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Family Caregiving and Consequences for Carers: Toward a Policy Research Agenda

by

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Foreword

Demographic, social, economic and policy trends have made family caregiving a policy issue of emerging significance in Canada. Professors Janet E. Fast and Norah C. Keating of the University of Alberta have begun to tease apart this complicated issue in order to outline a research agenda for the future. Ultimately, this will lead to a better understanding of policies that affect those who care for adult family members in need.

This paper is the first in a series of research reports that will be prepared by the Family Network of Canadian Policy Research Networks in the multi-staged research program *The Best Policy Mix for Canada's Ageing Society*. The intent of this program is to contribute to a societal strategy for the aged that incorporates a policy blueprint to support Canada's aging population and their families. Identifying a research agenda for the family caregiving aspect of this multi-layered issue marks an important beginning to this work.

I want to thank Janet Fast and Norah Keating, who undertook this project for CPRN as an extension of their own research in this area. I also want to thank our funders, the Canadian foundations that provided most of the financing for this segment of the Family Network's research program. They are listed at the end of this report. In addition, I want to acknowledge the contributions of the internal and external reviewers whose advice and constructive criticism helped shape this discussion paper.

Judith Maxwell
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Executive Summary

The collective effect of demographic, social, economic and policy trends has made family caregiving a policy issue of utmost importance in Canada. The nature of these trends is relatively well-understood. Families are smaller, more diverse, more complex, and less stable. Further, the gendered division of labour within families is being supplanted by ‘double duty’ lives, typified by simultaneous participation in paid and unpaid work for both men and women. At the same time, population aging, new patterns of chronic illness and disability, and increased survival after catastrophic illness and injury, are changing the landscape of care needs.

Health and continuing care policy reform is shifting responsibility for care from formal to informal carers. Changes in the income security system are reducing the ability of care receivers and care providers to absorb the financial burden that often accompanies the need for care. Conversely, policies and programs intended to defray these costs are evolving. Public and private workplace policies that may mitigate the impact of care responsibilities on carers’ employment also are evolving.

Somewhat less is known about the effects these trends will have on family caregivers. Social trends appear destined to stretch the capacity of family members to care for those in need. Population health trends likely mean greater demand for care, higher expectations about the level of care, and more variability in the nature of care demands. Policy trends, too, are probably increasing the demand for family care, but their effect on families’ caring capacity, and on caregivers’ lives, is unclear. The research agenda that will best inform policy decision making as it relates to family caregiving will:

- Address questions about the nature of caregiving transactions and the extent to which policies affect, or are affected by, caregiving transactions
- Address questions about the effects of changing family environments on informal caregivers’ capacity and willingness to provide care, and the extent to which policies mediate the effects of these changes
- Address questions about the effect of the changing health environment on care needs, the availability of care, and the extent to which policies mediate these effects
- Address questions about the way in which changes in the policy environment affect the distribution of responsibility for care between the formal and informal care sectors, and the consequences this distribution has for caregivers and care receivers
- Bring together diverse and isolated literatures, each dealing with different aspects of family caregiving
- Be multi-disciplinary
- Be responsive to rapid changes in family, health and policy environments
- Employ gender-based analysis, and
- Employ a full range of conceptual and empirical tools.

Family Caregiving and Consequences for Carers: Toward a Policy Research Agenda

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In Chinese, the character denoting the word *crisis* can mean either danger or opportunity. Current trends in health and continuing care in Canada may be seen the same way. The language surrounding fiscal debates is magnanimous, claiming the changes to be client-based rather than fiscally motivated. Yet budget cuts, shifting government priorities and the emergence of a strong conservative voice have changed the delivery of health and continuing care in ways that many consider dangerous. Pressures to cut costs have increased reliance on family and friends to meet the needs of frail, ill or disabled adults. Regardless of intent, the changes have had a major impact on those receiving care and on those giving it. Yet even from dangerous situations, opportunities may emerge.

Few would argue the desirability of fiscal responsibility. With downsizing comes the opportunity to streamline services and forge new relationships among stakeholders. There is the opportunity for client input regarding the changes. There is the opportunity for more clarity, consistency and inclusiveness in both terminology and action. There is the opportunity to recognize and support the contributions of all those who participate in maintaining and enhancing the health and well-being of those in need. A research agenda is needed that will allow future policy reform to act on these opportunities, rather than simply focussing on cutting budgets.

The purpose of this paper is to outline a research agenda that will lead to a better understanding of, and more informed decision making about, policies that affect those who care for adult family members in need.¹ While the well-being of both those who give and those who receive care is likely to be affected by health and continuing care policies, the focus of this paper is on *care providers*. We begin by setting the boundaries around family caregiving to adults in need and describing the key environments within which they operate. This groundwork permits a brief analysis of the consequences of recent changes in the caregiving environment and identification of policy issues requiring attention. It is on this foundation that we have constructed our recommended policy research agenda.

1 The caregiving literature distinguishes between formal and informal care. Formal care is most often that which is provided by professionals who are paid from the public purse. Informal care is provided without pay by family and friends. There is some 'fuzziness' around the edges when family and friends are compensated, in whole or part, either through public expenditure (such as the new caregiver tax credit) or by the care receiver. There also is some 'fuzziness' with respect to volunteers working through a non-profit agency which may or may not receive some public financial assistance. For the purposes of this paper, we will deal exclusively with informal family caregivers, *those who provide care directly to family members*, regardless of whether or not they receive any compensation. It should be noted, though, that non-kin (friends and neighbours) are a significant source of informal care to seniors (20 percent of all informal carers) and that they experience many of the same consequences as family caregivers (Keating, *et al.*, 1999).

