

Research on Informal Caregiving: Gaps in Knowledge and Next Steps

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Overview

Family members have historically been and will continue to be, now and into the future, involved in the health and care of older adults (Spillman and Black, 2005; Spillman and Long, 2009; Wolff and Kasper, 2006). Family involvement is a global phenomenon occurring across all socioeconomic levels, within all race and ethnic groups, and in developed and developing countries (Gitlin and Schulz, 2012). Because caregivers are the linchpin of the informal support system, when their health is jeopardized, so too are the lives of the people for whom they provide care (Gitlin and Schulz, 2012). Caregiving and caregiver well-being thus remains a critical public health issue in its own right, given the number of persons engaged in this role (>45 million, National Alliance on Aging, 2005) and the potential health risks caregivers confront (Pinquart and Sörensen, 2003).

Caregiving research has a long history. The research question originally posed as to whether family members care for one another in late life has been clearly and unequivocally answered in the affirmative (Pruchno and Gitlin, 2012). Moreover, the costs to family members in terms of their physical health, emotional well-being, and economic livelihood have also been consistently and well documented. Additionally, effective supportive interventions, over 50 have been tested and more trials are in progress particularly for dementia caregivers (Gitlin and Hodgson, in press; Maslow, 2012). These interventions using rigorous trial designs, have shown effectiveness in reducing caregiver burden and for some interventions, reducing institutionalization and patient-related symptoms (Brodaty et al, 2012; Gitlin et al., 2006, Gitlin et al., 2008). Thus, over 30 years of research on caregiving has produced an extensive, robust, nuanced and complex body of knowledge.

Nevertheless, key dramatic societal and demographic transitions and trends are placing increasing demands on families such that there are important differences in care provision now than at previous historical junctures. Differences in the care context and unaddressed caregiving issues require continued and new research. Key trends include the following. First, the unprecedented aging of the population, 1 in 5 Americans will be 65 and older by 2030, combined with the desire of Americans to age in place at home, have placed increased responsibilities on families to attend to

aging relatives who are living longer with complex health conditions and diverse and wide-ranging care needs (Coleman, Boulton, & American Geriatrics Society Health Care Systems Committee, 2003; Coleman & Pandya, 2002; National Alliance for Caregiving & AARP, 2009). Second, the characteristics of family caregivers are changing; more men are involved in care of an aging adult; more families provide long-distance caregiving; and the “sandwich” generation is expanding with more men and women who are caught in the middle of caring for an aging parent and children at home (Alzheimer’s Association, 2012; Brody, 2006). Third, medical advances, shorter hospital stays, and expansion of home care technologies have transferred the cost and responsibility of a range of care responsibilities to families. Central to emerging geriatric care models (e.g., patient-centered care, hospital at home, collaborative primary care, and transitional care models) is inclusion of family members in assessment and treatment processes (Bielaszka-Duvernay, 2011; Bodenheimer, 2008; Boyd et al., 2007; Brown, 2009; Coleman et al., 2003). Medical organizations as well uniformly endorse standards and treatment principles that integrate family members in care transition processes (Coleman & Boulton, 2003). Furthermore, the health care system has become increasingly dependent upon families to provide information to inform diagnosis (particularly for dementia), provide feedback to evaluate treatment effectiveness, and attend to transitional care needs (medication management, follow-up with doctor appointments).

A related point is that families are now providing, and will continue to do so in the foreseeable future, much more on-going, intensive and complex care to older adults than previously. This includes addressing care transition needs, medical care and medical decision-making such as medication management, wound care, blood pressure monitoring, monitoring of infusion therapies at home, and/or deciding upon treatment options (Reinhard, Levine, Samis, 2012). Fourth, care provision is now longer in duration and much more expansive in terms of roles and responsibilities than previously. Care begins much earlier than previously examined in research and may include accompanying an older adult to physician appointments (Wolff, Roter, Boyd, Gitlin, and Bruce, 2010), helping with hospital to home and other care transitions and progressing to more physical and hands-on care that may continue even with nursing home placement (Gitlin and Schulz, 2012). Fifth, families are typically unpaid for their efforts, yet their contributions to long-term care services are critical to the economy of the United States. Care provision affects a family’s economic well-being and employment status. With the shrinking pool of available family members to serve as caregivers, increase in work force participation of women, the economics of providing care for families is dramatically changing.

