Canada's Complex and Fractionalized Home Care Context: Perspectives of Workers, Elderly Clients, Family Carers, and Home Care Managers[1]

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Abstract

In Canada, home care provides health and social services to an estimated one million people, most of them older adults. In the absence of national policy directives, services vary considerably from one jurisdiction to the next, in what has been called a "checkerboard" of policy and practice. This paper examines policy-relevant issues in the provision of home care services, focusing specifically on "home support" services delivered by unregulated workers. We examine findings from our seven-year program of research, and highlight three policy issues that emerged from our study of workers, older clients, family carers, and managers. These are: scope of services, scheduling of services, and the presumption of availability of family/friend carers. For each issue, we give examples of policy or practice initiatives being undertaken and current challenges. We then examine these issues in relation to guiding principles for services, as identified by the Canadian Home Care Association.

Résumé

Au Canada, des services de santé et des services sociaux à domicile sont fournis à environ un million de personnes, pour la plupart des personnes âgées. En l'absence de directives politiques nationales, les services varient considérablement d'un territoire à l'autre, dans ce qui a été appelé une « mosaïque » de politiques et de pratiques. Ce document examine les questions liées aux orientations politiques en matière de prestation de services de soins à domicile, et plus particulièrement les services de « soutien à domicile » proposés par des travailleurs non réglementés. Nous analysons les conclusions de notre programme de recherche mené à bien sur six années, et mettons en

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avant trois problèmes de politique qui ont émergé de notre étude sur les travailleurs, les clients âgés, les aidants familiaux et les gestionnaires. Ces trois problèmes sont : la portée des services, les horaires des services et la disponibilité présumée des aidants familiaux ou amicaux. Pour chaque point, nous présentons des exemples d'initiatives entreprises en matière d'orientation politique ou de pratiques, ainsi que les défis rencontrés. Nous considérons ensuite ces questions à la lumière des principes directeurs de ces services, identifiés par l'Association canadienne de soins et services à domicile.

Introduction

The Final Report of Canada's Special Senate Committee on Aging described home care as "what Canadians want when their health makes it difficult for them to manage the activities of daily life… an essential part of providing integrated care to Canadians" (Carstairs & Keon, 2009). However, beyond recognizing home care's general desirability, one can say little else about it in a pan-Canadian context. Because home care services are not included in the Canada Health Act, service goals and program delivery vary not only across provincial jurisdictions but also between regions within a province, and sometimes even within health authorities.[2] For most of the one million people who receive home care services (the majority of whom are older persons)[3], the reality is that "where Canadians live, rather than what they need, determines access to services, residency requirements, the payment of user fees, and the continuity of service providers" (Shapiro, 2002, p.18).

This paper examines the perspectives of public sector home care managers, "unregulated" workers who provide the bulk of home care services, and older people who are clients of these services and their family carers in British Columbia (BC). Their experiences of home care are framed and interpreted through the lens of policy statements of the guiding principles of home care service delivery, with a particular focus on home care's place within an integrated Canadian health care system.

The Policy Context of Home Care in Canada

Over a decade ago Leduc Browne concluded that, in Ontario "the balance in home care is tipping from public to private payers, from non-profit to for-profit providers, but also from paid to unpaid workers" (2000, p.132). Despite the desire of older people to age in their own residence and the demonstrated cost-effectiveness of home care (Hollander & Tessaro, 2001, in reference to British Columbia), neo-liberal developments across Canada have brought substantial reductions in the public provision of home support services. This downsizing has coincided with shifts from provincial systems of care to regionalization (Konkin, Howe & Soles, 2004) and home care "re-engineering" (Leduc Browne, 2000). Thus the tipping observed by Leduc Browne is even more pronounced and more widespread today (Aronson, 2006; Aronson, Denton & Zeytinoglu, 2004), with increased evidence of "privatization by stealth" (Armstrong, 2001).

[2] The federal role in Home Care is confined to the First Nations and Inuit Home and Community Care program, and the Veterans' Independence Program (CHCA, 2008).

[3] Approximately 40% of home care clients are over the age of 85 (Health Council of Canada, 2012).

