

Position Statement on Access to Home Care

Approved by the HCCC Steering Committee

July 23, 2007

Canada's health charities are part of the vast network of services that care for people before they go to the hospital, and after they leave. Through these charities, hundreds of staff and millions of volunteers serve Canadians in their communities year-round. Because so many of the people they serve rely on or could benefit from home care, the Health Charities Coalition of Canada (HCCC) is very concerned about the future of home and community care in this country, even more so as the aging population implies a greater burden on the health care system.

The voluntary health sector, with its wealth of knowledge, expertise, experience and resources, plays a key role in supporting patients, strengthening communities, and advocating for the services they need. To contribute in a tangible way to the strategic planning and redesign of health care delivery, the HCCC offers the following position statement on access to home care. This statement is based on the day-to-day experience of adults and children living with illnesses and the organizations that serve them.

All Canadians should have equitable access to quality home care services to help meet their primary, acute, mental health, chronic and palliative care needs, and to improve their quality of life.

Recommendations

To ensure that “all Canadians have equitable access to quality home care services to help meet their primary, acute, mental health, chronic and palliative care needs, and to improve their quality of life”, the Health Charities Coalition of Canada recommends that:

- 1. Governments take responsibility for providing the resources that home care programs need to meet the diverse and growing needs of Canadians, including:**
 - an adequate number and mix of home care providers with appropriate training, knowledge and skills in primary care, acute care, mental health, chronic care and palliative care to meet the specific needs of the populations they serve (i.e. infants, children, youth, adults, seniors);
 - ongoing education for home care providers so they can continue to meet clients’ changing needs;
 - competitive salaries and benefits, and safe working conditions;
 - appropriate equipment to deliver more complex high-tech care in the community;
 - adequate funding to provide a comprehensive, accessible services for all home care clients within their jurisdictions;
 - expand the role of home care in chronic disease management to serve a broader scope of clients who would benefit from earlier interventions; and
 - the creation of a reciprocal billing agreement on home care services, which would allow out-of-province patients to access home care services when undergoing treatment in provinces and territories other than their own.

- 2. Governments work with the organizations that speak for consumers and home care providers to develop comprehensive strategies and supporting policies to support the future demands on this growing health care sector:**
 - develop flexible, innovative and/or population-specific programs designed to fill gaps and meet the needs of diverse groups including children, adolescents, and adults with a range of acute, chronic and mental health needs, people at end of life, people living in rural and remote areas, people with disabilities, and ethnocultural groups;
 - ensure all Canadians have equitable access to home and community services – including homemaking services -- to meet their needs and improve quality of life;
 - support linkages and partnerships with other services in the community, such as the mental health sector, education sector, and primary care;
 - identify and test new team-based models for delivering home care services that make the best use of providers’ skills and time (e.g., group education and prevention programs, transporting clients to a central site in the community for care, Telehomecare);
 - identify strategies to ensure an adequate supply of health care providers to meet home care needs now and in the future, including recruiting, assessing, upgrading (if required) and licensing internationally trained providers; and
 - determine effective ways to involve consumers/volunteers in partnerships with professionals to support adults, children and youth in their homes and at the end of life; and

- support the application and uptake of information and communication technologies in the home and community care sector.
- 3. Governments support the implementation of case management¹ as a strategy for systems integration to improve the effectiveness and efficiency of health care delivery and support the ability of the client/caregiver to make progress toward their goal by providing individuals with seamless one-stop access to:**
 - information about and coordination of services available in the community;
 - culturally sensitive services;
 - timely referrals to health, education, and social services;
 - a range of flexible services to meet the current and future needs of the client / family caregiver, including support for instrumental activities of daily living (housekeeping or homemaking services); and
 - professionals who will advocate on clients' behalf for services.
 - 4. Governments recognize the critical role that family caregivers², including dependent children and youth play, and work with the health charities/consumer groups and home care programs to provide appropriate support, education and respite programs.**
 - 5. Governments require all home care programs they fund to establish benchmarks and indicators for assessing the impact of home care services on client health outcomes, and establish norms, standards and evidence formed practices.**
 - 6. Governments ensure home care programs and providers are involved in primary health care models and leverage their expertise to provide more comprehensive, coordinated and better integrated services.**
 - 7. Governments monitor and evaluate the home care initiatives to be implemented by 2006 to ensure that they are effective and reflect the needs of Canadians.³**

¹ “Case Management is a collaborative client-driven strategy for the provision of quality health and support service through the effective and efficient use of resources in order to support the client’s achievement of goals”, Canadian Home Care Association definitions, October 2005.

