Caring for Frail Older Adults
A Theoretical and Methodological Agenda

An estimated 45 million family members, friends, and neighbors provide unreimbursed home care services for older adults who require some form of assistance to remain in the community because of one or more chronic illnesses or disabilities (National Alliance for Caregiving & AARP, 2009). Research reports indicate these informal caregivers often feel burdened and unprepared to provide home care (Dunbar, Clark, Quinn, Gary, & Kaslow, 2008; Pinquart & Sörensen, 2003). A wealth of studies describe in-home and telephone interventions for informal caregivers related to:

- Counseling and affective support (Mittelman, Haley, Clay, & Roth, 2006; Winter & Gitlin, 2007).
- Strategies for improving caregiver mood (Buckwalter et al., 1999).
- Skill training for managing everything from the caregiver’s personal stress response (Akkerman & Ostwald, 2004) to the care recipient’s resistance to bathing (Sloane et al., 1995) and disease-related problem behaviors (Haupt, Karger, & Jänner, 2000).

The following precepts are offered as the next elder care intervention studies are considered.

INDIVIDUAL STRESS AND COPING THEORY IS NOT SUFFICIENT

With few exceptions, studies of chronic illness caregiving for older adults have been centered on the difficulties and challenges of being the primary caregiver for an older adult with some degree of dementing illness. Thus, caregiver skill training has focused on caregiver stress and coping difficulties around dementia home care, and intervention strategies have emphasized helping caregivers (usually adult daughters and wives) to develop better illness care problem appraisal and coping skills (e.g., better activities of daily living skills mastery), which, in turn, are expected to improve caregiver outcomes (e.g., less care burden, fewer depressive symptoms). This emphasis on individual stress and coping has generated an impressive body of literature on dementia caregiver outcomes but far fewer care recipient outcomes. Caregiver skill training should also benefit the care recipient. We need elder care studies that focus on developing and testing stress and coping theories and models that explore whether and how dementia caregiver stress and coping skill training interventions improve care recipient stress and coping outcomes.

In addition, the focus on caregiver stress and coping around caring for an increasingly dependent and passive older adult with dementia has resulted in neglect of theories that could illuminate the intensely interpersonal and interactive nature of the caregiver-care recipient relationship when the chronically ill older adult wishes to—and is capable of—participating in home care (e.g., collaboration theories, decision making theories, conflict management theories). The concept of the “care partnership” between the caregiver and chronically ill older adult and between caregivers is relatively absent from the literature. Elder care studies are needed that focus on developing and testing caregiving theories and models of caregiver-care recipient collaboration in home care.

TRIAL DESIGNS SELDOM EMULATE CHRONIC ILLNESS TRAJECTORIES

A frequently used caregiving trial design consists of participant randomization to groups who receive short-term, intensive care skill training contacts (for the experimental group) and usual care/placebo/attention-control maintenance contacts (for the comparison group). Key outcome measures are administered at baseline and then repeated when group contacts are completed (to compare outcomes from the contacts) and repeated again without group contacts to explore change over time.

This type of trial design has limited clinical relevance in progressive diseases such as Alzheimer’s disease, Parkinson’s disease, and cancer when negative change over time actually reflects the downward trajectory of the illness, not the skill training or placebo outcomes. If caregiving trials followed the evolving clinical course of many age-related, progressive chronic illnesses, one would see study designs in which caregiver skill training begins with skills for managing the
illness in its current manifestations and then includes episodic training to help caregivers develop new skills to handle new problems, as the chronic illness trajectory evolves over time. Researchers need to design caregiving studies that enable us to identify and capture the optimal sequence, timing, and dosage of caregiving skill training when chronic illnesses transition from stable to downward trajectories.

THE SPOUSE IS NOT THE ONLY CAREGIVER

Although an estimated 40% of chronically ill older adults live alone (Bott, Kapp, Johnson, & Magno, 2009), the majority of caregiver interventions are designed for the spouse or partner (usually an adult child) who lives with the older adult. While primary caregiver studies (those restricted to the spouse, adult child, or other informal caregiver who lives with the older adult) can provide important micro-level perspectives of chronic illness care, the paucity of intervention studies with the older adult’s neighbors or friends as informal caregivers (who help with meals, medications, and transportation) and long-distance caregivers (who use a variety of strategies to coordinate care from afar) remains a limitation in chronic illness caregiving science. Researchers need to develop and test ways to tailor caregiver skill training to make them portable for a diverse group of informal caregivers.

BIVARIATE ANALYTIC TECHNIQUES DO NOT CAPTURE “FAMILY” CAREGIVING OUTCOMES

Family-level studies of chronic illness intervention outcomes may include care dyad (chronically ill older adult and one caregiver) and/or multiple family member responses to interventions. Bivariate statistics have typically been used to present these family data; for example, with dyad studies, there are correlated caregiver-care recipient scores to show relationships, and subtracted caregiver score from care recipient score to show discrepant views. If future family caregiving studies are to inform practice and policy on family caregiving for older adults, more thought needs to be given on how to interpret and present the richness of these data.

The exclusive use of the statistical mean may obscure family-level outcomes. In such cases, subgroup analyses, with careful attention to moderating (e.g., family demographics) and mediating (e.g., number of family members who use the skill training) factors may explain differential family caregiving outcomes. Techniques that capture family changes as well as illness progression over time, such as growth curve modeling, may be helpful in identifying families who benefit from skill training over the course of the older adult’s illness.

Newer analytic techniques indicate researchers should consider cluster analysis to identify high-risk older adult family caregiving situations, multilevel modeling to present inter-dyad elder care relationships, and latent class analyses to explore the fit of family data with our theories.

SUMMARY

Families, friends, and neighbors provide the majority of community-based care for frail older adults in the United States. As we develop the agenda for future studies of informal caregiver interventions, it is timely to consider whether existing theoretical and methodological approaches still fit the complexities of community-based care of older adults today.

REFERENCES


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