Editorial: Hidden Costs and Invisible Contributions in Family Caregiving: An Introduction

Caregiving defies encapsulation. Few subjects have inspired such consistent interest in the gerontological, disabilities, and health care communities. This journal and others in these fields, as well as association newsletters and even the popular press, have focused on the dimensions of caregiving. What is caregiving? The contributors to this issue examine this simple but profound question, revealing the complexity of the ascribed meanings and imbedded values that illuminate and inform this continuing inquiry. Some contributors examine caregiving within families, some the relationships between families and outside agencies such as government, and some the relationships among providers who are outside the family.

What is caregiving? Is it best characterized as a labour of love, a duty, a relationship between the provider and receiver of care, a one-way provision of services, or a reciprocal relationship? Is it a catalyst for polarizing siblings, a challenge to or an exemplar of intergenerational equity? Is caregiving a private matter, or is it open to public discourse? Is it state-encouraged or state-discouraged? Is it becoming increasingly monetarized or insufficiently supported? Is caregiving a business, a part of the mixed economy of care, an under-tapped resource, exploitation of women and of the sexual division of labour, a means of community inclusion or exclusion, or the mainstay of chronic care? To some degree, it is each of these things, as the contributors to this issue report. Similarly, is support of family caregivers a fundamental right of citizenship, a reversion to stay-at-home status for women, a means of strengthening, or a corrosive acid against the family as the natural unit of caring, an instrument of cost-containment in long-term care public policy, or a way of strengthening the health of caregivers? The underlying policy question, of course, is whether caregiving is a dyad between caregivers and care receivers or a triad with the addition of the state or another public entity.

This issue represents some of the diverse and thoughtful work of the Hidden Costs, Invisible Contributions research program intended to deepen our understanding of "the place in society of 'dependent' adults, specifically older adults and adults with chronic illness or disability". Why "hidden costs"? There are several interpretations. The costs are "hidden" because they do not appear on the public ledger and because they are incurred by individuals privately behind closed doors. *Private* has a double meaning: The costs are paid privately rather than from the public purse, and they are incurred as part of individuals' private lives. The same logic applies to "invisible contributions". Contributions are invisible because they are not "counted" the way public contributions (entitlements) are and yet they count immeasurably toward maintaining the well-being of fellow citizens with disabilities; further, like some costs of caregiving, these contributions are truly hidden from view, occurring in the privacy of individual homes and lives. They are also "invisible" in the sense that they may be taken for granted as part of what families do.

This issue opens these hidden costs and invisible contributions to public view and, we hope, to the scrutiny of researchers and the consideration of policy-makers and service providers. It offers both an internal Canadian history and an international perspective. Several articles contain assessments of the normative or values dimension and the empirical or factual dimension that are at play in the practice of caregiving. Some focus on people with specific disabilities, such as intellectual disabilities or Alzheimer's disease, while others have a broader perspective on conditions that may create the need for assistance, including injury and incapacitation or growing old and frail.

Most of the papers are about families. Governments no longer suggest that families are shirking their responsibilities for older members – a rhetoric we heard in the past. Struthers demonstrates that the caregiving spouses of World War II veterans provided extraordinary care and came to be recognized in their own right as deserving government benefits. However, recognition of the caregiving work families do for older members or members with disabilities has not usually been accompanied by an increase in government support for that work. One of the themes running through many of the papers in this issue is

the pressing need for home care and home support services. For instance, Daly reports that in Ontario health care has been privileged over "social care", home-maker services have been cut from home care, and home support services are more medical than social. These changes are a step backward in providing the types of long-term home supports that family caregivers need. At the same time, Hollander and Chappell demonstrate that home care can be a lower-cost alternative to residential care for individuals with similar care needs. Of course, the need to improve community-based support services has been noted before in the editorial pages of the *Canadian Journal on Aging*, with Neysmith (1999, 18.2) referring to community support services as the "poor cousin in a mixed economy of care".

