

Next steps in Cross-National Research on Informal Caregiving

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Introduction

This paper reviews the state of research into the realm of informal caregiving, defined as the provision of personal care and other supports by family, friends and others who are not formally remunerated for their role in the delivery of such assistance. The main focus of the paper is to examine the potential of panel studies, particularly the Survey of Health, Ageing and Retirement in Europe (SHARE), for furthering the inquiry into informal care. Following a brief review of the state of research into informal caregiving, the paper summarizes the aspects of the phenomenon addressed by three key panel studies: the Health and Retirement Study (HRS), the English Longitudinal Study of Aging (ELSA) and SHARE. It also notes selected aspects of the informal care phenomenon that are not yet fully covered. Finally, the paper details a new direction taken in SHARE for the measurement of social networks, an approach that has significance for widening the inquiry into informal caregiving as well.

Informal caregiving in the literature: Research foci

The literature of the last few decades on informal caregiving reflects three main lines of inquiry. These include the examination of the context of caregiving, consideration of its nature, and contemplation of its implications. Each of these respective research foci has been variously addressed at both the micro and the macro levels.

In terms of context, research has studied who it is that provides informal care, especially in terms of the sociodemographic characteristics of the caregivers and the sources of their motivation (Henretta, et al., 2011; Pezin, et al., 2009; Shuey & Hardy, 2003; Jang, et al., 2012; Szinovacz & Davey, 2008; White-Means & Rubin, 2008). Study of the context of informal caregiving also addresses the broader structures and social forces that enhance or restrain the informal provision of personal care and support (e.g. Bonsang, 2007; Bonsang, 2009; Haberkern & Szydlik, 2010; Jang, et al., 2012; Oudijk, 2011). Three key realms stand out in this regard. The first is the place of family values, such as filial piety, in the orchestration of informal care and the decline (or resilience) of familial values in light of modernization (Khalaila & Litwin, 2012; Ryan, et al., 2011; Soldo & Hill, 1995). The second area of contextual caregiving research is the effect of urbanization and intergenerational mobility on geographic proximity and the association of the latter with informal care provision (Gottlieb, et al., 2009; Henretta, et al., 2011). The third realm is the role of the Welfare State and its social service systems, currently challenged by population aging, in relation to informal caregiving (e.g. Albertini & Kohli, 2012; Tomassini, et al., 2007; Suanet, et al., 2012; Van Grouenou, et al., 2006). This last line of inquiry has spawned a fair degree of consideration as to whether formal services complement the efforts of informal care providers or substitute for them (Geerts & Van den Bosch, 2012; Litwin & Attias-Donfut, 2009). In addition, this attention to the role of the Welfare State examines whether social policy "crowds out" natural helping systems or actually facilitates informal helping that might not otherwise be accessible or available (Bolin, et al., 2008a; Bolin, et al., 2008b; Brandt, et al., 2009; Hanley, et al., 1991; Künemund & Rein, 1999).

The specific nature of informal caregiving constitutes another important area of inquiry. Basic in this respect is the specification and enumeration of caregiving tasks fulfilled by family and/or friends, calculation of their frequency and duration, and estimation of their efficacy (Bonsang, 2007; Bolin, et al., 2008a; Hank & Stuck, 2008; Lima, et al., 2008; Penrod, et al., 2011). Recent research into this realm also considers caregiving convoys, or more specifically, the changing composition and evolving nature of informal caregiving networks over time (Szinovacz & Davey, 2007).