In summary, the reliance on families to provide short and long-term care to older adults is only increasing. Research has not kept up with understanding the current and future care context nor the development and testing of interventions that address the full range of needs of families caring for older adults across their illness trajectory and for a wide range of chronic health conditions. This has contributed to the lack of a coordinated, systematic public health response to supporting family involvement in the care of older adults. This concept paper presents key gaps in caregiver research and suggestions for next research steps.

Current Gaps in Caregiver Research

Theoretical Gaps: Most caregiver research has been dominated by variants of a stress process model. This almost exclusive focus for understanding caregiving, framing caregiver interventions, and identifying outcomes to consider has limited the types of research questions asked and confined the development of measures and interventions to those which address psychological outcomes. However, a stress-process model may not adequately explain the experiences of all caregivers. For example, male caregivers typically do not evaluate their experience in emotionally laden terms; thus measures of caregiver burden consistently show that men report less distress and burden than women (Pinquart and Sörensen, 2005). As most interventions target concerns of female caregivers and seek to reduce distress and burden, it is not surprising that women tend to demonstrate better outcomes than men in most tested interventions (Pinquart and Sörensen, 2006).

New theories and models for understanding caregiving are needed. An exemplar is the recent “healthy caregiver” hypothesis which has been used to explain emerging findings that not all caregivers experience decline in health during caregiving (Fredman, Doros, Ensrud, Hochberg, & Cauley, 2009). This hypothesis suggests that because caregiving demands are significant, individuals who become caregivers may have exceptional health. Using data from the Caregiver Study of Osteoporotic Fractures, Fredman and colleagues (2009) found that at baseline, high-intensity caregivers reported the most stress but had the best physical functioning, whereas non-caregivers had the poorest physical functioning. Low-intensity caregivers experienced greater declines in performance-based functioning than did non-caregivers over a two-year period, but high-intensity caregivers did not. These data suggest that caregiving tasks may have kept respondents physically active, caregivers may have had stronger feelings of purpose than non-caregivers, and satisfaction from caregiving experiences, especially among low-stress caregivers, may have benefitted their health. Furthermore, as caregiving families continue to become more culturally diverse, it will be important to develop and test conceptual models across ethnic and racial groups (Knight & Sayegh, 2010).

Naming and Framing Gap: The exclusive focus of previous research on the “primary” caregiver and the imposition of this label on families have precluded an understanding of the complex context in which care occurs in diverse families. Similarly, there is inconsistency in the descriptive label applied to family members in research. For example, research examining sporadic involvement of families in medical visits has referred to families as “medical visit companions” (Wolff & Roter, 2008), or “companions” (Wolff & Roter, 2011); whereas families assisting with transition from hospital to home or home care have been referred to as “informal caregivers” (Burton, Zdaniuk, Schulz, Jackson, & Hirsch, 2003); alternately, families providing medical information for an older relative with mild cognitive impairment or dementia have been referred to as “key” or “proxy informants”; and families involved in end-of-life care or individuals who are incapacitated have been referred to as “proxy decision-makers” (Winter & Parks, 2008). Families themselves may or may not use the term “caregiver” to describe the multiple roles they perform. Furthermore, those who do self-identify as a “caregiver” may differ characteristically from those

who perform similar tasks but do not identify themselves using that term (Pruchno et al., 2008). The term informal 'caregiver' may not accurately reflect or capture the wide range of care experiences, roles and responsibilities of family members that may be episodic, sporadic, or related to transitions between health states and/or health settings, but which have consequences for their physical, social emotional and economic well-being. Thus, the next generation of research needs to include a broader definition of care provision, and examine care arrangements among family units or informal networks in addition to designating a "primary" carer in order to more fully understand the dynamics of care provision to older adults. Defining and operationalizing the term "family involvement" may enable a broader focus for the next generation of research and better encompass the wide array of tasks, responsibilities and organizational structures that emerge in response to caring for an older adult and as it unfolds over time.