Collectively, the contributors to this issue offer a rich menu of selections. The reader will discern, and may organize, a number of themes among them. Because *caregiving* connotes various meanings and interpretations and reflects sometimes conflicting values, we hope that the reader will gain a fuller appreciation of this complexity. It includes how one conceptualizes and measures care and the caregiving unit. Grant shares how families may go to great lengths to keep invisible the help they provide to their children with intellectual disabilities, and how they may redefine social exchange or reciprocity within the family. Several of the papers offer refreshing approaches that expand the caregiving unit beyond the care receiver–primary caregiver dyad that has characterized, and sometimes hampered, so much caregiving research. Sims-Gould and Martin-Matthews, for example, examine the complex dynamics of the caregiving unit (the "convoy"), asking, "Who helps whom?" and distinguishing between direct help (to the older adult) and assistive help (to the caregiver). They consider family caregiving to consist of people helping one another in the larger enterprise of helping the care recipient. Within families, many individuals with multiple responsibilities are involved in the caring. This approach helps to reveal the involvement of grandchildren and other family members who are less typically engaged in direct care and who are not usually primary caregivers.

Clark, Daly, and Keefe and Rajnovich, in quite different ways, raise the matter of the purpose of caregiving and who controls it. Clark discusses fundamental differences between aging-related and disabilities-related advocates in their values and philosophy – differences that affect how caregiving is practised – but offers some hope for a middle ground. Daly chronicles the ascendancy of a medical model of caregiving and of administering caregiving through a health bureaucracy. Keefe and Rajnovich note the likely continuation of narrow, gender-defined roles as among the purposes of financial support of family caregiving.

The complexity of caregiving is further illustrated in the paper by Lashewicz, Manning, Hall, and Keating, who elaborate upon family tensions emanating from caregiving by analyzing legal disputes over parents' wills. They focus on sibling tensions and fairness and equity, finding that some siblings view others as "over-involved" and feel excluded from caregiving. The concept of over-involvement makes an interesting conceptual contribution to the "costs and contributions" of caregiving and stands in stark contrast to the more common finding (when only the primary caregiver is included in the study) that caregivers think their siblings are not carrying their share of the caring work. Conflict is a related theme, reflecting the complexities of family life and specifically of family care. Much, if not most, of the caregiving literature has focused on conflicts faced by primary caregivers, such as conflict between work and family, and inter- and intra-role conflict, but not conflict among family members. Lai, examining caregiving among Chinese Canadians, demonstrates the inner conflict associated with the practice of filial piety in several Asian cultures and the heterogeneity of care and responsibility among them. The Lashewicz et al. paper delineates sibling conflict and the pitfalls families face as they journey through the caregiving process. Carpentier and Ducharme find evidence of conflict and ambivalence in their subjects' reports of social networks and network transformations. Research on families and caregiving needs to address the challenge of uncovering both the positive and negative currents in family relationships. A task-based approach that asks "Who does what?" misses this entirely. Carpentier and Ducharme make a direct methodological contribution by showing the limitations or gaps in network data as it is typically gathered and argue that the networks of persons caring for people with Alzheimer's disease (or with worsening illness or disability of any kind) are undergoing transformation. It is harder, emotionally and practically, for people to describe networks undergoing transformation, yet this may be when researchers gather their data.

We turn, now, to a brief summary of each of the 10 papers in this issue. We have ordered them according to those related primarily to *invisible contributions* and then those related primarily to *hidden costs*. We acknowledge that these categories are imprecise, for the complexity we have noted in caregiving spills over to papers written about caregiving.

