

Another side to caregiving: Negative reactions to being helped

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Abstract

Until recently, caregiving research has focused almost exclusively on caregivers of older adults with health problems, and there has been little focus on care recipient perceptions of the care they receive. The present article reviews relevant research on reactions to caregiving assistance. Several recent studies indicate that helping transactions in these contexts can be viewed negatively by care recipients. Between 40% and 60% of physically impaired older adults who receive assistance with daily activities, such as preparing meals, climbing stairs, or dressing, experience negative reactions to some of the help they receive. These reactions seem to have important consequences for the care recipient, because negative reactions are associated with more depression symptoms concurrently and as much as one year later. A general theoretical framework for understanding the causes of negative reactions is briefly discussed.

Keywords: care receiving, caregiving, aging, negative interactions, helping, social support

With thousands of scholarly articles written on the topic, research on caregiving has become an important focus in a wide range of disciplines. Interest in the topic is greatest among gerontologists because of its relevance to factors associated with aging, psychologists because of its relation to mental health and interpersonal processes, and health researchers because of its public health implications and relevance to health care provision. Beginning in the late 1970s and early 1980s, researchers began to study the important impacts on the health and mental health of the spouses, children, and others who provide daily assistance to people with mental or physical disabilities (for reviews, see George, 1990; Schulz, Visintainer, & Williamson, 1990; Zarit & Toseland, 1989). The regular provision of care is viewed by psychologists as a type of chronic stressor for caregivers (e.g., Pearlin & Skaff, 1995), and those who provide care on a regular basis often experience greater levels of depression and anxiety and are more likely to experience psychiatric and physical health problems.

Despite this fervid attention to caregiving, researchers have almost summarily neglected the recipient's perspective on caregiving. Little attention has been paid to the health or psychological benefits of receiving care or to any of its potentially harmful effects. A recent search in the *Psychinfo* database found that the text word "caregiver" appeared in the title or abstract of 2,687 articles, while the text words "care recipient" were mentioned in only 66 articles. Moreover, nearly all of these 66 articles had caregivers as their primary focus. Interestingly, early research on caregiving seemed almost more cognizant of recipient's perspectives (Cantor, 1975; Parmelee, 1983) than research currently being conducted².

In the present article, I will briefly review research that is relevant to care recipient reactions to assistance, exploring their frequency, causes, and consequences. Recent research indicates that many care recipients react negatively to some of the care they receive and that negative reactions to assistance may have very important psychological consequences for recipients. Because few existing studies have focused on positive responses to caregiving, and because of the potentially serious

consequences of negative reactions, the present article focuses primarily on negative responses to assistance. Finally, I will discuss a general theoretical framework for understanding the recent findings in the area and some potential future directions for research in this area.

HELPING

The study of reactions to aid from others is not new. Extensive laboratory research has been conducted on reactions to help (Fisher, Nadler, & Whitcher-Alagna, 1982), and negative reactions to help are not uncommon (Fisher, Nadler, & DePaulo, 1983). The majority of these studies have used undergraduate psychology student participants³ and have involved achievement-related tasks such as solving a puzzle. Negative reactions are usually measured by poorer performance, lower task motivation, lower evaluation of the help, or lower liking ratings of the helper. The factors that have been found to lead to negative responses to aid include the inability to reciprocate and thus indebtedness to the helper (Greenberg, 1980), restriction of freedom (Brehm & Cole, 1966; Gergen, 1974), greater internal locus of control (Nadler & Fisher, 1986), and higher self-esteem (Nadler & Fisher, 1986). The primary theoretical framework to explain results in this area is the threat-to-self-esteem model (Fisher et al., 1982). The threat-to-self-esteem model states that help is perceived as threatening because help implies that the aid recipient is inferior or is incapable of completing the task alone.

HEALTH AND SOCIAL CONFLICT

Another highly relevant area of research concerns the negative social interactions experienced by people with serious health problems. In general, the detrimental psychological consequences of social conflict are well-established in the literature (for reviews, see Coyne & Downey, 1991; Okun & Keith, 1998; Rook, 1992). Most often, studies have shown that individuals with more negative social ties or more frequent negative social interactions are more likely to be depressed. One focus within this literature has been on social conflict between family members and patients with chronic or serious

health problems. Although patient responses to assistance are not measured directly, one potential source of social conflict that arises during times of serious illness may be negative reactions to the assistance provided by others.

