

The Berger Population Health Monitor
 **Le sondage Berger de la santé publique**

with The Hay Health Care Consulting Group

Survey #23
Special Report on Palliative Care
for Health Canada

Executive Summary

SUBSIDISED QUESTIONS

Introduction

This report is based upon questions subsidised by Health Canada. The questions were administered as part of Survey #23 conducted during January-April 2002.

Ownership

Subsidised questions are the property of The Berger Population Health Monitor (BPHM) and part of the BPHM's database and for use by the BPHM as it deems appropriate. Organisations subsidising questions are entitled to use this information, with the exception that the subsidising organisation is not entitled to sell, lease or otherwise receive financial benefits from other parties for the transfer or use of the information from the subsidised questions. The right to sell, lease or otherwise receive financial benefits remains solely that of the BPHM.

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Subsidised and proprietary questions can be published by the subsidising organisation as it wishes. If results are to be published, the organisation is asked to follow the standards established by the Canadian Association of Marketing Research Organisations (CAMRO) to ensure that legitimate questions of methodology and interpretation are addressed.

Publication standards include the following:

Clients will specify they are the sponsor of the questions; the BPHM is the research organisation carrying out the survey; the period during which the interviews were administered; the mode of interview (telephone); the criteria defining the population to which the questions were administered; the size of the sample to which the questions were administered; the wording of the questions upon which the results were based; the allowance to be made for sampling error; and the percentages upon which the conclusions are based.

The Client will ensure that dissemination of the findings will not give rise to misleading interpretations or be quoted out of context. If the Client's interpretation of the data differs substantially from that published by the BPHM, the Client will review this interpretation with the Monitor prior to publication and indicate in its report where substantial differences, if any, exist in interpretation. The BPHM is entitled to decline to allow its name to be used in connection with the dissemination of the results of questions in cases where it finds that the proposed report on the results does not fairly reflect the data.

When the Client publishes the results of subsidised questions, the BPHM is entitled to release to bona fide enquirers the technical information listed in #1, should the Client not provide that information.

Results - Technical Summary

Survey Administration. The interviews were conducted by the Institute of Social Research, York University, Toronto, using computer-assisted telephone interview (CATI) procedures. The response rate for the questions was approximately 52%.

Sample and Sample Size. The data in these charts are based on the subsample of half the respondents 25 and older, N=1,779, in the 10 provinces and three Territories. For a sample this size, the margin of error is ± 1.4 percentage

Margin of Error. The margin of error for samples of 1,779 is plus or minus 1.6 percentage points at the 95

percent confidence level where the response distribution is 50%/50%. As the response distribution is skewed more to one response or the other, the margin of error decreases.

Findings

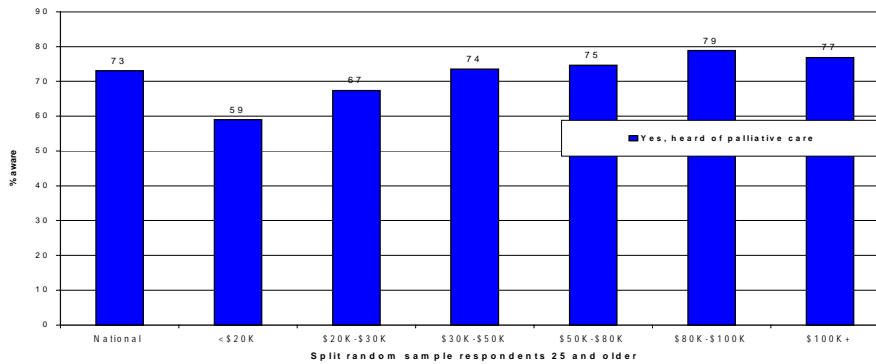
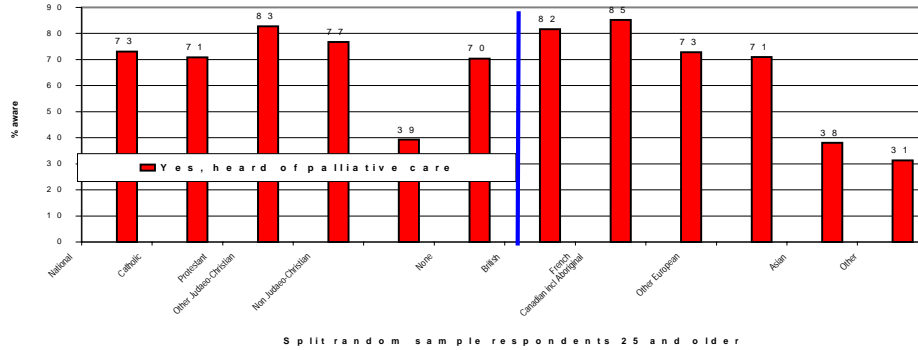
Three quarters of Canadians report being aware of palliative care. Awareness is lower among those of non-Judaeo-Christian religions and Asian ethnicity. Awareness is also higher among higher income groups.

Of those aware of palliative care:

- Six in 10 say a member of their extended family has used it
- One in four expects it to be needed for someone in their family in the next two year.
- This translates into a demand for about two million palliative care places.
- Four in 10 think more information on palliative care would be useful. Seniors are among those least likely to think so, and informal caregivers are among the most likely to think more information would be useful.
- By a wide margin, people would go to their physician to obtain palliative care
- Seven in 10 report services available in their community
- Home is by far the preferred option for receiving palliative care, with the palliative care centre garnering about twice the support as the hospital and nursing and long-term care facilities. However, the preference for home can vary considerably among religions, ethnic groups, regions and urban centres.
- The family physician, by far, is the most frequently chosen care giver, but there are significant regional variations.
- The single preferred option is to receive information on palliative care by mail. However, 'printed information at doctor's office' and 'private meeting' (presumably with physician) combined indicate that people large prefer to receive information in an informed and informative environment. There are no differences in preferences between those whose families had used palliative care and those whose families had not, nor between those who were and were not informal care givers.
- Consistently, across all groups, about two-thirds of respondents report they prefer to receive information on palliative care at home.

Looking at the dataset on palliative care as a whole, it appears that many people regard it as something that has to be dealt with in private. The attitudes underlying this are not clear. The data suggest that age and ethnic and religious considerations are significant factors.

Palliative Care: Three Quarters of Canadians Report Being Aware of Palliative Care; Awareness Associated with Religion, Ethnicity and Income



PC-AWARE I would like to ask you about palliative care which is a type of care for people who are very sick or dying. Palliative care focuses on making the patient comfortable, managing their pain and allowing them to have the best quality of life possible for the remainder of their life. Have you heard of palliative care before now?