Invisible Contributions

Grant's paper on caregiving rewards in families with relatives with intellectual disabilities positions itself as diametrically opposed to the perspective of social network analysis, highlighting the intimate, invisible nature of chronic caregiving. He notes, "Family caregiving…takes place under conditions of trust and privacy," with few people outside the household being involved. This privacy nurtures the relationship but, as Grant concedes in a rare acknowledgement of its dark side, privacy can also nurture the abuse and neglect of people with intellectual disabilities. Grant contributes the valuable distinction between caring *for* (direct labour) and caring *about* (indirect labour) and proposes a taxonomy of the different types or purposes of care: *anticipatory*, *preventive*, *supervisory*, *instrumental*, and *protective*. He considers the form and substance of reciprocity in the caregiving relationship, where intellectual disabilities may limit the scope of exchange with the care receiver. Yes, reciprocity does exist; it may take the form of *hypothetical* exchange, where the caregiver imagines that "if the intellectual disability were not present, then the care receiver would", and *deferred* exchange, where the caregiver adjusts expectations of reciprocity and looks for smaller signs of return that can be interpreted to have significance. The invisible contributions and benefits that develop within the intimacy of the family can include caregivers' greatly admiring a child's persistence in some task, even when the child fails; caregivers' continuing to expand their coping repertoire over the life course; caregivers' deliberately choosing to keep their assistance to the care receiver invisible, as when they give sub rosa help with a zipper, or, more long term, when they keep the recipient from learning about society's devaluing people with intellectual disabilities. There are costs of this "protection", to be sure, and Grant reports them.

Carpentier and Ducharme endeavour to cross-validate data gathered by the name-generator technique that is commonly used to identify a person's social network – a relevant array to consider in family caregiving analyses. Social relations, they argue, are the "raw material of network analysis". They peek inside the caregiving bubble and find an imperfect fit between chronic care and social network data. They state that social network theory posits stable relationships among the players identified, the ego and the alters, but that caregiving is essentially always in flux, and the data are derived from people whose daily lives are being altered. They distinguish between support ties perceived by the caregiver and network ties that broadly envelope the caregiving process.

They ask what we actually obtain when a caregiver is questioned about her support ties. For example, how does the respondent treat new acquaintances or separations from old acquaintances because of disagreements? Carpentier and Ducharme maintain that there are biases in social network data, including a common underestimation of the value of professional interveners (PI) such as physicians and nurses. Many times PI are not identified as being in the caregiver's support network and are perceived as not helping people in need, being too busy, and overworked. Also affecting the validity of name generator–derived data on social support networks are the constant stress and continuous failure that frequently accompany chronic care; these condition in caregivers a negative perception of self and of their support network. Carpentier and Ducharme cite five common occurrences that challenge the social network approach used by researchers, including the caregiver myopia regarding help from PI just mentioned and questions about the degree of caregiver cooperation and of caregivers' understanding of the logic of the name-generator process at a time of concentrated focus on the care receiver.

Sims-Gould and Martin-Matthews also ask, "Who helps the helper?" They reference social network research where there are multiple players or convoys. Their research goes beyond the assumption that caregiving is primarily a one-to-one relationship to examine what we might call the "caregiving mosaic". They ask how or if adult children help each other in caregiving. They conducted a secondary data analysis of CARNET, the Work and Eldercare Study. Respondents were "primary" caregivers and "not-primary" caregivers or helpers, both of whom had to identify direct helpers (of the care recipient) and assistive helpers (of themselves). While subject to Carpentier and Ducharme's critical assessment of social network research, Sims-Gould and Martin-Matthews finesse the issue by maintaining a closed system, where primary and not-primary caregivers have self-identified. Their analysis suggests that family caregiving often comprises multiple individuals helping each other in addition to caring for the care receiver and that both primary caregivers and helpers have a great range of help. Moreover, those not-primary caregivers tended to provide financial assistance more frequently than did primary caregivers, and this may have enabled the primary caregivers to focus on care. While acknowledging two important study limitations inherent in the data set used, they nonetheless offer a typology and nomenclature of help and elucidate a broader conceptualization of caregiving as a multi-pronged effort. Fuller appreciation of the multiple-caregiver mosaic

has public policy implications that the authors enumerate.