Interpersonal conflict seems to be more likely to occur after an individual experiences a health decline. For instance, decreases in patient marital satisfaction or increases in marital problems are known to occur following a serious illness such as cancer (Smith, Redman, Burns, & Sagert, 1985), chronic pain (Maruta, Osborne, Swanson, & Halling, 1981), and a heart attack (Michela, 1987; Skelton & Dominian, 1973). Increasing marital conflict resulting from illness may subsequently affect the patient's psychological (Gotlib & Whiffen, 1989) and physical health (Margolin & McIntyre-Kingsolver, 1988). One source of marital conflict for these couples may be the frustration, critical comments, and unsupportive behaviors of the healthy spouse.

A number of studies have examined patient reports of unsupportive family behaviors surrounding their illness that are predictive of depression or other forms of psychological distress. Such behaviors may include critical remarks about the illness or physical limitations (Manne & Zautra, 1990), pushing the patient to be more independent or self-reliant (Thompson et al., 1990; Zautra, Reich, & Newsom, 1995), overprotectiveness or restriction of the patient's freedom (Thompson & Sobolew-Shubin, 1993), overly optimistic or pessimistic comments (Affleck, Pfeiffer, Tennen, & Fifield, 1988; Lehman & Hemphill, 1990), unhelpful suggestions or unempathetic behaviors (Revenson, Schiaffino, Majerovitz, and Gibofsky, 1991), and even too much help (Thompson & Sobolew-Shubin, 1993; Thompson, Sobolew-Shubin, Graham, & Janigan, 1990). The association between such unsupportive behaviors and psychological outcomes does not appear to be due to a confounding with the severity of the illness or the level of physical impairment (Thompson & Sobolew-Shubin, 1993; Norris, Stephens, & Kinney, 1990).

Such unsupportive behaviors seem to be reported by a considerable number of patients. Norris et

al. (1990) found that 34% of stroke patients in their study indicated they had social networks with some problematic members. Affleck et al. (1990) found that one-third of their sample of arthritis patients reported that people in their networks either made pessimistic comments or minimized the severity of their illness. These studies indicate that interpersonal difficulties are not uncommon when individuals experience serious health problems and that the consequences of these difficulties are serious. But because patients' subjective reactions to help are not assessed, it is not clear to what extent the relationship between social conflict and psychological outcomes is due to negative reactions to assistance. To examine this issue, it is necessary to review the handful of studies that assess negative reactions in particular.

CARE RECIPIENT REACTIONS

The first study to specifically measure care recipients' reactions to caregiving assistance was conducted by Parmelee (1983). With a focus on comparing recipient reactions to assistance from spouses with assistance from adult children, Parmelee measured feelings of dependency and uselessness, negative feelings toward the caregiver (anger, resentment, or depression resulting from interacting with the caregiver), perceived negativity of the caregiver's affect (e.g., indications of rejection and unwillingness to assist), and reports of the caregiver's negative behaviors (e.g., criticisms, interference, or shouting). Although there were no differences in feelings of dependency, negative feelings toward the caregiver, negativity of the caregiver's affect, and negative caregiver behaviors were more likely for spousal care than for child-provided care. Neither the overall prevalence of negative reactions nor the relation between recipient reactions and depression was reported.

In a study by Thomas (1993), which included a community-residing sample of older adults with and without health problems, participants indicated on a checklist whether they had ever experienced a list of fourteen possible problems relating to help their children provided to them.

Approximately two-thirds reported one or more of the fourteen problems, with the most commonly-reported problems including: help provided in an “unsatisfactory manner” (35%), unwise advice (33%), and concern about being a burden on their children (32%). In other findings, older parents (ages 75-90) reported more concerns about the amount of help provided than did the younger parents (ages 60-74).