The third main focus of research in the realm of informal caregiving involves the implications of such helping activity. At the individual level, there has been much research about caregiver burden and the presumed negative effect of intensive or prolonged provision of informal care on the physical health, mental health and general well-being of the caregiver (e.g. Amirkhanyan & Wolf, 2006; Fisher, et al., 2011; Jenkins, et al., 2009; Killian, et al., 2005; Lee, et al., 2001; Muller, et al., 2009). A related aspect is consideration of the individual caregiving career and whether enactment of the role of informal caregiver is associated with early exit from the work force and subsequent economic stress (Bolin, et al., 2008b; Dentinger & Clarkberg, 2002). Additional work has explored the ways to mitigate caregiver stress, through the provision of information and/or interventions aimed at supporting the informal caregivers, and the ways to enhance caregiver satisfaction (e.g. Acton & Kang, 2001; Brodaty, et al., 2003; Buckley, 2007; Chien, et al., 2011; Docherty, et al., 2008; Fakhoury, et al., 1996; Northouse, et al., 2012). More recent investigations have looked at the positive aspects of caregiving and their contribution to psychological growth on the part of the informal care provider (Al-Janabi, et al., 2010; Peacock, et al., 2010; Semiatin & O'Connor, 2012).

As for the macro implications of informal caregiving, the main thrust has been the attempt to estimate the fiscal value of the informal care sector to the overall economy and the contribution of this activity to the lessening of the need for formal care expenditures or, at least, to their delay (Bolin, et al., 2008 a; Van Houtven & Norton, 2004). Less common is the estimation of the opportunity costs involved in the provision of informal care and their respective effects on the economy (Hanratty, et al., 2007; Johnson & Lo Sasso, 2006; Rhee, et al., 2009; Wakabayashi & Donato, 2006).

Informal caregiving in panel studies of the older population

Longitudinal population surveys, such as the HRS and its sister surveys in Europe, ELSA and SHARE, provide a unique opportunity to examine the changing patterns of informal caregiving over time. However, since such surveys seek to address a wide range of aging-related topics and issues, the attention they give to informal caregiving varies across surveys and across waves within surveys. This section of the paper reviews the main areas in the realm of informal care provision that are covered in the three respective studies.

HRS provides extensive tracking of the specific types of help that survey respondents receive and the identity of the caregiver who assists with specific needs. The survey gathers information on the identity of all caregivers of survey respondents and distinguishes informal caregivers through the specification of payment for services. Selected characteristics are also gathered about the caregivers, such as gender, relationship and the total number of hours of care provided. In addition, HRS tracks the care that survey respondents provide to others via the recording of the number of hours such help was given. But, other than questions about providing care to parents, the survey does not query the identity of persons receiving help from survey respondents. Nevertheless, data merging allows for identification of whether or not the spouse was the care recipient. Unique to HRS are questions concerning residential relocation for the purpose of providing or receiving care and the specification of the availability of potential informal caregivers, as identified by the survey respondent, if needs should arise in the future.

ELSA gathers basic data on informal caregiving that survey respondents give or receive. Help received is classified by the specific type of care provided and the relationship of the caregiver to the respondent. Information about care provided by respondents is distinguished between help given within the household and help given outside of the home, and is further differentiated as to help given to relatives outside the home and to others. Additional data is gathered as to the frequency of the help given and the reasons why the help was provided. Another line of inquiry in ELSA is the examination of work force exit and re-entry due to informal care provision or its cessation. The questionnaire also includes subjective queries into the satisfaction felt by caregiver respondents (queried also in SHARE waves 1 and 2), the appreciation received and whether or not the care that was received met the needs of care recipient respondents. Finally, ELSA's most unique contribution to the informal caregiving research domain, perhaps, is its inquiry into the use of caregiver respite services.

SHARE similarly identifies informal care provided and received by survey respondents and looks separately at personal care provided or received within the household and at assistance of any kind given or received outside the household. The role relationship of the caregiver and the role relationship of the care recipient are obtained as well as the frequency of care provision, which is currently indicated on an ordinal scale. Similar to ELSA, reasons queried in SHARE for temporary or permanent exit from employment include aspects of informal caregiving. Also as in ELSA, the third wave of SHARE (SHARELIFE) gathered retrospective biographical information on individual respondents using an event history calendar. These variables may be taken into account as antecedents to or correlates of subsequent individual informal care behaviors. Lastly, a new social network module implemented in the fourth wave of SHARE provides additional means by which to consider micro-level dynamics of informal caregiving. It is discussed in a later section of this paper. For the purpose of macro level analyses of informal caregiving, an advantage of the SHARE data base is that it includes harmonized data from up to 20 participating countries. Thus, it is possible to explore the wider contextual concomitants of caregiving, as for example the effects of country, region, and welfare regime. In addition, during the third wave of SHARE expert teams produced summaries of social policy developments in each country over time. This provides additional means for considering the different rates and different styles of informal caregiving across countries and their association with individual caregiving behaviors and outcomes.

