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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 ‘sharing’ 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
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; Philip, 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 (Arkey 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 assessed 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

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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.
is devoted to a critique of the quality and sufficiency of these categories and sub-categories of the taxonomy. The discussion section we present findings from the scoping review that informed the cat-

plexity of activity has been facilitated in part by the availability of more and better data and the evolution of analytic methods and

in characteristics of caregivers and care receivers, sampling frames which may have been chosen based on these characteristics, and analytic methods employed. The full set of risk factors for economic consequences cannot be explored within the scope of this paper. However, where possible, we provide examples that help explain some of the variability in estimates of the incidence and/or magnitude of the costs of caregiving.

Employment consequences

Much of the investigation of the economic consequences of caregiving that has been undertaken since 1999 has focused on employment consequences. Of the 126 articles reviewed for this paper, 108 examined the impact of caregiving on caregivers' labor force participation or the extent to which they otherwise accommodated their paid work to caregiving demands. Not only has the volume of research on these topics mushroomed, but it also has become increasingly nuanced and more empirically rigorous and sophisticated, allowing a much more comprehensive picture of care-related employment consequences to emerge. This expanded body of knowledge attests to the relevance of the employment consequences domain, its sub-categories of costs, and their long-term monetary implications than is possible for the out-of-pocket or caregiving labor domains. This level and complexity of activity has been facilitated in part by the availability of more and better data and the evolution of analytic methods and software.

Four sub-categories of employment consequences were prevalent: labor force exit or preclusion; restricted work hours or absences; decreased productivity; and career limitations. Accommodating one's paid work to care demands is fairly common among caregivers (Fast et al., 2013). For example, US studies have shown that 69% of employed caregivers to adults report making one or more changes to their paid work because of their caregiving responsibilities (NAC, American Association of Retired Persons (AARP) and MetLife Foundation, 2009).

Labor force exit/preclusion

Labor force exit/preclusion includes withdrawing from the labor force (quitting or losing a job or taking early retirement), or never entering the labor force because of caregiving responsibilities. Articles reviewed provide evidence from across a number of countries that there is a negative association between providing care and labor force participation. In their review of more than 35 studies conducted primarily in the US and the UK, Lilly et al. (2007) found evidence of a strong relationship between labor force participation/continuation and intensity/hours per week of caregiving involvement. Those spending many hours on care tasks, performing more intense care tasks such as personal and medical care, caring for persons with high levels of complex needs, and serving as the primary caregiver were more likely than non-caregivers or caregivers performing less intense forms of care to be out of the labor force at a point in time.

Others have found that having ongoing caregiving responsibilities is associated with a 25% increase in the risk of retirement among older workers, with women at higher risk than men (Humble, 2009; Uriarte-Landa and Hébert, 2011a). Carers UK (2007) reported that caregivers retired an average of eight years earlier than non-caregivers. Previous periods of caregiving over the life course were found to be associated with delayed retirement for women for whom the risk of retiring fell by one percent with every additional year of care accumulated (Uriarte-Landa and Hébert, 2011b).

Estimates of the proportion of caregivers who quit or lost a job because of their care responsibilities vary widely in part because of differences across studies in how care is defined and in the intensity of care provided. In one recent US study, 47% of caregivers of veterans reported quitting paid work entirely or taking early retirement due to care responsibilities (NAC and United Health Foundation (UHF), 2010). A similar Canadian study of caregivers for non-senior adults with disabilities found that almost one third of caregivers quit a job as a result of care demands (Fast et al., 2008). In contrast to these specific samples of caregivers to people with very high needs, less than 2% of nationally representative samples of Canadian caregivers age 45 and older reported that they had quit or lost a job over the previous year because of caregiving responsibilities (Cranswick, 2003; Fast et al., 2013).

Evidence from studies using large, representative panel data files from the EU and UK suggest that caregivers also are less likely to be in the labor force post-caregiving (Casado-Marin et al., 2008; Heitmüller, 2007; Heitmüller and Inglis, 2007; Heitmüller et al., 2004; Spiess and Schneider, 2003). This may be attributable to caregivers' erosion of skills or care-related health declines during their leave of absence, and/or age discrimination at the point of a new job search.