Setting the Boundaries and Defining the Terms

The words we use, and how we use them, are critical to both research and policy making. Further, common understanding and use of words across the research and policy communities are critical to the ability of research to inform policy making. Therefore, central to the task of this paper is a discussion of how the key constructs of *family*, *care*, and *need* are understood within and across the research and policy communities. This discussion allows us to set boundaries around the task and gives rise to questions that need to be addressed by any research agenda on family caregiving.

Ideological and structural diversity in Canada are reflected in a diversity of definitions of family. Moreover, because definitions of family are ideologically based, how family is defined is a source of much controversy. Definitions of family also change over time in response to changes in predominant ideologies, values and social trends. Rather than adopting, or developing, a single definition of family for this paper, we will instead focus on research questions that flow from variability in the way family is defined (whether across stakeholders or across time).

Defining Family

Families tend to be defined according to either *structural* criteria (what they look like) or *functional* criteria (what they do). ‘What they look like’ definitions are exemplified by Statistics Canada, in which the census family is defined as (1994, 10):

A now-married couple (with or without never-married sons and/or daughters of either or both spouses), a couple living common-law (again with or without never-married sons and/or daughters of either or both partners), or a lone parent of any marital status, with at least one never-married son or daughter in the same dwelling.

Definitions based on ‘what they do’ de-emphasize formal relationships as the basis for inclusion or exclusion, and emphasize instead the activities of the group. The Vanier Institute of the Family definition illustrates this approach (1994, 10):

Family is defined as any combination of two or more persons who are bound together over time by ties of mutual consent, birth and/or adoption/placement and who, together, assume responsibilities for variant combinations (for such things as) physical maintenance and care of group members.

As can be seen just from the two examples provided, different definitions of family imply different obligations for family members to care for one another. Generally speaking, structural definitions do not imply an obligation to care, whereas functional definitions do. Policy makers typically use *structural* definitions of family, when such definitions are made explicit. Ironically, many existing policy instruments assign obligations to care based on *functional* relationships. For example, non-custodial parents may be legally required to provide financial support to their children even though, according to structural definitions, they would not be considered family. Similarly, both statute and case law is now evolving in Canada that makes adult children responsible for supporting their parents whether they live together or not.

How family is defined, and whether obligations to care are explicit or implicit in that definition, will have important implications for how policies related to caregiving affect individual caregivers. Indeed, definitions of family can be used to achieve specific policy goals. For example, more inclusive definitions will cast the net wider with respect to who is obligated to care for adults in need, thus facilitating the policy goal of shifting more responsibility for caregiving from the public to the private sector. More inclusive definitions of family could also make more people eligible for the supports and services to which caregivers are entitled under some policies.

However, existing policies seem inconsistent with respect to how inclusive they are, implying that they are also inconsistent in the way in which family is defined. On one hand, we have seen more inclusive definitions of family evolve (such as the increasing acceptance of gay and lesbian couples as families) that will increase the pool of those who are seen as obliged to care. On the other hand, we see policies aimed at supporting caregivers that use more exclusive definitions, such that eligibility for caregiver supports is restricted to a narrower range of people, usually close kin.

Of course, all this ignores the fact that people construct their own definitions of who is a family member, regardless of how a researcher or policy maker defines it. In fact, little is known about how individuals construct their personal boundaries around who is family or around their obligations to care. Even less is known about how more or less inclusive definitions of family used by policy makers will influence who *becomes* a caregiver and how they will be affected by their caregiving activities. How caregiving is defined will have an equally profound effect on who is *considered* to be a caregiver and how they are affected by their caregiving activities.

Three issues must be considered in defining caregiving: (1) what tasks and services comprise caregiving, (2) how caregiving differs from the everyday things that family members do for one another, and (3) whether tasks and services are ‘care’ only if there is a need for those services. The latter point naturally raises the further question of how need is defined. There is no consensus on any of these issues. Again, rather than suggesting that we should subscribe to any one definition of caregiving, we focus instead on the relevance of how caregiving is defined for a research agenda intended to inform policy making related to family caregiving.

Defining Caregiving

In most cases caregiving is defined as a set of tasks that may be categorized as:

- Personal (bathing, feeding, grooming, toileting, administering medication)
- Physical (housework, home maintenance, shopping, transportation)
- Organizational (linkage between the care recipient and the formal service sector), or
- Emotional (maintaining social interaction, cheering up an individual when she is depressed, reassuring and validating attitudes or perceptions).

As with the definition of family, the wider the net is cast with respect to what tasks comprise caregiving, the larger the group of people who will be considered caregivers. Policies that recognize a wider range of care tasks may make supports and services available to more care providers. Even when a wide range of tasks *may* be recognized as care, they may be included or excluded in specific instances, depending on the context within which they are provided. One important context is the boundary between the everyday things that people do in families and caregiving, which appears to be something more.

Family members do things for each other throughout their lives that only under some circumstances are considered care. Some tasks are relatively easy to distinguish from everyday family interaction. For example, we tend to assume that it is normal to bath and dress children, but similar tasks done for an adult family member are not generally considered part of typical family activities. With most other tasks, the boundaries are not as clear. For example, when does buying groceries for a family member become a care task?

Tasks or services are most often considered to be care if they are deemed to meet a recipient's need (Harlton, Keating, and Fast, 1998). Thus, *how need is defined* becomes another key contextual issue.

Defining Need

Defining need is challenging because:

- Need is discussed in different disciplines in terms of disability, frailty, or a life-threatening illness, and such differences make it difficult to transfer knowledge from one discipline to another
- Needs may arise from such diverse sources as age, accident, illness, and genetic defect
- Needs may be lifelong or short term, and
- Needs may be stable, variable, or steadily increase or decrease over time.