Survey #23

Sample: Split random sample respondents 25 and older

January-April 2002

N=1,779

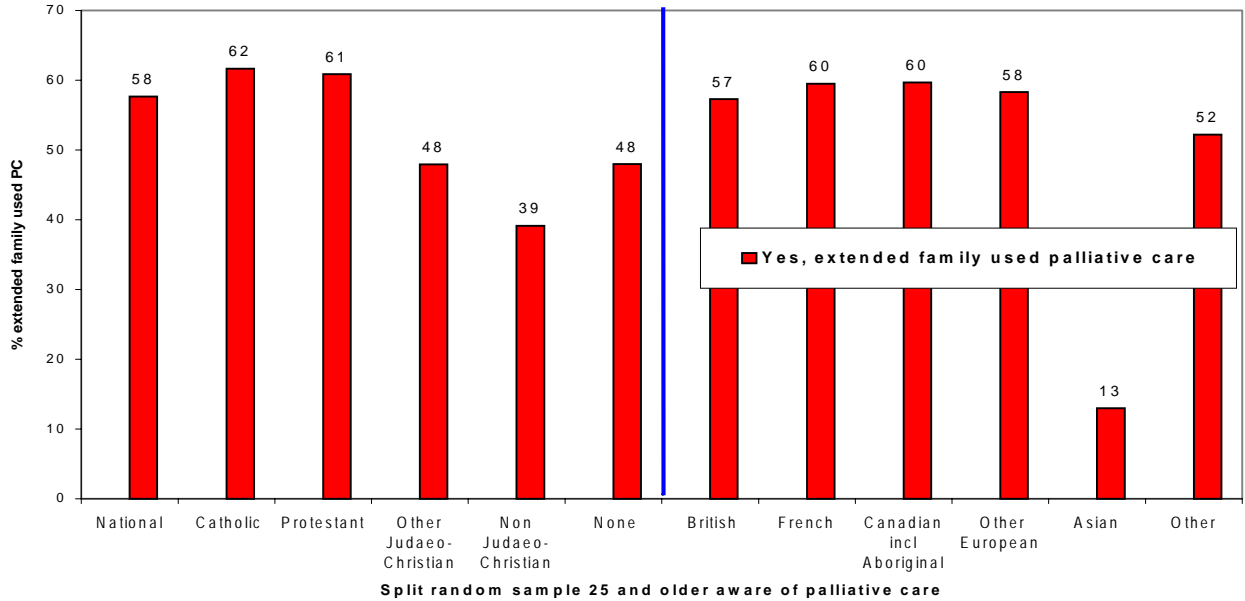
Overall:

Three-quarters of Canadians claim to be aware of palliative care.

Awareness, however, is much lower among non-Judaeo-Christian religions and among those who claim Asian and 'Other' ethnicity.

Awareness also associated with income. Those with higher income are more likely than lower income to report being aware of palliative care.

Palliative Care: Six in 10 of Those Aware of Palliative Care Report Extended Family Member Has Used It. Use Associated With Religion and Ethnicity



PCFAM Has anyone in your extended family, or a friend received palliative care services? (Extended family includes grandparents, parents, brothers, sisters and children.)

Survey #23

January-April 2002

Sample: split random sample 25 and older aware of palliative care

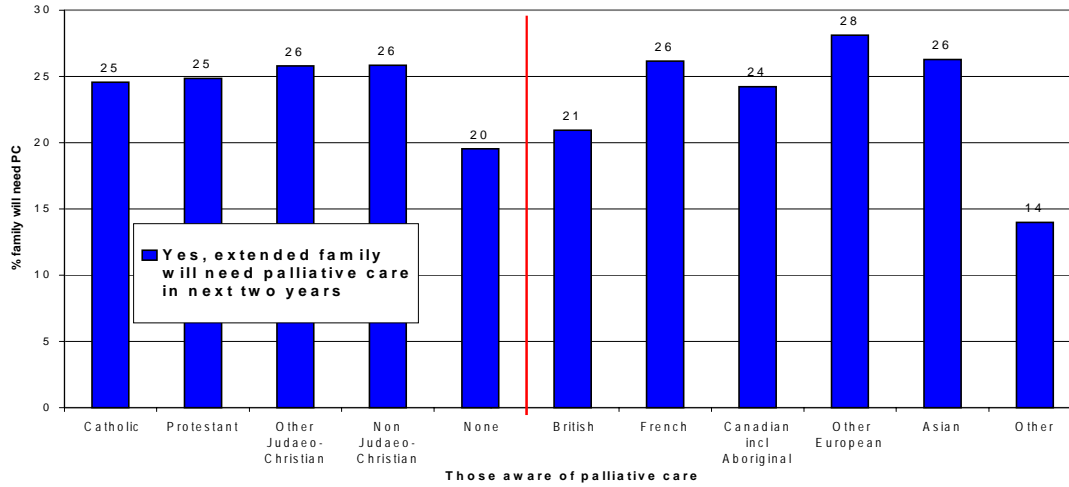
N=1,292

Overall:

As with awareness, use of palliative care by extended family members is more common in some religions and ethnic groups than in others.

Levels of use may relate to age averages of the various groups.

Palliative Care: One in Four of Those Aware of Palliative Care Expect Someone in Extended Family To Need It Within Two Years. Estimated Two Million Palliative Care Places Required



data

income

PCNEED Do you think anyone in your extended family will need palliative care services in the next two years? ((Extended family includes grandparents, parents, brothers, sisters and children.)