Restricted work hours and absences

Restricted work hours and absences are care-related changes in employment arrangements such as working fewer hours, missing days of work, working part-time, rearranging schedules, or changing jobs or positions in order to reduce pressure or increase flexibility in paid work hours. Taking a leave of absence (paid or unpaid) also is included in this category.

There is considerable evidence that many caregivers work fewer hours for pay, including moving from full-time to part-time work.
or turning down overtime in order to be able to combine work and care. North American estimates of the proportion of caregivers reporting these consequences range from 5% (Lai and Leonenko, 2007) to 60% (Mennemeyer et al., 2006; Moore et al., 2001; NAC and UHF, 2010) depending on pre-caregiving usual hours of paid work and the intensity of caregiving, among other factors. Similarly, in Australia there was a significant relationship between intensive caregiving responsibilities and fewer hours of employment (Bittman et al., 2007). Women caregivers in Canada who reported reducing their work hours reported cutting back by more than a full work day (8.3 h) each week on average while men reduced their hours of work by 5.8 h each week (Fast et al., 2013).

Studies reporting absences among caregivers are common in the recent literature. Analyses of Canadian General Social Survey (GSS) data indicate that, in 2007, 21% of men and 30% of women had missed an average of 2½ (men) to 3 (women) full days of work per month during the previous year because of their care responsibilities (Fast et al., 2013). Aggregated to the population level these estimates translated into nearly 1.5 million work days of absenteeism each month attributable to caregiving responsibilities.

Reports of care-related absences are similarly common in the US. In its report on productivity losses to US businesses, the Metlife Mature Market Institute (MMMI) estimated that full-time employed men who provided care missed an average of 9 days per year and women missed an average of 24.7 days per year (MMMI and NAC, 2006). A study by the National Alliance for Caregivers and the American Association of Retired Persons also concluded that “one in five caregivers took a leave of absence at some point while they were caregiving” (NAC, AARP, and MetLife Foundation, 2009, p. 9). The MMMI subsequently estimated that an average of 10 days of leave was taken by more than 2.5 million employed caregivers (MMMI and NAC, 2006).

Other strategies to accommodate caregiving demands include changing work schedules, using holidays or sick days to meet care responsibilities (often used as a way to avoid a loss of pay), declining promotions, and changing jobs. Available evidence suggests that these strategies tend to be used by high proportions of caregivers since they have somewhat less drastic economic implications than leaves of absence. For example, MMMI and NAC (2006) reported that fully 58% of caregivers left work early or came to work late to attend to caregiving responsibilities.

**Decreased productivity**

Decreased productivity may occur because of the absences noted above, and as a result of mental preoccupation, distractions such as taking or making phone calls, low morale, interruptions at work, stress, and caregiver fatigue, which can reduce job performance, and may affect job security. Loss of clients or customers may be a significant risk to those who are self-employed and whose absence or failure to provide goods or services on time can affect directly their current and future income. The MMMI and NAC report (2006) on productivity losses estimated a loss of one hour per week for each of 50 weeks for 34% of men and 52% of women employed caregivers.

**Career limitations**

Career limitations are other opportunity costs that caregivers may experience due to their care responsibilities, such as postponing job-related or other education, and turning down additional work-related opportunities such as promotions, work travel and relocation. Many studies document such costs but estimates of how many caregivers experience them vary widely. Fast and colleagues (2013) report that, among the general population of Canadian caregivers aged 45 and older, less than 5% of employed women caregivers and 3% of their male counterparts turned down a job offer or promotion because of caregiving responsibilities. In contrast, as many as 40% of employed caregivers in one study indicated that caregiving had an impact on their ability to advance in a job because they had turned down promotions or training or declined relocation (Koerin et al., 2008).

**Outcomes of employment consequences**

Employment consequences have economic implications for caregivers, including reduced or foregone income and reduced pension or other benefits (Dunham and Dietz, 2003; Fast et al., 2008). There is evidence of reduction in current income from a number of countries. Average annual incomes of Australians with caring responsibilities were found to be 30% lower than those of non-caregivers (Bittman et al., 2007), while women caregivers in the US who lived with an elderly parent with long-term health problems experienced an income loss of over $4000 per year (Leger, 2000). A study by MMMI, NAC and the Center for Long Term Care Research and Policy (CLTCRP) (2011) found that the lifetime impact on wage income of caring for a parent was $142,693 for women and $89,107 for men based on the median wage of the sample, the reduced hours of paid employment attributed to care, and estimates of early labor force exit by a typical caregiver.

