

Next Steps in Research on Caregiving: Using Large Scale Surveys

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The importance of research on caregiving by and for older adults can be motivated by a number of factors but I highlight three central issues in the paragraphs below. These are 1) the potential for “unmet need” for care among the elderly population; 2) the (potentially) high costs of care both for recipients and providers; and 3) the issue of gender equity that arises because the elderly and their informal caregivers are disproportionately female.

Potential Unmet Need for Care

Demographic trends affect both the demand for care and the supply of informal family caregivers. Three large scale changes may portend an increased possibility for unmet need for care on the part of the elderly, or increased burden on those available to provide informal care, or both. First, population aging, the result of increased life expectancy but also very low fertility levels in many Western countries (Lee 2007), increases the number of the elderly relative to the working age population. Replacement or below replacement fertility shrinks the number of adult children (and grandchildren) each older person can potentially call upon in late life (Uhlenberg 1993). This does not in and of itself mean elders will not receive the informal care they need but it does increase the potential burden on any given adult child caregiver because each has fewer siblings with whom to share care of an elderly parent. Wolfe and Kasper (2006) report a decline in caregivers per recipient and some research says that one way to avoid burnout is to have multiple caregivers (Szinovacz & Davey, 2007).

Second, greater marital instability among cohorts now reaching older ages means that a larger fraction of the elderly in the future will be divorced or separated without the support of a spouse at older ages. This is counterbalanced by longer co-survivorship of married couples that attends improvements in life expectancy and delays widowhood for those who remain married. Yet the increase in family disruption, both in the parental and the adult child generation, may strain family relationships and make it less likely that potential caregivers feel obligated to provide support. More family disruption means that more adult children will have potentially estranged relationships with parents, especially fathers (Ganong and Coleman 1999; Lin 2008). We need to know more about the long term caregiving consequences of family disruption.

Finally, the informal caregivers of the past – women – have gone to work in great numbers and this potentially limits availability when elderly parents (or parents-in-law) need informal care (Bianchi 2011). There is some suggestion in the literature that care recipients who dependent on

a caregiver who is employed full-time may be at higher risk of having their needs unmet (Scharlach, Gustavson, & Dal-Santo, 2007).

Costs of Care

Many estimates suggest that the informal care system of family support, if assigned a monetary value, would far outstrip the cost of institutional care. In a recent review of the value of unpaid care in the United States, Folbre (2012) estimates the value of unpaid care as 20-40% of Gross Domestic Product, depending on the valuation method used. An early estimate of the value of unpaid personal assistance to adults with disabilities was \$168 billion in 1996, five times the expenditures on paid care (LaPlante et al. 2002). A more recent review of estimates placed the annual economic value in the \$350 billion range for adult care in 2006 (Gibson & Houser 2007). There is growing concern about the looming crisis in long term care. Public policies aimed at reducing the costs of institutional care will likely affect the informal system of family care. If families are to maintain or even increase their role in the care of the elderly, is the capacity there?

Gender equality

On the recipient side, because women outlive their husbands, they more often need to rely on caregivers other than a spouse in old age. The strength of the informal support system thus has disproportionate impact on elderly, unmarried women. One exception to this generalization is noted above – older, divorced men may lack adequate support from their children because children of divorce (or unmarried partnerships) generally grew up living with their mother and are emotionally closer to their mother than their father (Seltzer and Bianchi Forthcoming 2013).

On the caregiver side, a number of reviews of the literature or meta analyses find consistently that women provide more care than men and are more burdened by caregiving responsibilities (Bianchi et al. 2008; McGarry 1998; Silverstein, Gans & Yang 2006; Pinguart & Sorenson 2006). If women curtail paid work to provide care, they may jeopardize their own future income security. If caregiving leads to lower health, more stress and decreased well-being, women may again bear disproportionate impact of any costs of providing informal care (Folbre 2012).

Summary

The findings on these issues - the potential unmet need of the elderly, the costs of care for recipients and providers, and the disproportionate impact on women - are all in need of updating and require more conclusive empirical support. Unpaid family support and care can be difficult to measure for a number of reasons: family caregiving can be underreported because family members do not consider themselves caregivers; those in need of care may receive care from more than one caregiver; and caregivers may provide care to more than one recipient (Folbre 2012: Chapter 3). Data often only capture a portion of the transfers that occur.

