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The Effects of Suffering in Chronically Ill Older Adults on the Health and Well-Being of Family Members Involved in Their Care:

The Role of Emotion-Related Processes

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Abstract

A large literature shows that caregivers of chronically ill older adults have a higher risk for impaired health and decreased longevity. In this paper we review research that addresses pathways through which family members experience negative health consequences from exposure to a partner's suffering. We first provide a conceptualization of suffering and describe how it can be measured, then review empirical evidence that exposure to suffering uniquely influences caregivers' health, and discuss individual differences in caregivers' emotional reactions to partners' suffering using three emotion theories (Gross' process model of emotion regulation, attachment theory, and a functionalist perspective on emotion). Finally, we discuss implications of the effects of suffering for the health and well-being of family caregivers.

Keywords

caregiving; emotion regulation; suffering; health; attachment

There is a great deal of research showing that providing care to an older adult family member has negative consequences for one's own the health and well-being (Schulz & Beach, 1999; Vitaliano, Zhang, & Scanlan, 2003). Much of this research has focused on the physical demands of providing care, heightened vigilance to the needs of carerecipients, and dealing with complex bureaucracies to access support services for carerecipients as reasons for increased stress and associated health effects among caregivers. Less attention, however, has been paid to the emotional toll it takes on caregivers who watch their loved ones suffer on a daily basis. It is important to understand the processes through which caregiving impacts health and well-being because caregivers have become a critical global health care resource. Families often are a primary source of home care and support for older relatives, contributing services that would be extremely costly if they had to be purchased. Evidence on the health effects of caregiving gathered over the last two decades has helped convince policymakers around the world that caregiving is a major public health issue.

In this paper we review research that addresses pathways through which family members experience negative physical and mental health as a result of witnessing the suffering of a chronically ill older adult partner. We start by providing a definition of suffering and a conceptualization of how to measure perceptions of suffering. We then review recent studies

showing that exposure to suffering uniquely influences the health of caregivers. Next, we suggest that there are individual differences in how caregivers regulate their emotions and how carerecipients express their emotions, both of which impact caregivers' risk for poor health. We draw from three theories of emotion: Gross' process model of emotion regulation (2001), attachment theory, and a functionalist perspective on emotion (Clark, Fitness, & Brissette, 2001; Graham, Huang, Clark, & Helgeson, 2008). Finally, we discuss the implications of reactions to suffering for the health and well-being of both caregivers and carerecipients.

Definition and Measurement of Perceived Suffering

The experience of suffering has received increasing attention in the medical and health care literature (Cassell, 2004; Ferrell & Coyle, 2008; Schulz et al., 2007). Researchers interested in end-of-life care have been at the forefront of developing methods to assess various aspects of suffering, although existing measures have a number of limitations, including the fact that they rely on global impressions (e.g., Cassell, 2004), are disease-specific (e.g., Smith et al., 2007), or focus solely on the physical aspects of suffering (e.g., Bruera, Kuehn, Miller, Selmsler, & MacMillin, 1991). Furthermore, existing instruments focus only on one person's perspective of suffering, such as that of the caregiver (e.g., Cummings et al., 1994) or the patient's report (e.g., Büchi et al., 2002).

In reviewing existing conceptual and measurement literature on suffering, we found that there is consensus that suffering is a holistic construct with three distinct dimensions. First, suffering includes psychological distress, such as depression and anxiety, along with feelings of lack of control that reflect the individual's appraisal of his or her condition. Second, physical symptoms, such as pain, nausea, and difficulty in breathing, are a key feature of suffering. Third, suffering has an existential dimension that includes loss or impairment of inner harmony and of meaning and purpose of life. Suffering can be related to illness attributes such as disability, but it may also be independent of them inasmuch as a given level of disability may elicit varying levels of suffering. In our view, individuals automatically make appraisals about the magnitude of suffering based on an 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 that treat factors such as psychological distress and physical pain separately (see Monin & Schulz, 2009, for a further discussion).