Struthers offers a thorough summary of the inception and evolution of the Veterans Independence Program (VIP), enacted in Canada in 1981 to ensure counselling, housekeeping, transportation, and other supports for World War II veterans and their caregiving spouses, so that the veterans could remain in their communities. VIP was, from its beginning, an alternative to the veteran's right to a long-term care bed funded by the federal government, substantiating the public policy value that community care is cost containment. Time and again, program officials appraised family caregivers as maintaining the well-being of aging veterans, while the caregivers themselves benefited only indirectly and cost the government only minimally. Over the course of decades, the program increasingly came to recognize caregivers as entitled to government services in their own right, but the path was not straight and the implications are not necessarily generalizable to other caregivers. Early on, the question was raised as to whether the status of the care receiver would determine the rights of the caregiver. This deeply value-laden question remained and, in large measure, still remains unanswered, as the initially small number of participants and the diminishing number of survivors kept the issue from broad public consciousness. Struthers observes that administrators and elected officials gradually moved VIP from a veteran-focused to a family-focused program. Policy analysts with ideologies poles apart have characterized this shift as either a fuller recognition and embrace of caregivers or an example of benefits creep. A substantial Care for the Caregiver program within VIP was proposed in 1992 but never materialized, against a backdrop of federal fiscal constraint and cutbacks. Struthers sets the VIP initiatives for caregivers within a values framework of care and commemoration for veterans' spouses. He asks if the VIP offers a model for assistance to family caregivers or if, instead, veterans' caregivers were and are a unique population. He offers several points consistent with an ethic that public policy is a moral endeavour and that caregivers can lay moral claim to government assistance.

The Lashewicz, Manning, Hall, and Keating article is basically about fairness in caregiving, sharing the caring among those of "genealogical equivalence". They ask, by means of extensive analyses of the novel *Family Matters* and a summary of some recent court cases, what is equitable in distributing care and the benefits of caring among siblings. With nods to social exchange theory, the authors probe the moral dimensions of caregiving. Is one responsible for caring only to the degree of having been a beneficiary of previous care from the intended care receiver? Is there a moral leavening agent that fixes the appropriateness of care in regard to one's abilities to care? What, therefore, would be considered "extraordinary care"? Is caring something that resides in the heart or nowhere? What is the nexus between morality and legality? There is, in all Canadian provinces and some areas of the United States, "filial responsibility legislation", but, as is often observed, morality cannot be legislated; this legislation mandates not a duty to care but a duty to provide for one's parents. Lashewicz et al. examine the legal doctrine of undue influence, citing cases where sibling caregivers have alleged disproportionate benefits from care given to parents. The legal doctrine of undue influence must be interpreted through the eyes of the person influenced, usually someone who is dependent. Equity of process is the focal point of the law; that is, what was in the giver's mind and was the giver subject to undue influence rather than, what was the outcome of the gift and was the gift considered equitable?

Hidden Costs

Keefe and Rajnovich's paper, "To Pay or Not to Pay," is as rich with existential issues as the Shakespearean question to which it alludes. What are the values underlying financial support of family caregiving and, more fundamentally, who is responsible for chronic care? In an assessment of financial programs around the world to support family caregiving, Keefe and Rajnovich ask, is public policy a "moral endeavour"? Is it appropriate for the state to support caregivers? Who is responsible for dependent citizens? Should the primary objective of financial assistance be to support or maintain caregiving or to save the state money? Each country's stance on financial assistance for caregiving is consistent with its social architecture. A conservative approach might be to argue that care is for families to offer out of love, not for money, and that paying families to provide care substitutes money for love and introduces a new set of citizen entitlements. Others might contend, from conservative or utilitarian positions, that financial assistance enables more care by the family or, from more liberal positions, that caregiving is "a shared social policy" involving family and government. The form of financial assistance, further, may be cash to caregivers, services from public agencies, or some mix of both, as in the Netherlands and Germany, where paying more cash to the family reduces eligibility for public services. Inherent in some state schemes is the assumption that providing professional services ensures better care to care receivers than having care given by family caregivers – certainly a position open to debate. At the same time, some public policy is

