INFORMAL CAREGIVERS: COMMUNICATION AND DECISION MAKING

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IT IS ESTIMATED THAT 13 million to 15 million adults in the United States have chronic conditions that impair cognitive function, such as Alzheimer's disease, stroke, Parkinson's disease, and traumatic brain injury (Family Caregiver Alliance, 2000). The growing number of people with chronic conditions that include cognitive impairment and the family members who assist them face many challenges and stresses. For example, the high levels of stress experienced by people caring for those with chronic conditions can lead to their own poor physical and mental health (Vitaliano, 2002). Providing care for people with chronic or degenerative conditions that include dementia can also adversely affect the caregivers' relationships with family and friends, reduce their time for leisure and social activities, and undermine their physical and mental health (Aneshensel et al., 1995; Yee & Schulz, 2000). The needs of both patients and their caregivers must be better understood if they are to receive optimal support.

Regardless of a patient's diagnosis, any loss of ability can have a significant impact on the family. One of the most difficult challenges families face is making decisions for a family member who has impaired judgment and planning capacity (Whitlatch & Feinberg, 2003; Whitlatch, 2006; Whitlatch & Feinberg 2007). Families often must balance conflicting preferences for care. For example, a woman who is caring for her father might be forced to reconcile his desire that only *she* provide assistance with the fact that she desperately needs help in caring for him. It's often very challenging and stressful for a family to separate the needs, preferences, and best interests of the chronically ill person from those of family members (Feinberg et al., 2000).

Decision Making in Families Facing Chronic Illness and Dementia

Despite the large number of people requiring hands-on assistance, we know little about how families make decisions about in-home

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care and nursing home care. Consider the example of deciding whether to place a relative in a long-term care facility. Practitioners may suggest that a caregiver do so, assuming that the move would alleviate the stresses of caregiving. Although some caregivers are relieved after a relative has moved, most remain vulnerable to stress, sometimes for many years (Aneshensel et al., 1995). As time passes and caregivers adapt to their altered roles at the long-term care facility, they are more likely to adjust well at work and experience improved emotional well-being (Aneshensel et al.). Social workers, nurses, counselors, and other professionals must be aware that placing a person in a long-term care facility will not alleviate all of the caregiver's stress. As noted by Aneshensel and colleagues, such a move doesn't necessarily eradicate the "commitment, caring, involvement, or the pain associated with seeing a loved one go through a long period of decline" (Aneshensel et al.).

Although research on chronic illness and decision making has increased in its breadth and depth, few studies have examined the daily care decisions that family caregivers and patients make together (Young, 1994), especially when cognitive impairment is involved. One exception is Robinson and colleagues, who interviewed couples with one partner in early stage dementia (Robinson et al., 2005). Their findings suggest that such couples may adjust to their changing roles by creating a shared understanding of dementia. Practitioners could incorporate these findings into their clinical protocols and help couples develop a mutually acceptable plan of care.

Related research focuses on communication and decision making within the patient–family caregiver–practitioner care triad. (For more information on several studies, see http://links.lww.com.) Generally, research involving care triads or teams has found that there is a lack of communication and a high rate of misunderstanding of diagnosis, prognosis, care decision making, discharge planning, and home care follow-up. Taken together, findings from these and other studies suggest that miscommunication and lack of communication about care preferences and decision making may be fairly universal within caregiving families and not uncommon in the interactions between providers and families.

Do Family Caregivers Know Their Relatives' Care Values?

Relatively little is known about how well family caregivers understand their relatives' preferences for care. A growing but still sparse body of literature suggests that families have a general understanding of the importance of certain care values and preferences (Feinberg & Whitlatch, 2001; Whitlatch, 2006; Whitlatch et al., 2005a).But few studies have examined the views and care preferences of people with dementia. This means their views aren't well considered as care strategies are selected (Cohen, 1991).

It is important to acknowledge that family members and professionals often doubt the accuracy and consistency of impaired adults' responses to factual questions and their ability to express care preferences (Woods, 1999). Yet research suggests that those with mild to moderate cognitive impairment—with scores between 18 and 26 on the Mini-Mental State Examination—are able to state consistent choices, communicate preferences for daily care, make informed care decisions (Clark, 2004; Clark et al., in press), and choose someone, typically a family caregiver, to make decisions for them when they can no longer do so themselves (Feinberg & Whitlatch, 2001; Logsdon et al., 1999; Squillace et al., 2002). As cognitive loss becomes more pronounced, the person loses the ability to answer factual questions, such as those about age or birth date, but can still state preferences, such as a favorite color or food (Clark et al., in press). Family members caring for someone with cognitive impairment can understand their relative's preferences as long as care values have been discussed early in the course of the disease. Nurses and social workers should acknowledge the potential and ability of those with cognitive impairment to be involved in discussions about their care for as long as possible.

What Is the Effect of Misperceptions on Caregiver and Patient Well-Being?

Along with having a greater appreciation for the ability of functionally and cognitively impaired people to assert their preferences about care (Logson et al., 1999; Brod et al., 1999; Gerety et al., 1993; Parmelee et al., 1989), we must understand the impact of patient autonomy on family decision making (Whitlatch, 2006). In the case of the woman caring for the father who wants to make his own decisions, his active involvement in decision making may have a negative impact on his safety and on her level of stress. She might prefer that her father remain at home with a home health care aide providing help. However, he may decide to dismiss the aide, which would leave him unsupervised during the day. Should his desire to make his own care decisions override her need for assistance? (Whitlatch, 2006). Care preferences often change according to circumstances, which makes it difficult to anticipate needs and preferences (Hibbard et al., 1997).