Further, there are two common conceptualizations of the criteria that determine need:

- *Loss of functional status:* Care is the daily tending, support, and monitoring of adults who are *dependent* because they are incapacitated or have suffered a severe loss of autonomy (Baines, Evans, and Neysmith, 1992), and
- *Threats to independence:* Care includes tasks and services that augment individual competency and mastery of the environment, sustain the person within the community, and keep him or her functioning at the highest level of *independence* (Cantor, 1991; Neary, 1993).

Functional status has long been viewed as one of the major criteria that determines eligibility for continuing care services (Mahurin, DeBettignies, and Pirozzolo, 1991). Such definitions of need also are used implicitly or explicitly in gathering data on family caregiving.

For example, in the *1991 Health and Activity Limitations Survey*, need was seen as arising from impairment in mobility, agility, seeing, hearing, speaking, learning, or from emotional or psychological impairment. Similarly, the *1996 General Social Survey*, which is focused on caregiving, uses as the criterion for care a set of activities provided to someone with a long term health or other physical impairment.

In contrast, care can be viewed as assistance that meets someone's need to remain independent. Keating *et al.* recently undertook to develop a definition of caregiving to seniors that was grounded in the experiences of stakeholders. Stakeholders agreed that "elder care is a set of tasks and services that maintain or enhance seniors' independence" (1996, 5). Independence was, in turn, defined as control over what services are received and over who delivered the services. Others support the assumption that the needs and wishes of the cared-for person must be taken into account, as failing to do so creates dependence (Twigg and Atkin, 1994; Wenger, 1997).

Each of these criteria might lead to different policies or policy instruments for meeting the needs of those receiving care, or those who care for them. For example, policies driven by definitions of need based on functional status would most likely to lead to provision of such services as personal care for those with a chronic or acute illness. Those driven by the need to maintain or enhance independence might emphasize transportation or household work to help someone remain in their own home.

The Changing Caregiving Environment

As we near the end of this century, Canada is experiencing extraordinary social change. In order to appropriately address policy issues affecting those caring for adult family members, researchers and policy makers must understand the environments within which this caregiving takes place, and how these environments are changing. These environments, and the trends affecting them, are well documented elsewhere. Here, we provide only a summary for three environments of particular relevance to this paper: the family, health, and policy environments of family caregiving. Our attention will be devoted to a discussion of the consequences that trends in these environments have for caregivers, for policy, and for policy relevant research on family caregiving for adults in need.

The Family Environment

The past three decades have brought profound change to the family environment. The overall result is greater family diversity and changes in family roles (see Box 1). These changes have important implications for family caregiving. For example, the combined effects of delayed marriage and childbearing, the "cluttered nest" phenomenon, and increased longevity may increase the incidence of simultaneous multi-generational caring responsibilities (Kane and Penrod, 1995).

Box 1. The Family Environment

Changes in the family environment:

- Smaller families
- Less stability in families
- More diversity in family structure
- More complex family relationships
- Changing and more diverse family roles
- More diversity in felt obligation to care for family members, and
- Declining caregiving capacity within families.

Trends affecting the family environment:

- Slight declines in marriage rate
- Delayed marriage and childbearing
- Sharp increase in divorce and remarriage rate
- More common-law marriage
- Declining fertility rate
- Later launching and frequent returns of children to the parental home
- Population aging
- Women's increased labour force participation, and
- Increasing cultural diversity of the population and greater sensitivity to cultural differences.

At the same time, improved health and independence among seniors may make simultaneous child and elder care responsibilities less likely while lifelong caregiving responsibilities that simply shift from one generation of family members to another become more common (Keating *et al.*, 1999). Whichever scenario prevails, it seems likely that more of us will care for both children and parents during our lives.

Similarly, family fluidity arising from higher divorce and remarriage rates may result in broader networks of kin and former kin who are willing and able to provide support. Alternatively divorce and remarriage may create ambiguity with respect to moral and legal obligations to care for family members such as parents of former spouses, or a current spouse's children from a previous relationship.

Obligations in families emerge in part from a desire to reciprocate for care received. One source of obligation is long term reciprocity in which children have a desire to 'pay back' parents or grandparents for care received when they were young. We know little about how obligated children feel to care for step-parents, step-grandparents or step-siblings in families disrupted by divorce. Similarly, partners in long term marriages may feel a stronger sense of need to care for their spouse when she or he is ill than those in shorter term marriages. Ex-spouses probably will feel little obligation to care.

Greater diversity in family structure and greater complexity in family relationships also have implications for policy related to caregiving for adult family members in need. Even the most contemporary of policies still are based on assumptions of homogeneity among families and clear lines of family obligation. When the reality is quite different, there is great potential for isolation, lack of resources, and lack of support for those in need. Alternatively, when individuals are forced to assume responsibility for caring for those toward whom they feel little if any obligation, the potential for strained family relationships and even abuse increases. That is, policies can fail to achieve their goals, or even exacerbate the very situation they were intended to correct simply because they are based on outdated notions of family structure and relationships.

Changes in family roles and in preferences for and participation in paid work also have significant implications for family caregiving and for policy related to caregiving. Women, the traditional caregivers, face increasing demands on their time related to their paid work at the same time that demands related to unpaid work such as family caregiving are increasing as a result of demographic and policy trends. As a result, family caregiving capacity is severely challenged. Once again, policies are doomed to failure, both for adults in need and their family caregivers, if they are based on outdated assumptions about the family environment.

Culture and ethnicity inform familial expectations for care, arrangements for care, and obligations for care. Canada is a country of great cultural diversity. Canada's Aboriginal peoples, which include status Indians, Métis, Inuit and non-status Indians, comprise about 3 percent of the population.² First generation immigrants comprise another 17 percent and their cultural backgrounds are rapidly changing as European countries have declined in importance as source countries, while Asian countries have increased (Vanier Institute of the Family, 1994). Family may be defined somewhat differently within each of these groups. For example, Aboriginal peoples tend to include more extended family members and more non-kin in their family networks. They also tend to have more frequent contact with family than other cultural groups (Novak, 1993). Similar differences have been noted among immigrant families (McCallion, Janicki, and Grant-Griffin, 1997; Merrill 1997).