Survey #23

Sample: those aware of palliative care

January - April 2002

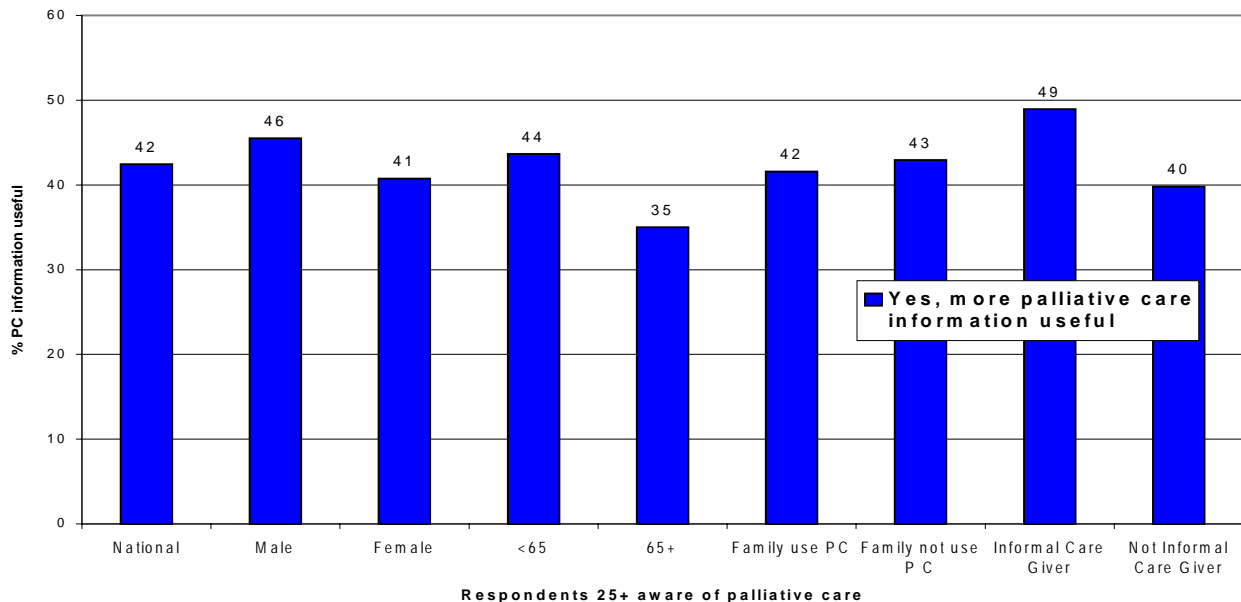
N=1,292

Overall:

Estimates of two-year need for palliative care suggests some two million places will be required. In 1998 (Survey #18) found that 13% of Canadians expected someone in their extended family would need palliative care services "in the next few years". The two estimates are close enough to provide a reasonable degree of confidence in what people expect to be needed.

Those who report no religion, and 'Other' ethnicity are among those least likely to expect someone in their extended family will need palliative care.

Palliative Care: No Major Differences Among Those Who Think More Information on Palliative Care Would Be Useful, Except Among Informal Care Givers



PCINFO Would it be useful for you to have more information on palliative care services in your community?

Survey #23

Sample: respondents 25 and older aware of palliative care services

January - April 2002

N=1,292

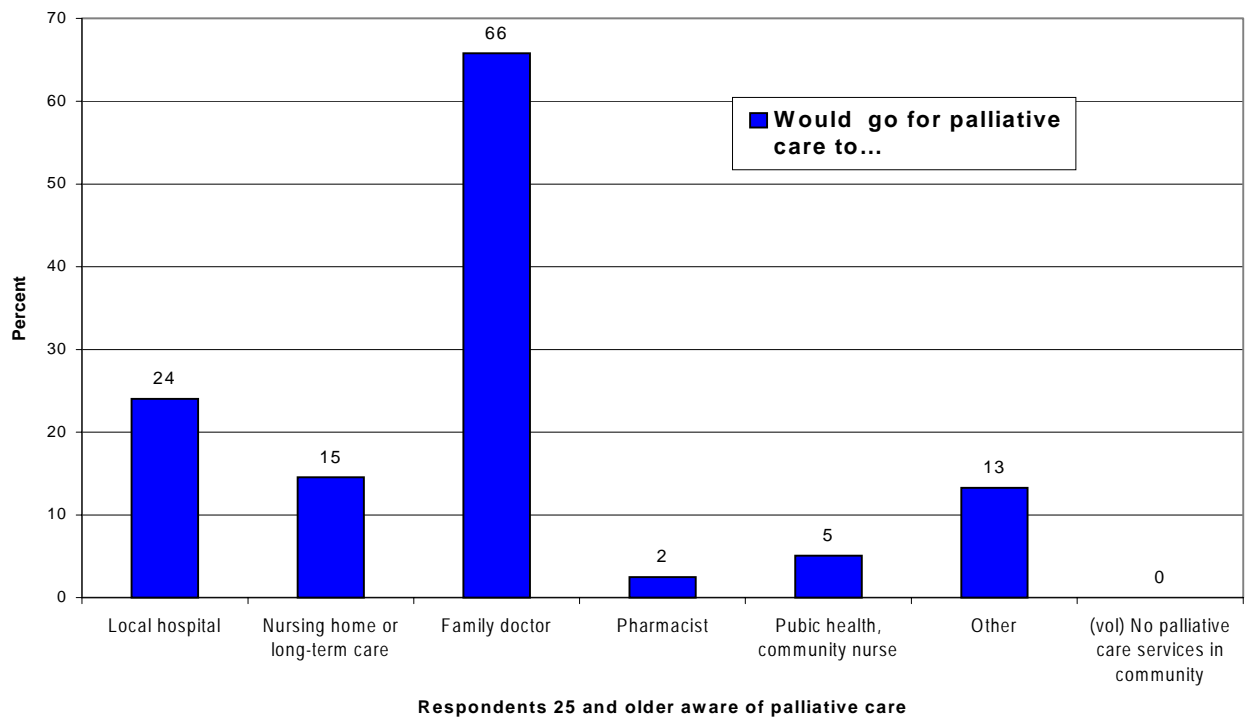
Overall:

There are no major differences among various groups who think that having more information on palliative care would be useful.

For example:

- Men are slightly more likely than women to think more information on palliative care would be useful - are the men simply being polite; perhaps the women think they already know what they think they need to know;
- There is no difference between those who expect extended family members to need palliative care services, or whose family members have already used such services, and those whose extended family have not had those experiences.
- There is a nine-point difference between those who are informal care givers and those who are not. This is the largest difference among the various groups - similar to that for seniors.
- Curiously, fewer seniors (65+) report interest in information on palliative care than do those under 65. We know from previous surveys that substantial proportions of those 65+ are informal care givers. One wonders if this reflects seniors' belief that they already know what they think they need to know, or perhaps are reluctant to acknowledge future needs. These possibilities might be considered in the development of marketing programs associated with palliative care.
- Asians, who rank among the lowest in terms of awareness and use of palliative care services, rank among the highest in believing that information on palliative care would be useful (62%) compared to about 40% for French and British combined.

Palliative Care: By A Wide Margin People Would Go To Their Physician To Obtain Palliative Care



PCWHO If you wanted to obtain palliative care for yourself or a family member, which of the following care givers would you go to in your community? Your local hospital, a nursing home or other long-term care institution, your family doctor, your pharmacist, or someone else?

Survey #23

Sample: those 25 and older aware of palliative care.