In collaboration with a multidisciplinary group of researchers at the University of Pittsburgh, we recently developed a measure of the experience and perception of suffering that incorporates the three dimensions and assessed the psychometric properties of this scale in a study of three samples: individuals with Alzheimer's disease (AD) and their family caregivers; married couples in which one partner had osteoarthritis (OA); and African American and Hispanic caregivers of carerecipients with AD (Schulz et al., in press). Each subscale was found to have high levels of internal consistency, test-retest reliability, and convergent and discriminant reliability. For example, Cronbach's α s for psychological and existential suffering scales were .83 or higher for all samples with the exception of OA patients ($\alpha = .77$ for existential suffering). Internal consistency was lower for the physical suffering index (range = .49 to .72 using the KR-20 measure), though this was expected because physical symptoms are not always related to one another. The test-retest correlations, resulting from administering the scales approximately 3–6 weeks apart in a subsample of the AD carerecipients and caregivers, ranged from .53 to .88. In addition, the scales were able to discriminate differences in suffering as a function of type of disease (OA versus AD), demonstrated high intra- and moderately high interperson correlations, and exhibited predicted patterns of association between each type of suffering and indicators of

quality of life (e.g., Dementia Quality of Life [DEMQOL]; Smith et al., 2007; Short Form 12 Health Survey [SF-12]; Ware, Kosinski, & Keller, 1996), and caregiver outcomes of depression and burden (Center for Epidemiologic Studies Depression Scale- 10 [CESD]; Radloff, 1977; Zarit Burden Inventory [ZBI]; Zarit, Reever, & Bach-Peterson, 1980).

Schulz and colleagues' (in press) measure overcomes disadvantages of prior instruments by capturing all three dimensions of suffering (physical, psychological, and existential); it can be used with individuals regardless of medical condition and can be used to measure both the carerecipient's experience of suffering as well as an observer's perception of suffering in the carerecipient. Measuring both the carerecipient's experience of suffering and an observer's perception of the carerecipient's suffering is an important advantage because it allows researchers to determine the degree of convergence/divergence between care-recipient and observer estimates of carerecipient suffering. Data from our two samples of caregivers and carerecipients with OA and AD showed that caregivers overestimated the magnitude of suffering of their carerecipients; AD caregivers perceived carerecipients' suffering to be almost twice as high as carerecipients' self-reports (Schulz et al., in press). If we assume self-reports to be the gold standard, these findings suggest that caregivers could benefit from bringing this discrepancy into their awareness. These findings also highlight the need for research examining potential sources of biases in both caregivers' and carerecipients' reports of carerecipient suffering.

Evidence on the Health Effects of Exposure to a Partner's Suffering

Although there is a large literature showing that caregiving is associated with negative health consequences, less research has focused on the unique influence of exposure to carerecipient suffering as a mechanism. There are a few exceptions. For example, in a large multisite sample of dementia patients and their family caregivers, Schulz and colleagues (2008) found that, controlling for the effects of patient physical and cognitive disability, memory problems, disruptive behaviors, the amount of care provided by the caregiver, and sociodemographic characteristics, both emotional and existential suffering as perceived by the caregiver were independently associated with caregiver depression and antidepressant medication use both cross-sectionally and longitudinally. In another study involving a large sample of older married couples, in which each partner reported on their own suffering, we found evidence that the combination of physical, psychological, and existential distress predicted prevalent and incident depression and prevalent cardiovascular disease (CVD) in the respective partner, independent of known risk factors for depression or CVD (Schulz et al., 2009).

Results from a recent experimental laboratory study also support the idea that exposure to suffering uniquely heightens the risk of caregivers for impaired psychological and physical health (Monin, Schulz, Martire, Jennings, Lingler, & Greenberg, 2010). This study involved older adults with OA and their spouses. Spouses' systolic and diastolic blood pressure (BP) and heart rate (HR) were monitored during two tasks designed to capture their partner's suffering. First, spouses watched a video of their partner carrying heavy logs across an 8 ft space for 3 minutes, a task that elicited pain expression. Second, spouses spoke about their partner's physical, psychological, and existential suffering. As hypothesized, results showed that spouses' BP and HR increased when watching and talking about their partner's suffering compared to watching a habituation stimulus and talking about a typical interaction with the partner, respectively. The results of this study also showed that spouses were more physiologically distressed by watching their partner perform the pain-eliciting task compared to watching an opposite-sex stranger perform the same task, even when the stranger expressed more pain as rated by independent observers. Together these studies

provide evidence that exposure to and perceptions of carerecipient suffering influence caregivers' health beyond the effects of the level of carerecipients' physical disability.