To date, few studies have examined how accurately family caregivers perceive their relatives' care preferences. McCullough and colleagues reported that older, cognitively intact adults were most concerned with the physical and social environments and their own identities, while family members were most concerned with care, security and safety, psychological well-being, and the older adults' happiness and activity (McCullough et al., 1993). Carpenter and colleagues reported that adult children were fairly accurate in predicting their parents' overall preferences for care, but overestimated parental desire for predictability, routine, and control while underestimating their desire for enrichment and personal growth (Carpenter et al., 2006). Recent work with family care dyads indicates that older adults with mild to moderate cognitive impairment place greater emphasis on autonomy, safety, quality of care, and not being a burden and slightly less emphasis on social interactions (Whitlatch et al., in press). This difference appears to intensify over time, not because of growing cognitive impairment but because caregivers increasingly misperceive preferences for care (Piiparinen et al., 2008). Because caregivers often misperceive their relatives' choices for care (Cicirelli, 1992; Horwitz et al., 1990), it is important for professionals to help care partners balance each other's preferences and values about care planning (McCullough et al., 1993).

The well-being of both caregiver and care recipient depends on finding a balance between the recipient's needs and desires and the caregiver's ability to fulfill them. Research indicates that caregivers' well-being depends on whether they understand their relative's care values and preferences. For example, caregivers who report that their relatives are more involved in decision making also report fewer negative interactions with the relative, higher quality of life, and less depression (Menne et al., 2008). Conversely, when caregivers misperceive the care values and preferences of their relatives, they report feeling trapped, having higher levels of depression, and sensing a loss of self (Whitlatch et al., 2007). While increased care recipient involvement in decision making may not necessarily lead to optimal outcomes for both members of the care dyad, these findings suggest a need for strategies that correct or clarify caregiver misperceptions.

Interventions for Patients, Caregivers, and Service Providers

One way to bridge the knowledge gap and improve patient and caregiver outcomes is a dyadic approach that brings together the caregiver and care recipient to discuss care needs (Whitlatch et al., 2006). This approach facilitates education on the illness, discussion of feelings and thoughts, and skill building for both care partners. A positive outcome for caregivers, such as improved mood or less strain in the relationship, may be another advantage to such interventions (Whitlatch et al., 2006).

Two interventions in particular show promise because they address a number of issues, including everyday decision making, relationship strain, and symptoms of depression. Both incorporate educational information with either a counseling-based or a skill-building approach. The first intervention, the Early Diagnosis Dyadic Intervention (EDDI), which my colleagues and I developed, promotes awareness and understanding of the symptoms of dementia and structured exploration and discussion of care preferences and needs, including the importance of autonomy, social interaction, and good care (Whitlatch et al., 2006). The goals of EDDI include educating both care partners about dementia and what to expect if the illness changes, how everyday decision making can be enhanced for both patient and caregiver, techniques for alleviating strain associated with the illness, and strategies to reduce negative outcomes such as depression and negative mood and enhance quality of life. Care partners attend structured sessions led by a trained EDDI specialist and discuss issues that many partners face as they cope with dementia. According to preliminary findings, the EDDI program is feasible (Whitlatch et al., 2006) and can enhance positive outcomes for both care partners (Whitlatch, 2007).

A second intervention is Project ANSWERS (Acquiring New Skills While Enhancing Remaining Strengths) (Judge, 2007), which trains care partners in how to manage specific issues such as memory loss, communication, staying active, and recognizing emotions. Care dyads work with an intervention specialist in six 90-minute sessions devoted to developing skills for coping with the symptoms of dementia. During the six sessions, ANSWERS introduces a variety of skills designed to improve decision making, decrease strain on both care partners, and decrease symptoms of depression.

These interventions promise to improve communication and mutual decision making for care partners facing the challenges of chronic illness. Assessing care values and preferences throughout the course of the illness also enhances the well-being of both care partners. The Values and Preferences Scale (VPS) (Whitlatch et al., 2005b) is designed for use by social workers, nurses, and other professionals who work with care dyads dealing with chronic illness, including cognitive impairment. After both care partners separately complete the VPS, a professional works with them to help each partner understand the care values and preferences of the other. Encouraging both caregiver and patient to express their preferences and expectations and understand their abilities may have lasting benefits for both. It is important to remember, though, that empowering one member can have a tremendous impact, negative or positive, on the other care partner. For example, a husband with dementia who feels he is maintaining his independence by staying at home alone rather than attending an adult day program may end up burdening his wife by calling her many times at work throughout the day. The results of and procedures for effective interventions that meet the needs of both care partners must be widely disseminated for use by researchers and practitioners.

While an increasing number of state and federally funded programs acknowledge and address some of the needs of family caregivers (Feinberg et al., 2004), no current program employs a dyadic approach that seeks to improve outcomes for both care partners. As well, practitioners can't assume they know the care preferences of their clients if these preferences are neither assessed nor discussed. Family members do not necessarily understand their relatives' preferences even when some discussion about care options has taken place. Increased understanding of the patient's preferences and the family caregiver's needs could improve decision making, lead to more informed decisions being made, and reduce strain for both members of the family care team.

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