² “The term family in “Family Caregiver” denotes both a biological family and/or a family of choice; the caregiver, whether legally related or not, is considered to be part of the family” Canadian Caregiver Coalition definition, 2005.

³ First Minister’s Meeting on the Future of Health Care 2004: A 10-yea plan to strengthen health care. September 16, 2004.

Background

What is home care?

“Home care” refers to an array of services provided in the home and community setting, including:

- health promotion and teaching;
- curative intervention;
- end-of-life care;
- rehabilitation, support and maintenance;
- social adaptation and integration; and
- support for the informal (family) caregiver.

The goals of home care are to:

- help people maintain or regain their health and independence while remaining in their home or community;
- enhance quality of life; and
- prevent, reduce or delay the need for admission to a hospital or long-term care facility.

To achieve these goals, home care programs combine the delivery of health services such as nursing, rehabilitation, social work, and dietetic counseling with community services, such as meals on wheels, day programs, respite care, volunteer services, school programs, transportation services, community health centres, and community mental health programs.

The Case for Effective Accessible Home Care Services

Canadians want care in their homes and communities

Canadians have made their voices heard. Consultations and surveys reveal that Canadians value their independence and quality of life, and that home is their health care setting of choice.⁴ Many believe that the provincial/territorial health systems already have consistent and comprehensive home care services in place.⁵ This is not the case. Only 35% of people who are dying in Canada receive palliative care services in their home.⁶ And even though more than 60% of Canadians would prefer to die at home, 75% of deaths still occur in hospitals and long-term care facilities.

⁴ Health Care in Canada Survey. 2000.

⁵ Angus Reid poll. 1997

⁶ Healthcare Quarterly, Vol 7 No2. 2004.

Canadians' need for home care is increasing

Between 1995 and 2002, the number of Canadians who received home care services each year increased by 60% to 850,000. With Canada's aging population, this trend will continue, making home care a "need" as well as a preference. Over the next 15 years, all health care systems across Canada expect to see a dramatic increase in chronic illnesses, such as cancer, heart disease, diabetes, and arthritis. Improved treatments may prolong the lives of those living with chronic disease, in turn growing the need for home care and community support during periods of recurrent illness. To improve their health and quality of life, people with chronic illnesses need access to care in their homes and communities. Furthermore, home care is no longer the preserve of the elderly as due to medical and technological advances the number of children requiring post-acute and long-term home care is steadily increasing. This trend was noted in the Kirby report⁷ (2002) where it was reported that in some jurisdictions across Canada up to 15 percent of home care recipients were children (p. 147).

Despite the clear preference and need for home care, many people fear the services are vulnerable. In 2001, eight out of ten Ontarians (81%) expressed concern that they won't have access to home care support as they age.⁸ In 2003, 35% of Canadians reported that they were dissatisfied with their access to home and community care.⁹

Canadian governments have made home care a priority

The Commission on the Future of Health Care in Canada described home care as the "next essential service", and noted that "home care can save money while improving care and the quality of life for people who would otherwise be hospitalized or institutionalized in long-term care facilities."¹⁰

All provinces and territories have made a commitment to promote and provide home and community care.¹¹

In the 2003 First Ministers' Accord on Health Care Renewal, all governments agreed to improve "access to a basket of services in the home and community [that] will improve the quality of life of many Canadians by allowing them to stay in their home or recover at home."

Under the terms of the 2003 Accord, by 2006, all provinces and territories will make available certain home care services, which "could include":

- nursing/professional services;
- pharmaceuticals and medical equipment/supplies;
- support for essential personal care needs; and
- assessment of client needs and case management."

A year later, the 2004 First Ministers' Accord on Health Care Renewal, noted that "access to timely care across Canada is our biggest concern and a national priority." The First Ministers agreed, to provide by 2006, first dollar coverage for:

⁷ The Health of Canadians – The Federal Role. October 2002

⁸ Ipsos Reid poll. April 11, 2001.

⁹ Health Care in Canada Survey. 2003.

¹⁰ Commission on the Future of Health Care in Canada. Building on Values. November 2002.

¹¹ Canadian Home Care Association. Realizing the Potential of Home Care. A Movement from Statements to Action. July 2004.