motivated by purposes that go beyond and may not even touch upon the improved care of the person with a disability or impairment, such as reducing unemployment rates by creating more home care workers. Keefe and Rajnovich observe that informal or family caregiving often means caregiving by women. They state that financial assistance for caregiving may, thereby, mean exploiting women or entrapping women in roles of low-paid caregiving. The ''male breadwinner/female caregiver'' concept may be used to rationalize providing low rates of remuneration for caring work; still others maintain that women are leaving the workforce to offer caregiving anyway, so financial assistance helps meet their economic needs and is gender justice. In any event, the authors demonstrate convincingly that consideration of values, motivation, and gender cannot be separated from the debate.

Lai's paper on predictors of sense of burden among Chinese-Canadian caregivers uses a cross-cultural lens to examine costs *and* contributions. He explains the Asian concept of filial piety as self-sacrifice for one's elders but notes that the concept is interpreted differently among different Asian cultures. For example, Koreans expect elders to become dependent with age. In some cultures, care providers are the daughters; in others the daughters-in-law. First-born sons have explicit and implicit responsibilities. Underlying the differences is a layer of Confucian core values: respect for parents, family harmony, and sacrifice for parents. These cultural beliefs manifest themselves in different ways, such as face saving, where personal and family problems are deliberately hidden from the outside world and where dementia care would, therefore, have to occur at home. Lai studied measurable variations in filial piety within the Chinese-Canadian community to see the effects on sense of caregiver burden and found that caregiving can exact its costs irrespective of culture. He found that caregiver burden correlated, among other things, with lower income, lower education, and lower competence in English, with providing more ADL and IADL care, and with the age and impairment levels of the care receiver. No surprise here. The strongest explanation of variance in caregiver burden in a multiple regression model (22.8%) was the ''health status variables'' (health of care receivers and caregivers' performing more ADL and IADL tasks). In contrast, cultural values added only 4.5 per cent of the variance. While caregivers across cultures would seem to have more similarities than differences, Lai suggests that filial piety may prevent the caregiver from seeking help outside the family, while at the same time it may be a buffer against a sense of burden and a

reinforcement of the caregiver's own sense of having meaning.

Clark, using what he labels a *narrative frame analysis*, carefully examines the interplay between facts and values in public policy on home care, as well as the stories and counter-stories of aging and disabilities advocates within this interplay. He maintains that every social problem is a reflection of the interrelationship between the empirical (facts) and normative (values) dimensions. Throwing more facts at a problem does not illuminate or manifest a public policy solution, for values shape the interpretation of the facts and, indeed, the very questions that generate the facts. After making the argument that a ''critical narrative'' approach can be useful ''in interrogating public policies to expose their underlying empirical and normative foundations'', Clark assesses the dominant voice in the home care narrative – the federal government – and notes disconnects between stated values and facts cited when the government postponed its launch of long-term home care services. The Romanow Commission Report invoked values of equity and fairness and referenced the Canada Health Act's five principles for when citizens receive services, including home care, but cited facts about presumed costs of home care as superseding these values and principles. In other words, accessibility and comprehensiveness for all . . . *as long as it doesn't cost too much*. Clark's review of differences between the aging and disabilities communities in how they see home care services is enlightening. While the community of those concerned with aging tends to see older adults as logical beneficiaries of home care legislation and supports its eventual passage, disabilities advocates are more charged, seeing the denial of chronic home care as further marginalization of people with disabilities. Disabilities advocates conceptualize home care services within a much broader, ideologically driven framework of supports necessary for an inclusive community; marginalization is both a reflection and a cause of the devaluation of people with disabilities. Here Clark elucidates the social constructionist model of disability; that is, society has created disabilities by choosing not to remove structural constraints or barriers that would enable people with disabilities to participate in the larger social context. The aging community, with its emphasis upon individual characteristics and behaviours as the keys to ''successful aging'', fails to recognize that social, environmental, political, and economic factors help to shape and determine well-being in old age. Clark closes this philosophical and practical paper hoping that the aging and disabilities communities may find common cause in public policy discourse on home care.

