

THE PALLIATIVE CARE VOLUNTEER: INCREASING KNOWLEDGE AND UNDERSTANDING OF A KEY PARTNER

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Society is confronted with questions that involve the appropriate use of health care resources for seniors approaching death (CIHR, 2004). In this respect, the Quebec Government, like other Western authorities, has stated major orientations: (1) development of home care, (2) interdisciplinary approach, (3) implementation of integrated service networks (Ancil, 2001, Carstairs, 2005; MSSS 2003, 2004; Neuwirth, 2004; Health Canada, 2004). In such a context, it is important to take into account the active participation of all partners, including that of volunteers. Historically, volunteers have played an essential role in palliative and end-of-life care (Mount, 1992; Payne, 1998; Rousseau and Bernard, 1999). However, they work for the most part in hospitals and specialized palliative care establishments, and their participation in home support is still poorly developed. In the context of the development of palliative and end-of-life care, it is important to increase volunteers' contribution in the home in order to meet a broader range of needs of seniors at the end of their lives (Gottlieb, 2002; Zimmerman, Sloane, Hanson, Mitchell and Shy, 2003). Until now, few studies have focused on volunteer action in palliative and end-of-life care, especially with regard to their work in the home. To promote equitable and optimal volunteer participation in this field of activity, it is important to gain further knowledge about the nature and scope of volunteer action in the home and the factors that facilitate or impede it. Current or future research projects are exploring these issues.

CURRENT OR FUTURE RESEARCH PROJECTS ON VOLUNTEERISM IN PALLIATIVE CARE

In this article, we present three projects dealing mainly with volunteerism in palliative care.

The first study is part of a postdoctoral project funded by the Strategic Training Program in Palliative Care Research. The study is entitled *Les pratiques bénévoles en soins palliatifs : une étude multi-sites au Canada* (Sévigny, Dumont and Cohen, ongoing study). The purpose of this study is to learn about, describe and compare practice models advanced by Community Action Agencies (CAA) active in the delivery of ambulatory or home palliative care. To achieve this

objective, the study was conducted in three Canadian provinces (Quebec, Alberta, British Columbia). Volunteers and coordinators working in CAAs involved in the palliative care field shared their opinions on five themes the Canadian Hospice Palliative Care Association (CHPCA) considers in its national practice model. These themes are: (1) An explication of health and illness and related problems; (2) A definition and foundational principles of palliative care; (3) Volunteer practices in palliative care: principles and foundations; (4) Identifying the principal duties of volunteers; (5) A service delivery model (volunteer training, required knowledge, attitudes or aptitudes, support provided to volunteers, vision of quality care). An analysis of the data produced in this study will be completed in the near future and published at a later date.

The second project focuses on seniors' participation in home palliative care. It is also part of an ongoing postdoctoral project funded by the *Réseau de Formation interdisciplinaire en recherche sur la santé et le vieillissement* (FORMSAV) (Sévigny and Tourigny). This exploratory study analyses four situations in which seniors receiving palliative care in the home obtain support from a person over 60 years of age. It is aimed at describing the nature and scope of volunteer action, taking into account the advice of volunteers as well as patients, their families and the workers involved. Furthermore, the study will examine how volunteer action is integrated, or why it is not integrated, into support and care services offered by a multidisciplinary team to meet the needs of elderly patients and their families.

A third research project that has just received funding from the Institute of Aging (CIHR) (Aubin, Sévigny, Tourigny, and Dumont) will begin in September 2006. This descriptive, comprehensive study will focus specifically on the factors that facilitate or curtail volunteerism in the field of end-of-life care for seniors living at home. Improved knowledge about these factors will enable workers and decision makers, among others, to establish mechanisms aimed at facilitating this participation or countering the obstacles that impede it. It is a preliminary step in the integration of volunteers into integrated service networks. First, the results of this study will help identify various factors that promote or hinder volunteer participation in home support for seniors nearing the end of their lives. Second, it will be possible to describe them to better understand the nature of these factors (What are they?), their provenance (To which type of caregiver are they linked? Which care setting? Which practice conditions?), and development (In which circumstances do they appear? At what time? Do they change over time?).

The three studies are therefore complementary and are aimed at examining the nature and scope of volunteer action, taking into account the fact that the volunteer acts in a context that evokes a response from persons belonging to informal networks (families, friends, neighbours) and formal (professional) help networks. They provide support for the development of integrated, coordinated and complete home end-of-life care. This question is at the core of the issues identified in recent policies in the field of palliative and home care delivery (Canadian Hospice Palliative Care Association, 2004; *Réseau québécois de soins palliatifs*, 2005; Lambert and Lecompte, 2000; MSSS, 2000, 2003, 2004). It should also be remembered that the CIHR statement of priorities for 2004-2007 emphasizes the importance of better documentation of the evolving role of unorganized volunteer services. (Canadian Health Services Research Foundation, 2003; CIHR, 2004). Furthermore, in 2006, the Canadian Volunteerism Initiative Knowledge Development Centre is giving priority to studies that will focus on the experiences and factors conditioning the involvement, integration and maintenance of volunteer programs. Better knowledge of the factors that facilitate or hinder recourse to care and services provided by volunteers is considered as a prior step essential to their integration into the network of services and care offered to seniors receiving end-of-life care in their homes. This integration is aimed at responding more effectively to the multiple needs of seniors nearing the end of their lives.

The results obtained from these studies will contribute to the recognition of seniors' participation in the crucial health and social services sector. They will be useful to decision makers and different participants in the public network or community agencies who are endeavouring to integrate various partners into the area of care delivery. This integration will help facilitate a better response to the needs of seniors receiving palliative care in their homes. The results could also serve to provide impetus for other studies aimed at developing a better understanding of the dynamics of integrating volunteer action with that of other active agents delivering end-of-life care to seniors. The results of these various studies will be available at a later date and the resulting publications will be mentioned in AVISO at the time of their publication.

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