

**Choices through Knowledge:  
community training in palliative care**

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**and**

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**March 5, 2004**

**1. Title: Choices through Knowledge: community training in palliative care**

A QAAL project for volunteers in the English-speaking minority in rural regions of Quebec

**2. Name of organization: Quebec Association for Adult Learning**

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(QAAL) believes that learning is a lifelong endeavour and a human right.

As an English-language adult-learning association that supports those who support learners, QAAL's mission is:

- Advocating for a culture of lifelong learning,
- Raising public awareness of adult learning issues
- Facilitating the exchange of information and resources,
- Bringing together everyone for whom a learning society is a shared ideal.

Major programs: QAAL has carried out major projects in recent years, including the 3-year initiative in partnership with the Canadian Deafness Research & Training Institute (CDRTI) entitled *A Minority Within a Minority: providing health services to English language deaf people wherever they live in Quebec* and the 2-year project just completed: *Choices Through Knowledge: training in palliative care*. In addition QAAL holds conferences & workshops, and publishes a Newsletter for members, to name only the major activities.

Regular Activities throughout the year: QAAL holds conferences, organizes workshops, and publishes a quarterly Newsletter, Linking for Learning.

**3. Project Summary**

- Although a senate report, *Quality End-of-Life Care: the Right of Every Canadian*, states that palliative care is the right of all Canadians, the reality is that only 15% receive it at present. (Aviso, Winter, 2004) Using a national training program, QAAL has begun to address this problem with 9 regional associations with 2-day workshops that brought the community together to increase their ability to provide palliative care (through increased knowledge) for seniors and others living with life-threatening illnesses.

Factors having a significant impact on the delivery of palliative care in Quebec):

1. Aging Anglophone populations resulting in an increase in the number of people with cancer and life-threatening diseases without family members in the province.

2. Closure of beds in acute care hospitals and cutbacks in palliative care beds resulting in more people to be cared for at home.

3. Insufficient long-term care facilities caring for residents until death (fewer bilingual institutions).

4. Increasing numbers of individuals who choose to die at home (prefer care in their own language and culture). See the key findings in the Mississquoi Report..

5. New 2004 Compassionate Care Benefit Program: an estimate 270,000 people annually are expected to participate to care for the approximate 160, 000 Canadians who die each year. (*Gazette, January 7, 2004*). To our knowledge there is no provision for care-giver training.

To provide quality palliative care, all care providers (family, volunteers & professionals) require training. Few standardized educational tools are available. In 1998, Health Canada (New Horizons) funded a joint project with the Canadian Palliative Care Association (CPCA) and the Canadian Association for Community Care, which resulted in a Training Manual for Support Workers in Palliative Care. Pilot testing in Quebec, Manitoba and Alberta and evaluation determined it a valuable resource that should be made available to care providers across the country. A train-the-trainer project followed *in 1999 but did not include the province of Quebec*.

To date 9 communities in Quebec have had the opportunity to utilize this resource through the Development Fund of the Department of Canadian Heritage (September 2002-2004). There was a waiting list in 6 of the 9 communities where 20 + people registered. The summative evaluations revealed that 100 % would recommend this workshop to others. Satisfaction level ranged from 100 % to 61 % extremely satisfied with the program. It consists of seventeen workshops, each designed-to-be-covered in 40 minutes with optional activities. It can be given over a weekend or 2-day sessions with the timing and content determined by the needs of the participants. The class size should be kept under 20 to maximize participation and sharing amongst the learners. A Health Care Professional skilled in both adult education and palliative care to ensure maximum benefit facilitates the curriculum.

The overall goal is to ensure that individuals needing palliative care and their families receive the best care in all settings. The training strives to effectively increase the participants' awareness and understanding of the palliative care process and enhance their ability to give care.

We are a death denying society. The aversion to discussing death has been identified as the most difficult obstacle to the delivery of palliative care.

The number one concern of English-speaking Quebecers is access to health care in their own language (CROP-Mississquoi, 2000\*). Through education we can encourage a coherent vision and support for the development of community-based palliative care services. A community workshop with a skilled facilitator brings individuals together to explore death and dying, encourages them to review their local resources, and strengthens them to organize activities/facilities to fill identified gaps and form Volunteer Palliative Care Groups, Hospice Facilities, and/or Bereavement Support Groups/Sessions.

Experiences of the workshops supported the overall goal which is to provide awareness and knowledge of end-of-life issues and practical ways in which a community can help a family, neighbour and one's self. The evaluations and follow-up have been positive with suggestions from participants for meeting their specific community needs including fundraising for future workshops, establishing a library for grief and bereavement and initiating two support groups for loss and cancer support.

The rewarding outcome has been the enthusiastic response and commitments from the participants in the regions; the following regional associations responded to the offer to host the projects. (Townshippers, (Lennoxville) Holland Centre (Quebec City), CSLC Lachute, Committee for Anglophone Social Action (CASA, Gaspé), Community Association of the Magdalen Islands (CAMI), Neighbours Association (Rouyn-Noranda), Gatineau, West Quebecers (Shawville), Chateauguay Valley English-speaking Peoples' Association (CVESPA Huntingdon), Concordia University (QAAL, Montreal & area). 6 of 9 groups had waiting lists.

## \* Appendix A

### **Community Experience**

In spring 2000, the Missisquoi Institute commissioned an omnibus survey from the Centre de recherche sur l'opinion publique, on the attitudes and experiences of English-speaking Quebecers. The survey provides a wide range of information about the real experience of English-speaking residents of each region as regards the ease with which they are able to access health and social services in their own language.

Among the key findings are the following:

- There is a dramatic variation between regions in the reported levels of access to services in English
- Services in English are more readily available from physicians, private nursing agencies and community-based resources than from public institutions such as Centres locaux de services communautaires (CLSCs, i.e. local community service centres and long-term care centres, or telephone help-lines such as info-Santé.
- English-speakers are much more likely than French-speakers to say that they would turn to family first in case of illness; French-speakers would turn to public services first.
- English-speakers are far less likely than French-speakers to have a family member living nearby.
- English-speakers consider long-term care centres and telephone help-line services (Info-Santé) as being particularly important in terms of ensuring linguistic access.

The survey findings support the Committee's view that the vitality of many communities is compromised by their tendency to use the public system less often than the majority, and also to rely more heavily on family first in the case of illness even though they are less likely than their Francophone neighbours to have a family member close by. This portrait of vulnerability is reinforced by the demographic reality of ageing communities and loss of caregivers in several regions.

Analysis also reveals that the six regions scoring very low with respect to ability to obtain a range of health and social services in English are regions where the English-speaking community forms 2.4% or less of the regional population: Bas-Saint-Laurent (0.5%); Saguenay-lac-Saint-Jean (0,6%); Québec (2.0%); Mauricie (1.3%); Chaudière-Appalaches (0.9%); and Lanaudière (2.4%). These communities appear to lack the demographic weight to influence regional priorities and obtain expanded access to services in English. This finding suggests that such vulnerable communities should be the focus of strategies to develop community capacity and increase the level of access to services in English.

*(Report to the Federal Minister of Health, Consultative Committee for English-Speaking Minority Communities, July 2002)*