Home care service delivery now includes a mix of public providers of services, private agency providers, public-private partnerships, and publicly paid services contracted out to the private sector[4] (Seggewiss, 2009). In addition, the home care sector has endured years of policy neglect and retrenchment in many jurisdictions across the country. Studies of home care in Ontario (Leduc Browne, 2000) and in British Columbia (Cohen, McLaren, Sharman, Murray, Hughes, & Ostry, 2006; Cohen, Tate & Baumbusch 2009; Hollander, Chappell, Prince & Shapiro, 2007; Hollander & Tessaro, 2001; McGrail, Broemeling, McGregor, Salomons, Ronald, & McKendry, 2008; Penning, Brackley & Allan, 2006) examine the consequences of home care reform and retreat. The result is a patchwork of programs with access and availability varying by geographic region, "if not chance" (Seggewiss, 2009). Significant variations in access, costs and wait times characterize the provision and receipt of home care, such that it has been described as "a crapshoot" and a "checkerboard … situation" (Seggewiss, 2009, p. E90). Service organization, funding, and policy-making in the delivery of home care in Canada are anything but monolithic, rational phenomena (Cohen et al., 2009; Leduc Browne, 2000).

There is a strong body of research on home care in Canada. Wide variability in the delivery of home care within and between jurisdictions is well documented. A comprehensive report by the Canadian Home Care Association (CHCA, 2008) specifies the diversity of regulations concerning eligibility, accessibility, comprehensiveness, and administration across the country. Research has also advanced understanding of the broad policy contexts of home care (e.g. Aronson, 2004; Aronson & Neysmith, 2006; Guberman, 2004) and of the perspectives of workers engaged in the delivery of home care services to older persons (Guberman, Lavoie, Pepin, Luazon & Montejo, 2006; Neysmith & Aronson, 1997). Safety issues in home care have been a recent focus of analysis (Craven, Byrne, Sims-Gould, & Martin-Matthews, 2012; Denton, Zeytinoglu, Davies & Hunter, 2006; Lang, Macdonald, Storch, Elliott, Stevenson, & Lacroix, 2009). Hollander and colleagues have examined home care policy in historical context, and amply documented the economic feasibility of preventive home care relative to other types of expenditures in the care of older persons (Chappell, Havens, Hollander, Miller & McWilliam, 2004; Hollander, 2003; Hollander & Tessaro, 2001; MacAdam, Hollander, Miller, Chappell & Pedlar, 2009). Projections of labour force availability in home care have been advanced (Keefe**,** Carrière & Légaré, 2004; Sims-Gould, Byrne, Craven, Martin-Matthews & Keefe, 2010), and their policy implications addressed.

Despite compelling findings in reports from the Canadian Centre for Policy Alternatives (Cohen et al., 2006; Leduc Browne, 2000) and cogent analyses by the researchers cited throughout this paper, home care has remained largely at the margins of current debates on health care in Canada. Nevertheless, Leduc Browne's observation over a decade ago that "home care arouses enormous interest" (2000, p.79) is true today. Numerous national agencies have recently framed position papers and policy statements on issues of home and community care and their implications for family carers (e.g., Canadian Home Care Association, 2008; Canadian Institute for Health Information, 2010; Chappell, 2011; Lazar, 2011; Keefe, 2011; Health Council of Canada, 2012).

[4] Home Care may also include self-managed care, where health authorities provide funding to eligible clients to hire their own employees or care providers. In British Columbia the program is "Choice in Supports for Independent Living" (CSIL): http://www.health.gov.bc.ca/hcc/csil.html.

National dialogues on home care have been sponsored by the Canadian Federation of Nurses Unions (2012) and Queen's University's School of Policy Studies (2011). The British Columbia Ombudsperson's report (2012) targeted home care as a crucial element in providing older people "the best of care." The Report of the Special Senate Committee on Aging (Carstairs & Keon, 2009), the Premier's Council on Aging and Seniors' Issues in BC (2006), and national media (e.g. CBC Cross Country Check-up, 2012; Howlett, 2011) have all sought to raise awareness of the policy relevance of home and community care for Canada's aging population.

In sum, there is a substantial body of research evidence and policy analysis regarding the complexities, diversity, contradictions, and challenges that characterize home care in all its manifestations across Canada. This paper builds on that knowledge to present a micro level approach to policy and practice. Its purpose is not to reiterate or refute the policy analyses of others; indeed, no one manuscript of journal length could pretend to capture the depth and complexity of issues relevant to home care policies across Canada. Rather, our purpose is to examine the perspectives of those at the receiving end of these policies and practices – the workers, elderly clients, family members, and managers engaged in the provision and receipt of home support services.