Clark and Stephens (1996) asked older adult stroke patients to list helpful and unhelpful actions by their spouse and asked about self-esteem-related responses to help. Although patients were twice as likely to list positive actions by their spouse, 58% of patients indicated that unhelpful actions occurred “some or a little of the time” or “occasionally or a moderate amount of the time.” The types of unhelpful actions listed most often were criticism or demandingness, under- or overestimation of the amount of help required, and helping incorrectly. After controlling for demographic variables and level of functional impairment, unhelpful caregiver behaviors and lowered self-esteem reactions were predictive of depression levels, and helpful actions were predictive of positive affect.

Newsom & Schulz (1998) more extensively investigated negative reactions and their possible causes in a sample of older adults with a variety of health problems (e.g., arthritis, stroke, heart disease, and lung disease). To measure negative reactions, recipients were asked about the amount of emotional strain they experienced in response to help with each of fourteen daily activities. Thirty-nine percent reported some emotional strain in response to help with one or more activities. The most important predictors of negative reactions were greater physical impairment, more fatalistic beliefs about life events, higher internal control, and lower self-esteem. Several interactions indicated that self-esteem, fatalism, and marital conflict were only associated with negative reactions for participants who received high levels of help. This latter finding may suggest that a greater sense of dependency or an inability to reciprocate may lead to greater negative feelings associated with helping. Negative reactions predicted depression concurrently as well as one year later after controlling for demographic

variables, physical impairment, and baseline depression levels. This longitudinal finding suggests that negative reactions are not merely a symptom of depression and that their effects may be fairly long lasting.

In a sample of older women with arthritis, Martire et al. (1998a) found that women's feelings of lack of control and incompetence in response to their husband's assistance with daily activities predicted depression and life satisfaction after controlling for the level of physical impairment and the amount support provided. Reports of the husband's emotional insensitivity (e.g., husband did not "listen to you talk about how you were feeling" or "told you not to worry too much about your pain") and feelings of rejection in response to the spouse's behaviors (e.g., "felt rejected" or "felt judged or evaluated") were also examined. Insensitive behaviors were related to depression after controlling for impairment level, but not after controlling for feelings of rejection. Feelings of rejection, however, independently predicted both depression and life satisfaction, suggesting that the caregiver's negative behaviors may be less important than the recipient's subjective responses to those behaviors. This study is an important addition to present research because reactions to caregiver behaviors other than help with daily activities were assessed.

In a subsequent report on this data set, Martire et al. (1998b) tested a model hypothesizing that the relation between lack of choice and depression is mediated by feelings of self-efficacy over the disease. Following the Baron and Kenny (1986) regression approach to mediation, support for a partial mediation model was found. That is, the prediction of depression by the lack of choice variable was significantly reduced but not eliminated after controlling for self-efficacy.

In analyses using the same data, Stephens et al. (1998) found that women with higher levels of disability were more likely to have husbands who indicated they had critical attitudes about their wife's arthritis (e.g., "she exaggerated her pain, or thought that it was worse than it probably was") and behaved unsupportively (e.g., "told her she worries too much about her pain"). Husbands' critical

attitudes (but not unsupportive behaviors) were related to their wives' depression levels and reported anger. Interestingly, the wife's level of pain did not predict critical or unsupportive behaviors by the husband once the level of disability was controlled, perhaps suggesting that the husband's frustrations were partly a result of the wife's mobility impairment rather than her reports of pain.

In a preliminary report, Newsom, Adams, Rahim, Mowry, & Rogers (1998) investigated some specific cognitive and emotional reactions to caregiving assistance in 70 care recipients with various medical conditions (e.g., arthritis, leg cramps, injury, visual impairment). General negative reactions were common, with 55% of care recipients indicating some unpleasantness in response to help with one or more daily activities. When asked about specific cognitive and emotional reactions, participants were most likely to report feelings of indebtedness, negative self-attributions, and concerns about the spouse injuring herself or himself (see Table 1). Negative self-attributions, however, were most strongly related to general ratings of unpleasantness (a measure of self-esteem reactions, $r = .58$, $p < .001$; embarrassment, $r = .41$, $p < .001$; feeling weak or incapable, $r = .40$, $p < .001$) than feelings of indebtedness or worries about spousal injuries ($r = .22$, $p < .10$ and $r = .24$, $p < .05$, respectively). These findings suggest that, although feelings of indebtedness and concerns about the spouse's health are common, negative attributions about the self may be the most important experiences underlying general reports of negative reactions to assistance.