Individual Differences in Emotional Reactions to Partners' Suffering

Not everyone reacts to a partners' suffering in the same way. Whereas most people feel some amount of personal distress along with compassion and typically offer support to their partners, others are more likely to simply feel overwhelmed by their own distress, impeding their ability to provide support to their partners. In our recent theoretical and review paper (Monin & Schulz, 2009), we proposed that, when faced with a loved one's suffering, there are a number of ways caregivers can respond. Partners may respond with (1) similar emotions, such as anxiety, through a process of emotional contagion (Hatfield, Cacioppo, & Rapson, 1994; Hatfield, Rapson, & Le, 2008), (2) complementary emotions, such as love or compassion, through the process of empathy and by accurately interpreting that the partner has a need or desire for care (Graham et al., 2008), and/or (3) defensive emotions, such as anger or apathy, stemming from discomfort with others' vulnerability and discomfort with being in a caregiving role (Bowlby, 1982). Here, we discuss sources of these individual differences in responses to a loved one's suffering using the following theories of emotion: Gross' process model of emotion regulation (2001), attachment theory, and a functionalist perspective on emotion (Clark et al., 2001; Graham et al., 2008).

Gross' Process Model of Emotion Regulation

The propensity to react to others' suffering with negative emotions, such as personal distress or anger, or more adaptive emotions, such as compassion, is likely to stem from the use of different types of emotion regulation strategies and the extent to which the strategies are successful. Gross (2001) provides a useful framework for understanding the different ways that people regulate their emotions, a framework that can be applied to the caregiving situation. Gross' model details five strategies that occur sequentially during the process of generating emotion: (1) situation selection, (2) situation modification, (3) attentional deployment, (4) cognitive reappraisal, and (5) response modulation (i.e., suppression). The first four strategies are called *antecedent-focused*, occurring before the emotional experience, and the last strategy is *response-focused*, occurring after the emotional experience. Employing a strategy early in the process of emotion generation precludes the use of a later strategy. For example, in the context of caregiving, a family member may pace activities throughout the day so that the carerecipient's suffering is avoided (i.e., situation selection), making it unnecessary for the family member to suppress negative emotions resulting from witnessing the care-recipient's suffering (i.e., response modulation).

Keefe, Porter, and Labban (2006) applied Gross' model to categorize how patients with a pain-related disease regulate their emotions through pain-related, partner-assisted coping skills. We also suggest that Gross' emotion regulation strategies have important implications for caregivers' reactions to carerecipients' suffering (see Figure 1 for the caregiver stress-health model incorporating the effects of perceived suffering and emotion regulation strategies; Monin & Schulz, 2009).

Based on Gross' model, we theorize that caregivers can engage in a number of strategies to minimize negative emotional reactions to their partners' suffering. First, the caregiver can use situation selection, for example, minimizing contact with the carerecipient and hence exposure to suffering. Second, if the caregiver is faced with a situation in which the partner is suffering, the caregiver may try to modify the situation, for example, by trying to alleviate the partner's suffering through support behaviors or having the carerecipient engage in activities that decrease suffering. Third, the caregiver may shift his or her attention from the

threatening information in the environment (attentional deployment), focusing on unrelated thoughts or future activities. Fourth, a caregiver may attempt to reappraise the potentially threatening situation (e.g., a partner carrying out a pain-eliciting household task, such as heavy lifting), by thinking about the positive aspects of the situation (e.g., “this is good exercise”), putting the suffering in perspective (e.g., “my partner hurts now, but it won't last forever”), by trying to distance the self from the suffering (e.g., focusing on the medical aspects of the situation as a nurse or doctor might) or by blaming the partner (e.g., “he knows he shouldn't be pushing himself that hard”). If antecedent-focused strategies are not successful, the caregiver may feel negative emotions (i.e., personal distress, anger) and use response-focused strategies to try to dampen the negative emotions, such as emotional suppression.