- short-term acute home care services (i.e., case management, medications related to the acute diagnosis, nursing and personal care);
- short-term acute community mental health home care (i.e., case management, crisis response services); and
- end-of-life care in the home (i.e., case management, nursing, pharmaceuticals required for palliation, personal care).

Home care services can help governments renew primary care and provide integrated seamless care

Home care services have extensive experience providing integrated care. They are ideally positioned to work closely with both acute care and community services to ensure clients receive all of services they need to maintain their quality of life and independence. In an era of scarce resources and growing demand for health services, home care has the potential to help governments manage the system and achieve their goals. Because home care can provide many components of primary care, - outreach services, immunization programs, medication management, palliative care services, chronic disease management and health teaching - it has the potential to play a critical role in primary care renewal.

Home care can also be a bridge to community services that can have an impact on health, well-being and independence and to other health settings, including the physician's office, the acute care hospital, respite care, rehabilitation centres, long-term care facilities, schools, chronic disease management programs, recreation programs, community mental health programs, and addiction services. By increasing access to home care services, governments can move closer to achieving the integrated, seamless, effective health system that Canadians want.

Challenges

The Health Charities Coalition of Canada supports government efforts to increase access to home care services. It is important to recognize, however, that there are several challenges that threaten equitable access to home care.

Increasing demands

The demand for home care continues to grow, fueled by consumer expectations, efforts to manage hospital costs, and medical advances that make it possible to care for people with highly complex needs at home. Since 1981, there has been a steady decrease in the number of Canadians age 65 and over who are in health care institutions, and a corresponding increase in the number who are receiving care in the community.¹² Between 1996 and 2046, the number of people needing home care is expected to double.¹³ Even with recent increases in funding, home care services do not have the capacity to respond to these needs. The demand for home care for elders, non-elders and people who are in need of palliative care is three times the current level of service

¹² Statistics Canada, Caring for an Aging Society. Catalogue no. 89-582.

¹³ Canadian Home Care Human Resources Study. December 4, 2001.

provided.¹⁴ The majority of people who need care in the home because of aging, chronic illness or disability receive no formal publicly funded services.¹⁵

More diverse needs

Home care programs were originally established to provide care for people with long-term chronic illnesses, and most clients were over age 65. That is changing. Home care programs now provide services for people in all age groups with a much wider range of needs. But home care programs that were designed for the elderly may not be flexible enough to meet the acute or chronic needs of infants, children and adolescents, or of disabled or ill parents who still have dependent children at home, or the needs of people with mental illness or with a physical illness and a secondary mental health problem, such as depression. For example, unlike seniors who use home and community care to maintain their independence, people with disabilities need services that help them participate in the workplace and they want more control over their services (i.e., self-managed care). The type of short-term home care that is appropriate for people recovering from surgery is inadequate for and may even be harmful for people with mental illness, who need consistent support over a longer period of time as well as help connecting with other mental health services in the community.

Even with the proposed expansion, home care programs will not have the capacity to address the needs of underserved groups, including people living in rural and remote areas, and the growing number of Canadians who are members of diverse ethnocultural groups. Governments, providers and consumer groups must assess new models for delivering home care services.

Rationing of services to respond to diverse and growing needs

In an effort to manage the growing demand for home care services within limited resources, more jurisdictions are rationing services (e.g., reducing the number of funded visits, cutting funding for home support services or changing eligibility criteria). Many do not provide or cover housekeeping or homemaking services, which have been identified as key supports for older people trying to maintain their independence and an effective way to reduce falls and hospitalizations associated with housekeeping mishaps.

New home care programs, such as short-term acute care, short-term mental health and palliative care home care, are being implemented at the expense of established programs, such as chronic care services. As a result, people are increasingly confused about which services are available to them, and families are now either paying privately for services that used to be funded or providing more care themselves. While home care services should expand to meet a wider range of needs, they must continue to provide adequate ongoing care for people with chronic illnesses.

Regional variations in funded services

Despite the commitment to develop a common basket of services, funding for and access to home care services continues to vary widely between provinces and even between regions in a province. Some provinces cover medications, while others do not. Some cover personal support services, others do not. Some cover palliative care, while others do not. Some provinces provide home care for people with short-term acute and mental illnesses, but not for those with longer term mental health needs. In many

¹⁴ The Berger Monitor. 1999.

¹⁵ The Health of Canadians – The Federal Role. October 2002.

jurisdictions, people with mental illness are not eligible for home care services. Some services are available in urban but not rural or remote areas. Some regional health authorities have give priority to home care; others have not.

