

# Caring for the Caregivers: Ensuring the Well-Being of Caregivers

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Chronic health conditions, or psychological or physical health conditions that persist for 3 months or longer (Newacheck & Taylor, 1992), are quite common. About half of all adults in the U.S. have at least one chronic health condition, and about 25% have two or more (Ward, Schiller, & Goodman, 2014). While arthritis and musculoskeletal conditions are the leading cause of activity limitations among working-age adults, psychological disorders are the second leading cause among individuals age 18-44 years old (National Center for Health Statistics, 2006). In 2007, approximately 39% of the nearly 41 million disabled individuals had mental disabilities, which include disorders such as schizophrenia, bipolar and chronic depression (U.S. Census Bureau, 2007).

Chronic health conditions also affect children. Among children, the prevalence rate for chronic health conditions is about 30%, with approximately 21% of children struggling with two or more conditions (Newacheck & Taylor, 1992). About 7% of all children have their daily functioning impaired by their health condition(s) (National Center for Health Statistics, 2006).

Chronic health conditions affect not only the patient, but their caregivers as well (Zarit & Femia, 2008). Often, primary caregivers are members of the patient's family, including the spouse, parent, adult child or other close

family member. With current health care trends shifting patient care for chronic health conditions, including mental disorders, more towards families (Martire, Lustig, Schulz, Miller & Helgeson, 2004; Shah, Wadoo, & Latoo, 2010), promoting the well-being of patients and their family caregivers is quite important.

The well-being of patients and their close family members have been shown to be closely intertwined (Martire et al., 2004), suggesting that supporting the caregiver's health will positively affect the health of the patient, and vice versa. For example, close family members have a significant influence on the patient's psychological well-being and the management of the illness, which includes treatment adherence and engagement in positive health behaviors (Martire et al., 2004). Additionally, diverse family characteristics and behaviors such as intimacy, emotional support, overprotective behaviors, and criticism have been found to influence patient outcomes across multiple health conditions, including chronic pain, heart disease, and rheumatic disease (Martire et al., 2004). For example, researchers investigating the role of fathers' involvement in the management of pediatric chronic health conditions have found that higher levels of paternal involvement are associated with improved treatment adherence and better quality of life for adolescent patients (Wysocki & Gavin, 2006), as well as improved maternal, marital, and family functioning (Wysocki & Gavin, 2006).

These studies and others suggest that family caregiving has value that transcends simply attending to the patient's daily needs. This paper will review the ways in which family members are affected by their role as caregivers, examine the factors that influence their experience, and consider recommendations for improving caregivers' well-being.

### How do chronic health conditions affect caregivers?

The manner in which chronic health conditions affect the family caregiver depend on features of the illness, as well as qualities of the family (McDaniel & Pisani, 2012). Rolland (1994) suggests that four characteristics of an illness may influence how it affects patient and family functioning: onset (i.e., acute or gradual), course (e.g., progressive, constant, relapsing/episodic, predictable/unpredictable), incapacitation (e.g., presence and severity of limitations), and outcome (e.g., fatal, shortened lifespan, nonfatal). For example, a terminal cancer that progresses predictably and slowly has a qualitatively different effect on the patient and his or her family than episodic and unpredictable inflammatory bowel syndrome.

The chronic health condition's influence on family caregivers also depends on the onset of its occurrence within the family's life cycle. The timing of the condition as it relates to when and how the family was formed is important to consider, as well as how this timing relates to significant periods of family transition (such as coupling, raising young children, and young adults leaving the childhood home; McDaniel & Pisani, 2012). For example, a daughter who is in charge of her father's caregiving after he was paralyzed from a car accident may have more difficulty coping with this role if the caregiving began when she was married with children, as opposed to during her adolescence while living at home. Depending on the onset of the condition in relation to

the family's life cycle, the chronic condition may cause isolation for patient and family members, shifts in family roles, and the necessity of balancing different coping styles amongst family members (McDaniel & Pisani, 2012).

### The burden of caregiving on families and individuals

Caregiving for family members with chronic health conditions is associated with several stressors. The family burden associated with caregiving can be categorized into two types: objective and subjective (Shah et al., 2010). Objective forms of family burden are practical problems that arise from caregiving, such as financial difficulties due to medical bills and loss of income, disruption in family relationships, lifestyle limitations (e.g., constraints regarding work, social activity, or leisure), and negative influences on physical health. Subjective forms of family burden are the psychological reactions that family caregivers experience, including sadness, anxiety, embarrassment, frustration, stress of caretaking, and grief. For example, grief can be triggered not only by witnessing the loss of the patient's lifestyle and identity, but also by experiencing the loss of the caregiver's own lifestyle and identity. Such grief can trigger caregivers to experience unconscious hostility and anger towards the patient; in turn, these feelings can cause guilt and shame for having such emotions towards their loved one (Shah et al., 2010).

Studies also show that the patient's close family members tend to experience poorer physical health, as well as decreased quality of their relationships with the patient (Martire et al., 2004).

Given these stressors, it is not surprising to learn that caregiving also negatively impacts family members' psychological well-being. Research shows that approximately 33%-50% of family caregivers experience

significant psychological distress, including higher rates of mental health problems than the general population (Shah et al., 2010). In fact, depressive symptoms are twice as common in caregivers as in non-caregivers, with some studies showing that up to 50% of caregivers meet criteria for clinical depression (Shah et al., 2010).

