

12/3/2007

Family Caregivers Essential Partners in Care

CHCA Interactive Workshop # 2

Canadian Home Care Association



Family Caregivers: Essential Partners in Care

CHCA Interactive Workshop # 2

Moderator: **Judy Knight**, Vice President & Manitoba Representative
Canadian Home Care Association

Panellists: **Marcus Hollander**, PhD, Hollander Analytical Services Ltd.
(Presentation WS2A – Family Caregivers)

Norah C. Keating, PhD, Professor and Co-director, Research on
Aging, Policies and Practice, Graduate Coordinator, Department of
Human Ecology, University Of Alberta
(Presentation WS2B – Family Caregivers)

Connie Clerici, BScN., RN, President and CEO Closingthe Gap
Health Care Services
(Presentation WS2C – Family Caregivers)

The panelists provided a number of thought-provoking ideas about family caregiving, starting with a view of the context of caregiving, a broader policy context, a profile of family caregivers and suggestions for next steps. Delegates challenged ideas and provided input into the suggestions and recommendations as described

THE CONTEXT

Caregivers should be viewed from a broad perspective which considers “families that care” not just an individual “family caregiver”. When a person considers “families”, it is important to look at “who are the people in your network, if you're on the receiving end of care?” “Who is the group that provides care?” Typically the type of family / friend care networks includes:

***Children at home** (primarily adult children who live with the person they're caring for, mostly likely in the labour force)*

***Friends, as well as close relatives** (often friends are nearby and may be doing some of those kind of episodic things like shoveling the snow and so on)*

Lone spouses

In order for policy planners, researchers and stakeholders to move forward we must lay some *ground rules* that respect the caregiver; and to respect the caregiver is to see the caregiver as being the expert in their family's care. Family caregivers provide some 75 % or more of the care provided to people with care needs. There are often **bigger picture factors** which are increasingly putting pressure on family caregivers such as financial considerations, exhaustion, ill health, etc.

Currently there is very little data on the actual financial contribution made by family caregivers using a broader societal perspective – the time and energy provided by caregivers in giving care to their loved ones, and the costing of that at replacement wages - this is an area that should be considered for more research.

Often it's not recognized that family caregivers continue to provide significant amounts of care even after the family member is admitted into a facility.

No Two Caregiving Situations are Alike

Panelist, Norah Keating, provided interesting statistics on caregiver situations. “Who are the care receivers who are: (a) receiving help only from their family members, (b) getting help from both their family members and others, and (c) getting only formal help?”

- The first group “a” - about 1/3 of care receivers. They report that it's only their families who are providing care. And among that group they're getting about eight hours of care a week on average.
- The second group “b” - about 1/4 of older adults, frail older adults receiving care. They are receiving formal care, but it is only when the families are providing huge levels of care before the formal comes in. This may be a result of limited formal resources and allocating services only when families are saying, “we're not going to be able to hang on very much longer”.
- In the situations in which only formal help is being provided (group “c”), care recipients are actually less frail. They're getting fairly low levels of support. This can be very important to people to stay in the community, but they report no family help.
- A fourth group - 25 percent of frail older Canadians - report that they receive no care. We need to know more about this group as they are often invisible, particularly to formal care providers.

THE BROADER POLICY CONTEXT

“Canadian health and social policy has historically assumed and continues to assume that care takes place in the family. The formal care system enters when families fail. When health performance in the 1990s brought a formal recognition of the contribution of informal caregivers, and while now giving rhetorical recognition, Canadian policy does not provide substantial support to caregivers and thereby does not reflect the critical role that caregivers play within society.”

Hollander, M.J., Chappell, N.L., Prince, M.J., & Shapiro, E. (2007)
Providing care and support for an aging population: Briefing notes on key policy issues
Healthcare Quarterly, 10 (3), 34-45.

The panellists suggested that in terms of the broader policy context there are a number of interesting things happening across the country that impact family caregivers. These include:

- Caregivers are not seen as part of the care system, as much as they should be.
- A rise in consumerism in the future will impact family caregiving as individuals will expect to get health care when and where they want it.
- The future delivery of health care must embrace innovation in order to effectively utilize resources and meet growing demands.
- There are huge differences in a family’s capacity to care - families in which all the caregivers are in the labour force provide fewer hours of care.
- If a care recipient doesn’t have a family advocate who can broker with the formal system they are invisible and it's hard to get formal care.
- Families are changing - getting smaller, but more is not necessarily better. Very often it's one or two children who are involved and rarely are there six or eight and in some families there are long-standing tensions and more definitely is not better.