In this study, we asked representatives from these groups about their daily experiences of home care and how it affects their personal and work lives. Their answers clearly reflected what they saw as problematic in the system. In turn we used these experiences to identify key areas of concern and to illustrate broader policy issues. We identified three key policy domains at the heart of the home care experience for older people. Because of the diversity of experience of home care across Canada, we analyze data from the Lower Mainland of British Columbia based on interviews with workers and clients affiliated with one regional health authority. Our study represents the experiences of all four "players" in the dynamic of home care, and thus adds another dimension to a multi-faceted, complex, and indeed, fraught, policy context.

Methods

Stakeholder Perspectives: Clients, Carers, Workers and Managers

Over the past seven years we have conducted a large, mixed-methods study (i.e. Martin-Matthews & Sims-Gould, 2008; Martin-Matthews, 2010; Sims-Gould, Byrne, Craven, Martin-Matthews & Keefe, 2010; Sims-Gould & Martin-Matthews, 2010a, 2010b; Byrne, Frazee, Sims-Gould & Martin-Matthews, 2012; Craven, Byrne, Sims-Gould, & Martin-Matthews, 2012; Sims-Gould, Byrne, Beck & Martin-Matthews, 2013) broadly focused on the ways in which experiences of home care intersect in the public and private spheres, professional and non-professional domains, and in the paid and unpaid labour of care. We have examined key issues in the delivery and receipt of home support services from the perspectives of unregulated home support/personal care workers, elderly clients of home care services, family members, and home care managers. In our program of research, there were four phases of data collection.

Table 1. Phases of Data Collection

Phase #	Participant Group	N	Location of Interviews	Timeframe
I	**Pilot Interviews:** Managers HSWs Clients Family Members	 11 32 14 23	British Columbia (Lower Mainland)	2005-2006
II	HSWs Clients Family Members	118 68 32	British Columbia (Throughout Province)	2006-2008
III	HSWs	68	Nova Scotia & Ontario	2007-2008
IV	Home Care Managers	7	British Columbia (One Health Authority)	2011

We have analyzed selected findings from our Phase II and IV data to identify issues relevant to home care policy. This manuscript is a synthesis of our findings and the narratives presented are taken from our Phases II and IV results. More information on the methodology of the Phase II data collection, including the procedures for recruitment and characteristics for each participant group, is available on our website (http://nexushomecare.arts.ubc.ca) or through other publications of our research findings (Byrne et al., 2012; Sims-Gould et al., 2010; Sims-Gould & Martin-Matthews, 2010a, 2010b).

We have thus far reported our findings in eight summary reports, ten peer-reviewed journal articles, one book chapter, and numerous academic and community presentations, each outlining the policy implications of our data. To determine which issues predominated in the accounts of workers, clients, caregivers, and agency managers, a directed content analysis (Hsieh & Shannon, 2005) was used, guided by existing theory and empirical research on this topic. The goal of a directed approach is to build on, validate, or extend existing research. Following this qualitative content analysis (Elo & Kyngäs, 2008; Hsieh & Shannon, 2005), three main issues of policy relevance were identified. Having been focused on the topic of home care and engaged with our data for seven years, we conducted the content analysis with knowledge of what other researchers have found to be "key issues" for workers, clients, caregivers, and agency managers. As such, references to this existing body of research are incorporated throughout this manuscript, in the presentation of our findings, and in the subsequent discussion of the broader policy context.

Each of these four groups of participants brings a unique perspective on home care. Managers oversee the implementation of policy and practice in the provision of services. Among the group of experienced managers whom we interviewed, several have worked long enough in the sector to have directly experienced the per annum doubling of home care costs in Canada between 1993 and 2003/4, from $1.6 billion to $3.4 billion

(CIHI, 2007*)*. This represents an average annual growth rate of 9.2% over a decade. Despite increased expenditures, policy changes in BC have led to a 24% drop in the number of individuals receiving home support between 2000-01 and 2004-05 and a 12% drop in hours (Cohen et al., 2006). Per capita public spending for home and community care grew an average of six percent per year between 1994-95 and 2003-04 (Sharman, 2010), while the number of government-subsidized home and community care users (26.1 per 1,000 population) increased by only one percent (CIHI, 2007).

In BC, as in many other provinces, there is increasing acuity among elderly clients of home care services. Individual users consume more resources, and service delivery is becoming more intense and specialized (i.e. a smaller number of clients are receiving more hours of care, but more nursing care, and less help with housework). Managers we interviewed were keenly aware of the increasing number of older people in BC reporting unmet needs for home health services (McGrail et al., 2008).