January-February 2002

N=1,292

Overall:

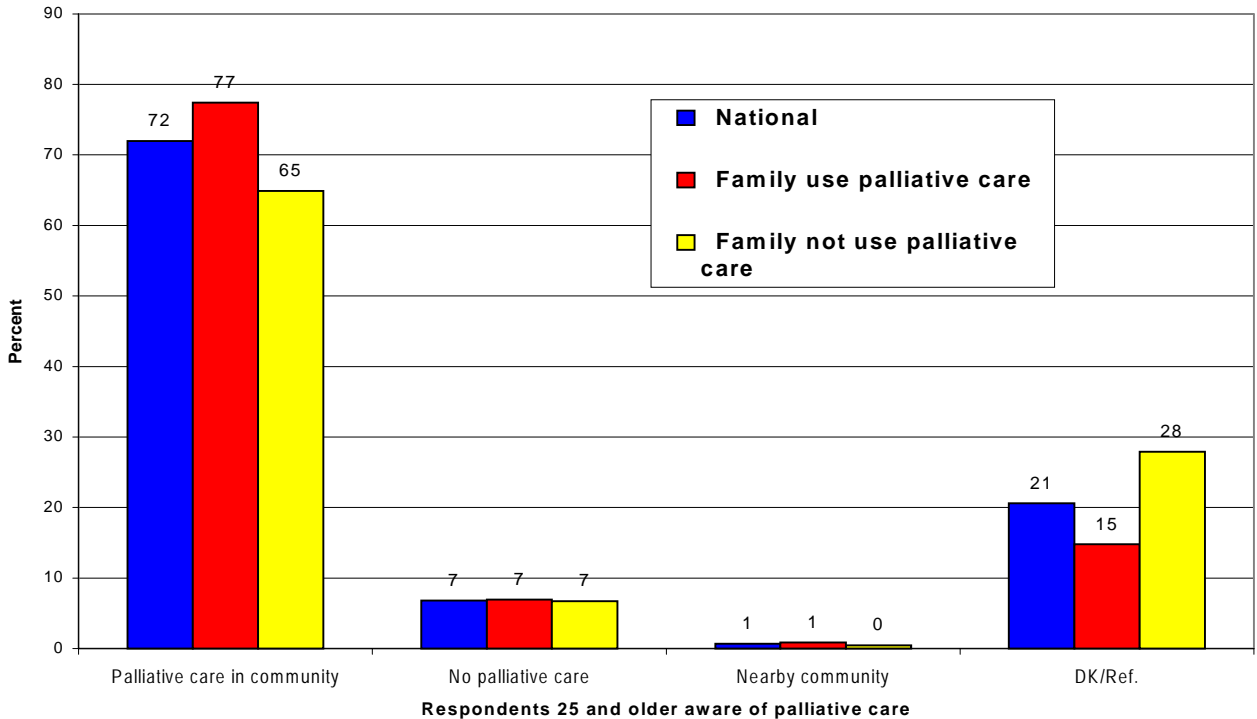
The physician is by far the favoured choice for people looking for palliative care for themselves or a family member.

The local hospital and nursing home are second and third choices respectively.

There are some differences among various groups.

- Those in the three largest cities - Vancouver, Montreal and Toronto - are the least likely to go to a nursing home or long-term care institution (10%), compared to 18% in rural Canada (communities under 10,000 population).

Palliative Care: Seven in 10 Of Those Aware of Palliative Care Report Services Available In Their Community



PCHERE Can someone who needs it obtain palliative care services in your community?

Survey #23

Sample: Respondents 25 and older aware of palliative care services

January-February 2002

N=1,292

Overall:

About seven in 10 (72%) of those aware of palliative care say that they have such services in their community.

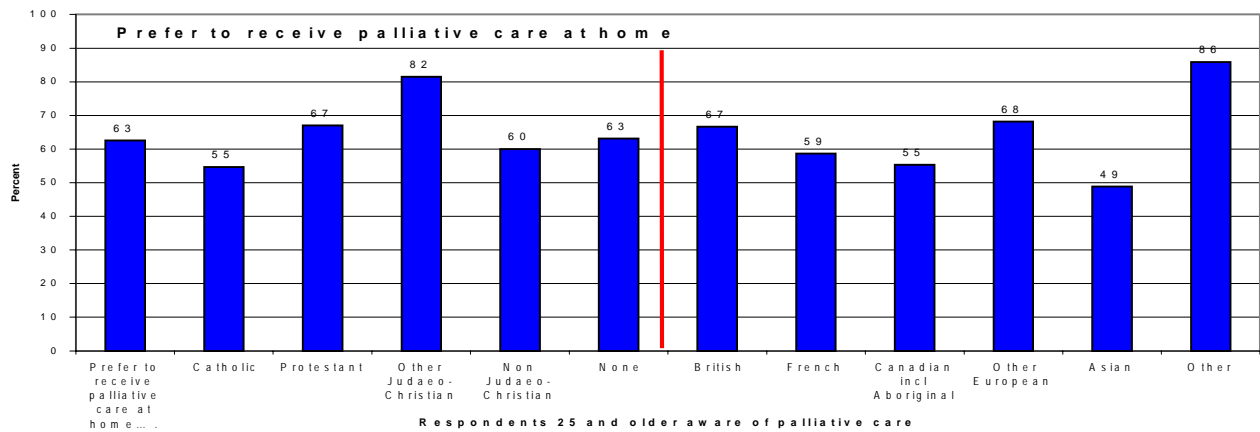
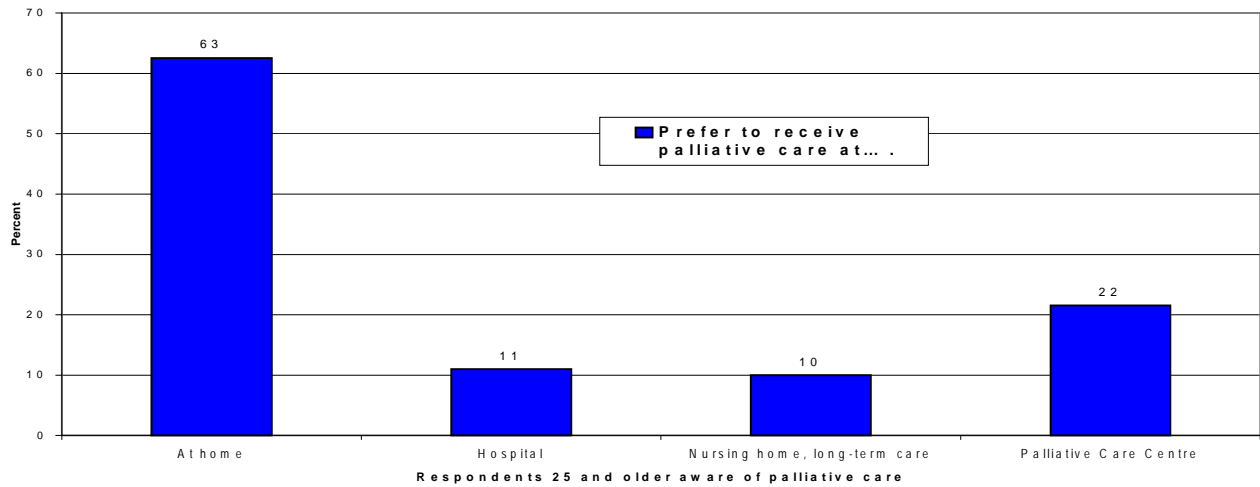
However, one in five (21%) report that they do not know.