CHARACTERISTICS OF FAMILY CAREGIVERS¹

Family Caregivers in General

- The majority of caregivers are female spouses (75% of caregivers are women and 70% are married or common law) and children as well.
- Many of these spouses are elderly themselves and may also have diminished health (36% of caregivers are 65 years of age or older).
- Many caregivers care for friends and neighbours. A fairly substantial proportion of people providing care are not related to the person they're caring for at all.
- Most caregivers care for more than one person and have had a history of care giving for others. It's a lot more common to have had several caregiving experiences than to currently be in this so-called "Sandwich Generation."
- Most caregivers do not plan their role, but are thrust into it with little warning and preparation.
- Most caregivers under the age of 65 are now in the labour force.
- Caring for frail, older adults can go on for a really, really long time.
- 2,384,000 Canadians aged 45 and over provide care for a senior² (16% of the total population aged 45 – 64 and 8% of the total population 65+)

¹ Hollander, M.J., Chappell, N.L., Havens, B., McWilliam, C., & Miller, J.A. (2002). Substudy 5: Study of the Costs and Outcomes of Home Care and Residential Long Term Care Services. Victoria: National Evaluation of the Cost-Effectiveness of Home Care

² Analyses from Statistics Canada GSS on Aging and Social Support (cycle 16)

Middle-Aged Caregivers (45 - 64)

- Most middle aged caregivers are looking after: (a) their parents (67%), (b) their spouses' parents (24%) and (c) their friends and neighbours (24%).
- There are just as many middle-aged men as women caregivers. Women average 30 hours and men 16 hours of care per month. Women do more of the hands-on day-to-day caregiving. Men do more of the home maintenance and other things, but everybody's in the labour force.
- Only 17% of middle aged caregivers get a break from caregiving. Those that do: (a) 82% get help from their siblings (b) 16% relied on paid help for back-up (c) 13% said life was very stressful (d) 51% said they'd like occasional relief or sharing of responsibilities

Senior Caregivers (Aged 65+)

- Most senior caregivers are looking after: (a) their spouses (25%), (b) their close friends (33%) and (c) their neighbours (19%).
- More women (59%) than men provide caregiving. Women do 33 hours / month, men 21 hours / month.
- Only 18% of senior caregivers get a break from caregiving. Those that do, get help from their children, formal services or other family members.
- Over 1/3 of senior caregivers said that life was stressful.

Cost Implications for Family Caregivers:

Marcus Hollander presented data from a recent study done of cost implications of family caregivers. In terms of contribution in time - contribution per day - this is dependent upon the condition of the care recipient.

For slightly independent our slightly dependent care recipients living in the community, a family caregiver may spend between 1.59 – 2.27 hours / day. If the care recipient is slightly independent our slightly dependent but living in a facility the amount of time required by the family caregiver decreased to approximately ½ hour / day.

For higher needs / more dependent care recipients the number of hours provided by a family caregiver more than doubles to between 3-4 hours / day.

POLICY ISSUES AND RECOMMENDATIONS

The panelists and participants discussed and identified four policy issues and recommendations for family caregiving:

1. FORMALLY RECOGNIZE THE CONTRIBUTION OF FAMILY CAREGIVERS IN POLICY.

- Include a statement of recognition of the importance and significant contribution of the family caregiver within a policy framework at the provincial, regional and organizational level.
- Look beyond health care into labour impacts and workplace policies that would allow people to take the necessary time off work and be guaranteed an income and a job when returning to the workforce (similar to maternity leave).

2. RECOGNIZE THE FAMILY AS THE UNIT OF CARE AND SUPPORT, AND INCLUDE SERVICES FOR THE CLIENT AND FAMILY CAREGIVER IN THE CARE PLAN.

- A challenge to this recommendation was identified by a delegate from a caregiver support network who shared their experience that many family caregivers don't see themselves as caregivers. They see themselves as good daughters, good wives, spouses, sons, but not as caregivers. And they don't reach out for support until they get to a crisis state. How can we provide education to help people understand that they are, in fact, caregivers and that they are eligible, or they have the right to ask for some kind of help?
- The important idea of the **family unit**, rather than just the client as recipient of services was discussed using an example from the Department of Veterans Affairs Canada. The DVA has currently shifted their policy eligibility to include spouses or the person who's providing the care as the recipient of DVA benefits if they need services to support their own quality of life, independent of whether the veteran has died or has moved into residential care.

3. INTEGRATE FAMILY CAREGIVERS INTO THE CARE TEAM TO DEVELOP MORE RELEVANT AND FOCUSED ASSESSMENTS

- It is the family caregiver who knows the client the best.
- The families are the experts in their own family member's care. Health care professional's role in supporting decision making is to support the informed consent process, and make sure that the knowledge transfer happens in a very timely way.
- Explore operational mandates that ensure professional staff talk to the family caregiver, involve them in care and explain things to them.

4. PROVIDE ADEQUATE RESOURCES TO CARE FOR CLIENTS AND TO PROVIDE NEEDED SUPPORT TO FAMILY CAREGIVERS

- Well-developed home, community and residential options and other respite choices.
- Homemaking and personal care services should be priorities for funding.