Direct care workers in home care have been described as "the eyes and the ears" of the health care system (e.g., Stone & Dawson, 2008), as they work in the private sphere of a client's home, working (typically) one-on-one with their clients. Home care includes both professional services (nursing, social work, physiotherapy, and occupational therapy), and non-professional or home support/personal care services. Our interviews were conducted with individuals identified as "unregulated" or "nonprofessional" workers who provide personal assistance with daily living activities and light household tasks. Across Canada, job titles include home support workers, personal support workers, community health workers, community health care aides, home helpers, and homemakers (Martin-Matthews, 2007). In our analyses, we use the term Home Support Workers (HSWs).

For clients of home care, 70-80% of the services provided to them are classified as home "support," giving them both personal care (bathing, toileting, grooming) and work related to instrumental needs, including food preparation, cleaning, and laundry (Havens, 2003). Typically, distinctions are made between long-term care support (which is not time limited and, in some jurisdictions, a fee applies) and short-term care support (time limited, but no fee applies). Short-term care includes acute care, convalescent care, and end of life care**.** Clients often have strong feelings about the care and the services they are (or are not) receiving. This is especially true of those who have experienced policy changes in the home care sector, affecting both service eligibility and scope of services, as did some clients we interviewed.

Family members play a vital role at the nexus of formal (paid) and informal (unpaid/family) systems of care. With reduced home care services for older persons with chronic care needs, informal (family and friend) caregivers increasingly provide essential care. Ninety-eight percent of a national sample of 131,000 older adult home care clients received some assistance from an informal caregiver (CIHI, 2010). Most caregivers are spouses and children, although friends, neighbours, and other relatives also provide support (CIHI, 2010). Informal caregivers working in concert with non-professional HSWs provide the bulk of care for older adult home care clients.

Findings

Our research identifies three broad areas of policy relevance in the verbatim accounts of those providing and receiving home care and home support services: scope of services, scheduling of services, and the presumption of availability of family and friend carers. As each issue is considered, we provide examples of policies that influence the everyday experiences of mangers, workers, and clients and their family members. We then examine the broader policy context and key challenges to change.

Scope of Services

> I can't remember just when they stopped it…you don't get any housework or anything done anymore. What bothers me is that unless you have a bath, they don't clean your toilet or anything, you know. And, to me, that's unsanitary,… I think that you should be able to have somebody. I don't have much strength because of my back, for me [to do it]. (Jana, aged 87 years, receiving home support for 10+ years)

The scope of home care services was a dominant theme in our interviews, especially among those workers, clients, and family carers who had experienced the shift in policies in BC, away from the preventive and maintenance functions of home support service provision, to policies focused more on specific health services deemed medically necessary. Clients lamented the loss of services that they had considered vital, such as housekeeping and companionship, describing them as essential for both well-being and physical health. This retrenchment of services was the result of key policy changes within the province in 1994-95: Clients with the lowest levels of care provision were no longer eligible to receive "housekeeping only" services (Hollander & Tessaro, 2001).

At the heart of the interaction between workers, clients, and families is the Care Plan (the organizational or agency tool that prescribes what services to provide). Workers in particular are challenged by the need to spend time defending the scope of services as defined in this Plan. Because the Care Plan does not necessarily reflect the actual service needs of an elderly client at a given time, workers often undertake additional or different work in order to meet client need. Managers similarly noted that Care Plans do not get updated as often as they should, due to limited resources.

Issues of unmet client needs arose repeatedly in our interviews with workers who acknowledged increasing pressures on the family members of their clients. Workers, family members themselves, and managers all stressed the role of families in "filling in the gaps" of limited scope of services. The complex needs of elderly clients with dementia and those requiring palliative care emerged as particular challenges to scope of services.

Finally, workers especially (but also managers, clients, and family members) identified limitations in the training they receive, access to necessary information when entering an unfamiliar situation, and their scope of practice, in terms of what they are and are not "allowed" to do for their elderly clients. Managers recognized the need "in the system" for policy reform in scope of services. While these managers did not work in positions to influence regional or provincial policies on scope of services, they

acknowledged the practice of "turning a blind eye" in many cases where workers strived to address unmet client needs. They recognized, however, the inherent problem of one worker providing service beyond the Care Plan, while another does not. This was echoed at a recent Vancouver conference on home care policy, where service providers called for a provincially-led and facilitated forum for "honest discussions" with the public regarding what home support is, and what it is not, and what home support can and cannot provide as a publicly-funded service (Mackenzie, 2012).