Research is needed to understand the extent to which caregivers use these different strategies as well as their effectiveness for reducing stress in the context of caregiving because negative emotions and heightened cardiovascular reactivity are associated with psychological and physical morbidity (e.g., Everson-Rose & Lewis, 2004; Kubzansky & Kawachi, 2000). Most research using Gross' model compared an antecedent-focused strategy, cognitive (distancing) reappraisal with a response-focused strategy (suppression). Including the entire range of emotion regulation strategies is important when studying older caregiving adults because recent experimental research demonstrates that older adults are likely to use attention-related strategies to regulate mood (Isaacowitz, Toner, Goren, & Wilson, 2008). At present, we do not know the extent to which different emotion regulation strategies (e.g., avoidance) are adaptive for older adult family caregivers (e.g., Blanchard-Fields, Mienaltowski, & Seay, 2007; Martini & Busseri, 2010).

Attachment Theory

Another approach to understanding why people exhibit different emotional reactions and behaviors in response to their partners' suffering is suggested by attachment theory, which provides a useful framework for understanding how different caregivers respond to their partners' suffering: It identifies individual differences in people's mental representations of the self and others that evolve out of experiences with close relationship partners (especially early experiences with parental figures) in times of need and that center around the regulation of distress and the maintenance of felt security (Bretherton, 1985; Sroufe & Waters, 1977). These mental representations, or working models, organize past experiences and guide social interaction (Bretherton & Munholland, 1999; Collins & Allard, 2001; Collins, Guichard, Ford, & Feeney, 2004; Shaver, Collins, & Clark, 1996). Because not all attachment figures fulfill their roles in equally reliable ways, people develop different attachment styles that are generally assessed along two dimensions – anxiety and avoidance. The anxiety dimension assesses the degree to which the self is perceived to be unworthy of love and the degree to which the individual is worried about being rejected by others. The avoidance dimension assesses the degree to which individuals are uncomfortable with intimacy and dependence on others.

Although attachment theory deals mainly with other's responses to one's own needs, it is also useful for explaining one's own reactions to others' needs (Bowlby, 1969; Mikulincer et al., 2001). According to Bowlby (1969), people have a caregiving system that is designed to protect and support others who are dependent or temporarily in need, and that is guided by an altruistic motive: to alleviate another person's distress. However, when one's own subjective security is disrupted, the caregiving system is inhibited, and people become egoistically self-focused on their own attachment needs and distress, impeding the ability to behave altruistically (Mikulincer et al., 2001). This self-focus is likely to impact the extent

to which caregivers perceive their partners' support seeking cues (e.g., negative emotion), how they interpret those cues, and how they react emotionally.

Studies have shown that attachment insecurity is predictive of personal distress in response to partners' vulnerability in the context of caregiving (Braun, Mikulincer, Rydall, Walsh, & Rodin, 2007; Crispi, Schiaffino, & Berman, 1997; Daire, 2002; Markiewicz, Reis, & Gold, 1997). For example, in our study in which caregiving spouses were exposed to their partners performing a pain-eliciting task (Monin et al., 2010), we found that caregivers' attachment anxiety was associated with greater distress, and avoidant attachment was associated with less distress in reaction to the partners' suffering (Monin, Schulz, Feeney, & Cook, 2010). Furthermore, we found that heightened perceptions of partner pain mediated the association between attachment anxiety and distress, though the same was not true for avoidant attachment. The results of this study suggest that people who feel less secure in their relationship with their partners are more likely to feel distressed by their partner's suffering, because they are particularly vigilant to signs that their partner is in pain. The results of this study identify an important mechanism linking attachment insecurity and heightened distress responses to carerecipient suffering.

Although attachment theory provides a basis for understanding complex interpersonal dynamics throughout the lifespan, research on late-life relationships using this perspective is relatively limited. More research with older adults, especially on caregiving processes, could benefit from this rich relational theory of emotion.