Longer term economic outcomes of employment consequences also are being documented. In the MMMI, NAC and CLTCRP (2011) study referred to above, men and women also were estimated to have lost $194,609 and $181,351, respectively in pension and social security benefits. Evandrou and Glaser (2003) similarly estimated that men caregivers who had left paid work altogether had, on average, accumulated 8 fewer years of contributions to occupational pensions than other caregivers. Caregivers also may lose other employment-related benefits if they leave employment to provide care. For example, Houser and Gibson (2008) reported that 15% of caregivers reported losing job benefits. Lost benefits may, in turn, lead to longer term expenses for caregivers, such as paying for health insurance, health services and medications for themselves and other family members that would otherwise have been covered by employer benefit programs. Evidence about whether such losses are experienced or their magnitude is very limited.

**Out-of-pocket costs**

In contrast to the large volume of research conducted on employment consequences of caregiving, a smaller number of articles (50 of the 126 articles reviewed) addressed out-of-pocket costs. While there have been some key studies published recently on this type of care-related cost, the overall state of knowledge has not expanded greatly since the development of the Fast et al. taxonomy of costs in the 1990s. Nor has this research reached the level of rigor and sophistication as that on care-related employment consequences. This lack of progress in part is due to methodological challenges in gathering detailed caregiver expenditure data over time. For the most part, the evidence remains largely descriptive with only a few attempts at explaining wide variations in estimates.

Out-of-pocket costs are expenditures made by the caregiver that would not have been made in the absence of their care responsibilities. The extant literature suggests that they occur in four sub-categories: housing; community services; supplies; and transportation/travel. However, there is not yet sufficient evidence about each sub-category to be confident that this is the definitive classification. Typically these expenditures are for care, services and supplies for the care receiver, but also may include services (such as child care or housekeeping) purchased by the caregiver that free up time that the caregiver needs to spend on care-related tasks.
Even this limited body of research suggests strongly that out-of-pocket expenditures can be a significant source of costs for caregivers. However, estimates of how many caregivers make care-related out-of-pocket expenditures vary widely. In Canada, estimates range from 35% in a population-based study (Duncan et al., 2013) to 80% in a study of caregivers to high needs care receivers (Fast et al., 2008). In the UK, 58% of caregivers reported incurring out-of-pocket expenses associated with caring for someone with a disability or illness (Carers UK, 2007). Variations in findings can be attributed to the jurisdiction, type and intensity of care being provided, and the types of costs measured, factors that will require further examination.

Estimates of amounts of care-related out-of-pocket expenditures also vary widely, ranging from $1532 (You et al., 2008) to more than $12,000 per year on items such as groceries, medicines, care attendants, and long distance travel (Evercare and NAC, 2007). In one recent nationally representative Canadian study, the vast majority (almost 82%) of caregivers aged 45 and older reported annual care-related out-of-pocket expenditures of less than $6000 while a small number (3%) reported annual expenditures in excess of $24,000 (Duncan et al., 2013). In another Canadian study, maximum expenditures reached $120,000 for caregivers to those with high care needs (Fast et al., 2008). These findings suggest that out-of-pocket costs can be substantial for some caregivers, but there has been no systematic evaluation of factors influencing these costs. Further, there is little information about the extent to which these expenditures create financial and other hardships for caregivers. However Duncan et al. (2013) did report that “those caregivers with less financial means have significant care-related expenses that represent a larger proportion of their household income compared to those caregivers with higher incomes” (p. 25).

Housing

Housing expenses include home maintenance and modification as well as residential care for the care receiver. There is evidence of additional costs for utilities and other regular household expenses when a care receiver co-resides with their caregiver (Carers UK, 2007; Dosman et al., 1998; Duxbury et al., 2009; Fast et al., 2001, 2008). There is less information about whether caregivers living at a distance contribute to the household expenses of care receivers. Only 5% of the sample in the Evercare study reported nursing home or assisted living facility expenses. However, the average cost for those who reported out-of-pocket expenditures in this category was substantial at $980 per month (Evercare and NAC, 2007). Given national and local differences in costs of residential care and the extent to which these costs are subsidized from the public purse, expenses will vary considerably across jurisdictions. There also has been little tracking of how such expenses are shared between caregiver and care receiver.