Managers also recognized that HSWs are regularly required to perform tasks beyond their level of training, thus requiring specialized additional skill development. With more complex care needs being identified among elderly clients, there is an increased need to elevate the competency levels of workers. Managers discussed a marked increase in the numbers of situations where HSWs are required to assume additional duties. Within BC, conferences and provincial think tanks have provided venues for discussion of these complex issues; pilot projects throughout the province have tested a variety of service models, including non-medical home support services. Standardized training for HSWs with core competency elements is also being pushed on several fronts.

For the four groups of participants in our study, the identification of "scope of services" as a key policy issue in home care was very much framed by two primary observations: first, many people had direct experience of cuts to service and changes to eligibility in British Columbia. Second, the Care Plan did not sufficiently address the increasingly complex care situations or training needs of workers. This occurred despite a shifting focus in home care to assist people assessed as having higher care needs. The nature of home support work and characteristics of the workforce in home support arise again in the next section and will be explored later in this paper in the broad policy context of integrated service delivery.

Scheduling of Services

> Running the bath, let's say, that's not a long time, an hour… You turn around, they have to say good-bye because someone else is waiting…so, so it's never a complete hour. That's not their fault. That's the way it's managed. (Jennifer, aged 78 years, receiving home support for three years)

Scheduling of services was identified as important in several ways. For workers, clients and family carers, reduction of service time and time compression were key issues. For workers and managers, labour force casualization and scheduler training were prime concerns. All noted the implications of each of these factors for the rotation of workers, the "revolving door" of home care.

Changes in and cutbacks to hours of service contribute to a perception of lack of time to provide adequate care, of a "tyranny of time" driving the provision of service (Martin-Matthews, 2010). Workers, clients, and carers also spoke of the compression of units of service time (the "50 minute hour") that leaves no room for an unexpected event in the client's home, or for addressing all but the most basic of needs. For workers, strict limitations on time with clients and transition time between clients lead to safety concerns and reduced job satisfaction when they must hasten their clients through each of their services.

Scheduling of service and casualization of the labour of home care are highly interconnected: in many agencies and health authorities, a majority of HSWs are employed as casual workers, "on call" and working irregular and split shifts at short notice. Issues of scheduling take on another meaning for workers who are granted hours with little advance notice, and who live with the uncertainty of how many hours of employment they will be assigned on a given day or in a given week.

Managers were keenly aware of the need for reform of scheduling processes and priorities. In areas where workers are not on salary or working in a regular rotation in cluster sites,[5] they are scheduled according to seniority for several hours, an hour or a portion of an hour, according to the needs of the client and the terms of labour agreements. While typically the hour is 50 minutes in length to allow for travel time between clients, recent urban initiatives such as cluster and neighbourhood care increase the likelihood of clients being "co-located," thereby reducing the stress of additional travel time for workers. This also increases the opportunity to schedule shorter but more frequent visit to clients throughout the day or week.

The traditional method of scheduling can result in many different workers being assigned to any one client. There are provisions in many agencies for the assignment of specially trained workers to clients whose health needs require a specific competency, consistent care, preferred gender, or particular language. But in reality, these assignments do not regularly occur. Managers described the scheduling of services as the "backbone of home support," while acknowledging that the training for staff who do the scheduling is limited and not standardized. For elderly clients, the compression of time and the lack of continuity of worker assignments (both problems associated with current scheduling practices) contribute to their perceptions of being devalued, and of being, in their own words, " reduced to a series of 'tasks' to be completed," and a "case to be managed".

In BC, a policy and practice review of select aspects of scheduling of services is currently underway. The Report of the BC Ombudsperson (2012) specifically questioned why time allocations for identical services vary from one region of the province to another. Standardization, as called for in the Report, may reduce inconsistencies within and across provincial jurisdictions, but does not address cuts and compression – issues important for clients, family carers, and workers.

Lack of continuity in the HSWs providing service was also identified in the Ombudsperson's Report as a key concern of elderly clients. While the Report recommended the adoption of the principle of continuity in home support by all health authorities in policies, service agreements, and performance measures, the health authority through which we conducted our research is identified as already having such a "principle of continuity" in place. In actual fact, the statement of this principle in health authority policy did not diminish client and worker concerns about the revolving door of service providers. This suggests that a policy statement without the resources (in this case, appropriately trained staff and allocable hours of service) to support it and without alignment with collective agreements for unionized workers, is without effect.