Depression has been found to differentially affect family caregivers by gender, ethnicity, and age. For example, female caregivers are more likely to develop clinical depression than male caregivers, with one study finding the risks to be 39% and 16%, respectively, over a two-year span (Schulz & Williamson, 1991). Differences by caregiver ethnicity have also been found. Latino caregivers report the highest levels of depression (Harwood, Barker, Cantillon, Loewenstein, Ownby & Duara, 1998), while White caregivers report higher levels of depression than Black caregivers (Farran, Miller, Kaufman, & Davis, 1997). Additionally, among White caregivers, older age is associated with more caregiver burden, while the reverse is true for Black caregivers (i.e., older age is associated with less caregiver burden; Lawton, Rajgopal, Brody & Kleben, 1992).

### Factors associated with well-being among caregivers

It is important to note that not all effects of family caregiving are negative. Evidence suggests that family caregivers also experience pride in fulfilling familial responsibilities, enhanced closeness with the patient, and satisfaction with personal competence. Notably, these effects are associated with lower levels of depression and caregiver burden (Shah et al., 2010).

Among the multiple factors that are associated with caregiver well-being, social support is possibly the most important (Shah et al., 2010). While caregivers often report social isolation and withdrawal, caregivers with the most social support reported the lowest levels of

depression and caregiver burden (Shah et al., 2010). Religious involvement is often associated with increased access to social support, and Black and Latino caregivers report using religious coping more often than White caregivers (Shah et al., 2010).

### Promoting well-being among family caregivers

Given the prevalence and importance of family caregiving, many interventions have been developed to help improve the well-being of caregivers and their patients. These programs include education, case management (i.e., matching people's needs with available programs and resources), and psychological interventions (Zarit & Femia, 2008).

In their review of interventions for family caregivers of individuals with dementia, Zarit and Femia (2008) identified the following four characteristics of effective interventions: active help given to caregivers in applying new skills and information (rather than just imparting information), addressing multiple stressors and risk factors, flexibility in addressing the caregiver's specific needs, and sufficient time given to address caregiver's needs. In their systematic review of interventions for family caregivers of individuals with dementia, Cooke, McNally, Mulligan, Harrison and Newman (2001) similarly found that while interventions can reliably increase the caregiver's knowledge about the illness, this increased knowledge did not correlate with improved psychological health for the caregiver. Rather, they found the cognitive and social components of interventions contribute most strongly to improved psychological well-being (Cooke et al., 2001). Cognitive interventions are those that address caregivers' unhelpful thoughts, such as, "I should never feel mad at the patient" and "This cannot be happening to us." Social interventions are those that help caregivers increase their social support. In their review of research investigating family caregivers

of individuals with mental disorders, Shah and colleagues (2010) found that family interventions which included components designed to modify caregivers' maladaptive cognitions and behaviors showed greater reductions in caregiver burden, anxiety, and depression compared to those interventions that were strictly educational (i.e., providing information about the illness and caregiving).

Other research underscores the value of family interventions compared to typical medical care. In a meta-analytic review of 70 studies that compared family interventions to treatment as usual for a variety of chronic medical conditions, Martire and colleagues (2004) concluded that these interventions have small but positive effects for both patients and family members. Specifically, patients experienced decreased depression (and in some cases even decreased mortality) when the spouse was included in the intervention. Caregivers also reported decreased caregiver burden, depression, and anxiety. Notably, interventions that directly addressed relationship issues between patient and family members demonstrated the largest improvements (Martire et al., 2004).

In light of these research findings, to enhance their own and their family's well-being, family caregivers are encouraged to address their beliefs surrounding caregiving, their own health behaviors, and their social support. Interventions that help caregivers modify potentially unhelpful caregiving-related beliefs may be especially beneficial, particularly if they help reduce the guilt surrounding normal negative emotions they may experience as a result of caregiving (Shah et al., 2010).

Additionally, family caregivers should be careful that they do not ignore their own health needs. As caregivers face increased risks for developing mild hypertension and serious illness (Shah et al., 2010), a healthy diet and regular exercise are particularly important.

Lastly, given the stress of family caregiving, garnering and managing social support may be the most important

ways caregivers can care for themselves. Having close friends and family members to share with and discuss the stresses of caregiving has been consistently linked with better well-being (Martire et al., 2004; Cooke et al., 2001; Shah et al., 2010).

## Conclusion

Family caregiving is an important and widespread responsibility that may become even more common as our society's elderly population grows (Cooke et al., 2001). Trends in health care are also shifting more patient care onto families (Shah et al., 2010), increasing the stress related to this role. Family caregiving is a very complex process that affects the caregiver patient, and family (Martire et al., 2004), with serious health consequences for the caregiver's own well-being if not properly managed (Shah et al., 2010). Given this complexity and the increased risk of depression and psychological distress (Shah et al., 2010), professional help for caregivers (including family-based intervention programs as well as psychotherapy, if warranted), may be useful to sustain and enhance the well-being of patients and their family caregivers.

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## Author Biography



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