Daly chronicles the medicalization of home care in Ontario and the state's growing control of caregiving. She attributes this process to shifts in government views of the "commercialization" of the home care sector through managed competition and to the priority placed on health care over social care. Funding streams for social care–oriented home support – for example, friendly visitors and adult day care – and health-oriented home care were merged in Ontario following the enactment of Canada Health and Social Transfer in the 1995 federal budget, which allowed provinces more control over program funding. What followed was a market model, where long-time service agencies competed for short-term contracts to provide services, while the government consolidated Ministry of Community and Social Services (MCSS) and Ministry of Health (MOH) responsibilities for long-term care into a single, centralized administrative structure, overseen by MOH, and reallocated responsibility for long-term care from the municipal to the provincial level. Policy-makers – for example, the Romanow Report – positioned home care as an extension of hospital care, diminishing the budget for chronic care users of home support. To determine the practical impact of these changes, Daly interviewed 48 key informants from for-profit and non-profit organizations providing home support and home care, government agencies, and associations representing non-profits. She catalogues a series of adverse consequences that have altered the landscape of support for people with chronic disabilities – which include loss of preventive supports (those that support morale and postpone more serious debilitation), like transportation to visit friends or the hairdresser, and loss of purely social services, like friendly visiting – because volunteers entering the home are now asked to help with dressing, exercises, and grocery shopping. Daly notes that "social care has been privatized and given over to family and friend networks...in violation of established relationship boundaries" between the state and people in need. She argues that this transition will result in insufficient care for those who are isolated or without networks of family and friends, and more people will leave their homes to enter long-term care facilities.

Hollander and Chappell offer a well-conceived comparison of the costs of home care and long-term residential care. The research literature on home care as a lower cost alternative to care in a long-term care facility has become less clear in the years since the channelling studies of 25 to 30 years ago, which called this premise into question. Individual life satisfaction and quality of life measures have generally favoured home care, but cost has been the standard of comparison. The authors took advantage of a relative anomaly in service provision when the British Columbia Continuing Care System had, for some time, a single point of entry for clients, case management, care-mix funding, and the same assessment process for both community-based and residential care services. This permitted direct comparisons of home care and residential clients with similar care needs – in fact, 25,000 clients aged 65 and above drawn from three cohort samples between 1987 and 1994, who were followed for 3 years. Hollander and Chappell obtained data for cost and utilization of hospitals, physician visits, drugs, direct care, homemaker services, adult day care, and residential long-term services. They creatively managed data sources, constructing an annual average full-time equivalent (FTE) for each level and type of care and applied a careful methodology to determine comparability of clients on their ADL needs and costs of units of service used. They found that costs for home care clients in comparable levels of care were 40 per cent to 75 per cent of the costs for long-term residential care. If clients remained at the same level of care over a period of 6 months, costs for home care were about half those in facilities; even if the care recipient's condition worsened over the 6 months, costs were 70 to 90 per cent of the costs of facility care. Hollander and Chappell answer the question of whether home care can substitute for residential care affirmatively. Of course, the episodic nature of home care contributes to cost savings because such care tends not to be delivered every day, while facility care is daily; family care tends to make up the difference; but even with opportunity costs and families bearing out-of-pocket expenses, the authors maintain that there are still "potential cost savings" with home care.

Collectively, these papers make a substantial contribution to our understanding of and the literature about family caregiving. Several add to a better appreciation of relationships in caregiving, caregiver burden, and sense of inequity. Perhaps their greatest contribution may be to the dialogue on public policy and its formulation. At least 8 of the papers address questions in this area and all 10 are relevant. We must observe as well that the issue presents a splendid compendium of related references and a launch point for further research.

We thank the many reviewers, anonymous for the reader but known and valued by us, for their diligent analyses and the helpful suggestions that brought these papers to publication.

Edward F. Ansello and Carolyn Rosenthal
Guest Co-editors