[5] Cluster sites have workers and clients grouped by geographic proximity, with the same group of workers serving a number of clients who live close to one another (for example, in a seniors' housing complex or in an apartment building).

Presumption of Availability of Family and Friend Carers

> …there should always be two people to push him and I'm always there, you know. I stay behind and the helper stays in front. And that's how we take him into the toilet. (Addison, aged 76 years, whose husband has been receiving home support for two years)

British Columbia, as other jurisdictions in Canada, makes fundamental presumptions about the availability of family and friend care. "Home support services are meant to supplement the care that families and others provide"(BC Ombudsperson, 2012, p. 32). The ideology and values inherent in this assumption merit debate, but there is in fact substantial evidence that families overall are active supporters of their older kin, providing an estimated 75-80% of the care that older persons receive at home (Chappell, 2012). In addition to the care they provide outside the context of home support (i.e., the other 23 hours of the day), family members also work collaboratively ("share the care") with HSWs. For example they prepare ready-to-heat meals for the client in advance of the worker's arrival, run a bath while the worker prepares the client for bathing, and perform lifts and transfers together (Sims-Gould & Martin-Matthews, 2010b). Family members also serve as care managers (Rosenthal, Martin-Matthews & Keefe, 2007), often by teaching and supervising the HSWs to ensure that care is provided in a consistent, high-quality manner. With a constant rotation of workers, family members must regularly (re)train workers on usage of mechanical lifts and commodes, the preparation of food, and how to best transfer the elderly client with mobility impairment. They are also repeatedly required to familiarize HSWs with the home and to provide relevant information regarding their older relative's needs and preferences, and any changes to their health, diet or sleeping patterns. When we asked HSWs how family members help them do their job, they acknowledged the important role that families play as care managers, especially in information sharing. Our research highlights the bi-directionality of assistance between unpaid (family) and paid (HSWs) carers in the context of home care (Sims-Gould & Martin-Matthews, 2010b), with the common goal of providing care to the older person.

However, there is limited recognition of the role of family carers, and virtually no support for their vital function in the continuum of care. As an illustration, the BC health authority that collaborated in our study does not have a formal or standardized approach to supporting the caregivers of home care clients. A handbook on its website provides a guide to family/unpaid caregivers, but the guide's utility and effectiveness are unknown. Managers acknowledge the need for much more robust caregiver support services, through policy changes and initiatives such as increasing the hours of day respite (see also Lilly, Robinson, Holtzman & Bottorff, 2012); improving the capacity, standardization, and staffing of adult day care programs; and the provision of increased overnight care services, as needed.

Thus, while home care policies presume the availability of informal caregivers but largely ignore them in policy, family carers are expected to provide essential care. Many family caregivers provide excellent care and gain personal satisfaction in doing so (Chappell, 2012; Cohen, Colantonio & Vernich, 2002). However, some family caregivers experience depression and distress (CIHI, 2010). Spouses caring for home support clients are usually older and often also frail. Family caregivers also function

largely in a system that responds to their need only when they have reached a breaking point, threatened with becoming patients themselves (Lilly et al., 2012). While the care that families provide has long been considered a private responsibility in Canada, its place as the lynchpin of home care experiences for many older people – bridging the worlds of paid and unpaid care, filling the gaps in that care, advocating for their elderly kin when that is required – underscores its public policy relevance.

These three issues – scope of services, scheduling of services, and presumption of family availability – are by no means the only policy issues confronting the home care sector in Canada. Recruitment and retention of workers, standardization of services, and the increasingly crucial relationship between health authorities and the providers of services they contract out, are highly relevant but beyond the scope of our focus here. Our purpose has instead been to highlight a selection of policy-relevant issues particularly salient in the experiences of managers, workers, clients, and carers engaged in the daily realities of home care in a regional health authority within one provincial jurisdiction.

Future Challenges and Opportunities for Home Care Policy Initiatives and Reform

Three guiding principles for home health services have been identified by the Canadian Home Care Association (CHCA, 2005). The first includes a national framework for home health services supportive of accessible and quality, publicly administered services responsive to social needs. The second characterizes home health services as a critical component of an integrated system of health services. The third principle recognizes informal caregivers and volunteers as vital and respected members of the home health services team, deserving of support. The key policy issues identified by our study participants reflect, to varying degrees, each of these core principles, and are considered here in that context.