Community services

Community services include fees or other costs related to purchasing services provided by professionals (e.g., physical therapist, geriatrician, lawyer, etc.) and for acute care situations (e.g., ambulance fees, hospital stays, emergency room visits or diagnostic or laboratory services). Home care services, respite services, day support, and household help are other services that caregivers may pay for. Such services are used primarily to address the needs of care receivers, though they also can allow caregivers more flexibility in their schedules and in the tasks they must perform for their loved ones. Caregivers also may purchase such services as child care or house cleaning for themselves in order to have more time to provide hands-on care or to get respite from intense caregiving demands (Keating et al., 1999).

There is a growing body of evidence about caregivers’ expenditures on these services. Fifty-three percent of caregivers in the US National Longitudinal Caregiver Study reported paying for some kind of formal care (Moore et al., 2001). In a more recent study, expenditures on all community services, including home care, day services, respite, counseling, care management, and legal services, accounted for 17.5% of total annual caregiver expenses (Evercare and NAC, 2007). A national Canadian study of caregivers reported that 19% of caregivers who had out-of-pocket expenses paid for respite services and 20% paid for professional services such as physical therapy for care receivers (Decima Research, 2002).

Expenditures on home care and acute care alone can be substantial. A study of 1000 caregivers reported costs of $547 annually for community services such as day services or home care (Evercare and NAC, 2007). In a recent Canadian study of palliative care patients and their families, home care accounted for 4.4% of the costs to families ($216 over 6 months) (Dumont et al., 2009). For acute care expenses, another US study reported expenditures averaging $2578 for 2.3 days of hospitalization and $166 for emergency room visits over a six month period by caregivers of non-institutionalized people with Alzheimer's disease (Small et al., 2002).

Supplies

Supplies include food, clothing and personal items for the care receiver, as well as health and care supplies such as medications (including over-the-counter supplements and vitamins), equipment (walkers, wheelchairs, etc.), personal care products (incontinence and wound care supplies, pressure stock- etcs.), and home adaptations (ramps, lifts, grab bars, etc.). Personal items such as food, clothing, household goods and bedding accounted for 15.7% of expenses, or $868 annually, for caregivers in the US (Evercare and NAC, 2007). Medications constitute a large proportion of out-of-pocket expenses, particularly in jurisdictions without prescription drug insurance plans (Fast et al., 2008). In the US, 21% of caregivers’ annual out-of-pocket expenses went to medication costs (Evercare and NAC, 2007). In a sample of Canadian caregivers, 71% reported paying for non-prescription medications, and 43% for prescription medications (Decima Research, 2002).

Transportation and travel

Transportation and travel expenditures include taxis, parking, gas, airfare, accommodation and meals that caregivers incur in traveling to, traveling with, or traveling for the care receiver. One study found that caregivers spent 10% of their total care-related out-of-pocket expenses, or an average of $551 annually, on travel (Evercare and NAC, 2007). Lauzier and colleagues (Lauzier et al., 2010) conducted focus groups with Canadian caregivers of breast cancer patients and found travel to be a substantial cost category among caregivers who paid for accommodations, meals and transportation associated with travel for the care receiver’s treatment or consultations. In another Canadian study, 81% of family caregivers reported transportation costs associated with caregiving (Decima Research, 2002).

There has not been sufficient research on financial transfers from caregiver to care receiver to include it as a cost category, although research on these transfers has potential to inform understanding of care-related out-of-pocket costs. For example, a recent study of individuals aged 50 and over with one living parent found that one-quarter of respondents had provided financial assistance in the amount of $500 or more to a parent in the last two years (MMML, NAC, and CLTCRP, 2011) while another study reported that 15% of women caregivers transferred an average of $696 to their parents in the previous 12 months (Johnson and Lo Sasso, 2004). The purpose of such transfers is not always identified. Further
Outcomes of out-of-pocket costs