Methodological Limitations: Most of what we know about caregiving has been based on small, non-representative samples of people restricted to a particular geographic region or socioeconomic status, with studies often relying on recruitment strategies that target individuals using formal service programs and the generalizability of findings is questionable. As discussed above, a recent analysis contrasting data derived from respondents recruited using convenience strategies and those recruited using random digit dial (RDD) procedures found significant mean differences in demographic characteristics of caregivers, care recipient characteristics, and outcome variables (Pruchno et al., 2008). Respondents identified using convenience methods had higher levels of education and income, were more likely to be married to and living with the care recipient, were more likely to be caring for a recipient diagnosed with Alzheimer's disease, had higher levels of caregiver burden and depressive symptomatology, reported more negative relationships with the care recipient, provided more hours of help to the care recipient, and were more likely to be the sole provider of care than those recruited using RDD methods. Moreover, correlations among stressors and outcomes were significantly stronger for the convenience sample, suggesting that the effects of caregiving may be experienced more intensely by study volunteers than among family members in the population at large who are providing care, and that reliance on results from convenience samples may result in programs and policies that do not adequately address the circumstances of the broader population of caregivers.

Recent studies using representative sampling strategies yield conclusions that are strikingly different than those developed using convenience samples. They reveal that most caregivers do not experience psychological problems and that adverse effects are experienced only by those people providing the most intensive levels of care (Hirst, 2005). Three recent epidemiological studies found that caregivers had lower mortality risks than non-caregivers when adjusted for sociodemographic, care recipient demands, and health variables (Brown et al., 2009; Fredman, Cauley, Hochberg, Ensrud, & Doros, 2010; O'Reilly, Connolly, Rosato, & Patterson, 2008). These studies help explain some of the inconsistencies in findings of previous studies that did not use representative samples and confirm that many of their conclusions about the effects of caregiving may not be generalizable.

In addition to limitations imposed by non-representative samples, most caregiving studies have used cross-sectional designs; hence conclusions regarding causality are not possible. Even studies

using longitudinal designs have typically enrolled people who were already providing care at baseline. As such, research to date is unable to distinguish between health status before caregiving began and changes in health that resulted from caregiving. In the few studies to include information about health before caregiving began, Burton, Zdaniuk, Schulz, Jackson, and Hirsch (2003) found no difference in baseline measures of depression or self-rated health between spouses who remained non-caregivers and those who began caregiving. McCann, Hebert, Bienias, Morris, & Evans (2004) found that physically healthier individuals were significantly more likely to become caregivers and to continue caregiving. Moreover, although McCann et al. (2004) found that mental health had little influence on initiating the caregiving role, those whose mental health deteriorated over time were more likely to cease being a caregiver.

A related methodological limitation is that little is known long-term as to the trajectories of caregiving. Most of the knowledge base has been developed using cross-sectional research designs that focused on a self-identified primary caregiver, yet the typical care recipient requires assistance for many years and many family members are involved throughout the person's illness trajectory. Little is known about the experiences of either becoming a caregiver or relinquishing the role of caregiver. We do not know, for example, the extent to which there are changes in the person assuming the role of primary caregiver over time, how families negotiate these changes, delegate and share responsibilities. The ability to address these issues will require sophisticated longitudinal designs that combine both short- and long-term follow-up assessments (Pruchno and Gitlin, 2012).

A related point also discussed above, is the tendency to study caregiving individuals rather than caregiving families. Although some studies examine caregiving dyads (Pruchno et al., 2009; Wilson-Genderson, Pruchno, & Cartwright, 2009), we need more research that broadens our understanding of how multiple lives are affected by caregiving demands and how families, rather than only primary caregivers, provide care. This goal will require collecting data from multiple family members and using sophisticated multi-level modeling analyses that control for nesting (Lyons & Sayer, 2005). It will also be critical to better incorporate the care receiver's voice in both basic and intervention research and link caregiver assessment needs to care recipient conditions, stage of illness and other characteristics. Making these linkages would enable more rapid translation of the evidence to practice.