A National Approach

In the 2002 report of the Romanow commission on the future of health care in Canada, the role of home care as a short-term post-acute service was emphasized:

> While it is not possible to include all home care services under the Canada Health Act, immediate steps should be taken to bring services in three priority areas under the umbrella of the Canada Health Act – home mental health case management and intervention services, post-acute home care, and palliative home care. (2002, p.32)

Romanow's casting of home care within such a narrow frame has been contentious over the past decade, and its implications have been wide-ranging. Certainly, many of the scope of services issues identified in our study reflect this shift of resources away from those with chronic needs (Health Council of Canada, 2012). Despite Romanow's contention that "it is not possible," many commentators call for national standards and more ready access to the full spectrum of home care services, not limited to those identified by Romanow (Carstairs & Keon, 2009).

To this end, in a related strategic effort to reduce confusion and disparities in the planning of home care policies across the country, the Canadian Home Care Association is drafting a national framework to outline the role of home care within the health care

system. The tool, the "Home Care Policy Lens", is intended to assist health authorities to "develop and evaluate integrated care policies and identify issues that impact performance and responsiveness of the home and continuing care sector" (Health Canada, 2012, para.5).

Integration of Services

We began this paper with a reference to the Special Senate Committee on Aging's statement on home care as an essential element of "integrated care." But, as it stands, home care embedded within an integrated health care system remains an aspiration, not a reality for most Canadians.

The report of the Health Council of Canada highlights some practices and programs that "are successfully integrating home care with other parts of the health care system" (2012, p.39). There are numerous pilot projects and apparent success stories across the country, although many are untested in terms of their sustainability and their capacity for "ramping up". Others are challenged by fundamental elements of their design, such as reliance on physician leadership and management, or failure to include the unregulated care providers so vital to the delivery of home care (Macleod, 2012). Ideally, demonstration and pilot projects on integrated health networks that include case-managed approaches to care and service integration system-wide, presage more coherence and integration of home care across the continuum of care. But, as Bégin, Eggertson, and Macdonald have noted, in a land "of perpetual pilot projects, [w]e seldom move proven projects into stable, funded programs, and we rarely transfer the outcomes of pilot projects across jurisdictions" (2009, p.1185).

For home care, the challenges to system integration are particularly substantial. As Vogel (2012, p.110) has stated, **"**Becoming an integrated system of managing clientele and services requires a change in the processes, as well as a new way of thinking, collaborating, and providing service." This is particularly true in a system where acute care services dominate health care discourse (Armstrong & Armstrong, 1996; Walker, 2011).

Conditions of Home Support Work as Obstacles to Integration

Our findings suggest that until home support work is better resourced and structured, it will be an unequal partner in integrated care programs (MacLeod, 2012). Issues identified in our data such as scope of services and scheduling of services underscore this point. Addressing scope of practice issues between health care professions in Canada is a priority in some areas (e.g., Council of the Federation, 2012). The discussions around these issues will likely be challenging and protracted, but there is potential for increased recognition of the role of unregulated workers in the mix of essential care services in the home care sector. There is considerable evidence of home support workers' desires for more respect and recognition from other health care professionals, clients, and society at large. Such sentiments were echoed by the workers in our study. Workers have also called for a greater role in care planning for their clients (Nugent, 2007 and Stacey, 2005, as cited in Keefe, Martin-Matthews & Légaré, 2011).

Wage equity with workers providing similar levels of care in other sectors (hospitals and long term care facilities) is also critical for ensuring higher levels of retention in this sector (and recognition of HSWs' place on care teams in integrated care).

Wage discrepancies between the home support sector and long term care and hospital care are significant. In Ontario there is a $4.55 per hour wage difference between home care and hospital settings; the wage difference between home care and long term care is $3.67 per hour (Health Council of Canada, 2012).

The home support sector is also currently challenged by a lack of knowledge of their workforce, including information about the kinds of people recruited into the sector, and how to respond to their needs and concerns. The creation of registries of workers – already underway in several jurisdictions – may enable agencies, health authorities, and provinces to use this information to develop better recruitment and retention policies. However, the creation of these registries is a recent initiative, with the potential benefits and limitations presently unknown. The value of these initiatives will largely depend on the quality of the data collected and their subsequent use.