Urban and rural cultures also are believed to be quite distinct. One assumption about rural culture is that family caregiving resources are plentiful because rural Canadians are embedded in large, close-knit family networks that have a strong ideology of taking care of their own (Keating, 1991). On the other hand, out-migration of young people from some rural areas, and in-migration of retirees to others, may instead leave people at a distance from family networks. Lack of formal caregiving services in rural compared to urban areas can leave these dependent adults without any support. Which assumption is the more valid is unclear, as yet.

There may also be cultural differences in the demand for care. Shorter life expectancy and higher birth rates among Aboriginal peoples mean that there is a higher proportion of children and lower proportion of elderly people in this population (Lemchuk-Favel, 1996).

2 This is a national average; proportions vary widely across the country. For example, 62 percent of the population of the Northwest Territories is Aboriginal.

Canada's Aboriginal peoples also experience poorer health status at all stages of the life cycle, such that the benefits of a larger family network may be off-set by higher caregiving demands.

The impact of caregiving on caregivers also varies according to ethnic and cultural characteristics. For example, African American caregivers appear to cope better with the demands of caregiving, reporting lower levels of caregiver burden, grief, depression, anger and hostility and higher levels of satisfaction from their caregiving than their Caucasian counterparts, despite facing more stressors and possessing fewer resources (Pruchno, Patrick and Burant, 1997). At the same time, research suggests that cultural minorities may be under-represented among formal service receivers (McCallion, Janicki, and Grant-Griffin, 1997).

Little is known about how caregiving relationships differ across cultural groups in Canada. However, once again, current policy seems to assume homogeneity, taking even less notice of cultural diversity than it does of diversity in family structure and roles. That is, "families from diverse cultures do present a caregiving picture different from that on which current services are based" (McCallion, Janicki, and Grant-Griffin, 1997, 355).

The Health Environment

While changes in the family environment seem destined to result in a reduction of and greater complexity in family caregiving capacity, changes in the health environment suggest an increased demand for same (see Box 2). Despite (perhaps even as a result of) advances in medical science, trends such as population aging, new patterns of illness and disease, and increased survival after catastrophic illness and injury are likely to mean that there are more people of all ages in our society requiring higher levels of care than ever before. According to the *Health and Activity Limitations Survey*, in 1991, upwards of four million Canadians, or 15 percent of the population, were living with some sort of disability. Indeed, it is expected that there will be a population bulge of persons with disabilities paralleling the baby boom.

Box 2. The Health Environment

Changes in the health environment:

- Population aging
- More variability in levels of need
- More variability in the length of need, and
- More variability over the course of illnesses or disabilities

Trends affecting the health environment:

- Better living conditions (sanitation, food, environment)
- New patterns of illness
- Advances in medical science and technology, and
- Increased survival after catastrophic illness and injury

Implications of these trends for family caregiving are profound. Increased longevity, coupled with the inevitable declines that come with age, and increased survival after catastrophic illness and injury mean that there are more frail, ill and disabled people to be cared for at home. It also means that these people suffer from more severe disabilities and illnesses which, in turn, means more intense care needs. Some have medically complex care needs that exceed family members' abilities. Further, medical technology has made it possible, and policy reform has made it necessary, for informal caregivers to provide higher levels of care at home (Patterson and Leonard, 1994). There also is great variability in the length of the caregiving commitment depending on the nature of the illness or disability, with more family caregivers facing a commitment to many years, even a lifetime, of caregiving. Further, there are vastly different patterns of need across the course of different conditions.

A 90 year old parent who suffers a massive stroke may require a few days or weeks of intense palliative care. Survivors of heart attack may require a few weeks or months of care which declines in intensity over that time and ends with full recovery. Many chronic diseases are characterized by periods of both severe disability and relative independence such that their caregivers face instability, uncertainty and continually shifting responsibilities (Given and Given, 1994). AIDS has some unique features that make it particularly challenging for family caregivers. Kahana, Biegel and Wykle describe it as "life-threatening as well as stigmatizing and having an unpredictable but inevitable trajectory of decline" (1994, xxii). Brennan and Moore add that the course of the disease is frequently "interrupted by periods of bizarre and unusual clinical manifestations ... and is always fatal" (1994, 159).

It also should be noted that illnesses and disability trends do not affect all segments of the population equally. Aboriginal peoples, the poor, and the elderly are more likely to experience activity limiting disabilities. As a result, care needs will vary across these groups.

The Policy Environment

In the broadest sense, the policy environment is a reflection of the value systems and structures of the society within which they are developed (Brooks, 1993). Since value systems change over time, so too do social policies (see Box 3). While Canadians today express deep mistrust of elected officials and bureaucrats, and frustration over waste and inefficiency, Peters (1995) reports that the result is a desire for better, more responsive government, not a desire to minimize government's role. Canadians are concerned about the cost of social programs but do not believe cost should be the only criteria determining how we express our value of collective responsibility. We believe equality means universality of social programs. We see health care as foundational to the Canadian identity and a universal right of all Canadians. Democracy means we want to be involved in policy reform.

Box 3. The Policy Environment

Changes in the policy environment:

- Reduced government expenditure on health, income security and social services
- Push toward the privatization of health and continuing care
- Shift from institutional to community-based health and continuing care, and
- Increased geographic inequity in health and social service delivery.

Trends affecting the policy environment:

- Emergence of new values
- High levels of government deficit and debt
- Devolution of responsibility for health and social services from federal to provincial, and from provincial to regional, governments or agencies
- Re-emergence of political conservatism, and
- Changes in the family and health environment, as described above.