Among those who have someone in their extended family who has used palliative care, or expects to use palliative care services, a somewhat higher percentage (77%) report the availability of palliative care services in their community compared to 65% of those whose extended families have not used, or expect to use palliative care.

In communities of 10,000-75,000, 81% say they have local palliative care services. This higher percentage, however, is due to a decrease in those who do not know, suggesting that in smaller communities some people have a better feel for what services are available.

Overall, the data suggests that perceptions of the availability of palliative care services tend to vary depending upon personal experience.

Palliative Care: Home is the Much Preferred Option for Palliative Care



PCWHERE If you needed palliative care, where would you prefer to receive it: 1. at home, 2. in a hospital, 3. in a nursing home or other long-term care housing, 4. in a palliative care centre?

Survey #23

Sample: those 25 and older aware of palliative care.

January -April 2002

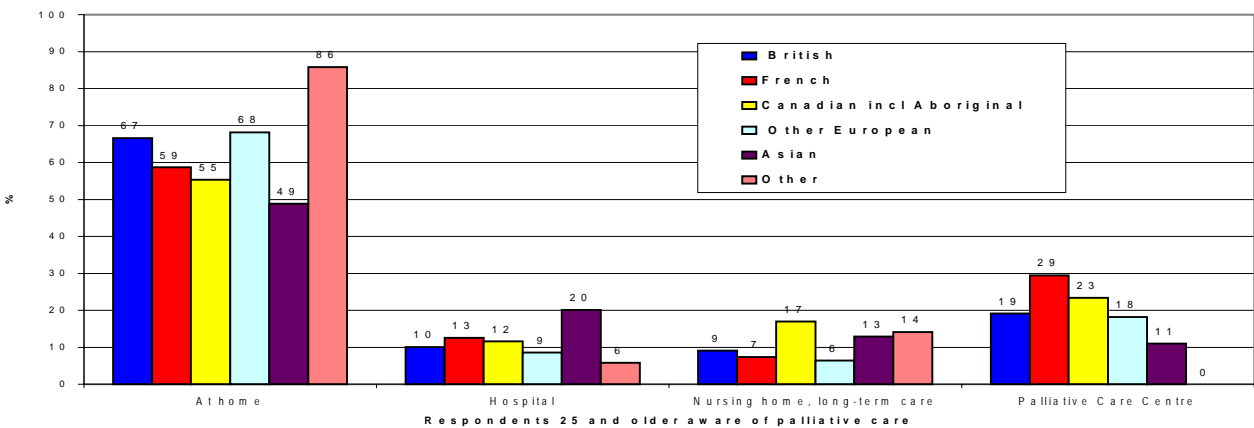
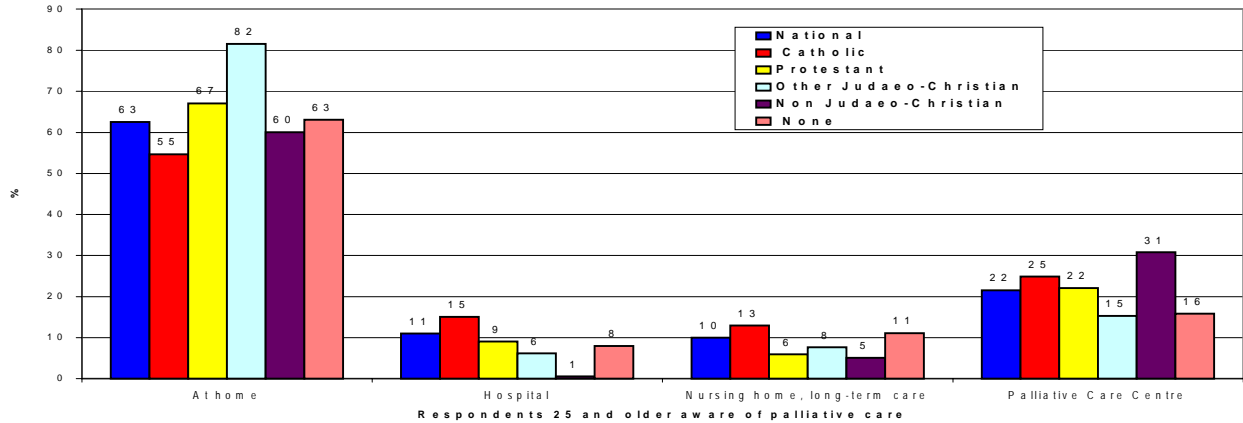
N=1,292

Overall:

Home is by far the preferred option, with the palliative care centre garnering about twice the support as the hospital and nursing and long-term care facilities.

However, as the lower chart indicates, the preference for home can vary considerably among religions and ethnic groups.

Palliative Care: Preferences for Preferred Site of Palliative Care Can Vary Significantly By Ethnicity and Religion



PCWHERE If you needed palliative care, where would you prefer to receive it: 1. at home, 2. in a hospital, 3. in a nursing home or other long-term care housing, 4. in a palliative care centre?

Survey #23

January -April 2002

Sample: those 25 and older aware of palliative care.