Yet another related point is that most caregiver research draws upon Euro-American samples rendering questionable the generalizability of findings to other race and ethnically diverse caregivers in the United States. Similarly, our understanding of the "caregiver" role has been based primarily on responses from females using scales (e.g., burden measures) that are more sensitive to the expressions of this group. We know little about the needs, concerns and health and psychosocial risks of men whose involvement in episodic and on-going care is increasing exponentially. For example, up to 40% of dementia caregivers (Alzheimer's Association, 2012) are now men. Although living in a rural setting is associated with reduced availability of and access to formal health services, little is known about the effects of rural residence on informal care provision (Goins, Spencer, & Byrd, 2009); hence this should be a priority for future research.

Finally, the traditional pipeline from discovery to effectiveness and then implementation and diffusion for caregiver programs is over 17 years and even then, few evidence-based programs are available (see below for further discussion of this point; IOM, 2003). Using hybrid trial design such as pragmatic trials or integrating efficacy with effectiveness study aims, effectiveness with implementation study aims and/or combining trial methodology with mixed methodologies may help to shorten the time from test phases to implementation phases (Curren et al., 2012).

Intervention Gaps: Despite proliferation of caregiver interventions and progress in this area, much more needs to be achieved. First, the vast majority of caregiver interventions have been developed and tested for those caring for persons with dementia. In turn, most of these interventions target families providing care for individuals at the moderate disease stage. Thus, less than a handful of interventions have been developed for mild cognitive impairment despite evidence that caregivers experience burden and distress and need knowledge and skills even at this early stage. Also, there are very few end of life supportive care interventions despite wide need. Intervention development and testing is needed for each disease stage. Despite the robustness of dementia caregiver interventions, comparative effectiveness studies that compare the relative advantage of one intervention versus another do not appear warranted. Each tested intervention addresses different outcomes and serve different purposes. Monies should be directed at developing more robust, effective and tailored interventions at each disease stage as well as developing comprehensive service delivery interventions that enhance family involvement in dementia care throughout the disease trajectory.

Second, few studies target other conditions for which families provide support such as in stroke, cancer, depression, physical impairments, vision loss, or for individuals with multiple comorbidities and complex conditions. The paucity of interventions for carers of older adults transitioning from one care setting to another reflects an additional gap. A related point is that it is not clear how caregiving is the same and/or different for persons with different health conditions/diagnoses and whether a single multi-component intervention could be developed for families regardless of condition of the person. Candidate domains of a multi-component intervention that traversed conditions might include: education about the disease, skills in care coordination, problem solving, care management and referral and linkage, in which each domain is tailored to the particular issues, health conditions and environmental conditions and resources of carers.

Third, most intervention studies have been conducted with small sample sizes (less than 600), use non-probability sampling, are geographically bounded, not representative of diverse populations, include a limited set of outcome measures (caregiver burden and institutionalization), and do not always reflect the needs of caregivers as documented by the epidemiological record. For example, with regard to this latter point, Spillman and Long (2009) using data from the 1999 National Long Term Care survey identified financial strain and physical burdens of providing care as the key triggers for nursing home institutionalization. Yet, with few exceptions, caregiver interventions have not addressed financial strain or physical aspects of care in tested protocols (Cornman-Levy, Gitlin, Corcoran, and Schinfeld, 2001). Thus, developing and testing interventions that address the physical demands of caregiving and that offer economic incentives and financial counseling may

have a stronger impact on delaying or preventing nursing home placement than other approaches tested thus far.

As to geographic and race/ethnic diversity, with the exception of the multi-site NIH REACH I and II dementia caregiver intervention initiatives, caregiver studies have been geographically bounded and single site, thus limiting generalizability.

