

Spouse Caregivers and Dementia Relationships

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A review of the literature shows an association between depression and perceived burden in caregivers of dementia patients. These caregivers are often the spouses of cognitively impaired elders, and they experience an emotional toll with negative effects on their mental health and well-being. Findings from past research focus on spouses as caregivers and the influences of primary and secondary stressors on their depressive mood symptoms. The experiences of male caregivers with demented spouses differ from those of female caregivers with demented spouses, suggesting that either the gender of the patient, the gender of the caregiver, or both affect the experience of caregiving. The potential reasons for this difference are highlighted and compared. Implications for future work are discussed, such as the need to create and research interventions and assessments that can recognize and reduce caregiver burden and depression.

Depression in Caregivers of Dementia Patients

Dementia poses a significant public health problem because of the debilitating and progressive nature of the decline. Problematic aspects associated with dementia include the loss of independence, social limitations and interpersonal withdrawal, and personality and/or behavior changes that result from cognitive, behavioral and affective losses in functioning (Moritz, Kasl & Berkman, 1989).

Dementia affects more than just the patient – it can negatively impact the people that bear the responsibility for their care. It is estimated that 8.5 million people care for a dementia patient at home (Gallicchio, Siddiqi, Langenberg, & Baumgarten, 2002). Caregivers within this population experience considerable psychological and physical morbidity (Dunkin & Anderson-Haley, 1998), with the most consistent and deleterious of these effects experienced in the mental health domain (George, 1994).

Caregivers for demented patients versus non-demented patients experience higher levels of strain and burden due to the nature of dementia symptoms, such as wandering, screaming, and destroying property (Ory, Hoffman, Yee, Tennesedt, Schulz, 1999; Schulz, O'Brien, Bookwala, Fleissner, 1995). Primary stressors affecting the caregiver (such as feelings of loss in the marital relationship, functional capabilities of the impaired, and the impaired's level

of problem behaviors) combined with secondary contextual factors associated with the caregiver (sociodemographic, gender, and economic strain) have been correlated with negative caregiver outcomes (Bookwala & Schulz, 2000; Moritz et al., 1989; Whitlatch, Schur, Noelker, Ejaz, & Looman, 2001).

Dementia caregivers are negatively affected by “employment complications, caregiver strain, mental and physical health problems, time for leisure and other family members, and family conflict” (Ory, et al., 1999, p. 184). Negative symptoms arising from the caregiving situation can include significant distress (Karlavish, Casarett, Klocinski, & Clark, 2001), poor psychological well-being (Schulz et al., 1995), depression and anxiety, medical problems, and deterioration in occupational and social functioning (Chentsova-Dutton et al., 2002).

In the research on this topic, the terms caregiving burden and caregiving impact are often used interchangeably, although the two concepts are distinct. Impact is used to describe the change in the caregiver's life, such as health, social activities, occupation and familial relationships. Burden describes the subjective experience of caregiving tasks (Moritz et al., 1989). Distinguishing between these similar terms is imperative in clarifying the findings of various studies.

In addition to the importance of differentiating between burden and impact, there is evidence of a difference in experience between male and female caregivers, and understanding this gender difference is an important aspect of understanding caregiving depression. There have been inconsistent findings in the literature regarding gender differences in terms of depression and caregiver burden with demented patients (Gallicchio et al., 2002). Select studies indicate that female caregivers are more likely to report greater burden (Miller & Cafasso, 1992; Yee & Schulz, 2000), while other

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studies have failed to find gender differences (Hinrichsen & Niederehe, 1994; Shields, 1992).

The discrepancy among the results may be attributed to women constituting 73% of the caregiving population (Ory et al., 1999), yielding an over-representation of women in caregiving research. Differences in study designs, including lack of control groups, may have created results that suggest a greater impact upon women rather than men in the caregiving role (Moritz et al., 1989). This contradiction points to a need to further examine gender differences in the effects of caregiving. Both the caregiving experience and the interpersonal relationship between the caregiver and their demented spouse need to be considered.

The effects of caregiving for a patient with dementia have not been systematically reviewed. Accordingly, the existing literature is scattered and unable to provide a complete and representative picture of the experience of a dementia caregiver. The goal of this review is to examine critically caregiver depression and burden, investigating the emotional experiences of spousal caregivers of dementia patients. The investigation into this matter will consider different studies and meta-analyses that have identified specific stressors and predictors of caregiver depression and evaluated gender differences among caregivers. Further, the review will interpret theoretical and practical implications of caregiver depression for designing interventions and educational programs.

General Differences Among Caregivers and Caregiving Situations

Data shows that dementia caregivers experience varying levels of distress in their response to the challenge of caregiving. Two classes of primary stressors affect the caregiver's mental health: the level of impairment of the patient and involvement of the caregiver in the caregiving situation (Miller & Cafasso, 1992; Bookwala & Schulz, 2000). Secondary variables, which are defined as the stressors that are triggered because of the primary caregiving stressors, include the caregiver's relationship to the patient (Schulz et al., 1995) and attributional style (Stull, Kosloski, Kercher, 1994; Schulz et al., 1995).

