability of pain: Congruence between older adults with cancer and their family caregivers. *Journal of Family Nursing* 2005;11:225–241. [PubMed: 16287826]
- Rizzolatti G, Fogassi L, Gallese V. Neurophysiological mechanisms underlying the understanding and imitation of action. *Nature Review of Neuroscience* 2001;2:661–670.
- Rizzolatti G, Fadiga L, Gallese V, Fogassi L. Premotor cortex and the recognition of motor actions. *Cognitive Brain Research* 1996;3:131–141. [PubMed: 8713554]
- Robles TF, Kiecolt-Glaser JK. The physiology of marriage: Pathways to health. *Physiology & Behavior* 2003;79:409–416. [PubMed: 12954435]
- Rosenbloom CA, Whittington FJ. The effects of bereavement on eating behaviors and nutrient intakes in elderly widowed persons. *Journal of Gerontology* 1993;48:S223–S229. [PubMed: 8315246]
- Schulz R, Beach SR. Caregiving as a risk factor for mortality: The Caregiver Health Effects Study. *Journal of the American Medical Association* 1999;282:2215–2260. [PubMed: 10605972]
- Schulz R, Beach SR, Lind B, Martire LM, Zdaniuk B, Hirsch C, et al. Involvement in caregiving and adjustment to death of a spouse. *The Journal of the American Medical Association* 2001;285:3123–3129.
- Schulz R, Beach SR, Hebert RS, Martire LM, Monin JK, Thompkins CA, Albert S. Spousal suffering and partner depression and cardiovascular disease: The cardiovascular health study. *American Journal of Geriatric Psychiatry* 2009;17(3):246–254. [PubMed: 19454851]
- Schulz R, Belle SH, Czaja SJ, McGinnis KA, Stevens A, Shang S. Long-term care placement of dementia patients and caregiver health and well-being. *The Journal of the American Medical Association* 2004;292:961–967.
- Schulz R, Hebert RS, Dew MA, Brown SL, Scheier MF, Beach SR, et al. Patient suffering and caregiver compassion: New opportunities for research, practice, and policy. *The Gerontologist* 2007;47(1):4–13. [PubMed: 17327535]
- Schulz R, Heckhausen J. A life span model of successful aging. *American Psychologist* 1996;51(7):702–714. [PubMed: 8694390]

- Schulz R, McGinnis KA, Zhang S, Martire LM, Hebert RS, Beach SR, et al. Dementia patient suffering and caregiver depression. *Alzheimers Disease & Associated Disorders* 2008;22(2):170–176.
- Schulz R, Mendelsohn AB, Haley WE, Mahoney D, Allen RS, Zhang S, et al. End-of-life care and the effects of bereavement on family caregivers of persons with dementia. *New England Journal of Medicine* 2003;349:1936–1942. [PubMed: 14614169]
- Schulz R, O'Brien AT, Bookwala J, Fleissner K. Psychiatric and physical morbidity effects of dementia caregiving: Prevalence, correlates, and causes. *The Gerontologist* 1995;35(6):771–791. [PubMed: 8557205]
- Schwartz L, Slater MA, Birchler GR, Atkinsons H. Depression in spouses of chronic pain patients: The role of patient pain and anger and marital satisfaction. *Pain* 1991;44:61–67. [PubMed: 2038490]
- Shortt JW, Pennebaker JW. Talking versus hearing about Holocaust experiences. *Basic and Applied Social Psychology* 1992;13:165–179.
- Silinanda, U. *The four foundations of mindfulness*. Boston: Wisdom Publications; 1990.
- Singer T, Seymour B, O'Doherty J, Kaube H, Dolan RJ, Frith CD. Empathy for pain involves the affective but not sensory components of pain. *Science* 2004;303:1157–1161. [PubMed: 14976305]
- Soskolne V, KaplanDe-Nour A. The psychosocial adjustment of patients and spouses to dialysis treatment. *Social Science Medicine* 1989;29:497–502. [PubMed: 2756436]
- Specia M, Carlson L, Goodey E, Angen M. A randomized wait-list controlled trial: The effects of a mindfulness meditation based stress reduction program on mood and symptoms of stress in cancer outpatients. *Psychosomatic Medicine* 2000;62:613–622. [PubMed: 11020090]
- Spielberger, CD.; Gorsuch, RL.; Lushene, R.; Vagg, PR.; Jacobs, GA. *Manual for the State-Trait Anxiety Inventory (Form Y)*. Palo Alto, CA: Consulting Psychologists Press; 1983.
- Stephens MP, Martire LM, Cremeans-Smith JK, Druley JA, Wojno WC. Older women with osteoarthritis and their caregiving husbands: effects of pain and pain expression on husbands' well-being and support. *Rehabilitation Psychology* 2006;51:3–12.
- Stotland, E. Exploratory investigations of empathy. In: Berkowitz, L., editor. *Advances in experimental social psychology*. Vol. Vol. 4. New York: Academic Press; 1969. 1969
- Strack F, Martin LL, Stepper S. Inhibiting and facilitating conditions of the human smile: A nonobtrusive test of the facial feedback hypothesis. *Journal of Personality and Social Psychology* 1988;54:768–777. [PubMed: 3379579]
- Taylor SE, Brown JD. Illusion and well-being: A social psychological perspective on mental health. *Psychological Bulletin* 1988;103:193–210. [PubMed: 3283814]
- Teri L, Truax P, Logsdon R, et al. Assessment of behavioral problems in dementia: The Revised Memory and Behavior Problems Checklist. *Psychology and Aging* 1992;7:622–631. [PubMed: 1466831]
- The Canadian Study of Health and Aging Working Group. Patterns and health effects of caring for people with dementia: The impact of changing cognitive and residential status. *Gerontologist* 2002;42:643–652. [PubMed: 12351799]
- Thera, N. *The heart of Buddhist meditation: A handbook of mental training based on the Buddha's way of mindfulness*. London: Rider and Company; 1962.
- Tomkins, SS. Affect, imagery, consciousness: The positive affects. Vol. Vol. 1. New York: Springer; 1962, 1963.
- Tomkins, SS. Affect theory. In: Ekman, E., editor. *Emotion in the human face*. 2nd ed.. New York: Cambridge University Press; 1984. p. 353-395.
- Tower RB, Kasl SV. Depressive symptoms across older spouses and the moderating effect of marital closeness. *Psychology and Aging* 1995;10:625–638. [PubMed: 8749590]
- Tower RB, Kasl SV. Depressive symptoms across older spouses: longitudinal influences. *Psychology and Aging* 1996;11:683–697. [PubMed: 9000299]
- Vitaliano PP, Russo J, Bailey S, Young H, McCann B. Psychosocial factors associated with cardiovascular reactivity in older adults. *Psychosomatic Medicine* 1993;55:164–177. [PubMed: 8475231]
- Vitaliano PP, Zhang J, Scanlan JM. Is caregiving hazardous to one's physical health? A meta-analysis. *Psychological Bulletin* 2003;129:946–972. [PubMed: 14599289]

