

Next Steps in Family Caregiving Research: Interventions Designed for Impact

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Overview

Family caregiving has grown from a social issue primarily studied by social science and nursing researchers into a topic of national importance, debated across social, economic, health and political arenas. The most parsimonious explanation for this change in interest is the dramatic increase in the need for family caregiving and the widespread recognition that caregiving is associated with emotional, physical and financial hardships.

In 2009, there were an estimated 42.1 million family caregivers in the US providing care to an adult with activities of daily living (ADL) or instrumental activities of daily living (IADL) limitations, and an estimated 61.6 million provided care at some time during the year [1]. The care they provided was valued at approximately \$450 billion, up from an estimated \$375 billion in 2007 [1]. For Alzheimer's disease and other dementias specifically, 15.2 million US citizens provided 17.4 billion hours of care for a family member or close friend in 2011 [2]. The economic value of care provided "informally" by family and friends in 2011 was estimated to be \$210.5 billion [2]. Practically, the value of informal caregiving is priceless as the infrastructure and workforce resources are not available to transition the existing care demands placed on informal caregivers to formal care settings (e.g., assisted living facilities and nursing homes).

Informal care, however, does not come without a cost. The emotional demands (i.e., depression, anxiety) of family caregiving have been the driving force in family caregiving research to date. An estimated 40-70% of family caregivers report clinically significant symptoms of depression with perhaps as many as a quarter to half of these caregivers meeting the diagnostic criteria for major depression [3]. Informal caregiving is also accompanied by poor health outcomes. The total economic impact of family caregiving is not yet well understood; however, the caregiving role can be associated with direct costs (e.g., respite and home care services), loss of wages and time at work, diminished productivity, and a negative impact on retirement plans.

Research has produced evidence-based interventions that partially address the negative consequences of family caregiving. The strongest evidence exists for multi-component, skills training-based interventions to improve overall quality of life and reduce depressive symptoms

and caregiver burden (e.g., Resources for Enhancing Alzheimer’s Caregiver Health (REACH-II)[4], New York University Caregiver Intervention (NYUCI)[5], Skills2Care[6]). At least one of these interventions also appears to delay time to institutionalization for persons with dementia [5]. Other interventions successfully target a specific caregiving challenge with theoretically derived treatment approaches. Improved caregiver well-being has been achieved with interventions based on cognitive behavioral therapy principles [7, 8], environmental manipulation [6], and physical activity [9]. There is still little evidence of the effects of intervention on caregiver physical health, or how interventions can maximize healthcare utilization for older adults with care needs while reducing the financial toll placed on caregivers.

Translation of evidence-based interventions into community-based support programs for caregivers is underway with leadership from federal and private organizations (e.g., Administration for Community Living, formerly Administration on Aging, and the Rosalynn Carter Institute for Caregiving). Translation efforts, challenged by the implementation demands of current interventions, are insufficient to address future caregiver needs. Current interventions are designed and tested within academic settings with little thought for, and even fewer resources dedicated to, the translation of a successful intervention into community support services, creating a chasm between the evidence and the community service providers positioned to assist family caregivers.

Core attributes of current evidence-based interventions make them seemingly out of reach and/or unusable to providers. The need to focus on a prescribed “intervention” rather than provision of proven therapeutic techniques is the foremost challenge to translation. Scientific methods have been essential in building the evidence base; however, the evidence is limited to prescribed interventions that serve as rigidly constructed sets of therapeutic activities and implementation rules. Understandably, deviating from set protocols is discouraged to preserve the integrity of the intervention. Yet, current evidence-based family caregiving interventions share a common set of therapeutic activities, making it hard for service providers to discern the unique contributions made by each. Attempts toward implementation of current interventions as designed is also frustrated by the lack of a workforce similar to that used in the research setting. Efforts are hampered by financial demands of delivering services and a lack of available training resources. Lastly, evidence is lacking in key areas of importance to service providers of family caregivers. For example, the lack of health and healthcare utilization outcomes from current evidence-based interventions deters translation within healthcare settings.

The three characteristics of family caregiving delineated above - increasing prevalence; combined emotional, physical, and financial impact of caregiving; and the chasm between current evidence and service providers - calls for a caregiving research agenda that differs from the past. More specifically, these characteristics suggest the need for a coordinated research agenda to design, implement and evaluate interventions that significantly impact important outcome variables across the multiple threats to the caregiver (emotional, physical and financial). Most importantly, these interventions need the potential for rapid and broad

dissemination across community and healthcare settings. For maximum impact, this research agenda should be informed by current evidence and the needs of caregivers, yet respectful of the context in which service providers are willing and able to reach and serve them. Thus, translation of interventions into support services should be a core driver of the next generation of intervention research, which methods are used for evaluation, and which populations are targeted. This is a fundamental change from past interventions, which are not currently meeting the needs of the growing population of family caregivers.

Generation of New Evidence versus Comparative Effectiveness Trials of Existing Interventions

The current body of evidence for family caregiving interventions is not sufficient to meet the needs of family caregivers and the providers who are positioned to serve them. Rather, existing evidence frames the curriculum and identifies therapeutic techniques that are beneficial when intervening with family caregivers. Most were designed and tested to improve emotional well-being. Health, healthcare utilization and financial variables have not been well integrated into this approach. Even within the area of emotional well-being, a single “gold standard” outcome has yet to emerge. It is important to note that most of the existing interventions share many of the same therapeutic components. This is especially true of the multi-component skills-based interventions, where differences are most often limited to treatment delivery characteristics (intensity, style, length of treatment). Lastly, the challenges of translating current interventions into deliverable services are proving too great, suggesting that the characteristics of current interventions are not compatible with real world conditions.