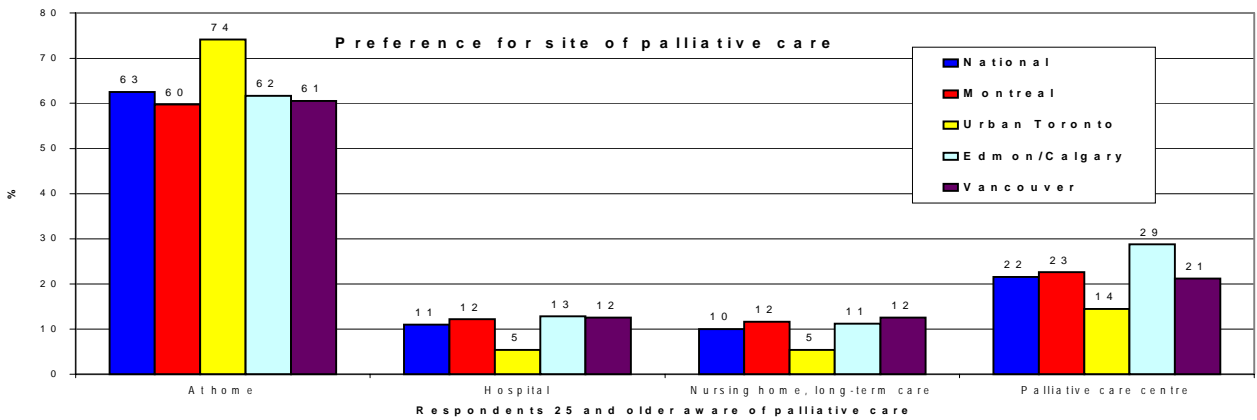
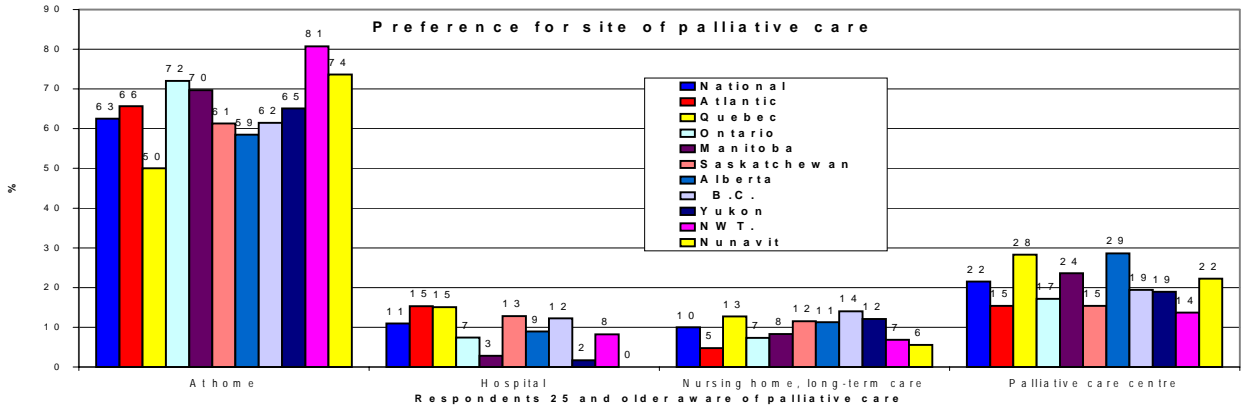
N=1,292

Overall:

These two charts provide a visual indication of the range of preferences by ethnicity and by religion. The Asian, Other and non-Juaeo-Christian subgroups are small, nonetheless, the indications are that preferences in these groups are not necessarily similar to those of other groups.

For example, it seems clear that non-Judaeo-Christian groups definitely do not want to receive palliative care in a hospital.

Palliative Care: Preferred Site for Receiving Palliative Care Varies By Region and By Major Urban Centre



PCWHERE If you needed palliative care, where would you prefer to receive it: 1. at home, 2. in a hospital, 3. in a nursing home or other long-term care housing, 4. in a palliative care centre?

Survey #23

Sample: those 25 and older aware of palliative care.

January -April 2002

N=1,292

Overall:

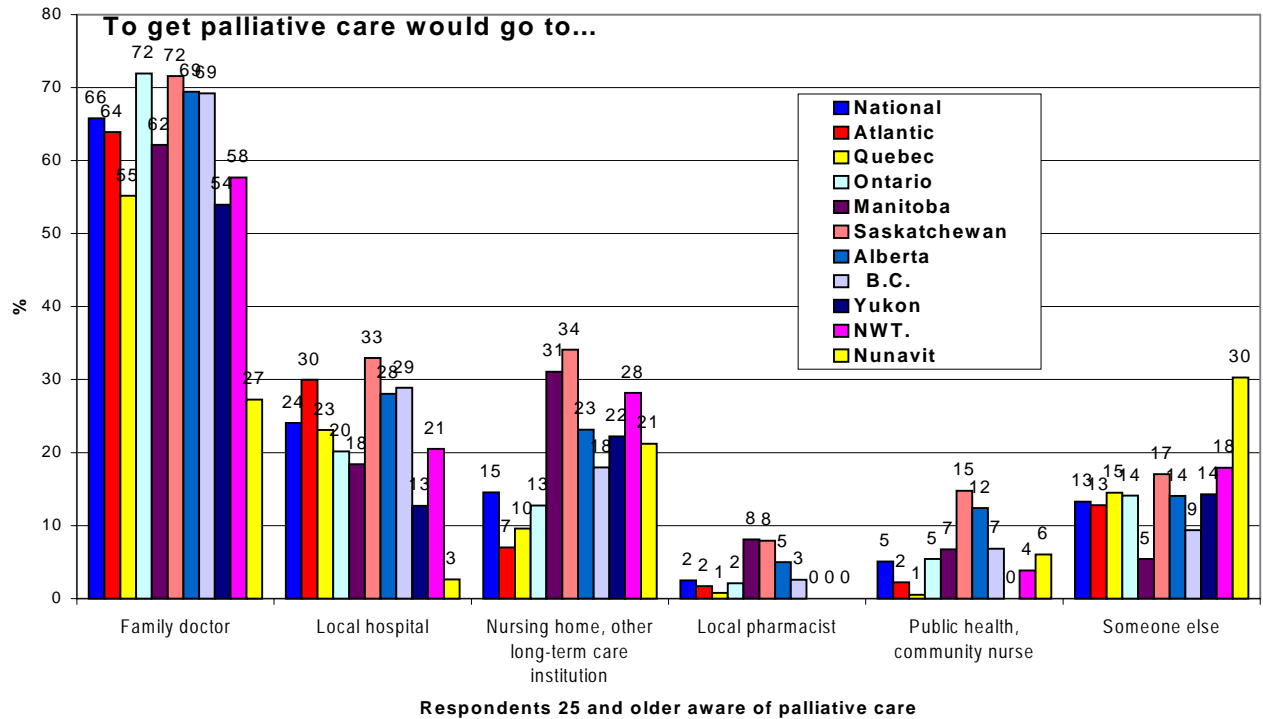
These charts provide a visual indication of differences among the major regions in the country, and the major metropolitan area (Urban Toronto reflects the former city of Toronto, not the Toronto CMA)

Here, as with religion and ethnicity, we see significant differences which reinforce the need to be sensitive to local and personal preferences.

For example:

- Quebec is the least likely to want palliative care at home.
- Manitoba and Yukon are the least likely to want palliative care in the hospital.
- Quebec is the least likely to want palliative care in a nursing home or other long-term care institution
- Urban Toronto is the most likely of the major urban centres to want palliative care at home.
- Urban Toronto is also the least likely to want it in the hospital, a nursing or other long-term care facility or a palliative care centre.

