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A taxonomy of the economic costs of family care to adults



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ABSTRACT

A systematic scoping review was conducted to evaluate the current state of knowledge of the economic costs incurred by family caregivers to adults with long-term health problems or disabilities. A narrative synthesis of 126 articles published since 1999 was undertaken to develop a taxonomy of the economic costs experienced by these caregivers. Three broad domains of sources of economic costs for caregivers were identified: employment consequences, out-of-pocket expenses and caregiving labor, with sub-categories within each domain. Economic outcomes were identified for each cost domain. Generation of new knowledge across the three cost domains has been uneven, with disproportionate interest in employment consequences. There are knowledge and methods gaps around all of the domains of care arising from failure to measure, or measure consistently, the costs; failure to account for contexts within which care is delivered; and lack of consistency in specifying care thresholds influencing labor force exit and employment consequences. An expanded research agenda on costs of family care should address cumulative and cross-domain care costs. Links between economic and social and health costs are fertile ground for a comprehensive understanding of the full costs of family care.

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Introduction

In recent years, considerable attention has been paid to issues of population aging. This interest has been driven in part by the belief that costs to society will escalate with the growing population of dependent older adults. Economists and gerontologists have argued that the alarm about the costs of population aging is overblown; coining the term ‘apocalyptic demography’ to describe what they believe to be an unexamined view of population aging as inevitably costly (Börsch-Supan, 2013; Denton et al., 2006; Friedland and Summer, 2005; Gee, 2002). There is now a substantial body of literature supporting their claim, providing evidence of the considerable contributions of older adults through their productive activities and their civic engagement (see for example, Dosman et al., 2006; Hank and Stuck, 2008; Morrow-Howell et al., 2001).

This more positive view of the assets of population aging does not negate the analogous evidence of costs. In particular, there is

concern about the costs arising from care needs among increasing numbers of people who are aging with disabilities and those who have reached advanced age (World Health Organization, 2011). In both Europe and North America, formal care costs are closely monitored. There is remarkable consistency across these regions in reports which indicate that public (government) expenditures have grown faster than gross domestic product, that the status quo of state involvement is unsustainable, and that responsibilities for care need to be shared between families and the state (European Social Network, 2008; Hagist and Kotlikoff, 2006; UK Parliament, 2013).

Policy analysts have been arguing for some time that this ‘shar-ing’ already is occurring (Hong and Kim, 2000). In Canada, Armstrong (1996) noted that much of the work once done at state expense had been transferred to families with little evaluation of their ability to assume such work and its associated costs. Indeed it has been argued that care provided by family members and friends is the solution to escalating public sector costs precisely because it is invisible, lying as it does outside the formal economy, and its costs are hidden (Arno et al., 1999). More than a decade later, Cooney and Dykstra, 2011, p. 1027 re-emphasized this point in relation to Europe. They argue that a shift away from the welfare state in some countries and its absence in others have led to a policy of “familialism by default...when there are few publicly

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provided alternatives to family care and financial support". Given high levels of concern about escalating costs of dependent care, it seems timely to include the family care sector more centrally in the debate about the economic costs of population aging.

Families and the costs of care

For almost 20 years, family care to older adults has been a key topic of research in the field of aging. It was during the 1990s that the first major studies of family care to older adults were conducted in Europe and North America (see for example: [Metlife and National Alliance for Caregiving, 1997](#); [Keating et al., 1999](#); [Philp, 2001](#)). In these seminal reports, researchers began to make visible the nature of this care work and its consequences. For the first time, the types of care tasks and experiences of family caregivers were given national attention. The emphasis was on social and health consequences of care, especially the burdens of long term care work. In many countries, they provided an important impetus to the development of social policies such as caregiver support groups and respite services ([Döhner, 2006](#)).

Nonetheless, during this period of rapid growth in knowledge about family caregiving, there was relatively little conceptual or empirical research on the economic costs incurred by family caregivers. [Fast et al. \(1999\)](#) made an early attempt to address conceptual gaps with respect to the costs of informal care. Based on what was then a small body of literature on the costs of care, they developed a taxonomy of the domains of costs to a broad set of stakeholders including care receivers, caregivers and their families, the formal care sector and society. In the intervening years, the taxonomy has served to motivate and frame numerous studies as caregiving became a prominent research theme in many disciplines ([Dew, 2008](#)).