Another related gap concerns the outcomes of interventions. As they have primarily focused on psychosocial benefits, little is known about the effects of interventions on other critical outcomes such as skill enhancements, hospitalization rates, morbidity and mortality rates of carers and care receivers and cost savings to families or society.

Also unknown are the underlying mechanisms by which caregiver interventions are effective, what interventions are effective for what groups and types of care conditions and which interventions are most effective at which stage of a family member's illness trajectory. Mining the data sets of existing dementia caregiver intervention studies could contribute to understanding what groups of caregiver benefit most from which types of interventions. Additionally, future research interventions need to better categorize care recipients, link the intervention to disease stages, and explore a wider range of outcomes as discussed above.

Of equal importance is the need to translate existing proven interventions for families into service delivery settings, as caregivers continue to be underserved or to receive services that are not evidence-based. With few exceptions, proven interventions remain out of the mainstream of service offerings (Burgio et al., 2009; Gitlin, Jacobs & Vause-Earland, 2010). Most families continue to have unmet needs (Sörensen, et al., 2002). A related point is to take the evidence and repackage it for delivery in practice settings. There is a critical need to develop and test practical clinical tools to help practitioners address family caregiving needs and to enable families themselves to provide better care at home. Use of technologies (monitoring tools, tailored education applications) may hold promise.

Essential to translation is an understanding of the costs associated with interventions. The few economic evaluations of dementia caregiver interventions suggest that interventions are highly cost-effective when considering outcomes such as quality-adjusted life years and time spent caregiving (Gitlin et al., 2010c; Graff, Adang, & Vernooij-Dassen, 2008; Nichols, Chang, & Lummus, 2007). However, with few exceptions, interventions have not been evaluated for their cost-effectiveness nor do we have an understanding of the willingness of caregivers to pay for them (Jutkowitz, Gitlin, & Pizzi, 2010). Economic evaluations are critical in order to effectively translate proven interventions for delivery from theory into practice

Finally, efforts at the federal and state levels to modify policies in order to meet the growing need to support caregiving families, and to close the gap between research, policy, and practice, need to be evaluated. Interventions at the societal level are limited. For example, adult day services provide families brief time away from care responsibilities and can reduce burden. Augmenting adult day services with systematic care management can boost benefits including delaying nursing home placement and improving caregiver well-being (Gitlin, Reeve, Dennis, Mathieu, and Hauck,

2006). Studies which integrate family care support in a variety of settings (assisted living, nursing home, hospitals, area agency on aging services) may be a promising approach for intervention with multiple benefits to families, agencies and society at large.

Specific Research Recommendations:

1. **Comprehensive Surveillance and Data Monitoring:** Information available on the prevalence, characteristics and health effects of family caregiving throughout the United States, remains fragmentary. Although some surveillance data exists, it is inconsistent and not comprehensive. Thus, to assess the comparative importance of health risks in different caregiving populations and derive comprehensive and consistent estimates of mortality, morbidity, care challenges and unmet needs from which effective interventions can be developed and tested, a comprehensive surveillance approach is necessary. Innovative approaches to following more than the “primary” caregiver and capturing how and when families enter into the caregiving role, the ways in which families make care decisions and coordinate care among family members is important.

There may be opportunities to extend the utility of existing national probability surveys by expanding questions to include a more focused description of family involvement in activities beyond those that which have historically been fielded and are based on traditional conceptualization of a primary “caregiver”.

2. **Research on Health Disparities between those Who Do and Do Not Provide Care:** While a strong relationship between caregiving and health has been established, many areas require further systematic inquiry, particularly as it concerns mechanisms linking caregiving to health decline and mortality. Also, examining special populations of caregivers such as those with comorbidities, and geographically, racially and ethnically diverse caregivers are important areas for continued investigation.
3. **Context of caregiving:** Critical questions need to be addressed concerning how families make care decisions, how families divide care responsibilities, how the physical and social environment of the home facilitates or serves as a barrier to providing care. There is little to no research for example on how the home environment factors into care decisions including relocation or how the home environment supports care provision. For example, some home features may make it difficult for caregiving (e.g., not having a first floor powder room; lack of stair glides). Also needed is the short and long-term impact of care on children and other members of a household, the special needs of men as carers, and the context of care for race/ethnically diverse families.