Palliative Care: In All Regions People Go To Family Physician, But Significant Regional Variations for All



PCWHO If you wanted to obtain palliative care for yourself or a family member, which of the following care givers would you go to in your community? 1. Your local hospital, 1. a nursing home or other long-term care institution, 3. your family doctor, 4. your pharmacist, 5. public health or community nurse or 6. someone else? (multiple choice)

Survey #23

Sample: those 25 and older aware of palliative care.

January -April 2002

N=1,268

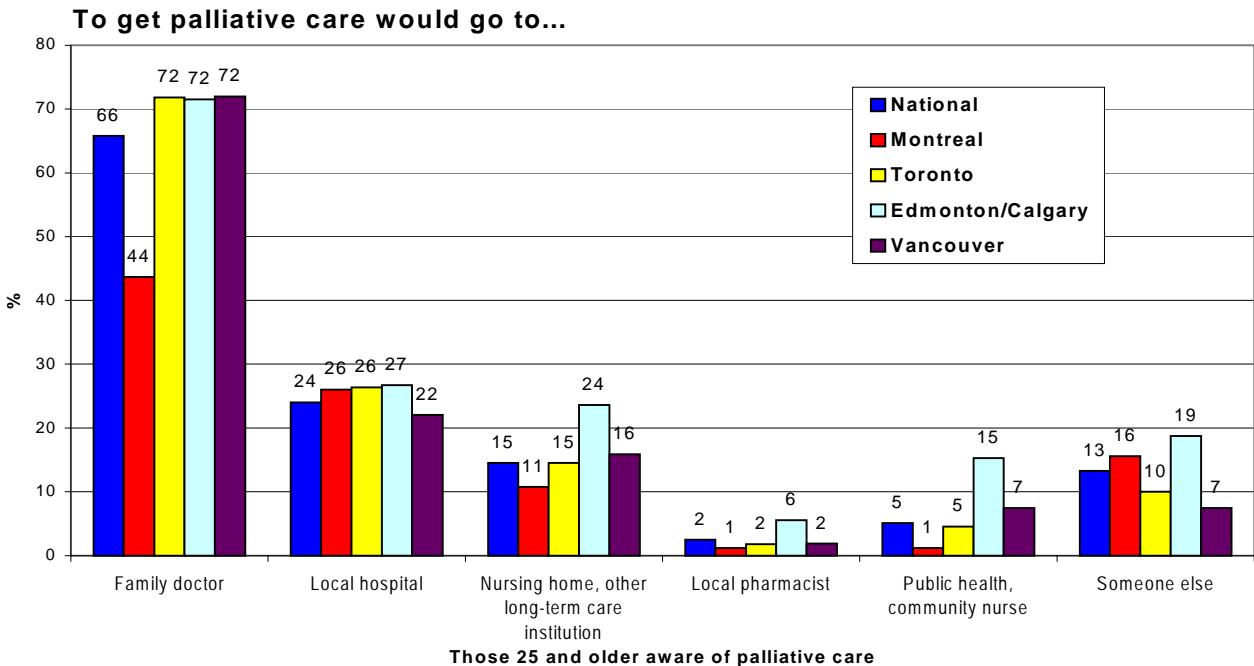
Overall:

The family physician, by far, is the most frequently chosen care giver, but as the clustering indicates there are significant regional variations.

For example:

- Quebec, Yukon and Nunavit are the least likely to select family physician.
- Manitoba and Yukon are the least likely to select the local hospital.
- Atlantic and Quebec are the least likely to select a nursing home or other long term care institution.
- Nunavit is the most likely to select 'someone else'.

Palliative Care: People Most Likely To Go To Family Physician, But There Are Variations Among Major Urban Centres As Among Regions



PCWHO If you wanted to obtain palliative care for yourself or a family member, which of the following care givers would you go to in your community? 1. Your local hospital, 1. a nursing home or other long-term care institution, 3. your family doctor, 4. your pharmacist, 5. public health or community nurse or 6. someone else? (multiple choice)

Survey #23

Sample: those 25 and older aware of palliative care.

January -April 2002

N=1,268

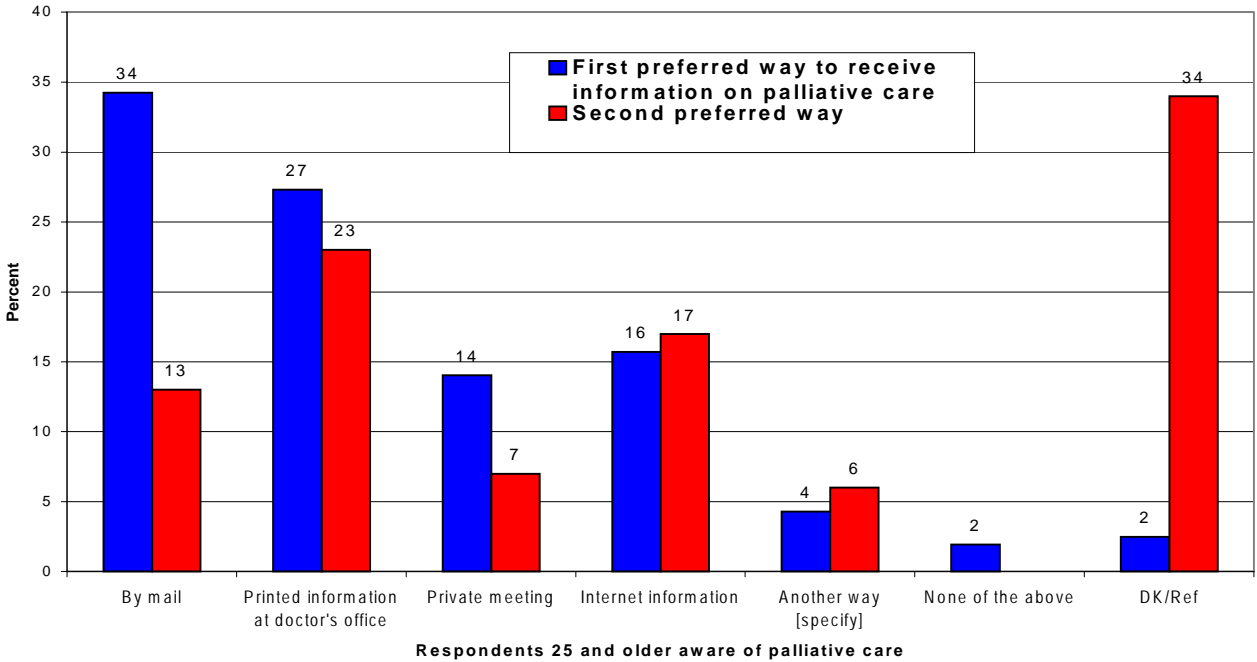
Overall:

Looking at the major urban centres across the country, we can see significant variations.