Similarly, the standardization of education and training of home support workers has already begun in many areas of the country. The need for this form of education is not particular to Canada: In a study of 600 direct care workers in the United States, 40-50% of workers (in various settings) reported the need for further training and education, in such areas as time management, teamwork, conflict management, and assisting clients with mental illness and dementia (Menne, Ejaz, Noelker & Jones, 2007). Research with Canadian HSWs has also found inconsistent or limited worker training in various areas, including ventilator use (Brooks, Gibson & DeMatteo, 2008) and caring for clients with dementia (Craven et al., 2012). Standardized training has the potential to benefit both the clients receiving care and the workers providing that care (Bawtinheimer, 2012).

The Role of Family Carers in Home Care

CHCA's third principle recognizes informal caregivers and volunteers as vital and respected members of the home health services team, deserving of support in their roles. Our findings, like those of others, have emphasized the role of family caregivers as frequently unacknowledged but essential participants in the delivery of home care services. Projections to 2030 and beyond suggest a decline in the number of Canadians aged 75 and over with a surviving child (Gaymu, Busque, Légaré, Décarie, Vézina & Keefe, 2010). A home care system unable to rely on the availability of family members to "share the care" will need to be a very different kind of system indeed.

Other factors also impact the role of family carers in home care. The greater acuity of clients is expected to increase even further with the advancing longevity of the population. The anticipated rise in the number of people living with, and living longer with, dementia will provide particular challenges (Alzheimer Society of Canada, 2011) to capacities of family carers (Lilly et al., 2012). Issues of end of life care will become more prominent when the number of deaths outstrips the number of births, as is already the case in some Canadian provinces. Families also vary in their economic circumstances. Socio-economic variability in the population, its range of preferences, and abilities to pay for services are all highly relevant to the delivery of services in this sector. Home care is already a two-tiered service in Canada, with more financially able individuals (and their families) paying for "top-up" home support services privately.

In their analysis of international literature on aging-at-home strategies, Williams and colleagues (2009, p.16) made several recommendations for successful community-based care programs for older adults, concluding, "an evaluation of aging-at-home

initiatives should… consider both the costs of supporting informal caregivers and the consequences of failing to do so." There has been overall failure to follow this recommendation in assessments of the quality of service and evaluations of success in many such initiatives across Canada (see, for example, Starr-Hemburrow, Parkes & Bisaillon, 2011).

Conclusion

In accounts of their experiences of home care in their work and personal lives, home support workers, elderly home care clients, family carers, and public sector managers in British Columbia identified key policy-relevant issues of scope of services, scheduling of services, and the presumed availability of family carers as challenges to the delivery and receipt of home care services. Our findings align substantially with the Canadian Home Care Association's guiding principles of a national framework for home care, its place in integrated care systems, and recognition of family carers as vital players in home care.

Our findings underscore the need for home care policy in Canada to move away from a "quick fix" approach and, despite political agendas and realities, to develop longer-term planning windows (Foot, 2011). The consequences of short-term planning and short-sighted strategies are evident. As home support has shifted from a preventative and maintenance model to one focused more on short-term post-acute care, chronic care clients increasingly face unmet needs. At the same time the home support labour force frequently lacks the skills and flexibility to adapt approaches to meet both post-acute and chronic care needs. While both service users and providers present a rationale for improved service models, there is also an economic rationale. Studies in Canada (Hollander & Tessaro, 2001) and the United States (Howes, 2010; Shapiro, Loh & Mitchell, 2011) have demonstrated that stronger investments in home and community-based services result in savings to other segments of the health care system, including acute and long-term care.

There is compelling evidence, ranging from individual client, family, management and worker testimonials, to sound economic decision making, that highlights the importance of a strong home care policy agenda. In the absence of inclusion in the Canada Health Act, home care policy that addresses the complex, variable, and evolving nature of work and care is required to meet the growing needs of an aging population. Whether or not home care policy in Canada is consolidated in a national framework (CHCA's first guiding principle), the second and third principles of home care within integrated care and recognition of family carers are essential (and cannot wait for enactment of the first). Home care policy must be both responsive to growing population demands and proactive to address current and emerging health human resource issues.

There is considerable evidence that the way to achieve these goals is through system integration, but the challenges to an appropriate role for home care are many, especially in a health care system so focused on acute and episodic care, and short-term interventions by physicians and in hospitals (MacLeod, 2012). As we have noted, so many of the current conditions of the labour of home support (the unregulated and non-professional work essential to home care provision) are inconsistent with their fully equitable partnering on integrated health care teams. And yet, as Armstrong and

Armstrong (2002) have noted, the conditions of work are the conditions of care. Home "care" can only benefit when the nature and characteristics of home care "work" (scopes of practice, training, wage equity) are given the priority they require, both in policy and in practice.

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