Final Commentary for *CJA* Supplemental Issue: The Hidden Costs of Care

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In early 2008, the *CJA* published a special issue (*CJA* 26 Supplement 1, 2007) based on the Hidden Costs / Invisible Contributions (HCIC) research program, funded under the Social Sciences and Humanities Research Council (SSHRC) Major Collaborative Research Initiatives (MCRI). The overall purpose of the HCIC program is to create a deeper understanding of the place of older adults and adults with disabilities. In Canada, these groups of adults are often characterized as *dependent*—costly because of the care they require and because of their lack of societal contributions. Throughout this program, we have interrogated these notions, placing costs and contributions in social, political, historical, and cultural contexts that make explicit hidden assumptions regarding the ''dependencies'' of older adults and adults with disabilities.

An explicit objective of the MCRI funding program is to ''promote broadly based collaborative research as the central mode of research activity—both within and among disciplines, departments, and faculties as well as with other sciences at universities across the country and abroad'' (SSHRC, 2007). Members of the HCIC team were chosen because of both their disciplinary expertise and their commitment to active collaboration. We have worked face to face, flown across continents to meet together, and used various communication technologies to achieve this goal. Our student and new professional members have brought new meaning to collaboration, through their workshops and through the articulation of the process itself in presentations and publications.

We believe that the cross-disciplinary mix of HCIC scholars has added greatly to the knowledge-creation exercise in which we have been engaged. Historians on the team have reminded us of the evolution of our contemporary policies and programs. Scholars in English literature have illustrated powerful and pervasive cultural beliefs about families and care. Family gerontologists have challenged our notion that we can understand ''family'' caregiving by focusing on one individual, with no reference to the families in which that individual is embedded.

Members of the HCIC team who have contributed to the supplement represent a broad set of disciplines in the social sciences, health sciences, and humanities. These include social/family gerontology, human ecology, elder law, literature, nursing, disability studies, social work, history, gender studies, health ethics, and health services administration. Authors come from academic institutions across Canada, the United States, and the United Kingdom. Such interdisciplinary inquiry leads to a broader understanding of critical social issues by uncovering the underlying values, assumptions, and contexts within which both the costs and rewards of care are studied.

Integration of findings across disciplines and across projects is an important objective of both the HCIC research team and MCRI programs in general. The papers in the supplement represent one such integration exercise. They share a common focus on care, the consequences of care, and approaches to supporting caregivers. They represent findings from multiple projects and from multiple disciplinary perspectives. As the French novelist (1871–1922) Marcel Proust (1948) said, ''The real voyage of discovery consists not in seeking new landscapes but in having new eyes''. These papers reflect our attempt to see care with new eyes.

When the supplement is examined as a body of work, several themes emerge: that policy values underlie approaches to addressing social problems; that costs shift when public policy values change; that care is provided by a complex, shifting network of people; and that rewards and challenges co-exist in caregiving careers. In the first three papers, authors examine public policy through multiple lenses. They bring new insights, refocusing the debate on the core values of community, caring, and connectedness rather than primarily on cost containment. Keefe and Rajnovich illustrate how different countries and communities balance these social values. They show how some countries have similar programs to support family/friend caregivers, yet differ in their underlying objectives and program implementation processes. They raise questions about the responsibilities of the

doi: 10.3138/cja.27.1.3

state and family for providing care, the commodification of the care relationship, and the potentially conflicting values of individual choice for care receivers and reduced choice for caregivers. They highlight the importance of social values in defining what problems we seek to address and in creating the pathways through which we hope to solve them.

Clark offers enhanced understanding of the public policy process for addressing social problems by analysing home care policies through a narrative frame. He reminds us that, in order to understand policy outcomes, we must be aware of the process of policy discourse and of the government context in which programs are developed. Struthers documents this process by looking backwards to an important period in twentieth-century Canada. He traces the shifting arguments over public responsibility for care from compassion for those who are dependent, to the need to reduce costs of care, and finally to entitlements arising from and commemoration of caring work. His paper documents the 23-year struggle of veterans' widows to win lifetime eligibility for selected home care benefits provided through the Veterans Independence Program.

In the second set of papers, authors confront assumptions about the economic costs of care. They directly address hidden costs for some stakeholders, especially those in the unpaid family/friend and voluntary sectors. By examining the comparative costs to government of long-term home care and residential care services, Hollander and Chappell demonstrate that home care can be cheaper than residential care for clients with similar care needs, except in the case of those who require end-of-life care. However, home care policies in some provinces are undergoing reform, turning to managed-competition delivery models and privileging *health care* over *social care*. The net effect of these changes in Ontario, as documented by Daly, is a growing number of people who are no longer eligible to receive publicly funded home care and who are searching for alternatives, including drawing on family and friend networks. Shifting care responsibility to those with care needs, their family members and friends, and the voluntary sector means shifting the costs as well.

In his paper on caregiving rewards and transformations, Grant illustrates how people with intellectual disabilities can contribute in ways that augment the strengths and resources of their families. His paper provides a strong challenge to the notion that dependency is an inevitable correlate of disability. Grant reminds us of the rewards and transformations that occur in families caring for persons with intellectual disabilities, and he emphasizes the importance of having a balanced view of the caregiving experience. Rewards, transformations, and contributions touch the lives of different stakeholders—caregivers, cared-for persons, and families as a whole. Caregiving contributions need to be seen as much more than the product of dyadic encounters that benefit only one group of people—there is, in fact, a multiplier effect within families or personal support networks that is perhaps typical of family caregiving experiences.

In the final four papers, authors address the advancement of our conceptual and methodological understanding of family/friend caregiving by moving beyond a focus on individual caregivers toward enhanced understanding of the social and cultural contexts of care. The research by Sims-Gould and Martin-Matthews as to "who helps whom" advances our conceptual understanding of family caregiving in later life, documenting the contributions not only of adult child caregivers who provide direct help but of those who help them in the provision of care to older adults. Carers themselves may be embedded in a network of supportive family members and friends who can buffer some of the negative consequences of care. Carpentier and Ducharme validate a social network approach to caregivers' support-network potential. They remind us of the caregiving partnerships that evolve as care needs change, and they add methodological rigour to the measurement of support networks. Both Carpentier and Ducharme's methodological work and the multidisciplinary examination of equity by Lashewicz et al. underscore the complexity of studying caregiving relationships.

In their article, Lashewicz et al. provide an innovative look at a group of caregivers most often viewed as adult children. They address issues of equity among siblings who share equivalent generational responsibility for care but for whom issues of equity are quite complex. Having more children does not always equal having more or better care. Lai also refuses to take as a given that children inevitably are the best caregivers. He shows how ethnicity adds to the complexity and consequences of care in culturally diverse populations. As Lai notes, the Chinese tradition of filial piety does not exempt these family caregivers from feeling burdened.

On behalf of the HCIC team, we offer this set of papers in hope that they will encourage ongoing discussion and debate among research, policy, and practice constituencies in aging. In our view, we need to continue to make the invisible visible through a critical perspective on issues related to family/friend care and the relative responsibilities of the state, families, and individuals in supporting older adults and adults with disabilities.

References

Proust, Marcel. (1948). *The Maxims of Marcel Proust* (J. O'Brien, Ed. & Trans.). New York: Columbia University Press.

Social Sciences and Humanities Research Council of Canada. (2007, November). Major Collaborative Research Initiatives (MCRI) Objectives. Retrieved 26 Feb. 2008 from http://www.sshrc-crsh.gc.ca/web/apply/program_descriptions/mcri_e.asp#1