The policy sectors with the greatest the potential to affect families' decisions about how to meet members' care needs and the consequences of those decisions include:

- Health and continuing care, since this may determine which formal care services are available to whom and under what circumstances
- Income security, which will affect the economic well-being of those providing and receiving care, and
- Labour market policy, which determines the extent to which family caregivers may engage in paid work in tandem with their unpaid caregiving work, which will, in turn, affect their economic, social and psychological well-being.

Recent reform in the health and continuing care policy sector in most provinces has included devolution of responsibility for the delivery of health and continuing care services from provincial governments to regional health authorities, a shift in emphasis from institutional to community-based care, privatization, and the emergence of a two-tiered health care system. These reforms are having a profound, but little understood, impact on family caregiving.

Fiscal and philosophical imperatives among policy makers have resulted in a new policy paradigm in the health sector that de-emphasizes formal care for those in need and emphasizes instead informal, largely family, care (Guberman, 1999; Keating *et al.*, 1997). The two principle tenets of this paradigm are *caring partnerships* and *client-centred* care. The best care is seen as a collaborative effort involving formal and informal caregivers and those in need of care (Alberta Health, 1993; Manitoba Health, 1992; New Brunswick, 1992; Nova Scotia Department of Health, 1990).

Thus the interface between formal and informal care becomes a cornerstone of a new model of caring for those in need. This choice, it is said, is both more cost effective and dignified (Dossetor and MacDonald, 1994). Keating *et al.* (1997) suggest, however, that there is a subtext to this new paradigm arising from concerns about the cost of continuing to provide formal services to a growing number of seniors and other adults in need. Recent policy reform seems to be more about shifting responsibility for (and, not incidentally, more of the costs of) care to informal caregivers and to those in need of care than it is about dignity or quality of care. In fact, little is known about how this new paradigm will affect the overall costs of care, the distribution of those costs, or the quality of the care itself. Nor is enough known about how the formal and informal care systems interact, or about how these interactions might be affected by the policy environment.

Regionalization of health and continuing care service delivery is likely to result in inequities in service availability, choice and quality of services across regions, even within a given province. Indeed, one of the objectives of regionalization is to allow regions “to tailor health programs to assess local needs, emphasizing community-based delivery” (Minister’s Task Force on Regionalized Health Care in Nova Scotia, 1999). Both empirical evidence (Northcott and Northcott, 1999; Northern and Rural Health Task Force, 1995) and anecdotal evidence (Consumers’ Association of Canada (Alberta), 1996) of differences in access to and quality of health services, and confusion about roles and responsibilities across regions, are being observed. Expectations and support services for informal caregivers are likely to vary across regions as a result.

Privatization has obvious implications for health care consumers. As such measures place more people in greater need of care outside of institutional settings, it has equally important implications for family caregivers. In the absence of adequate support within the community, there will be a growing “care gap” to be filled by informal caregivers (Fast and Mayan, 1998).

Income security policy will affect caregivers both directly and indirectly. Poverty adversely affects health by limiting both health care choices and access to health care services (Williamson and Fast, 1998). Thus, the poor will have more health needs and fewer resources with which to meet needs that are not covered by the public system from the private market, so they will have more need for family care. Poor caregivers will themselves be less healthy and less able to absorb the financial consequences of informal caregiving responsibilities. Moreover, real access to health care services appears to be affected by the nature of income security policies within a given jurisdiction (Williamson and Fast, 1998).

Key elements of the income security system in Canada include social assistance and retirement and disability pensions. In most provinces, eligibility for social assistance is becoming more restricted and benefits are declining, especially for those deemed to be employable (Gorlick and Brethour, 1999). However, eligibility criteria vary across provinces in ways that will almost certainly result in geographic inequities for caregivers. In all provinces, efforts are being made to decrease welfare roles, principally by requiring employable social recipients to seek employment.

In all provinces, those caring for very young children are exempt from this requirement. Few provinces exempt those caring for adults in need.³ Disabled persons' access to monetary supports for the costs of care vary from province to province and even within provinces. Different levels of government and private-sector organizations are involved, creating a system of programs and services that is often confusing, fragmented and inadequate (Federal Task Force on Disability Issues, 1996).

Policies and programs that provide some compensation for the costs that accrue to caregivers when they take on the responsibility of caring for a family member also have the potential to affect caregivers' economic security. While common in some countries, Canada does little to compensate caregivers directly. A new, very limited, Caregiver Tax Credit was implemented in 1998 that enables low income taxpayers caring for a co-resident relative over age 65 to reduce their tax payable by a maximum of \$400. A sales tax exemption for respite care expenses also will benefit caregivers.⁴ Quebec alone provides an allowance to caregivers with which to purchase respite care (Fast and Mayan, 1998; OECD, forthcoming).

Caregivers also may benefit indirectly from tax credits targeted at disabled adults. For example, any portion of tax credits for medical and attendant care expenses for which the disabled taxpayer is eligible, and which is not needed to use to reduce their own tax payable to zero, may be transferred to a caregiver (Fast and Mayan, 1998). Similarly, programs that provide attendant care allowances to care receivers may indirectly benefit family caregivers if there are 'no strings attached' to who may be hired to provide the care. Veterans Affairs Canada and the governments of the provinces of Quebec and New Brunswick provide such benefits (Fast and Mayan, 1998; OECD, forthcoming).

Given the increasing numbers of Canadians who face simultaneous paid and unpaid work responsibilities, policies that govern the rights and responsibilities of employers and employees also may have an impact on caregiving capacity and on the consequences of caregiving. Indeed, such policies may themselves determine the extent to which we can fulfill both paid and unpaid work demands. Relevant policies include those related to family leave, child care, adult dependent care, and flexible working arrangements. Today, the public policy mix includes provincially legislated entitlement to leave for attending to family emergencies,⁵ federally mandated maternity and parental leave for meeting the special demands of childbirth and newborn care (with partial income replacement), and some tax relief for those with responsibilities for child care and dependent adult care.