There is evidence that care-related out-of-pocket costs can threaten the economic security of some caregivers, including reducing their ability to meet current expenses and to contribute to their own savings or investments. Fifteen percent of caregivers of adult receivers in the AARP Caregiving Study (NAC, AARP, and MetLife Foundation, 2009) reported a high degree of financial hardship. Among Canadian caregivers to non-senior adults with high levels of disabilities, the figure exceeded 40% (Fast et al., 2008.). The Evercare study highlighted the potential for care-related expenses to diminish caregivers’ ability to meet current personal/household expenses, especially among poor caregivers (Evercare and NAC, 2007). In a recent Australian study, twice as many caregivers as non-caregivers reported that they were unable to pay utility bills or their mortgage/rent on time, had had to pawn or sell something, or had had to ask friends or family for financial assistance (Edwards et al., 2008). Carers UK reported that “three out of four (72%) carers are worse off as a result of caring, rising to four out of five (83%) among those aged 45–54”, in part because of care-related out-of-pocket expenses (2007, p. 3). Many (60%) of these caregivers reported worrying about their financial circumstances a lot of the time and spoke explicitly of being unable to afford their own rent or mortgage payments and home repairs, and even such essentials as heat and food.

Caregiving labor

Caregiving labor refers to time spent by family caregivers performing tasks and providing services to the care receiver because of that person’s long-term disability or chronic illness. The body of literature on caregiving labor is considerably smaller than that on employment consequences: 31 of the 126 articles included in this review addressed caregiving labor. While there has been much documentation of the social and health consequences of care (see for example, Fisher et al., 2011; Ho et al., 2009), there has been much less investigation of the economic consequences of care labor. This may reflect an ongoing reluctance to make public the ‘private’ work of families (Folbre et al., 2013). As with other domains of care-related costs, there is great variability in estimates of the incidence and magnitude of care labor undertaken by caregivers. In this case the variability arises from inconsistencies in the way in which care labor is defined operationally (e.g., which care tasks are included) and from deficiencies in data collection methodology. The articles reviewed pointed to four sub-categories of caregiving labor: time spent with the care receiver; time spent on care management; time spent getting to the care receiver; and time spent monitoring the care receiver.

Studies have been conducted in many countries in which the amount (incidence and time spent) of care labor undertaken by caregivers is estimated, though estimates of time spent vary widely as a result of inclusion criteria for caregivers and care tasks. For example, UK research shows that 1.8 million of its 6.5 million caregivers provide over 20 h of care per week (Carers UK, 2007) while 34 million caregivers in the US provided an average of 21 h of care per week (NAC, AARP, and MetLife Foundation, 2009). Median hours of care in Australia were estimated at 10 h per week, with those in the 80th percentile reporting more than 24 h per week (Bittman et al., 2005). In contrast, in a nationally representative Canadian survey, caregivers aged 45 and older reported spending an average of between 7.0 and 8.9 h per week on a specified set of care tasks which excluded time spent getting to the care receiver and care management (Fast et al., 2013). Care management, in particular, has been shown to be very time consuming (Rosenthal et al., 2007) and its absence from the Canadian calculation may account for the lower estimates.

Time spent with the care receiver

Time spent with the care receiver involves face-to-face activities that are important to the quality of life, or even the survival, of the care receiver. Care activities identified in the literature include: providing personal care (feeding, dressing, bathing and toileting); household help; attending medical appointments with the care receiver; being a companion; facilitating social interactions and reducing social isolation; providing transportation for shopping, recreation and/or medical appointments; performing indoor and outdoor household chores such as basic housekeeping and meal preparation, home and yard maintenance work; and in-person monitoring of the care receiver to ensure their health and safety.

Much of the extant literature has probed on such questions as the proportion of caregivers who engage in different types of tasks. For example, Fast et al. (2013) reported that providing help with transportation, shopping and banking were the most common care activities reported by Canadian caregivers (83%). Provision of personal care was least common, performed by 17% of men caregivers, and 36% of women caregivers. Relatively few studies report on the amount of time spent on personal care. One study estimated time spent on personal care at 649 h annually, with an additional 345 h spent on help with chores and errands (Johnson and Lo Sasso, 2004). In a Canadian study of caregivers for adults aged 19–64 with high levels of disability living at home, more than one-quarter of caregivers (26%) provided almost around the clock assistance for someone with cerebral palsy (Fast et al., 2008).