Primary Stressors: Level of Impairment and Involvement of the Caregiver

According to the meta-analysis of correlates of psychiatric morbidity in caregivers by Schulz and colleagues (1995), a number of patient characteristics were unrelated to caregiver distress, but the one patient characteristic that powerfully predicted caregiver depression was the degree to which the dementia patient experienced problem behaviors. Problem behaviors, which include wandering, screaming, and destroying property, are generally a result of a decrease in the cognitive functioning of the patient and the increase in the level of severity of the illness. Evidence of such problem behaviors in

the patient predicted caregiver depression (Schulz et al., 1995) and poor coping mechanisms of the caregiver (Hinrichsen & Niederehe, 1994).

Moritz et al. (1989) found living with a cognitively impaired elderly spouse negatively affected the health and well being of the caregiver. Male caregivers exhibited an increase in depressive symptoms as their wives' level of cognitive functioning decreased. However, the reverse was not the case, as wives did not show a significant relationship between cognitive functioning in their husbands and their own levels of depression and perceptions of burden.

In at least some caregiving situations, however, the level of the severity of impairment and evidence of problem behaviors were implicated as predictors of caregiver depression. The findings underscore the importance of recognizing problem behaviors and seeking additional help when these behaviors arise.

Secondary Stressors: Attributional Style and Relationships of the Caregiver

The analyses thus far encourage further understanding of the etiology of caregiver depression. Are specific individuals more resilient to stress and burden in the caregiving situation? Are there personal attributes of the caregiver, or an attributional style, that allow one to persist longer in this role than others or cause an individual to seek support or treatment? Attributional style refers to the way a person determines which forces they hold responsible for successes and failures. For our purposes, attributional style in caregiving refers to the way a caregiver perceives the caregiving situation.

Psychosocial and personality variables predictive of depression in caregivers have not been fully identified (Dunkin & Anderson-Haley, 1998). However, specific attributes of the caregiver are predictive of the caregiving outcome. This includes the feeling of perceived enrichment in the caregiver's life and the caregiver's ability to find personal meaning through his or her relationship (Stull et al., 1994). Conversely, it is also possible that caregivers' attributional styles can leave them more vulnerable to depression, as caregivers may have basic assumptions about caregiving being burdensome. Therefore, they may have a preconceived belief regarding how they are supposed to feel about providing care.

The attributional style of the caregiver in terms of other relationships has been evaluated in the literature and judged to be of importance. In addition, the presence of a strong social network for the caregiver was protective, and satisfaction with this support was predictive of positive outcomes (Dunkin & Anderson-Haley, 1998). Furthermore, the quality of the relationship between the caregiver and the patient has been shown to impact the level of depression and/or burden experienced within the caregiving situation (Schulz et al., 1995). Tower and colleagues (1997) found that closeness of the spousal relationship moderated the impact of depressive symptoms of male caregivers whose

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wives were cognitively impaired. Those whose marriages were described as being closer prior to the cognitive impairment were more affected by depressive symptoms than those who were less close before the onset of their spouse's dementia. However, this result was found with male caregivers only. Female caregivers' levels of depression were not significantly associated with their husbands' levels of cognitive impairment, regardless of the strength of the spousal relationship.

Beeson and colleagues (2000) hypothesized that increases in loneliness and depression in the caregiver resulted from experiencing the loss of closeness in the relationship due to cognitive changes in the patient. They found that caregivers who experienced higher loneliness and depression also experienced higher levels of relational depravity and a higher dissatisfaction with the lower quality of the current relationship with the patient. In contrast to Tower and colleagues (1997), Beeson and colleagues (2000) found that female spouse caregivers reported a significantly higher level of relationship depravity, loneliness and depression than the daughter caregivers. Thus suggests that the nature of the relationship between the caregiver and the care receiver is important in determining likelihood of caregiver depression and subsequent quality of the relationship between the caregiver and demented family member.

Gender Differences and Gender Role Socialization in the Caregiving Experience

Previous research has examined gender as a variable relative to caregiver depression, yet results have been inconsistent as to the effect of gender. Is it possible that gender can be a risk or protective factor for caregiver depression? Yee and Schulz (2000) compiled a review of empirical research from 1985 to 1998 on caregiver differences in psychiatric morbidity in terms of gender, including depression as an index measure. In investigating gender differences in caregiving with the elderly (physically ill and demented adults), the authors found higher distress in female caregivers versus male caregivers. The 30 articles reviewed suggested that women exhibit more psychiatric symptoms than men, specifically on the domains of depression, anxiety, general psychiatric symptoms and lower life satisfaction. Compared to women who are not in the caregiving role, caregiving women experience more psychiatric morbidity attributable to caregiving. It is suggested that women have a greater susceptibility to psychiatric morbidity than men because they respond differently to all stages of stress. In addition, men do not tend to engage in behaviors that would put them at a greater risk for psychiatric morbidity. For example, they are more likely than women to seek additional help or relinquish the caregiving role (Yee and Schulz, 2000).