Although the study of negative reactions to caregiving assistance has just begun, there have already been a number of very important findings. It is clear from the few studies conducted that negative reactions to assistance are neither rare nor inconsequential. Studies have shown that between 40% and 60% of older adults being cared for by a spouse report negative reactions and that these reactions are related to depression, anger, and life satisfaction. One study (Newsom & Schulz, 1998) found that negative reactions were predictive of depression one year later. Lower self-esteem, lower perceived control, lower self-efficacy, caregiver's criticisms, and greater physical impairment are all

associated with negative reactions and may be potential causes.

MAKING SENSE OF THE LITERATURE

Helping

The threat-to-self-esteem model is inconsistent with findings on care recipient reactions to help in several ways. Those with *lower self-esteem* tend to experience greater negative reactions to caregivers' help (Newsom & Schulz, 1998), and this contradicts laboratory helping studies indicating that those with *higher self-esteem* are more likely to react negatively to help (see Nadler & Fisher, 1986 for a review). Moreover, threat-to-self-esteem effects should be more likely to occur in the caregiving situation, because the helper is more similar to the recipient than in laboratory studies in which the helper is usually a stranger (Nadler, Jazwinski, Lau, & Miller, 1980).

The threat-to-self-esteem model also predicts that those with higher internal control will be more likely to react negatively to help, but this prediction is not supported by in the caregiving literature. Both Martire et al. (1998b) and Newsom & Schulz (1996) found that those with lower control were more likely to react negatively to assistance.

A recent study by Daubman (1995) suggests that there may be limitations to the threat-to-self-esteem model even when laboratory conditions are similar to the conditions used in most experimental helping studies. Her findings indicate that when help recipients have little or no hope for improvement on a task, individuals with lower self-esteem and lower control are more likely to perform poorly on the task when help was provided. This situation may be similar to many caregiving situations in which the "task" involves physical activities. In many instances, care recipients may feel there is little hope for improvement in this area.

A Social Support and Negative Exchange Framework

The social support and social conflict literature may provide a more useful context for understanding the existing findings on negative reactions to caregiving assistance. Assistance with

daily activities can be classified as instrumental support (i.e., material or physical assistance), although caregivers also provide emotional and informational support. Negative reactions may result from positive support that is interpreted negatively or behaviors that are not intended to be supportive (e.g., criticisms). Thus, just as perceptions of social support do not necessarily correspond to actual support (e.g., Cutrona, 1986; Newsom & Schulz, 1996), subjective perceptions of caregiving interactions may not be consistent with the objective interactions. In caregiving studies, the amount of help provided is unrelated or, in some cases, positively related to negative reactions (Newsom & Schulz, 1998). Subjective perceptions of social interactions are considered to be more important for mental and physical health outcomes than actual levels of support or conflict (Barrera, 1986; Vaux & Wood, 1987; Doeglas, Suurmeijer, Briancon, & Torbjorn, 1996), and, similarly, caregiver behaviors may have less impact on mental health than subjective responses to assistance (Martire et al., 1998a).

Barrera and Baca (1990), who investigated the link between actual and subjective support, conceptualized two ways in which the factors that influence subjective perceptions of support and conflict may have their effects. Variables that have a *direct effect* on perceptions will lead to more positive or more negative perceptions of social interactions independent of other factors. Those with greater interpersonal competence experience greater satisfaction with support (Hansson & Carpenter, 1994; Tolsdorf, 1976), and extroverts tend to rate interactions with others more positively (Cutrona, Hessling, & Suhr, 1997; Graziano, Feldsman, & Rahe, 1985). Lower self-esteem is also associated with lower support satisfaction or more social conflict (Druley & Townsend, 1998; Keefe & Berndt, 1996; Lakey, Tardiff, & Drew, 1994; Searcy & Eisenberg, 1995);

