Maritime Centre of Excellence for Women's Health

Moving Towards Women's Health

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The Caregivers Research Project*

A recent result of Canadian health care reform is a shift in health care from institutions to communities. This shift to community-based care is not gender neutral. When seniors, the disabled and the chronically ill receive less institutional care, more responsibility is transferred to informal caregivers – in most cases, family members. Sixty-six percent of informal caregivers are women – this represents approximately 14% of all Canadian women over the age of 15. Yet governments are redirecting only a fraction of savings from hospital closures to programs that support informal family care in the community. It is estimated that the needs of family caregivers are likely to be greatest, and the resources fewest, in small communities and in rural areas.

The Caregivers Research Project was designed to gather the views and experiences of rural family caregivers. Researchers used story telling and structured dialogue to gather knowledge from the personal experience of 46 family caregivers** through four day-long workshops, held in each of the four health regions of Nova Scotia. The knowledge gained from the study is intended to inform policy makers and service providers in an effort to increase support for caregivers.

Findings

- The majority of the family caregivers reported they were on duty 24 hours a day, seven days a week, caring for people whose ages ranged from four years old to nearly one hundred.

- Fifteen percent provided 24-hour care “with no relief”, while 63% received only “occasional relief”.

- While some had been providing care for only a few months, others had been doing so for as long as 40 years. Many of these caregivers had given up employment in order to provide care; fewer than 25% had paid employment.

- Fifteen percent of family caregivers reported not having enough money to feed all the members of the household.

Themes

Participants felt the government had not provided comprehensive community care when closing local hospitals. These family caregivers spoke of:

- the considerable burden associated with care-giving responsibilities

- the need for more support services, better matched with their actual needs and the needs of those they care for

- the need for information on how they can provide care more effectively

- the need to include a transfer of resources in the shift from institutional to community care so that services become comparable to the best available in urban centres

- the need for relief time in order to maintain their health as they carry out caregiving as a contribution to their communities

The Caregivers Research Project was conducted by community-based researchers Gail Bruhm, Joan Campbell and Susan Lilley and was guided by a multi-sectoral advisory committee.

*****Participants included Blacks, Aboriginals and Acadians. Although the workshops were open to male family caregivers, all participants were women. Half of these were between the ages of 31 and 50; roughly one third were between 51 and 65; a few participants were over 65; and one was under 31 years old.***

Messages for Policy Makers

The social process used by researchers gave caregivers the opportunity to speak about their life experiences, to be heard, and to have their experiences validated by other caregivers. This research goes beyond documenting needs. Insights gathered from this group of family caregivers in rural Nova Scotia point to a pressing need for caregivers' contributions to be recognized. This group of caregivers feels that the formal care system does not value their role as primary caregivers; nor are their needs being met for appropriate information, training, and services to support their caring efforts. They need to be involved in shaping the policies, programs and treatment choices that affect them and those they care for. Their insights are of considerable value to everyone directly involved in home care, and to anyone interested in enhancing the well-being of families in rural communities. The caregivers who participated in this study have four critical messages for policy makers:

Recognize Caregivers' Contributions. Health policy must recognize caregivers as essential to the success of home care programming. The health care system neither acknowledges nor appreciates the contribution of primary care providers, which results in frustration and the creation of inappropriate services and programs.

Engage Caregivers in the Policy Process. Although *Nova Scotia's Blueprint for Health System Reform* (1995) recommended that informal caregivers be included in policy development and planning, caregivers feel they have not been included. Caregivers' knowledge, experience and practical suggestions for supports and services are essential ingredients for home care policy development.

Provide Support Services and Information. Caregivers are trapped in a downward spiral of stress and ill-health that impairs their effectiveness as caregivers. Caregivers need timely and appropriate relief care, up-to-date information and training.

Value Caregivers' Work. Sustainability of a community based health system that relies on family care depends on providing compensation to family caregivers. Caregivers want compensation for their contributions to the economy, through payment for their work, tax relief, pension benefits or other means.

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