Critical ethical questions for research also are important to examine including the following: 1) under what circumstances can family care substitute for nursing home placement?; 2) are we placing undue expectations and demands on families to provide care that is too complex and medically demanding and at what expense to the caregiver's own health and well-being?; 3) how

can we create a health care delivery system that balances the roles of families, recognizes what they can and cannot do, and supports families in the care tasks they provide?; and 4) is the economic savings of having families provide care a societal savings when those at high risk have higher health care utilization rates?

- 4. Interventions for families:** Several directions for intervention research are warranted. First, developing interventions that are more closely linked to or aligned with epidemiological findings of the factors most associated with caregiver distress and nursing home placement or other care outcomes is important. Second, strategies for boosting treatment effects are needed as interventions, particularly for dementia caregivers, yield small treatment effects and interventions are time limited – the need for longer term support and the long-term outcomes of even brief interventions require attention. Testing different tailoring strategies, matching caregiver characteristics to intervention approaches for example are promising approaches that need further development. Third, developing and testing interventions that address the full range of care responsibilities across various illness trajectories and for older adults with a wide range of chronic illnesses are needed. New interventions are needed that specifically address the role of the family in care transitions with the intent of evolving best practices as to how to incorporate and partner with families as a contributing member of the treatment team, including how to overcome obstacles that preclude access to effective involvement of families. This is particularly the case for older adults with cognitive impairments, those with long-distance caregivers, and for individuals with health literacy limitations. New interventions are also needed for families caring for older adults with a wide range of chronic illnesses such as depression, heart disease, hospitalization, sepsis, cancer care, to name a few (Davydow, Hough, Langa, & Iwashyna, 2012). Evaluating whether disease specific or a general multi-component intervention approach that encompasses for example disease education, problem solving skills, support regardless of chronic illness of the older adult may be a productive and efficient approach. Fourth, evaluating the cost and cost effectiveness of interventions is critical and these types of evaluations would facilitate translation and implementation of proven interventions. Other methodological approaches should be considered for intervention research. For example, both moderator and mediational analyses should be included in all randomized trial designs to provide more nuanced and in depth understandings of who benefits the most and the pathways by which an intervention approach has its desired effects. Multi-site pragmatic trials and hybrid designs may yield interventions with greater promise for dissemination and integration into practice settings.

Finally, a persistent significant concern is that families do not have access to the existing proven or evidence-based interventions which is particularly the case for dementia caregivers. Few evidence-based supportive services are available to families nationwide – that is, with few exceptions, effective interventions have not been widely translated for and integrated into practice and service settings nationally. For existing proven programs, the next research step is to test implementation strategies, and identify contextual barriers and supports for their widespread implementation and sustainability. With regard to the latter, urgently needed is the testing of new economic payment

models as well as approaches for preparing the workforce in these programs - these are all highly significant research gaps with important impact on practice and policy.

In summary, changing demographic and societal trends as well as the movement towards providing health care at home have placed unprecedented pressures on families to perform increasingly complex care tasks for extended periods of time. Future research based on representative samples will ensure that findings are generalizable and that the magnitude of effects and characteristics associated with risks are understood. Such research will in turn drive innovations in both the types and targets of interventions. A greater range of interventions specific to different conditions, disease stages and which address a broader range of issues than psychosocial considerations are needed. Also needed are development and testing of new interventions that are tailored to an increasingly diverse caregiver population, as well as those who provide care long-distance and intermittently. Simultaneously, greater effort needs to be focused on translating tested and proven programs for delivery in service settings, and on determining supportive structures necessary for their sustainability, in current and changing reimbursement structures. As unparalleled expectations are placed on families to carry out complex medical, social and emotional supportive tasks, new theories of care provision beyond the traditional psycho-social stress process models need to be advanced.

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