Time spent on care management

Care management includes the time caregivers spend organizing and maintaining services for care receivers. Rosenthal et al. (2007) include under care management the organization of formal services, negotiations with other family members and the care receiver, dealing with financial matters, paperwork and seeking information. A number of studies have found that a majority of caregivers are involved in care management. These include 84% of employed caregivers to older adults (Rosenthal et al., 2007); 60% of those caring for veterans with high levels of service-related disability or persons with schizophrenia (Fast et al., 2008); and 46% of caregivers who live an hour or more away from the care receiver (NAC, MMMI, and Zogby International, 2004).

Time spent getting to the care receiver

Most care is provided to family members who do not live with their caregiver (Fast et al., 2013). This means that a considerable amount of time may be spent traveling to the care receiver in order to provide care. In a study of work-life conflict of employed Canadians, Duxbury et al. (2009) found that, of the 34.4 h per week spent caring for children and older adults, 4.1 h were spent commuting. Other research has shown that caregivers who live within a half-day commuting distance of the care receiver are under more time stress than those living near the care receiver or those living more than a half day’s commute (Keating et al., 1999). Time spent
getting to and from care receivers is a cost domain that likely will become more important with high rates of geographic mobility in large countries with dispersed populations such as the United States, Canada and Australia.

**Time spent monitoring**
Monitoring involves overseeing the status of the care receiver, checking in with them, and problem solving with or for them. This is a commonly identified care task. Estimates of participation rates range from 41.4% (Fast et al., 2008) to 92.4% (Port et al., 2005). There is less research on the amount of time spent monitoring and findings are context-specific. Results from a study in Israel found that caregivers spent an average of 100 h per month monitoring individuals with Alzheimer’s disease (Beeri et al., 2002). Time spent monitoring may be somewhat reduced when the care receiver resides in an institution, although proportions differ depending upon type of residential care. Family caregivers of elderly care receivers living in a nursing home spent less time monitoring the receiver’s medical status and well-being than caregivers of those living in an assisted living or other residential care settings (Port et al., 2005).

**Outcomes of caregiving labor**
The economic outcomes of care labor can be measured neither as lost income, nor as expenditures on out-of-pocket purchases (since both are accounted for elsewhere in the taxonomy). Rather, economic consequences of care labor lie in the inherent economic value of time spent on unpaid work (Folbre et al., 2013). Time is a finite resource such that spending time on one activity makes it unavailable for any other purpose. Thus time spent caring for others is no longer available to the caregiver, for example to perform his/her own paid or unpaid work or to engage in leisure or other activities. While the caregiver may enjoy intrinsic benefits from providing care for a family member, they receive no direct economic benefit. Rather the economic benefit of the activity is essentially transferred to the care receiver and to society in the form of reduced burden (and expenditure) for public health and continuing care and other social services.

The value of unpaid work typically is measured either as its opportunity cost (foregone wages) or its replacement cost (cost of purchasing similar services from the market). Few attempts have been made to estimate the value of unpaid care (Feinberg et al., 2011) despite arguments that families will continue to be the largest source of long-term care services (Coughlin, 2010). There may be a lingering assumption that, while caregiving labor is valuable, it is ‘freely’ provided by caregivers whose rewards lie in their fulfillment of family obligations and reciprocity to spouses or parents. Exceptions include Feinberg et al. (2011) who valued caregivers’ services at $450 billion. In Canada, Hollander et al. (2009) estimated annual costs of care labor in the form of household tasks and personal care at between $9 million and $21 million depending upon the costing method used. Carers Australia used an opportunity cost approach to estimate Australians’ foregone earnings to be approximately $6.5 billion (Access Economics, 2010).

**Discussion**
In this final section of the paper, we provide a critical summary of advances in knowledge of the costs of family care across the three cost domains, as well as remaining knowledge and data gaps. We conclude with recommendations for an expanded research agenda with the goal of providing a roadmap for future research.

**Advances in knowledge of domains of costs of family care**
Our review has illustrated considerable progress in understanding the economic costs of care. Together the 126 articles on the economic consequences of caregiving are a testimony to advances in the state of knowledge about the subject. Research evidence reviewed here provides support for earlier findings that employment costs, out-of-pocket costs, and caregiving labor are the three major domains of costs of care (Fast et al., 1999). It also allows for a more comprehensive specification of categories of costs within each of these domains, contributing to a more inclusive and nuanced understanding of the nature and extent of costs. The level of detail now reflected in the taxonomy provides clearer guidance for future research regarding what costs to measure and differentiates among metrics and measurement approaches appropriate to each sub-domain.