The good news is that work that is underway to improve the accessibility of the family data in the Health and Retirement Study (HRS), new data collection on transfers and on disability and well-

being in the 2013 Panel Study of Income Dynamics (PSID), and the new data collected in the 2011 National Health and Aging Trends Study (NHATS), and its soon to be released National Study of Caregiving (NSOC), all circumvent the shortcomings of many earlier data collections and offer new opportunities for studying caregiving need and caregiver burden.

Longitudinal Data Collections for Studying Later Life Caregiving

Three large, longitudinal data sets are particularly promising because of the richness of the family relationships that are included. These are the HRS, the PSID, and the NHATS.

The [Health and Retirement Study \(HRS\)](#) is arguably the “gold standard” for data collection on families at later stages of the life cycle, given its national representativeness, large sample size, expansive data collection on employment, income and assets, and extensive innovation in areas such as the collection of biomeasures, measurement of cognition, and assessment of health status. It represents the population age 50 and over in the U.S. A number of other studies in Europe, Mexico and elsewhere have been modeled after the HRS, enhancing the possibilities of comparative research in differing public policy, economic and demographic contexts.

The HRS obtains information on both spouses in married couples, facilitating the study of spousal caregiving and need for care. It gathers information about *all* of a respondent’s children, not just a “focal” child, and this is important for the study of transfers of time and money to/from parents and adult children and for the inclusion of siblings in such analyses. To date, the family data on children have been underutilized in the HRS because they have been very difficult to access and use. Currently, RAND is producing “family files” that provide clean, easy to use files on adult children and that can be merged with the full HRS. At this time, “family files” have been released for 1998, 2000, and 2002. As these family files become available for all years of the HRS, they will greatly facilitate studies of kin networks of care and change over time in caregiving.

The [Panel Study of Income Dynamics \(PSID\)](#) is the longest running panel study of families in the world, initiated in 1968 and continuing to the present. In 2009, 8,738 family units provided interviews, representing over 23,000 individuals. Heads and Wives, numbered over 13,400 in 2009 (more than 4,900 of whom, were at least age 50 and for whom data had been collected throughout adulthood). PSID offers a large over-sample of African Americans (currently ~1/3 of the sample). Since its inception, the PSID core has covered employment, income, consumption, housing, demographics, and family composition. Over time the core has added coverage on health, wealth, expenditures, and philanthropy.

With funding from NIA, a Family Roster and Transfer Module has been designed and will be included in the 2013 PSID (Bianchi et al. 2011). Information on the full roster of parents, step-parents, parents-in-law, children, and step-children of PSID Heads and Wives is being collected in the 2013 PSID. For each such relative, information is collected on characteristics such as relationship to head/wife, gender, date of birth or age, marital status (including cohabitation), city and state of residence, educational attainment, subjective general health status (excellent, very good, good, fair, poor), income, homeownership, and employment status. In addition to

characteristics of the family network, the module assesses two types of transfers: recent transfers of time and money given to and received from parents and parents-in-law and given to and received from adult children and step-children in the last year. The module also assesses larger transfers made at any time in the past, including help with college expenses, first home purchase, and other transfers of wealth. These data will enhance researchers' ability to analyze transfers, including transfers of time or care, over the life course and across generations. A unique aspect of the PSID is its intergenerational design: The genealogical design of the PSID provides large samples of middle-aged adults and their older parents where both generations are PSID respondents and report their current economic circumstances, their recent transfers of time and money, and longer term financial assistance for education, housing and other purposes.

A second innovation in the 2013 PSID, also funded by NIA, is the DUST II data collection that will allow researchers to study factors that buffer the detrimental effects of disability on time use and wellbeing. The sample will be drawn from the 2013 PSID and time diaries will be collected by telephone from 1700 individuals ages 60 and older and spouses/partners of individuals that age, for one random weekday and one random weekend day.

Supplemental questions will focus on disability, stylized time use, and evaluative wellbeing. New items will address quality of relationships, as well as psychological factors such as personality. An added novelty will allow linkage of diary-based activities to the child and parent rosters (from the Family Roster and Transfer Module just described) so that familial characteristics can be incorporated into analyses of sharing and exchanging time.

The [National Health and Aging Trends Study \(NHATS\)](#) and its supplemental data collection, the [National Study of Caregiving \(NSOC\)](#), offer rich new data on both need for and receipt of care among the population over age 65. The NSOC provides a unique data collection on the caregivers of respondents to the NHATS. In the first wave of NHATS, fielded in 2011, a representative sample of Medicare beneficiaries ages 65 and older (with oversamples of Blacks and those at older ages) was interviewed. The sample included those in residential facilities and nursing homes as well as those residing in the community. Information was collected on a variety of health and well-being topics, including assessments of physical and cognitive capacity, how activities of daily life are carried out, the social, physical, and technological environment, participation in valued activities, living arrangements, economic status and well-being, and aspects of early life. To assess need for care, the NHATS collected traditional measures of functioning (activities of daily living, instrumental activities of daily living, functional limitations) and expanded the scope of disability assessment to include assessments of accommodations (adoption of devices, changes in the environment or in behavior, obtaining help or services). NHATS also collects performance-based measures of physical and cognitive capacity to complement the self-reported measures.

