



Quarterly Index

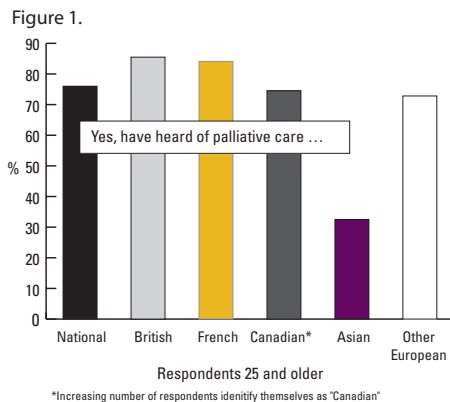
PUBLIC EXPECTATION FOR PALLIATIVE CARE

Since 1998 (Survey #18) The *Berger Population Health Monitor* has been tracking the public's use of, and expected demand for, palliative care services – typically administered in or in association with hospitals. The following summarizes selected findings from *Monitor* surveys in the previous five years, including Survey #25 comprising the national surveys conducted monthly from January to June 2003.

AWARENESS OF PALLIATIVE CARE

There are significant differences in awareness of palliative care among different ethnic groups.

These differences are consistent with those we found in previous surveys regarding advanced care planning – also an issue important to hospitals.



- In 2003, the question on the use of palliative care was addressed to respondents 25 and older who said they were aware of palliative care, defined as “a type of care provided to people who are dying. Palliative care focuses on making patients comfortable, managing their pain and helping them live out their lives with dignity.”
- In 1998, respondents were asked if members of their extended family had used or were using palliative care. In 1993, respondents were asked if members of their extended family had used palliative care in the previous three years.
- In 1998, “extended family” included anyone living in the home and brothers, sisters, parents and grandparents living in another home. In 2003, “extended family” was defined more simply as grandparents, parents, brothers, sisters and children.

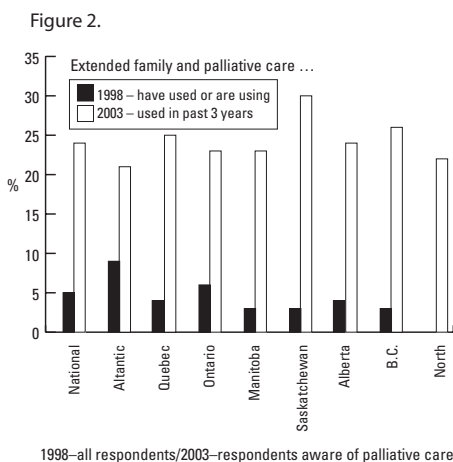
Even with these differences, the shift over the past five years in the use of palliative care is remarkable. In all regions of the country, there has been approximately a three-to-five-fold increase in the proportion of the population in all provinces reporting that someone in their extended family has used palliative care. In the north, *Monitor* data is available only for 2003.

CURRENT USE OF PALLIATIVE CARE SERVICES

This chart indicates the substantial growth in the current use of palliative care services over the five years between 1998 and 2003.

The questions were framed differently in the two surveys and the samples to which the questions were administered were also somewhat different.

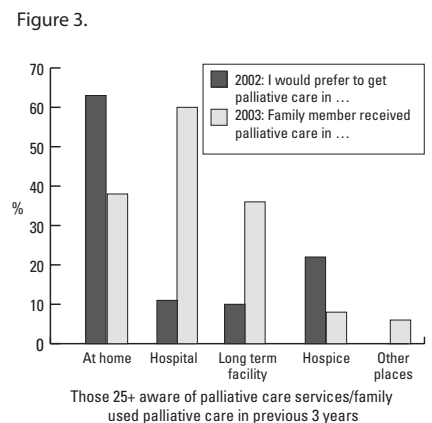
- In 1993 all respondents were asked about palliative care as “care for people who are terminally ill and want to live in their home as long as possible.”



DISPARITY BETWEEN PREFERRED AND ACTUAL SITES FOR PALLIATIVE CARE

There is a substantial disparity between where people would like to receive palliative care services (Survey #23, 2002) when their time comes, and where the services have been provided to members of their extended families (Survey #25, 2003).

Most people, when their time comes, want to receive palliative care at home or, as a distant second, at a hospice. In the case of their extended family members, however, by far the most common site of service was the hospital, with long-term facilities and the home tied as distant seconds, and the hospice far behind.