The body of knowledge has grown across the three cost domains, though this growth has been uneven with disproportionate interest in employment costs in comparison to out-of-pocket costs and caregiving labor. The conclusion that caregivers experience employment consequences as a result of their engagement in caregiving is robust—there is substantial consistency in this finding across countries, across disciplines, and across a wide range of methodological approaches. Contrary findings can be explained largely as a function of the way in which caregiving is defined (in particular whether intensity of caregiving demands is accounted for). The extensive research activity on employment consequences provides a basis for an expanded understanding of mechanisms through which people modify their paid work to accommodate caregiving. We now have a much better sense of the variety of ways that people may exit the labor force to provide care—through early retirement, quitting or losing a job.

The new research on out-of-pocket costs has allowed us to generate a more useful and compelling specification of both broad categories and sub-categories of costs. It also is beginning to provide more reliable evidence about the amounts spent by caregivers to support care receivers, supporting a conclusion that these expenses can be substantial for some.

Caregiving has been the subject of an enormous volume of research, resulting in high levels of concern about the sustainability of the family care sector in the face of population aging and other demographic and economic trends. However, in this review we found only a small number of studies focused on caregiving labor as a source of economic cost, perhaps because of a lingering assumption that this type of unpaid work is a private family matter. However, in contrast to out-of-pocket costs, the long research tradition in family caregiving in general and on the conceptualization of care has led to a higher level of confidence that the main sub-categories of caregiving labor have been captured. Further, well-developed and theoretically and empirically rigorous techniques for estimating the monetary value of unpaid work yield reliable assessments of the monetary outcomes of care labor.

**Knowledge and data gaps in domains of costs of family care**
While we have learned a good deal about the economic costs of care over the last 15 years, knowledge and data gaps remain. In the domain of employment consequences we still know little about those who may have been precluded from labor force participation early in their working lives because of long-term caregiving or who are unable to re-enter after a period of providing care. These situations warrant further examination for their potential to increase the risk of the long-term financial consequences identified: foregone income, lost benefits, and reduced or foregone pension benefits.
Given the high proportion of caregivers who are in the labor force, employment costs and long-term consequences will continue to be an area of importance in understanding caregiver economic sustainability. A particular challenge arises from persistent knowledge gaps about the magnitude of financial losses from foregone income and benefits, perhaps especially for those who may have left the labor force at an early age or not entered because of the magnitude of caregiving costs. Such decisions will have ongoing and cumulative implications for economic security, but much of the literature exploring the financial outcomes of care-related employment consequences continues to be cross-sectional. Panel data such as those employed by Spiess and Schneider (2003) can be particularly useful in determining both the relationship between starting and stopping caregiving and extent of labor force participation and in understanding how these relationships differ across policy and cultural contexts. Research focused on calculating the magnitude of these losses would benefit from engagement of public, private, and NGO employers who may be motivated by knowledge of the potential losses they incur if employees are unproductive or leave the labor force. Raising awareness among employers may be a requisite first step. In a recent national survey of employers, Lero and her colleagues (Lero et al., 2012) found that the majority of employers knew that they had employees providing chronic care, but addressing these workplace costs was either ‘not on the radar screen’ (22%) or was a low priority (35%).

There has been much less research on out-of-pocket than on employment costs, perhaps due to a lingering devaluation of these private family costs compared to employment costs, which have a more direct impact on the formal economy. Yet, wide variation in findings and lack of strong empirical evidence in some subcategories suggests that the evidence to date is not yet sufficient for us to be confident in these findings. Lack of specificity about out-of-pocket costs may also be a consequence of methodological and conceptual challenges.

Our findings related to out-of-pocket costs represent a call to action together with a strategy for moving forward. Four specific deficiencies deserve further attention. First, greater clarity and consistency is required as to what ‘counts’ as an out-of-pocket cost. Are costs that may (or may not) be shared among stakeholders (caregivers, care receivers, and public services) to be included? (How) can caregivers’ portion of shared costs be isolated? (How) can expenses attributable to provision or receipt of care be segregated from “normal” everyday expenses? Second, data collection approaches need to consider how to overcome problems with recall data that threaten data quality without burdening caregivers with time-consuming expenditure diaries. Third, while there was insufficient evidence to support inclusion of economic transfers from caregiver to care receiver as a separate subcategory of out-of-pocket costs, there is evidence that such transfers occur and sufficient indication that some portion of these may be made explicitly for the purpose of meeting care needs to warrant further investigation. Fourth, there is a need to better understand the outcomes of out-of-pocket expenses. The incorporation of a measure of financial hardship or income adequacy (Zaidi, 2012) would allow for specification of the depth of reduced ability to meet expenses or to save or invest, and risk of current or future poverty.