The NSOC is an exploration of the caregivers of NHATS respondents. The study attempts to survey the full array of caregivers and obtain information from the providers on what caregiving activities they perform, the length of time they have been engaged in providing care for the focal NHATS respondent, as well as detailed information on their own networks of support, their

health, demographic and socioeconomic background, and their employment and the ways in which their caregiving responsibilities may interfere with their paid employment.

Promising Areas of Future Research

- 1) **Estimating and Projecting the Need for/Potential for Care.** Data on the availability of parents, children, siblings, and grandchildren have been used in demographic projections and microsimulations that provide a valuable look at how demographic change affects the informal, intergenerational family support system (see, for example, Uhlenberg 1993; 2005). Wachter's (1997) much-cited study simulates the availability of different types of kin, pointing to a decline in biological ties that may be compensated by the increase in ties to stepkin. Wachter's estimates are consistent with data from the National Survey of Families and Households (NSFH), collected in the early 1990s, but they have not been updated with recent U.S. demographic data. These useful simulations could be updated and enhanced by inclusion of evidence-based assumptions about how likely it is that step kin (versus biological kin) will actually provide care to older relatives who need assistance. Such evidence-based assumptions could be derived from analysis of the data recently collected in the NHATS/NSOC on caregivers of those over age 65 and to be collected in the Family Roster and Transfer Module in the 2013 PSID.
- 2) **"Sandwich Caregivers"** – are middle aged adults increasingly caught between the need to financially support "slow to launch" young adults at the same time that their elderly parents require care? A clear consensus on the effect of caring on work has not emerged, nor has the literature attempted to consider demands from multiple generations. There is speculation that longer life expectancy and delayed fertility are increasing the likelihood that women (and men) have both adolescent and young adult children to support at the same time that their aging parents begin to require care. In the United States, women who live with elderly disabled parents are less likely to work (Ettner, 1995; Pezzin and Schone, 1999) but women with very strong labor attachment do not seem to respond to caregiving by exiting the labor force (Detinger and Clarkberg, 2002), nor do hours of work differ between working women who care for elderly parents and those who do not (Wolf and Soldo, 1994; Ettner, 1996; McGarry, 2006). Longitudinal evidence is scant and findings are mixed: McGarry (2006) finds that the onset of caregiving is not associated with leaving employment; Pavalko and Artis (1997), using different data and methods, find that beginning a spell of caregiving decreases hours worked and that women who stop work to care tend not to return to the labor market. The evidence in Europe almost universally indicates that caregiving, particularly intensive caregiving, reduces labor force participation and hours worked (Bolin, Lindgren and Lundborg, 2008; Heitmueller; 2007; Carmichael, Charles, and Hulme, 2010; Lilly, Laporte, and Coyte, 2010; Michaud, Heitmueller, and Nazarov; 2010). Most studies focus only on women. In the few studies that include men, the effects of caring on the labor supply of men are slightly smaller than for women (Ettner, 1996; Bolin, Lindgren and Lundborg, 2008). New PSID data will allow more thorough investigation of this topic.