Families have continued to be seen as a first line of defense in providing care and support to their members with a chronic illness/disability ([Carmichael et al., 2008](#)). Researchers and policy makers have expressed concern about the sustainability of the caring capacity of families in the face of increasing care needs as well as structural changes in families including divorce ([Han et al., 2009](#)), geographic mobility ([Keefe et al., 2012](#)), and high labor force participation rates ([Ferrao, 2010](#)). There is evidence that high levels of health, social and economic consequences accrue to family caregivers (see for example [Lai and Leonenko, 2007](#); [Rubin and White-Means, 2009](#)). Yet to the best of our knowledge, there has been no recent systematic consideration of the types or extent of costs to families who comprise an important caregiving sector.

Given these trends in population aging, in formal care and in family structures, it seems timely to review the current state of knowledge of the economic costs incurred in caring for family members with chronic health problems. The purpose of this study reported here was to synthesize the state of knowledge on costs of care in order to create a taxonomy of the domains of costs. The goal was to create a foundation for future research that would determine risks of incurring these costs and their magnitude.

Methods

To develop the taxonomy of economic costs of care to family caregivers, a comprehensive scoping review was conducted. A scoping review is a type of systematic review, used when the body of literature is diverse in its disciplinary base and methodological approaches ([Brien et al., 2010](#)) and when there is a need to create clarity for constructs of interest ([Arskey and O'Malley, 2005](#); [Davis et al., 2009](#)). Both these criteria are relevant to the body of literature on the domains of economic costs for family caregivers. The published literature comes from a number of disciplines including

family economics, labor economics, family studies, sociology, human ecology, health sciences, gerontology and social work and reflects methodological approaches ranging from secondary analyses of large scale national surveys to narrative, grounded theory and other qualitative approaches.

Inclusion criteria

Manuscripts were included in the review if they met all of the following criteria: (1) unit of analysis was family members who provide care to an adult; (2) examined care tasks and services were provided because of the recipient's long-term health condition or disability; and (3) study addressed caregiver outcomes with implications for the caregiver's income or expenditures that are directly related to occupying a caregiver role. Care needs related to population aging result from both increasing numbers of adults who have reached advanced age and those who are aging with disabilities. Thus our review includes research on care to adults. Research from the past 15 years was reviewed, following earlier foundational work to classify costs of care ([Fast et al., 1999](#)). Articles were excluded if their focal topic was not economic costs to family caregivers (such as those that focused exclusively on consequences such as caregiver burden, health or well-being); if their primary focus was on cost measurement tools or instrument development; or if they addressed only policy implications or recommendations.

Search strategy and data sources

A review protocol was developed and electronic search strategies were guided by a librarian experienced in systematic and scoping reviews. Searches were restricted to the English language and were conducted in a number of databases¹ chosen to capture the diversity of this body of literature. Gray literature also was searched on websites of policy institutes, government agencies and departments, and relevant caregiving organizations and associations. Search terms included caregiving economic costs, caregiver outcomes, family caregivers, informal care, employed caregivers, caregiving and work, working caregivers, economic costs, and elder care. Material published in the past 15 years was reviewed.

The search strategy involved screening titles and abstracts, reviewing full articles and identifying relevant studies based upon full article review. The final selection comprised 126² articles that met the inclusion criteria. Based on these articles, a narrative synthesis was undertaken ([Popay et al., 2006](#); [Rodgers et al., 2009](#)) to identify the primary domains and sub-domains of economic costs of caregiving for family caregivers. The narrative synthesis proceeded in three steps: developing a preliminary synthesis of findings of included studies; exploring relationships within and between studies; and assessing the robustness of the evidence.

Results

The review of the literature highlighted three broad domains of sources of costs of care for caregivers: employment consequences; out-of-pocket expenses; and caregiving labor. A number of sub-categories within each domain were identified. Economic outcomes that flow from the three domains of sources of costs for

¹ Abstracts in Social Gerontology, Academic Search Complete, Ageline, Business Source Complete, Business Source Elite, EconLit with Full Text, Family and Society Studies Worldwide, Family Studies Abstracts, Human Resources Abstracts, MEDLINE, PsycEXTRA, PsycINFO, Psychology and Behavioral Sciences Collection, Social Work Abstracts, SocINDEX with Full Text, Sociological Collection.

² Only articles cited in this manuscript are included in the reference list. A full list of references for the 126 papers included in the systematic review is available from the first author.

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