An additional point of note concerning all three of the panel surveys is that they provide the opportunity to explore the centrality of the caregiving role in the lives of respondents and the association of the degree of caregiver role centrality with subsequent health and well-being. The construct of role centrality considers the extent of involvement in a given role (role occupancy—in this case caregiving) vis a vis other roles fulfilled by the same person. Yet another area of research that all three of the panel surveys facilitate is consideration of multi-generational caregiving, i.e., assistance that is provided simultaneously to parents and to adult children by the middle or "pivot" generation. This latter realm of inquiry has increasing immediate relevance for the aging "baby boomer" generation.

The strength of panel studies vis a vis the inquiry into informal caregiving is their ability to provide measures of the phenomenon in question over time. However, there are also shortcomings for informal care research in the current structure of such longitudinal surveys. Administered biennially, the surveys can capture long term trends but are less efficient at identifying short term fluctuations in care provision and their outcomes. (These may be addressed to some degree through information obtained in the proxy end-of-life interviews, but only for the deceased respondents). Another shortcoming is that caregiving probes are often addressed only to the family respondents, who may change from wave to wave. This can raise questions as to the consistency of the longitudinal follow-up. Finally, insofar as panel population surveys seek to encompass a wide range of areas of interest

to researchers and to policy makers, the time allotted to any single area of investigation is necessarily limited. This constrains, to some degree, the potential of such surveys to deepen the inquiry into informal care provision and its implications.

Topics related to informal caregiving that can be expanded or introduced in panel surveys

1. There is need for greater specification of the extent and the essence of the informal caregiving experience. Such specificity can be obtained, for example, through application of Day Reconstruction Method (Kahneman, et al., 2004) or by the use of time diaries (Freedman, et al. 2012). Caregiving daily diaries and indication of subjective reactions to the range of daily tasks can provide valuable knowledge and insights.
2. Current probes in panel studies focus on respondents as the principal caregivers or recipients. It is not yet fully feasible to identify the presence of other informal caregivers within the caregiving network. It should be possible to add follow-up questions to respondents who indicate that they provide care, probes which ask about the presence or absence of other persons involved in the caregiving tasks and the nature of the relationship with them.
3. Another area that is currently lacking is information about the availability of formal community-based or domiciliary services for the care recipient, terms of eligibility for such services and the degree of local accessibility to them. This information can clarify whether informal caregiving is a default response to a lack of alternatives, or rather a conscious preference of those who provide the care. The SHARE data provide indirect measures of care availability in terms of welfare regime classification by country as well as information on actual home-delivered service utilization. However, more micro data in this realm is desirable.
4. A related topic that can add further insights into the caregiving experience involves the availability of and accessibility to caregiver respite services, such as caregiver support groups, expert guidance and short term temporary relief. A particular area of growing interest in this realm is the use of web-based communication in the provision and the sustenance of informal care. A key question to be considered in this regard is whether Information and Communications Technology can enhance the efficacy of caregiving and whether it can promote the well-being of providers and/or recipients.
5. Yet another unexplored area is the role of statutes, courts, and rights-discourse in the framing of the caregiving experience. This includes the awareness of respondents in relation to legal statutes that establish specific rights and entitlements for informal caregivers, as well as to legal statutes that regulate different aspects of the caregiver role, to the degree that they exist (Doron & Linchitz, 2004). Such information can clarify the role of such statutes in enhancing or restricting the informal provision or receipt of care.
6. In this same vein, more attention can be paid to how the coverage and, specifically, the depth of long-term care insurance policies affects informal caregiving behavior at both the micro and macro levels. SHARE's power of institutional policy variation is an asset in this regard, particularly if harmonized with HRS and ELSA.
7. Another interesting question for further exploration is whether the engagement in informal caregiving impacts one's own predilections for long term care in the future. Toward this end, questions concerning future care preferences can be posed. Periodic administration of such probes will allow the tracing of changes in care preferences over time and consideration of the extent to which they are correlated with prior informal caregiving or receipt.
8. Informal caregiving is generally conceived as facilitative of functioning on the part of the care recipient, but it can conceivably hinder autonomy in certain cases. The latter occurs if the caregiver performs tasks that can still be executed by the recipient, thus compromising his or her