A few Canadian employers have gone beyond these provisions with more extensive family responsibility leaves, a wide range of work scheduling options to better accommodate family demands, elder care referral and information services, and subsidies for elder care or respite care (Conference Board of Canada, 1999; Skrypnek and Fast, 1996).

3 One known exception is Ontario (Ontario Ministry of Community and Social Services, 1999).

4 The proposed legislative amendment to make respite care services exempt from GST/HST has not yet received Royal Assent. However, it is being treated as though it has come into force, such that respite care services are no longer subject to GST/HST.

5 In most provinces, family responsibility leave is available only to those fulfilling child care responsibilities. Only Ontario explicitly extends the right to use family responsibility leave to meet eldercare responsibilities.

Despite the vast amount of attention paid to family-friendly policies in recent years, there is remarkably little empirical evidence as to what, if any, impact these policies have on family members' ability to adequately meet the competing demands of family responsibilities and paid work.

The Policy Research Agenda

A truly holistic understanding of the relationship between the policy environment and caregiving should not stop at an examination of the three policy environments discussed above. Housing, transportation, and other policies also affect the care receiver's opportunities for independence from both formal and informal care systems, and important reforms are occurring in each of them. Even less research has investigated these policy sectors and no Canadian research has examined the collective effect of the complex web of policies that affect family caregivers (for a review of European efforts to do so, see Rostgaard and Fridberg, 1998).

Hitting a moving target, such as the ever-changing policy environment, has never been easy. But in recent years, fiscal imperatives have wrought profound changes in policies with the potential to affect family caregiving. It is, therefore, increasingly imperative that policy research be conducted in a timely manner and that policy researchers be aware of emerging policy issues. What follows, then, is a recommended agenda for policy research related to caregiving for adult family members that attempts to anticipate the *future* needs of policy decision makers.

Any research agenda emerges from gaps between what already is known and what needs to be known about a phenomenon. Thus we begin with a summary, from the foregoing sections, of *what is known about caregiving for adult family members, what remains to be discovered*, and its policy relevance. The knowledge gaps thus identified become the basis for research questions that comprise the recommended research agenda. These questions take two forms.

Questions related to the *environments* within which informal care is being performed at this time appear in the first section, in Boxes 4 through 7. Questions related to the *forces for change within these environments* that will affect caregivers in the future appear in the following three sections, in Boxes 8 through 12. Further, in our view, at least as important as the knowledge gaps identified are a variety of *methodological issues and challenges* that must be confronted if these knowledge gaps are to be redressed. Data requirements also change as the research agenda changes. These are delineated in the fifth and final section and are intended to be integral to the recommended policy research agenda.

1. What Do We Need to Know About Caregiving Transactions?

It is well known that the vast majority of care is done by informal caregivers, most of whom are female kin. We know the predominant characteristics of caregivers, we know the types of tasks caregivers perform, and we are beginning to know more about how much of what types of care is provided by caregivers (see Keating *et al.*, 1999 for a comprehensive picture of these questions related to eldercare).

However, what we know about caregiving relationships is almost entirely restricted to caregiving dyads -- that is, one family member (usually designated as the primary caregiver) caring for one other family member. However, emerging evidence (Connidis, Rosenthal, and McMullin, 1996; Keating *et al.*, 1999; Wenger, 1996) suggests the existence of caregiving *networks* involving multiple family members making a coordinated effort to care for the member in need. This work also is beginning to tell us a little about the size and composition of these networks, how responsibilities are divided among members of the networks, and why some family members become members of the caregiving network while others do not. However, much remains to be learned.

Knowledge of how informal care is organized is crucial to understanding the nature and capacity of the informal care sector (see Box 4). This understanding will, in turn, help policy makers and practitioners better target their policies and services. For example, policies that restrict eligibility for support services to a spouse or child who is the primary caregiver may so disadvantage other members of the care network as to reduce their capacity to care, with the result that the *network's* capacity also is reduced. Further, a sole caregiver may have quite different informal resources and support needs than one who is embedded in a group that shares caregiving responsibilities. This, too, requires quite different policy and practice responses.

Box 4. What are caregiving networks like?

- How are caregiving networks different from caregiving dyads?
- How do members of the family and social network become members of the caregiving network?
- How are care responsibilities distributed among members of the caregiving network?
- Do policies strengthen or weaken the capacity of caregiving networks?
- Do policies affect the way in which responsibilities are distributed among members of the caregiving network?
- Does policy have differential effects on different caregiving network members?

Further, even our knowledge of caregiving transactions within dyads is largely limited to the type and amount of assistance that flows *from* primary caregivers *to* family members. Yet evidence also is emerging that caring transactions flow both ways. Indeed, it has been hypothesized that care is provided to a family member in part because care has been received from that same (or another) family member at some time in the past, or is expected to be received at some time in the future. That is, caregiving transactions occur among family members on an on-going basis and each family member will be in the giver and receiver roles at some time, and sometimes even simultaneously (see Box 5). Patterns of reciprocity may determine the care needs of ill or disabled adults, the availability of informal care, and caregiver support needs, thus having implications for policy responses. They also be affected by policies. With the recent availability of appropriate data, some work is beginning on direct reciprocity between members of care dyads (Keefe, 1999) but little is known about multi-party, multi-directional exchanges beyond their existence.

Box 5. What role does reciprocity play in the provision and receipt of care?

- Is reciprocity a prerequisite in caregiving transactions?
- What are the predominant reciprocity patterns in family networks (long term versus short term, same generation versus across generations, gender)?
- How do policies influence reciprocal caregiving transactions? For example, is reciprocity more or less likely under different policy regimes?