Barrera and Baca (1990) hypothesized that other factors may *moderate* the relationship between social exchanges and subjective perceptions. With moderator effects, the relationship between provided support, for instance, and satisfaction with support may be stronger for certain individuals. In this relationship, the effect of actual interactions on subjective perceptions is dependent

on the level of the moderator variable. For example, feelings of dependency may lead to a greater degradation of satisfaction as more support is provided (Lee, 1985). Newsom and Schulz (1998) found that both self-esteem and fatalism (i.e., high external control) had a stronger relationship to negative reactions when more assistance was provided. Similarly, social support studies have demonstrated increased benefit from social support for those with higher self-esteem (Hobfoll, Nadler, & Lieberman, 1988) and perceived control (Hobfoll & Lerman, 1988; Lefcourt, Martin, & Saleh, 1984; Sandler & Lakey, 1982). Self-esteem may function as a direct as well as a moderating influence on negative reactions. In the Newsom and Schulz (1998) study, there was a significant direct effect of self-esteem on negative interactions independent of the interaction between self-esteem and amount of help. Negative interactions themselves may have a greater impact on negative perceptions when they come from someone who provides more support (Okun & Keith, 1998), because expectations are violated (Rook, 1990). Thus, the amount of support provided by the caregiver may act as a moderator of the impact of unsupportive actions.

Factors Likely to Lead to Negative Reactions to Caregiving Assistance

Barrera and Baca (1990) focused solely on personality factors, but there are several other kinds of variables that are likely to link caregiver interactions and subjective perceptions of those interactions, and each may directly affect or moderate negative reactions. In this model, there are five general factors that may lead to negative reactions to assistance (see Figure 1). First, the model assumes that the nature of the interactions themselves has some impact on the recipient's perceptions. Negative reactions to help, for instance, may result from too much or too little help, help delivered in an inappropriate manner or at the inappropriate time, or negative or critical behaviors. In the study by Clark and Stephens (1996) for instance, participants reported that too much or too little help were common types of "unhelpful actions" reported by recipients. Newsom and Schulz (1998) found that only insufficient help was related to general negative reactions, and neither too much nor too little help

were significant predictors after controlling for other factors. Although more difficult to quantify, more research is needed on inappropriate help and the general quality of the help provided to recipients. A number of studies suggest the link between actual support and subjective perceptions of support is rather low (see Barrera, 1986 for a review), and, similarly, helping behaviors may be only one factor that is important in negative reactions to help.

Second, the factors pertaining to the relationship between caregiver and recipient, such as the conflict in the relationship or relationship satisfaction, communication difficulties, social dominance, indebtedness, and amount of reciprocal helping, may also be important predictors of negative reactions. Marital conflict appears to be related to negative reactions, but marital support is not (Newsom & Schulz, 1998). Clark & Stephens (1996), however, found both helpful and unhelpful actions by the spouse were related to marital satisfaction. Longitudinal research is also needed to determine if negative reactions are a cause or consequence of marital difficulties or satisfaction.

Third, caregiver individual differences, such as their level of depression, caregiving burden or burnout, and social skills, may have an impact on care recipient reactions. Fazier, Davis-Ali, and Dahl (1995), for example, found that higher caregiver burden was associated with more unhelpful support. To date, however, little is known about how other caregiver variables may affect recipient reactions. Fourth, care recipient individual differences may affect how assistance is perceived and may affect reactivity to unsupportive behaviors. Self-esteem, control, and level of impairment appear to be related factors (Newsom & Schulz, 1998), but other factors such as preferences for independence and pessimistic style may be important. Finally, there are likely to be situational factors, such as experience of pain (Stephens et al., 1998), mood, current life stress, or current social conflicts that may be factors affecting negative reactions.

FUTURE DIRECTIONS

Despite the abundance of studies on caregiving, examination of caregiving from the recipient

perspective is just beginning and more study is needed on a variety of topics. Recent findings suggest that negative reactions to caregiving are neither rare nor trivial in their effects, and more knowledge is needed about the interpersonal, situational, and personality factors that increase their likelihood. In connection with this research, more should be learned about the particular cognitive and emotional responses involved in what we loosely refer to as “negative reactions.”