Most communities do not have a single easy point of access (i.e., one stop shopping) for home and community services. In many communities, individuals do not know what services are available or how to access them, and they do not have access to the kind of case management support that can help them navigate the health care system and negotiate for the services they need. All provinces and territories made a commitment in the 2004 First Ministers' Accord to provide case management services. However, the HCCC is concerned that the focus of those services will be on managing the system and triaging clients, rather than on advocating on behalf of patients so they receive the services they need.

The role of informal/family caregivers

The cost effectiveness of home care is due, in part, to the heavy reliance on unpaid informal caregivers – usually family members¹⁶ – to assist with care.¹⁷ With the rationing of services, demands on informal caregivers are increasing at a time when, there are fewer informal caregivers to share the care for reasons that include falling birth rates, more women working, higher divorce rates, more single parent families, and a more mobile society. The profile of those who provide care includes young children and adolescents, the elderly, and all age groups in between. Many caregivers are members of vulnerable populations themselves who do not get the proper support and care they need. A recent study indicates that, 70% of informal caregivers find providing care stressful, and 70% report needing a break from this responsibility.

Informal caregivers will continue to be a key partner in home care. In all efforts to improve access to home care, the health care system should involve informal caregivers in decision making and encourage effective collaboration between formal and informal caregivers. This will provide more support for the informal/family caregivers and better care for clients. They should also explore effective ways to use the skills of consumers and volunteers in supporting people in their homes and at the end of life.

Noncompetitive working environments

To provide effective quality home care, it is necessary to attract and retain skilled committed home care providers. Home care programs across the country face shortages of trained workers – particularly in rural areas – and high levels of turnover.¹⁸ While this situation is due in part to the overall shortage of health care providers, it is primarily due to the noncompetitive and demanding working environment.

Wages for home care workers are generally lower than those offered in hospital and long-term care facilities. Home care staff report that they need to work long hours to make a decent living. Over the past five years, workloads have increased noticeably.¹⁹ Home care staff are more likely to work on a casual or part-time basis, without benefits, than their peers in other health settings. Because they provide care in people's homes, they are also more likely to work in isolation and in unsafe settings.

¹⁶ “Family” includes anyone the client defines as “family”.

¹⁷ Canadian Home Care Human Resources Study. December 4, 2001.

¹⁸ Canadian Home Care Human Resources Study. December 4, 2001.

¹⁹ Ibid

Given current wages, work settings and workloads, home care cannot compete with other sectors, and it is paying the price in quality, experience, staff shortages and the ongoing need to recruit and train new staff.

Training and technology

More complex “high tech” care is now being delivered in homes and communities, but current training programs do not adequately prepare home care providers for the level of care they are expected to provide. Informal caregivers are also being asked to perform complex procedures or monitor technologies with little or no training. Both formal and informal caregivers need more appropriate training, and access to the right technologies.

To meet that need, home care programs must devote more resources to continuing education and technology. Current funding mechanisms for home care services may not support these investments, which are essential to the quality, effectiveness and sustainability of home care services.

Quality and Accountability

A growing number of home care programs are now accredited, but there are few common indicators to measure the effectiveness of home care services. There are also few best practice guidelines or preferred practice models to promote continuous quality improvement.

A Narrow Sector-Specific Approach

The current sector-by-sector approach to health services planning fails to take advantage of the potential of home care to enhance primary care services. A more integrated approach would give clients access to a greater range of health and social services, promote multidisciplinary care, and improve access to health promotion and prevention programs.²⁰ It would also help reduce the current pressure on the primary care sector.

Actions

After reviewing the current state of access home care across Canada it is evident that access to home care policies require both attention and refinement. As outlined above, in order to ensure equitable and quality access to home care to all Canadians, HCCC recommends that governments take action by providing resources to home care programs; working with organizations to develop a pan-Canadian service plan; implementing case management services by 2006; recognizing the critical role that informal and family caregivers play; focusing their funding on accredited home care programs; establishing norms, standards, best practices, benchmarks and indicators to better assess the impact of home care services; involving home care programs and providers in efforts to reform primary care; and monitoring and evaluating the home care initiatives.

These changes have the potential to enable and assist access to home care programs and caregivers in their pursuit to take care of Canadians in the best way possible. By doing so, Canadians will have equitable access to quality home care services to help

²⁰ Canadian Home Care Association. An Essential Partnership for Integrated, Client-Centred Care.

meet their primary, acute, mental health chronic and palliative care needs, and to improve their quality of life.

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