- 3) **Spousal Caregiving.** Much of the literature on late life caregiving focuses on unmarried women and adult children providers. Yet for married elders, a spouse is the typical caregiver (McGarry 1998) and when married couples co-survive to old age, both husbands and wives become caregivers (Folbre 2012). HRS and NHATS and PSID-DUST II data collections that include assessments of spousal disability and health care needs offer particularly promising avenues for increasing our knowledge about provision of spousal care in later adulthood. Some research suggests that low marital quality prior to the onset of caregiving need is associated with a greater decrease in happiness and increase in depression on the part of the caregiver (Choi and Marks 2006). Spouses have been found to get fewer rewards from caregiving than adult children (Raschick & Ingersoll-Dayton, 2004). However, much further work is needed on this topic, with attention to the comparison group and appropriate counterfactual. How comparable are spousal and adult child caregiving, especially given that a spouse is losing the companionship of a long time partner?
- 4) **Older Adults as Care Providers for Children, Grandchildren.** Older adults are usually studied as care recipients but many are also care providers in late life – for a grandchild or adult child with disabilities or difficulties achieving independence. Older people, suffering their own health decline, may nonetheless be called upon to provide care to grandchildren - especially among black families (Fuller-Thomson and Minkler 2001). Costs of caregiving and accumulated disadvantages may be especially great in “skipped generation” families where the full brunt of providing care falls to the grandparent generation (Baker and Silverstein 2008; Goodman and Silverstein, 2002, 2006). On the other hand, grandparents may benefit later from care from grandchildren they have helped (Fruhauf, Jarrott and Allen 2006) or from the parents they helped out by taking care of the grandchildren (Friedman, Hechter and Kreager 2008).
- 5) **Positive Aspects of Caregiving.** Caregiving for impaired adults later in life is now common and much of the literature has studied “caregiver stress” (Wolff & Kasper 2006). However, there are at least two ways in which this “caregiver stress” literature is being re-examined. First, Amirkhanyan and Wolf (2006) remind us that many studies have not carefully conceived of the “counterfactual.” They argue that those not providing care, the comparison group in most studies, is actually two groups – noncaregivers who have an aging relative who needs care and those who do not have an elderly relative in need of care. They find that noncaregivers and caregivers who have an elder who requires care are similar on indicators of “stress” and both score higher than those who do not have a relative who needs care. This suggests that “caregiver” stress is confounded with sadness or depression about declining health or cognition of an aging parent or parent-in-law. Second, recent meta analyses suggest that giving care may cause stress but it also can also improve well-being (Pinquart & Sorensen 2003a, 200b). New data that will be collected in the DUST-II of the PSID and the NHATS are designed to assess both negative and positive aspects of care and perhaps also allow for better identification of who is burdened by “worry” about a relative who needs care, whether or not the individual is the provider of care.

- 6) **Social Networks and Care.** Ripe for further investigation is the topic of caregiver networks and the new, experimental collection in NHATS/NSOC may make this possible. More generally, the support networks of older adults are of growing interest. NHATS adapts questions from the National Social Life and Healthy Aging Project (Waite and Das 2010) to collect support network data, e.g., the names of five people an elder “talks to about important things.” The DUST-II PSID data collection on activities and connections to others provide new data with which to explore support networks. Another area of needed research is on sibling networks: how siblings coordinate (or not) the care of an elder parent, the level of conflict this engenders, and the effects on relationship quality among siblings and between parents and children in later life (Connidis, 2007; Connidis and Kemp 2008). Whether smaller families handle the tasks of parental care in late life either better or differently than larger families will be important going forward, given changes in fertility and family size.
- 7) **Cognition and Dementia and Care.** Pinquart and Sorenson’s (2003a; 2003b) meta analyses find that caregiving for persons with dementia is associated with greater caregiver health problems (e.g., stress, mental health consequences) than caregiving for those without dementia. The relative costs and benefits of caregiving may be different depending on whether the older adult is experiencing cognitive decline. Careful assessments of cognition that have been introduced into the HRS and the NHATS allow for assessment of this important topic.
- 8) **Changing Family Forms and Caregiving Need/Receipt.** As noted, the bias in the caregiving literature has been toward the study of older, unmarried mothers. But this means that we know far less about older fathers than mothers. Given the increase in unmarried/cohabiting partnerships and divorce, more study of older fathers is warranted because results from studies of older mothers may not generalize to fathers. There has also been an increase in childlessness and thus studying how the caregiving needs of the childless are met is an important topic. Also, what happens to family support when the child generation experiences family disruption? How does family stability and instability in the child generation affect parental health and support in late life?
- 9) **The Role of Technology.** NHATS goes to great length to measure devices and environmental changes that may affect the respondents need for care from others. New communication technologies also affect caregivers’ ability to monitor care needs from a distance. More study of the interaction of technology, care recipients’ need, and family members’ ability to provide care is needed.
- 10) **Government Policies.** Policies that affect the cost of paid care can potentially “crowd out” or “crowd in” unpaid family care. Comparative analysis, such as afforded by the HRS with harmonized data collections in other vastly different national policy setting, might be especially valuable in this area. Also, within the U.S., the use of geocoded files under special arrangements may allow researchers to assess the impact of policy changes on the balance of paid and unpaid caregiving.

Finally, in all areas of study on caregiving, it continues to be difficult to assess race/ethnic variation. The PSID and NHATS are useful for studying black-white differences but caregiving in other populations remains understudied and the literature on other groups is dominated by small scale studies, often local in scope and of unknown generalizability.

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