To achieve the first goal of improving our knowledge about negative reactions to caregiving, there are several research areas that need further study. Nearly all research in this area has focused on spousal caregiving, and more needs to be known about factors that might influence negative reactions when care is delivered by children, professionals, or multiple parties. Much of this research may be important for recent work on doctor-patient relationships (Benbassat, Pilpel, & Tidhar, 1998). At present, most studies have focused on physical assistance, but more research is also needed on the potential problems that may arise from emotional and cognitive types of caregiving support (e.g., Stephens et al., 1998). Second, more longitudinal research is needed. Nearly all research on negative reactions has been cross-sectional and a number of sticky issues about causal directionality remain. For instance, marital quality, self-esteem, and perceptions of control appear to be related to negative reactions to care, but it is not known whether these factors are causes, consequences, or merely correlates of negative reactions.

In light of some of the counterintuitive findings on reactions to caregiving assistance, a revisitation to some of the theoretical and empirical work on helping that sharply tapered off during the 1980s may be needed. The present article suggests fitting care recipient findings into the context of research on social support and negative social exchanges, but this eschews the larger task of integrating this literature with helping research (Wills, 1991).

A next step after these investigations should be to develop interventions that will reduce the frequency and impact of negative reactions. Such interventions might include improving

communication between caregiver and recipient (Melamed & Brenner, 1990), improving living conditions and environmental factors that are implicated in negative reactions, or training to improve the quality of care delivered by the caregiver (Archbold et al., 1995). To this end, expanding research on congruence of caregiver and care recipient reports (Fingerman, 1996; Horowitz, Goodman, Reinhardt, & Cantor, 1998; Pruchno, Burant, & Peters, 1997) will be critical to understanding how to improve recipient-caregiver communication. It is extremely important, however, that interventions to improve upon caregiving transactions be informed by research. It might be unfair, for instance, to attempt to focus interventions on the care provider alone if negative reactions stem from other problems such as marital difficulties, caregiver burden (e.g., Helgeson, 1993), or recipient personality characteristics. Other factors may affect negative reactions in complex ways. For example, encouragement to be self-reliant and encouragement to be reliant on others may both be harmful under certain conditions (Reich & Zautra, 1996; Zatura et al., 1995). Thus, interventions designed to reduce dependence uniformly (e.g., Baltes, Neumann, & Zank, 1994) may not be beneficial for all impaired older adults.

Research on negative reactions to caregiving should not imply that caregivers are not good at what they do or that caregiving is not typically valued. Most participants express a profound sense of gratitude to their family for their assistance, and nearly half of participants do not report any negative reactions. Moreover, when asked about helpful and unhelpful caregiver behaviors, approximately two thirds of the behaviors listed are helpful ones (Clark & Stephens, 1996). Although recipients are likely to under report negative interactions for a variety of reasons (e.g., indebtedness, social desirability), it is reasonable to assume that informal, in-home caregiving is of great benefit to recipients in most instances. Thus, an important focus of future research is also the beneficial aspects of care from the recipient's perspective.

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ENDNOTES

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² One reason for focus on caregivers rather than recipients is a major interest in caregiving with Alzheimer's patients (Cotrell & Schulz, 1993). When dementia is advanced, it is difficult to assess recipient perspectives with self-report. However, because caregiving may be most challenging when providing help to the Alzheimer's patient (Schulz et al., 1995) and because of the emotional lability associated with the disease, the amicableness of helping transactions may be even more critical for these patients than it is for individuals suffering exclusively from physical impairments.

³ One exception to the use of undergraduate psychology students as participants is a study by Avorn and Langer (1983) which involved older adults in a residential care facility. The experimental paradigm used was similar to that which has been used in other laboratory helping studies. Findings, which were consistent with other research, indicated that those receiving help perceived the task to be more difficult and to have lower self-confidence than those who were merely encouraged by another.

Table 1

Reports of specific cognitive and emotional reactions to caregiver's help from Newsom et al. (1998).

Negative reaction	% agreeing or strongly agreeing
Concerned about spousal injury during help	66
Felt dependent on spouse	54
Felt indebted to spouse	30
Wished could give more in return	31
Felt never able to return favor	27
Felt like a weak or incapable person	26
Not a person of worth, at least as much as others	23
Not able to do things as well as most others of same age	23
Wished they could have more respect for self	23

Figure 1. Direct and moderator effects of five factors that may affect negative reactions to caregiving assistance. Black arrows represent direct effects and gray arrows represent moderation of the relation between help and negative reactions.

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