Conversely, more recent research has suggested a different gender effect. Gallicchio and colleagues (2002) investigated the relationship of gender, burden and depression among 259 female and 68 male caregivers working with the

dementia population. They found female caregivers to have a significantly higher risk of experiencing caregiver burden and stress. On average, women reported greater burden than the males but did not exhibit depressive symptoms, indicating burden was not a risk factor for depression for women.

It is suggested that the burden women experience is not correlated with the caregiving situation, but instead reflects gender differences in nurturing roles seen within the general population (Gallicchio et al, 2002; Hooker, Manoogian-O'Dell, Monahan, Frazier & Shifren, 2000) and within the age cohort (Moritz et al., 1989). Observed gender differences may be attributed to the gender-role socialization and social roles that women and men each assume (Miller & Cafasso, 1992; Collins & Jones, 1997). Women have been found to experience a greater burden because of their sense of responsibility to provide good care. They also tend to feel more comfortable in expressing their feelings and reporting their depression and burdensome feelings (Miller & Cafasso, 1992). It is possible that female caregivers are affected by different dynamics and therefore experience different consequences than their husbands (Tower et al., 1997).

Miller and Cafasso (1992) initiated the first analysis of gender differences in caregiving, and their findings support the notion of gender differences in the larger population rather than in the caregiving sample. The authors aimed to provide a foundation of the implications of gender differences in caregiving, however they did not specifically measure depression. Within the parameters of their analysis, they found women were more likely to report caregiver burden, but could not specifically explain how this burden was expressed. These results supported elements of a hypothesis based on both gender-role and social role socialization. Even though there was an effect for gender, this was small, and did not specifically explain which aspects of gender socialization contributed to the overall caregiving stress effect in women.

Summary of Major Findings

Given the narrow field of empirical and practical studies in the literature, the evidence linking psychiatric health effects and caregiving is robust, with virtually all studies reporting elevated levels of distress and depressive symptoms among caregivers (Schulz et al., 1995). Although the literature clearly demonstrates a link between the burden and psychological distress of caregiving, the underlying cause of this distress may relate to a number of different factors.

In terms of primary stressors within caregiver relationships, the level of impairment in the patient and the caregiving situation impacted the level of caregiver depression. The evidence of problem behaviors in a patient (which goes hand in hand with cognitive impairment) was implicated as leading to greater depressive symptomatology in caregivers. In addition, living with a cognitively impaired elder also predicted negative effects for the caregiver. The level

of impairment was found to be associated with depressive symptoms in males as their wives' cognitive impairment decreased, but this was only found for the male caregivers. Female caregivers did not exhibit more depressive symptoms when caring for a cognitively impaired husband.

In terms of secondary stressors, having a social network was found to be protective for both male and female caregivers. However, the level of closeness in the spousal relationship before the onset of illness was protective for females, but a risk factor for males. The literature suggests that while female caregivers may exhibit psychiatric morbidity, they do not exhibit more depressive symptoms than male caregivers. This suggests that other differences experienced by male and female caregivers may be more related to overall social role differences that exist between the sexes in general.

Limitations of Current Research and Future Directions

Several limitations of the literature emerged from this review. In terms of research design, caregivers were often recruited from support groups, educational classes, or other support services. Using these samples may over represent the negative effects of caregiving. Furthermore, most studies used relatively small sample sizes and did not control for other factors known to influence mental health outcomes, such as level of involvement in the caregiving role and sociodemographics (Ory et al., 1999). The lack of control groups and the overall predominance of women caregivers may point to women being more negatively affected, but this may not be an accurate representation. There is also a lack of valid and reliable measures in caregiving research. The Zarit Burden Interview (Zarit et al., 1980) is heavily relied on for research on caregivers, yet it may not clearly delineate the degree of encumbrance the patient causes or the ways in which patients burden caregivers. To further understand other factors possibly implicated, a measure needs to be able to capture the entire clinical picture.

In addition, baseline levels of depression should be assessed, requiring prospective research designs. Including a measure that looks retrospectively at life prior to the onset of the illness would possibly control for the perceived gender role-socialization difference. Moreover, research in this field would benefit from using a different measure that evaluated the patient-caregiver relationship, as well as the quality of other relationships between patients and family members prior to the onset of the patient's dementia.

As stated previously, major limitation of research on caregivers surrounds conclusions about gender differences. Women are historically over-represented in caregiving research and account for almost three-quarters of the caregiving population. Further studies need to take into account the higher levels of emotional stress found in women before considering the caregiving situation. The meta-analyses reviewed clearly indicated that women tend to report higher levels of emotional distress in the life course—without the

caregiving aspect being considered (Miller & Cafasso, 1992).

Examining differences within caregiving in terms of both impact and burden is important to the field for both needs assessment and intervention purposes. The data gathered from this research can be used for informing mental health professionals and primary care physicians responsible for treating this population.

Conclusion

Further research on caregivers of demented spouses is imperative. Future directions should include better recruitment, more stringent study design and thorough, well validated measures. Gender, interpersonal relationships, and characteristics of the patient and the patient's experience have been examined in this review; future research should continue to focus on these factors, all important aspects of the caregiving stress model, and work to clarify how each affects caregiving outcomes.

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