For example:

- Montreal, like Quebec as a whole, is the least likely to mention the family physician.
- Selection of the local hospital is consistent across the country.
- Edmonton and Calgary are the most likely to select a nursing home - although they are no more likely than people in other locations to want to receive palliative care in a nursing home or long-term care institution
- Edmonton and Calgary are also the most likely to select a public health or community nurse.

Palliative Care: Mail is the Single Preferred Option To Receive Information on Palliative Care; But Aggregate Preferences Involve Contact With Physician



PCINFOHOW Which two of the following ways would best suit you to receive information on palliative care?

Survey #23

January -April 2002

Sample: respondents 25 and older aware of palliative care

N=1,292

Overall:

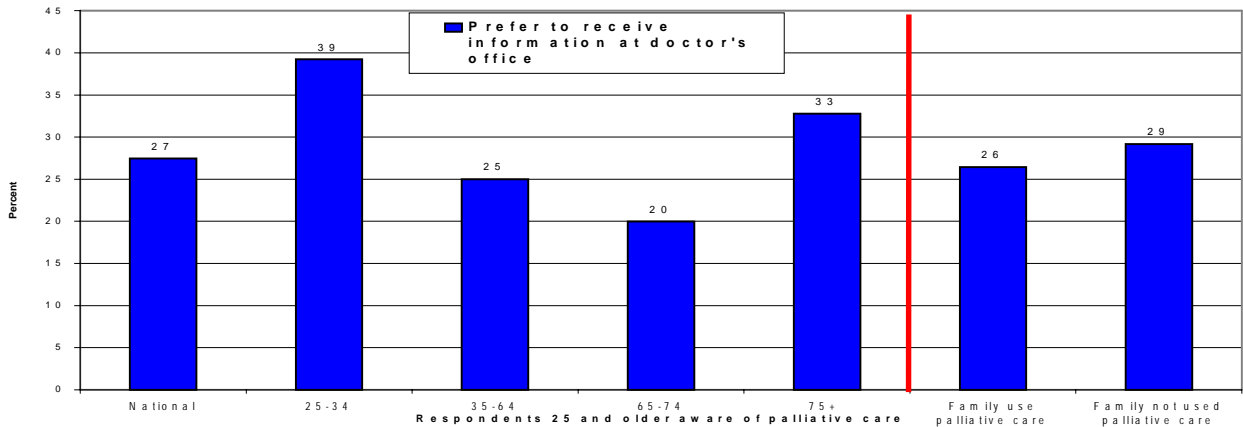
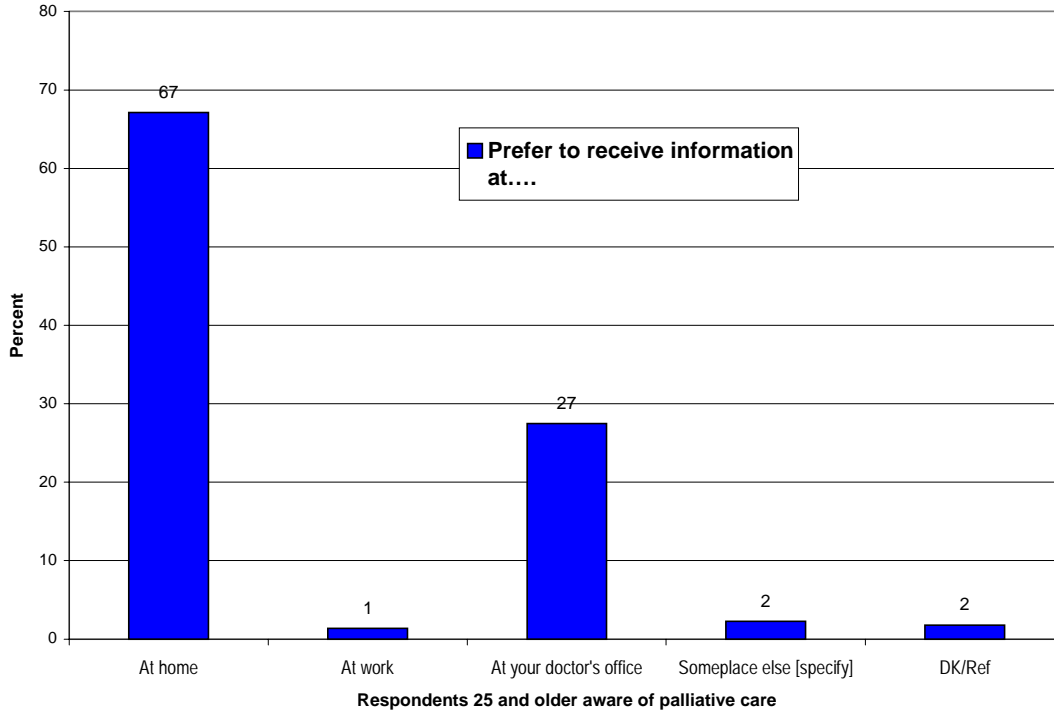
The single preferred option is to receive information on palliative care by mail.

However, 'printed information at doctor's office' and 'private meeting' (presumably with physician) combined indicate that people large prefer to receive information in an informed and informative environment.

It is interesting that 'Internet information' received such a comparatively strong showing. It may reflect a prefer among many to obtain information proactively but also privately without having to explain or ward off recommendations.

There are no differences in preferences between those whose families had used palliative care and those whose families had not, nor between those who were and were not informal care givers.

Palliative Care: Most People Prefer To Receive Information on Palliative Care At Home. Data Suggest Public Associates Palliative Care With Privacy



PCINFWHR Given your preferences would you prefer to receive this information: 1. at home, 2. at work, 3. at your doctor's office, or 4. someplace else?

Survey #23

January-April 2002

Sample: respondents 25 and older aware of palliative care

N=1,292

Overall:

Consistently, across all groups, about two-thirds of respondents report they prefer to receive information on palliative care at home.

There are differences, however, across age groups with regard to the doctor's office.

- younger and older people are more likely to prefer the doctor's office
- there is no statistical difference between those whose family members have used palliative care and those who have not.
- there is also no difference in the preferences of men and women.

Looking at the dataset on palliative care as a whole, it appears that many people regard palliative care as something that has to be dealt with in private. The attitudes underlying this are not clear. For example, is palliative care something not to be discussed because of its association with death? Is there something shameful associated with it? Perhaps, the subject is so painful that people prefer to face first in private.

The data suggest that age and ethnic and religious considerations are significant factors.