- Wagner AW, Logsdon RG, Pearson JL. Caregiver expressed emotion and depression in Alzheimer's disease. *Aging and Mental Health* 1997;1(2):132–139.
- White RW. Motivation reconsidered: The concept of competence. *Psychological Review* 1959;66:297–333. [PubMed: 13844397]
- Widmer, K.; Cina, A.; Charvoz, L.; Shantinath, S.; Bodemann, G. A model dyadic-coping intervention. In: Revenson, K.; Kayser, K.; Bodemann, G., editors. *Couples coping with stress: Emerging perspectives on dyadic coping*. Washington, D. C: American Psychological Association; 2005. p. 159-174.
- Wiesenfeld AR, Whitman PB, Malatesta CZ. Individual differences among adult women in sensitivity to infants: evidence in support of an empathy concept. *Journal of Personality and Social Psychology* 1984;46:118–124. [PubMed: 6694055]
- Wilson KG, Graham ID, Viola RA, Chater S, de Faye BJ, Weaver LA, et al. Structured interview assessment of symptoms and concerns in palliative care. *Canadian Journal of Psychiatry* 2004;49:350–358.
- Yeager KA, Miaskowski C, Dibble SL, Wallhagen M. Differences in pain knowledge and perception of the pain experience between outpatients with cancer and their family caregivers. *Oncology Nursing Forum* 1995;22:1235–1241. [PubMed: 8532548]
- Yeatman R, Bennets K, Allen N, Ames D, Flicker L, Waltrowicz W. Is caring for elderly relatives with depression as stressful as caring for those with dementia? A pilot study in Melbourne. *International Journal of Geriatric Psychiatry* 1992;8:339–342.
- Yee JL, Schulz R. Gender differences in psychiatric morbidity among family caregivers. *The Gerontologist* 2000;40:147–164. [PubMed: 10820918]
- Zarit SH, Whitlatch CJ. Institutional placement: Phases of the transition. *The Gerontologist* 1992;32:665–672. [PubMed: 1427279]
- Zeiss A, Gallagher-Thompson D, Lovett S, Rose J, McKibbin C. Self-efficacy as mediator of caregiver coping: developing and testing an assessment model. *Journal of Clinical Geropsychology* 1999;5:221–230.



**Figure 1.** Caregiver stress-health model showing how exposure to and perception of suffering affects caregiver emotional response and health