ADEQUACY OF PALLIATIVE CARE SERVICES

In 2003, respondents were asked, “From what you know or have heard, did the ill family member received adequate ...” and a range of services were listed. The wording of the question makes it plain that it is about adequacy rather than simply if the service were provided.

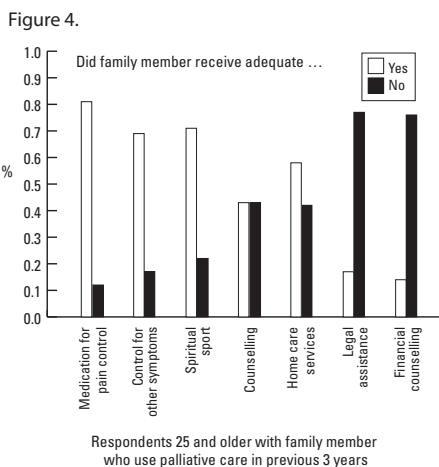
The results show substantial discrepancies between what the patient received and what the respondent considered adequate.

Responses are not adjusted for “don’t know/ no answer” receive however, most respondents had an answer.

Although medication for pain control and for other symptoms are the two services which

are most likely to be described as adequate, even here we find significant proportions reporting that these services were inadequate.

What is noticeable, moreover, is the high proportions reporting that counselling and advice regarding financial and legal matters were inadequate. Even taking into account the possibility that some or many respondents were not knowledgeable about the services needed or received, it is reasonable to conclude that there are significant inadequacies in the provision of palliative care services. This is not to suggest that the healthcare sector in general, or hospitals in particular, provide these or other services; rather, the conclusion is that there is a substantial absence of such services and, one expects, that the patient’s affairs are consequently not as well ordered, or the patient as comfortable, as they might be.

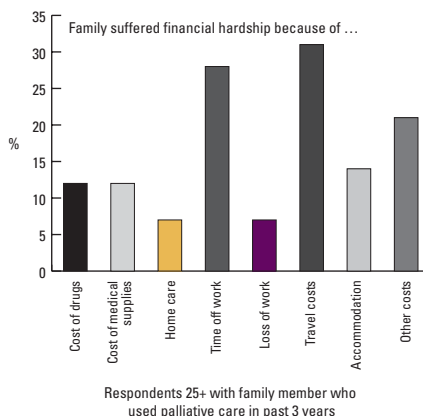


FINANCIAL BURDEN

The *Monitor* has addressed the issue of financial burdens of informal care givers in different ways since 1998. In Survey #25, the question was addressed specifically to those with extended family members who had received palliative care in the previous three years.

The findings are consistent with our data from previous surveys regarding informal care-giving. Families involved with palliative care undertake substantial financial burdens.

Figure 5.



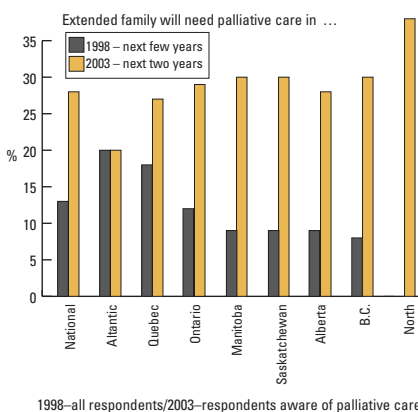
ESTIMATED DEMAND FOR PALLIATIVE CARE SERVICES

The next chart reports on respondents’ expectations of the need for palliative care services in their extended family.

Nationally, the forecasted “two-year” need for palliative care services seems to have doubled between 1998 and 2003. In some regions it appears to have tripled.

Assuming 10 million households in the country, and that respondents are referring to one person and not two or more in their extended family needing palliative care, it appears that there will be a demand for somewhere the order of 2.1 million palliative care cases in the next two years. Since, at present, about two-thirds of palliative care cases are in hospitals – although most respondents prefer to be at home or in a hospice – palliative care becomes an important component of hospital planning.

Figure 6.



Topics in The *Berger Population Health Monitor* are selected in consultation with subscribers, the Hay Health Care Consulting Group and the Canadian Fitness and Lifestyle Research Institute in Ottawa. The *Berger Population Health Monitor* surveys are conducted jointly with the Physical Activity Monitor of the Institute. National surveys are conducted monthly and administered by the Institute for Social Research, York University. The sample for the palliative care questions included in the surveys from January to June 2003 consisted of respondents 25 and older totalling 3,881 persons. For more information contact Earl Berger, 416-815-6405, or e-mail: Earl_Berger@haygroup.com.