Most research on caregiving transactions has been cross-sectional in nature. While we have some sense of how caregiving is different for caregivers of different ages, observed at a point in time, we have little confidence that these age-related variations tell us anything about how *one* caregiver's experiences will vary over time. Competing hypotheses about patterns of caregiving across the lifespan have arisen in the literature, such as "caregiving careers" (Keating *et al.*, 1999) and the "sandwich generation" (Kane and Penrod, 1995), but available empirical evidence on the existence of such patterns has been mixed.

Prior research on care provided to specific groups of recipients (frail elders, cancer patients, people with HIV-AIDS) also indicates that caregiving demands likely change over the course of the illness or disability. Yet little is known about the nature of those changes, about how the course of an illness or disability affects the pattern of caregiving demands over time or, in turn, how these patterns differentially affect those caring for adult family members with different conditions.

All of this suggests the need for policies that are flexible enough to accommodate significant variability in the needs of caregivers and care recipients over time. Understanding patterns of need and of caregiving over time is essential to the development of such policies (see Box 6).

Box 6. What are the dynamics of caregiving transactions over time?

- How do caregiving demands, caregivers' capacity to care, and caregivers' response to caregiving demands vary over the course of their lifetime?
- How does the caregiving transaction change over time (for example, which family members are on the 'giving' and 'receiving' ends of the caregiving transaction, what kind of care is being provided)?
- How do caregiving needs change over the course of an illness or disability?
- Is the course of an illness or disability different for different kinds of illness or disability?
- How does caregivers' capacity to care change over the course of an illness or disability?
- To what extent do policies accommodate the variability in caregiving transaction over time?
- What are the implications of continuing policy reform for long term caregiving situations?

Adults receive care from family members for a variety of reasons, including injury, acute or chronic illness, and the frailties of age. Even within each of these categories, there exists a wide range of specific conditions that lead to the need for care. The nature of the disability probably creates significant differences in the nature of the caregiving transactions that occur. However, prior research has tended to deal with caregiving transactions arising from specific disabilities in isolation from one another (see, for example, King and Koop, 1999; Leis *et al.*, 1998). Therefore, the differences in caregiving transactions and the commonalities that might exist across types of disabilities are largely unknown (see Box 7).

Box 7. How does the nature of the dependency affect caregiving transactions?

- How are caregiving transactions similar or different for different illnesses or disabilities?

2. *What Do We Need to Know About the Changing Family Environment?*

Profound changes are occurring in the family environment within which caregivers operate. Trends such as increased divorce, remarriage and common-law marriage, declining fertility rates, changes in immigration patterns, and changes in men's and women's preferences about participation in paid work and family roles all are known to contribute to increased complexity in family relationships.

We also have gained some understanding of the implications some of these trends may have for how caregivers are affected by their caring work. For example, results of research carried out by the Conference Board of Canada (1999), Keating *et al.* (1999), Gignac, Kelloway, and Gottlieb (1996), and Martin-Matthews and Campbell (1995) have demonstrated that caregivers' employment opportunities (especially those of women) are affected by their caregiving responsibilities. Thus, increases in women's labour force participation can be expected to increase employment, and therefore the economic consequences of caregiving.

Much less is known about how these changes will affect the ability and willingness of family members to care for one another and the role of policy in family members' ability to cope with caregiving demands in the face of greater complexity in their family relationships (see Box 8). Further, what little we do know about how families cope when there are differences between the dominant culture's expectation and the maintenance of traditional cultures comes primarily from research conducted in the United States.

Box 8. What are the implications of the changing family environment for the nature of family caregiving transactions? How does the nature of the dependency affect caregiving transactions?

- What are the consequences of divorce and remarriage for the capacity and willingness to provide care to adult family members?
- What are the consequences of changing family roles (women's increasing labour force participation and commitment and men's increased desire to be involved in family roles) for the capacity and willingness to provide care to adult family members?
- How do cultural norms regarding obligations to care for adult family members differ among the predominant ethnic groups in Canadian society?
- Which policies hinder and which facilitate family members' ability to cope with caregiving demands in the face of greater complexity in their family relationships?

3. What Do We Need to Know About the Changing Health Environment?

The health environment is changing in interesting and contradictory ways. Economic, social and technical progress have brought about a general improvement in the health of the Canadian population, increased longevity, lower infant mortality rates, and survival after ever more catastrophic illnesses and injuries. However, these same trends mean that an increasing proportion of the population is living with illnesses or disabilities that limit their independence. The result is an increasing need for care, and increasing diversity in the types of care required, for Canadians of all ages (see Box 9).

Box 9. What are the implications of trends in health status for care requirements (amount, length of commitment, type of care required)?

- How will long term care requirements of survivors of catastrophic illness or injury be met? In particular, how will the needs of survivors of childhood illness or injury be met when parent caregivers are no longer able to care?
- How will the long term care requirements of seniors, arising from increased longevity, be met in the face of reduced caregiving capacity of family members?

At the same time, these changes have not been experienced equally across the population. For example Aboriginal peoples and people living in poverty continue to exhibit poorer health, on average, than the rest of the population. Similarly, various illnesses and disabilities affect different segments of the population differentially. In addition, we know a great deal more about care requirements arising from some conditions (aging, cancer and HIV-AIDS) than others (see Box 10).

Box 10. How does the nature of informal caregiving vary across population groups and conditions?

- How does economic status affect need for and availability of care?
- How do care requirements and availability of care vary across health conditions?
- How do the provision of informal care, and the needs of informal care caregivers, vary across population groups and conditions?
- What role can policy play in leveling the playing field for care recipients and care providers across population groups and conditions?