A Functionalist Perspective on Emotion

Although a caregiver's emotion regulation skills and perception of relationship security are likely to be important predictors of caregivers' emotional reactions to a carerecipient's distress, it is also important to take into account the carerecipient's emotional behavior. In other words, caregivers' emotional reactions are likely to be influenced by the degree to which carerecipients are willing to express both their negative emotions and their positive emotions to their caregivers. A functionalist perspective on emotion asserts that being willing to express one's emotions to close relationship partners is beneficial for relationships because it can signal (1) a need and desire for care, (2) a lack of need or the success of care, (3) appreciation for care received, and/or (4) care for the partner (Clark et al., 2001; Graham et al., 2008). Expressing emotions can also convey intimacy and trust to a partner (Cutrona, 1996).

Our research shows that, normatively, caregivers experience physiological and emotional distress from being exposed to their partners' suffering; however, carerecipients' willingness to express, rather than suppress, their vulnerable emotions may also affect caregivers' reactions. In a study of older adults with OA and their caregiving spouses, we examined the associations between carerecipients' willingness to express emotions and their spousal caregivers' well-being and support behaviors (Monin, Martire, Schulz, & Clark, 2009). The results of this study revealed that caregiving wives actually benefited from their husbands' willingness to express vulnerable emotions (e.g., anxiety and sadness). In addition, we found that carerecipients' willingness to express happiness was associated with less insensitive response, and that willingness to express interpersonal emotions (e.g., compassion and guilt) was associated with less caregiving stress. These findings suggest that not only is it important for male carerecipients to be willing to share their negative emotions, but both male and female caregivers and care-recipients benefit from willingness to express positivity and warmth. More broadly, these results provide support for the theory that emotion expression is beneficial to relationships because it communicates important information about needs and fosters intimacy and trust.

Taken together, these three theories of emotion (Gross' process model of emotion regulation, attachment theory, and a functional perspective on emotion) provide unique but complementary information for making predictions about individual differences in caregivers' reactions to partner suffering. Gross' model provides detailed information about emotion-regulation strategies within an individual; attachment theory provides a developmental framework for understanding how people regulate their emotions specifically within close relationships; and a functional perspective on emotions emphasizes that emotion expression is an important means of communication between relationship partners.

Implications for Caregivers' and Care Recipients' Health

This work has a number of important implications for care-recipients and caregivers' health. For example, current health and social service policy focused on family caregiving places a strong emphasis on interventions designed to facilitate care provision. Although valuable, programs such as respite care, home alterations, and caregiver skills training are unlikely to address an underlying source of caregiver distress if they have little impact on carerecipient suffering. Because carerecipient suffering and caregiver compassion are closely intertwined, and because together they impact caregiver health, reducing suffering in the carerecipient should at the same time improve caregiver well-being. In addition, interventions that focus on relieving the emotional burden caused by exposure to a loved one's suffering are important. Identifying effective emotion regulation strategies – such as those outlined by Gross' model – that caregivers can incorporate into their daily routines may be one way of doing this.

Our focus on suffering may also help to explain why, under some circumstances, caregiving can actually have beneficial health effects (e.g., Brown et al., 2009) despite the fact that most studies of caregivers find negative health effects. We suspect that the predominantly negative effects observed in the caregiving literature are due to the fact that most caregiving studies selectively focus on caregivers in the middle to late stages of a caregiving career when both care demands and carerecipient suffering are high. Under these circumstances, caregivers likely have little control over carerecipient outcomes and garner little reward for the time and effort expended. On the other hand, studies that show positive effects of caregiving likely reflect caregiving experiences in which caregivers are better able to relieve their partners' suffering. Identifying how and when caregivers transition from a positive to a negative caregiving experience are important unresolved questions that need to be addressed in future research. Furthermore, future studies should examine protective factors in deferring the transition from a positive to a negative caregiving experience. Based on our preliminary work and existing theories of emotion, we suggest that people who are able to use effective emotion regulation strategies (e.g., situation modification, cognitive reappraisal), who feel securely attached in their close relationships, and who have partners who are willing to share their emotions are likely to have more positive caregiving experiences. However, more research, especially prospective research linking these potential protective factors with health outcomes is needed.

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Figure 1.
Adaptation of Gross' (2001) emotion regulation model for how care-recipients' suffering may affect caregiver emotions and health.