

## Research Letter

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## Psychology and Family Caregiving

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The term in-home family caregiver is used to describe a person who provides care and assistance (without pay) to a family member or close friend who has a disability, chronic condition or illness and is in need of help with daily living (e.g. walking, eating, bathing) and nursing (e.g. taking medication, monitoring of overall health and attending medical appointments) whilst living at home.<sup>1</sup> Available research suggests that in-home family caregivers are reported to provide around 90% of long-term care<sup>2</sup> and the majority of adults who care for a disabled family member are at least initially employed in the paid labor force.<sup>3</sup>

National surveys have illustrated the high prevalence of caregiving in the community. Census data from the UK shows that around 6 million people were providing informal care over a 15 year period to 2001.<sup>1</sup> Similarly, survey data from the US has reported that at any 1 time, 14-16% of adults provide unpaid care to ill, disabled or elderly people. This equates to over 29 million adults of whom 17% are caregivers for more than 40 hours per week. Similar estimates have been reported for Canada and Australia<sup>1</sup> where census data on family caregiving is also collected

Available published research suggests that the economic value of home-based family caregiving dramatically surpasses spending for institutional care or formal (paid) home care. For instance, it has been reported that the estimated cost of in-home family caregiving for individuals with dementia is over \$56,290 annually<sup>2</sup> and such estimates exclude related financial costs to the caregiver, including loss of income and other costs.

The burdens on family caregivers go beyond financial loss, however, since in the process of caregiving, family caregivers often lose contact with friends, neighbors, relatives, work colleagues and their social support networks. Frequently, no-one is visiting and talking with the caregiver when they most need support and help, including help with shopping or minor home repairs, time-off to attend their own medical appointments, and in times when they need sympathy and encouragement or advice and support.<sup>4</sup> Further, adult caregivers who live with their care recipients are reported to face greater challenges, often because there is an expectation by others (including other family members) that by virtue of their willingness to live with the care recipient they have little choice in taking on the caregiving role (e.g. an adult child living with a parent who suddenly requires assistance). Family caregivers living with the care recipient are also less aware of the physical and emotional cost of caregiving and may be more vulnerable as adults because of their age and associated morbidities (e.g. middle aged adult children).<sup>2,4</sup>

Fundamental to family caregiving are 2 important considerations: first, the availability of potential family caregivers, and second, their willingness and capacity to provide in-home care. In terms of the first issue, research suggests that the supply of family caregivers is projected to diminish as demand outstrips supply. This is because our aging population (increasing proportions of older people in the community) is predicted to continue to rise and this in itself will increase the demand for such in-home care. As our aging population continues to rise, the number of people in the primary care giving years (45-64 years of age) is likely to remain flat, due in part to the changing family structure.<sup>5</sup> The increasing participation of women in the workforce over the past 5 decades will undoubtedly impact on the supply of family caregivers and the work and career development of women, since available research suggests that the majority of caregivers are women—mostly daughters caring for parents who are not in paid employment—most likely because of their caregiving.<sup>6</sup> Further research is needed to identify the

circumstances under which caregivers undertake caregiving (i.e. how families decide who will undertake family caregiving and for how long?) and the extent to which caregivers need to forego work in order to provide family care.

Further research examining the prevalence of in-home family caregiving in our community along with research on the roles, responsibilities and needs of in-home family caregivers is needed.<sup>7</sup> Given that some studies<sup>4,6</sup> suggest that a large proportion of family caregivers maybe forgoing employment in order to provide full-time in-home family care and little is known about if and when such caregivers return to work, there is also a need for further research specifically examining the impact of caregiving on work.

Since now most of us will require care for several years in the last part of our lives, research designed to further contribute to our understanding of the work and support needs of in-home family caregivers and the extent to which government policies and programs are responding to these needs is urgently required.

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