Building upon prior research, a new generation of evidence in support of services to family caregivers has the potential to better define treatment options as well as “gold standard” outcomes for each treatment option. Ideally, research would yield information on treatments rather than on “pre-packaged” interventions. This would prove to be an important advance in a logical progression towards comparative effectiveness research given the standard definition that, “Comparative effectiveness research [CER] is designed to inform healthcare decisions by providing evidence on the effectiveness, benefits, and harm of different treatment options” [10]. For the reasons stated above, CER of current interventions would do little to inform decision making by service providers or family caregivers.

Attention to Treatment Delivery Methods

A new generation of family caregiver research should build upon the therapeutic components common to interventions of proven efficacy. In addition to the successful multi-component interventions, most of the other interventions also appear to cluster around topics or intervention themes that address known risks to family caregivers (e.g., dementia related behaviors, stress and depression, lack of social support, provision of ADL/IADL care). Using current evidence and experts to form agreement on the therapeutic content that is beneficial to

caregivers would allow the next generation of researchers to investigate other variables such as intensity, structure and format of the intervention delivery process. It would also allow research trials to more effectively investigate the delivery of services according to the level of risk or specific need of the caregiver or caregiving family at the time of service delivery. Risks that threaten the well-being of caregivers are known to wax and wane across the caregiving experience and are related to the changing abilities, emotions and behaviors of the person with care needs. This concept is well delineated as a recommendation within *Averting the Caregiving Crisis: An Update* produced by the Rosalynn Carter Institute for Caregiving [11]. Exploration of the variables identified above is critical if research efforts are expected to rapidly translate into evidence-based services for the diverse and growing number of family caregivers.

Inclusion of service providers positioned to implement future evidence-based intervention is also critically important to future research. This would allow the research agenda to be designed around therapeutic activities and delivery strategies that are compatible with real world settings. Thus, issues that create barriers to the translation of current interventions (e.g., workforce required for delivery, payment sources for delivery of services, adoption of new services by professional organizations) would be addressed during the research phase. This would also bring innovations from the field into the research setting (e.g., appropriate use of technology-assisted and web-based approaches to working with family caregivers).

Methodological Innovations

The impact of future research would also be enhanced by the use of multiple methodological approaches. While the randomized control trial (RCT) will continue to serve as the gold standard, innovations will be needed in the selection of appropriate comparison conditions and more effective use of cluster randomization. Much can be learned from the comparison of multiple intervention strategies within a single trial. Accrual of evidence could also be sped up by the application of alternative research designs that mimic real world conditions and/or allow follow-up research within specific populations of interest. Quasi-experimental designs could be used effectively and efficiently as rapid and pre-planned follow-up studies to randomized controlled trials. Three commonly used designs with merit are: 1) uncontrolled before and after; 2) time series designs (with or without a control/comparison group[12]); and 3) controlled before and after [13]. Other quasi-experimental designs include multiple baseline or regression discontinuity [12]. Statistical methods are also advancing and could be used to advance data abstracted from existing databases, practice settings, or administrative data from healthcare settings. The two most common approaches include regression modeling and propensity scores [14].

Comprehensive Assessment of the Financial Impact of Caregiving

The impact of caregiving includes both the financial impact of caregiving on the caregivers themselves as well as the economic value of their contributions to society. Estimates of the economic value of unpaid caregiving are most often based on the cost of replacing informal caregiving hours and the total hours of unpaid care provided to care recipients, as mentioned above at \$210.5 billion. For example, in 2011, dementia caregivers provided about 17.4 billion hours of unpaid care, a contribution to the nation valued at over \$210 billion. These data highlight the critical role that family caregivers play in the nation's long term care system, an area that has not been adequately studied in prior intervention research.

In addition to the direct economic cost of unpaid care, the productivity loss associated with caregiving to US businesses is also striking. Many caregivers reported that they had to make significant changes in their employment status due to caregiving responsibilities. In 2011, about 65% of caregivers reported that they had to go in late or take time off and 20% had to take a leave of absence. Alzheimer's disease and other dementias cost US businesses about \$61 billion each year [15]. These costs are associated with replacing employees, absenteeism, unpaid leave, and reduction in hours from full-time to part-time.

More research is needed to document the total economic impact of caregiving. Two critical areas that are understudied are 1) caregiving costs to US businesses associated with absenteeism and health problems related to caregiving, and 2) costs incurred by caregivers themselves including out-of-pocket expenditures; lost wages and retirement income; and healthcare costs associated with negative health effects due to caregiving. The caregiver intervention research arena would also benefit greatly from the inclusion of these variables and by routinely measuring the economic impact of community-based care versus institutional care. This could be achieved with the application of methods and measures from the field of health economics. For example, costs can be captured using the Work Productivity and Activity Impairment Scale [16].

Concluding Points

- Current family caregiving interventions demonstrate the positive impact of providing education, support and skills training to caregivers. Commonality in the content or curriculum is apparent across the successful interventions, yet significant differences are noted in the intensity and format of therapeutic interactions.
- The caregiver services provider base struggles to adopt current evidence-based interventions due to the demanding characteristics of existing interventions, confusion regarding the value of different interventions with similar content, and difficulty assessing the total cost and benefit of intervening with caregivers.
- A new generation of caregiver interventions is needed to meet the impending demand.

- New interventions should build on what has been established in prior research but be shaped to match real world conditions through significant input from social services providers, healthcare providers, and potential payers.
- Impact of new interventions will be increased if they are designed to address the full range of consequences associated with caregiving, especially health outcomes and direct and indirect economic variables.
- The prevalence of family caregiving suggests the need for a rapid cycle of evidence building with immediate translation. This will require innovative methods that blend the traditional RCT with cluster designs, single group designs and other nonrandomized methods.

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