4. What Do We Need to Know About the Changing Policy Environment?

Discussion of informal care cannot occur in isolation from discussion of formal care. Caregiving needs usually are met with some combination of formal and informal care. There is conclusive evidence that formal and informal care are complements and not substitutes (Penning and Keating, forthcoming). But we know little about the mechanisms or processes at work at the interface so we have little understanding of how variations in policy can affect the mix of formal and informal care provided. Further, despite overwhelming evidence that formal and informal care are complements, and not substitutes, there also is evidence that policy makers assume the opposite. Thus far, we have little understanding of how policy based on an assumption that informal caregivers cease caring for their family members when formal care is available affects informal caregivers or care receivers (see Box 11).

Box 11. What is the ‘ideal’ mix of formal and informal care provided to adult family members?

- What are the mechanisms and processes by which the mix of formal and informal care provided is determined?
- How is the mix of formal and informal care affected by policy?
- How are caregivers’ experiences different when the prevailing policy regime is based on the assumption that formal and informal care are substitutes versus complements?

It is clear that recent policy reform is shifting more responsibility for caring for adults from formal to informal caregivers. It also is clear that this is true whether the need for care arises from increasing frailty among aging family members or from injuries or acute or chronic illness. This reform seems to be driven by both fiscal imperatives and values and assumptions about what the best source of care is. Policy makers seem to assume that informal care is both *cheaper* and *better*. Recent evidence suggests that neither is universally true (Fast, Williamson, and Keating, 1999; Keating *et al.*, 1999) but has yet to tell us what we need to know about the circumstances under which informal care is, and is not, better and cheaper (see Box 12).

Box 12. What are the advantages and disadvantages of formal and informal care with respect to quality and cost of care?

- For whom is informal care better?
- For whom is informal care cheaper?
- How do policies affect the distribution of costs among stakeholders?

5. Methodological Issues and Challenges

The nature of the phenomenon of interest, the nature of policy research, and the nature of the Canadian policy environment pose some special challenges to anyone contemplating policy-relevant research about caregiving for adult family members. For example, as noted earlier, researchers need to pay attention to, and be clear about, how key concepts -- family, caregiving and independence -- are defined. Moreover, the implications that adopting different definitions of these concepts has for research results and for policy making remains largely an empirical question in itself.

As was also pointed out earlier, there is an urgent need for research on caregiving *networks*. Network analysis has only recently begun to be tackled and remains an empirically challenging task. Thanks to technological and theoretical advances, and the availability of public use data files (such as Statistics Canada's *1996 General Social Survey*) which support limited network analysis, the challenge is no longer insurmountable, but much remains to be learned.

Women consistently have been shown to comprise the majority of caregivers. While the most recent evidence on informal eldercare providers shows a less dramatic gender split (60-40) than has been found previously, it also shows dramatic gender differences in the characteristics that are related to the amount of time spent on various eldercare tasks, the extent to which caregivers experience economic, social, emotional and psychological consequences as a result of their caregiving, and the predictors of those consequences (Keating *et al.*, 1999). The same cannot be said about the state of knowledge about gender differences among caregivers to other adults in need. Nor can the same be said about whether there are differential effects of policies or of changes in the family, health and policy environments on male and female caregivers. It is thus imperative that gender-based analysis be employed in all future research on family caregiving.

Caregiving for adult family members encompasses caregiving situations where the need for care arises from a wide range of conditions: the frailty that comes with aging, a variety of injuries, and many different acute and chronic illness. To date, there has been little interaction among researchers addressing care provided to those with different conditions. As a result, much duplication of effort already has occurred. While each condition may present unique challenges, they share some challenges as well, especially with respect to caregiving demands and the effect of changing family, health and policy environments on those demands.

We highly recommend a meta-analysis of the separate literatures on caregiving across conditions and age groups to identify these common and unique challenges. Greater collaboration across disciplines and among researchers also is needed. As Kahana, Biegel, and Wykle conclude, “All too often, caregiving research with one chronic illness does not build on related research with other illnesses” (1994, xxii).

The policy environment within which caregiving to adult family members occurs is especially complex. The temptation for researchers, and policy makers, to limit their attention to health and long term care policy is evident in the existing literature. But policies in many different sectors, including pensions, housing and transportation, are relevant to the issue and need to be addressed by researchers. In addition, in Canada there is a unique division of responsibility among levels of government over many of the relevant policy areas. This presents both challenges and opportunities for researchers. For example, it raises questions about generalizability of research results across policy regimes. It also raises questions of equity in the way caregivers are affected by policies that can vary markedly across the country and, at the same time, provides the necessary variability to address such questions through research.

The need to capture the time dimension in caregiving (over the caregivers’ life course or over course of an illness or disability) was raised several times in the foregoing. As a result, calls for longitudinal and life course methodologies have begun to emerge (Kahana, Biegel, and Wykle, 1994). Fortunately, Statistics Canada is embracing longitudinal methodologies. For example, the *National Population Health Survey*, the *Survey of Labour and Income Dynamics* and the *National Longitudinal Survey on Children and Youth* all are following panels of respondents over time.

However, the skills and infrastructure (computer hardware, software and technical support) necessary to fully exploit these data files is relatively lacking. Collaboration between Statistics Canada, the research community (especially those in training institutions), and research funding agencies aimed at developing these new skills is being pursued and, if it happens, will greatly advance the research agenda proposed herein. Further, given the nature of policy reform, which increasingly is emphasizing community care over institutional care, there is a corresponding need to involve ‘the community’ in caregiving research. Community action research methodologies could make significant contributions to our understanding of the success (or lack thereof) of the shift to community care.

Finally, there is great variability in how much is known about the various aspects of the phenomenon in question and, therefore, great variability in the kind of information required. It follows, then, that there is likewise great variability in the kind of research required. Thus, the full spectrum of qualitative and quantitative methods must be brought to bear on the questions detailed above.

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