Major gaps remain in estimates of the proportions of caregivers experiencing different types of care labor costs and in estimates of the magnitude of those costs. Ironically, we know with some certainty that one of the economic consequences of care labor is that the work is not compensated despite widespread acknowledgement of the value of care work and the availability of analytic methods to estimate its value. Apparently, there has been relatively little appetite for addressing what is as much a values as a methodological issue.

While we have confidence in our findings regarding the primary categories of caregiving labor, substantial knowledge gaps around its magnitude remain. Much of the tradition in conceptualizing and operationalizing care labor stems from focusing on the hands-on tasks provided to the care receiver. Personal care (bathing, dressing, toileting) as well as essential household tasks such as meal preparation, shopping, and banking are now part of national surveys of caregiving. Other sub-categories are well recognized, but are not included consistently in determining the amount of care provided. The result is substantial variation in estimates of prevalence and time spent. Increased clarity by researchers about categories of care measured would contribute greatly to the quality of estimates of incidence and magnitude of sub-categories of labor costs. Further, while there is discussion in the caregiving literature of intensity of care labor as a metric for high cost, there is no consensus about the threshold of intensity beyond which care labor becomes unsustainable (Lilly et al., 2010).

Data limitations also have hampered knowledge creation. Time use diaries, generally considered the “gold standard” for collection of data on how time is allocated among daily activities (Harvey, 2002), do not capture care tasks well. This is likely because care tasks can be irregular and episodic in nature such that they are not engaged in on the diary day(s); because episodes of care may be too short to be captured in time use diaries that use fixed time periods; and because care tasks sometimes cannot be teased apart from other normal household tasks (e.g., meal preparation and laundry done for a care receiver at the same time as for other family members, or additional cleaning attributable to the presence of a care receiver in the household). Some surveys include personal care done for people in the household but no other care tasks; a few capture care tasks done for people outside the household but do not consistently capture the reason that the task was done. Many caregiving surveys, on the other hand, do not attempt to collect data on time spent on care tasks. Those that do tend to obtain retrospective ‘stylized’ estimates from respondents (e.g., how much time in a usual week do you spend providing care to...), which are often criticized for producing unreliable and biased estimates, especially of time spent on activities at a fine level of detail (Kan and Pudney, 2008). As a result, data on time spent caregiving are either absent or of poor quality.

Conclusion

The taxonomy of the economic costs of care resulting from this scoping review provides a framework for advancing our understanding of the economic consequences of family members caring for adults with long-term health problems and disabilities. Knowledge and data gaps in domains of costs of family care have been identified and costs have been made visible that otherwise have remained hidden or taken for granted.

An important next phase in research on costs of family care is to determine risks of incurring each of the domains of cost. An evaluation of the impact of economic and social policies on caregiver costs might provide a fruitful starting point because of their potential to ameliorate costs incurred by large numbers of caregivers. For example regulatory policies related to employment include the right to request flexible or reduced work hours without fear of job loss (e.g., The UK Work and Families Act, 2006). In contrast, out-of-pocket expenses are likely to be affected by such things as public coverage of services such as home care. Genet and her colleagues (Genet et al., 2012) have documented considerable differences across Europe alone in the extent to which governments provide publicly funded home care services. Finally, some programs address costs associated with care labor through carer allowances and cash benefits. These differ considerably across
jurisdictions. In a recent review of payment for care, the British Columbia Law Institute and the Canadian Centre for Elder Law (2010) found a great range in caregiver compensation where such benefits exist. Low income caregivers in Australia can receive up to AUD $1450 in monthly support compared to US $500 annually in the United States.

There is considerable further research needed to fill knowledge gaps in domains of costs of care and in their relative importance across caregivers and jurisdictions. Determining sources and magnitude of risks could go a long way toward creating a better understanding of caregiver vulnerability and of the economic and social policy levers that might best ameliorate these costs.

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