independence. This can be explored by comparative analysis in which caregiving availability and receipt are both considered in relation to changes in functional capacity.

9. Finally, informal caregiving might be mistakenly perceived to come to an end when the care recipient enters a formal long term care facility. More research is required to describe the extent of informal care that is given by family members or others within formal care settings, and its implications for the care recipient's well-being. The addition of supplementary samples from among long term care institutional residents might be useful in this regard.

Social networks and informal care: New possibilities for analysis in SHARE

The study of informal caregiving constitutes part of the larger field of inquiry that is known as social network analysis. The inquiry into the exchange of support by members of the family and other close relationships is a key part of HRS and SHARE. Thus far, however, these efforts have focused upon inferred social networks that are measured by means of sociodemographic proxies (Pescosolido, 2011), such as marital status or number of children.

The fourth wave of SHARE introduced a name generating mechanism for the mapping of respondents' personal social networks (Litwin, et al., 2012, forthcoming). The new social network module (SN) addresses the named confidants of the participants in the sample, obtained by means of a direct probe that asks with whom the respondent discussed important matters in the previous 12 months. This approach to ego-centered social network analysis, employed twice in the General Social Survey (GSS) and in the National Social Life, Health and Aging Project (NSHAP), enables the analyst to consider the interpersonal ties that are deemed to be the most important to respondents, and as such, are most closely reflective of their personal social networks.

This line of inquiry is important for the study of informal caregiving because it distinguishes between those who are simply given care and those who one "cares for." Stated differently, it allows the differentiation of care providers and recipients who are considered to be confidants from those who are not. This type of analysis was made possible by the unique linking of data from the social network (SN) module with data from the social support (SP) and financial transfers (FT) modules in SHARE. Such linking has not yet been done in any of the other HRS-inspired sister surveys. This distinction permits the acquisition of new insights into the dynamics of informal caregiving as well as the examination of confidant status (that is, membership in one's personal social network,) vis a vis a range of relevant caregiving outcomes.

An example of this stems from an initial analysis of the SHARE wave 4 data (unpublished). It examined the case of providing personal care to someone within the household. The analysis was necessarily limited to those households having more than one person (n=40,717). The data showed that some nine percent of the respondents provided personal care within the household. Multivariate regressions showed that after controlling for sociodemographic background characteristics, health status and country, the provision of personal care within the household was positively associated with depressive symptoms on the part of the provider, as measured on the EURO-D Scale. These findings support the generally accepted burden perspective of informal caregiving. However, when the care recipient was separated in the analysis by confidant status, a negative association with depressive symptoms emerged for those considered confidants, all else considered. That is, the act of providing informal personal care to someone within the household who was also a member of one's personal social network may have been protective against mental distress among the caregivers. This finding requires longitudinal confirmation, but it nevertheless points to the new analytic opportunities in the realm of informal caregiving that the SHARE SN module allows.

Conclusions

There is much about informal caregiving that has been uncovered by analysis of data from the prominent panel population studies of persons aged 50 and older. There is also room for further development of knowledge in this area using these same data sources. Given the rich base of information that is already available in HRS, ELSA and SHARE (and in related surveys), a logical next step would be to build upon the available data through selected additional lines of inquiry, some of which were outlined in this paper. The periodic addition of focused queries in the realm of informal caregiving can produce much added value for, and new insights into, the phenomenon in question, its evolution and its wider implications.

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