Care of the Seriously Ill in the Community

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Key Implications for Decision Makers

Many terminally ill people wish to die at home, causing an increased demand for homecare services, both from the patients and from their families and friends who give informal care.

- Palliative care in the community needs to be organized to allow different professions to work together in multidisciplinary teams, including the use of advanced practice nurses.

- Health professionals need more education about palliative care. This can start at a basic level by including palliative care in all health professional school curricula.

- People need more care the closer they are to death, and caregivers need more support as their family member gets weaker. Policies on providing palliative care in the community should be flexible to respond to this need. This will also make it easier for people to die at home.

- Governments need to address the following factors if they want to make palliative homecare more flexible and improve continuity of care: increasing staff, improving access to specialized care, increasing the availability of family physicians, increasing funding for support services, and re-examining the competitive process cities use to hire homecare agencies.

- People who die at home should be able to access palliative homecare earlier than they currently do. Most often, families are referred to the community care access centre only immediately prior to death.

- People who care for the terminally ill often lose income, as they have to reduce their work hours or stop working because of caregiving demands. Informal caregivers need financial support, which will make it easier for them to care for their family members, in turn making it easier for people to die at home.

- Caregivers of the terminally ill face emotional strain and isolation. They require practical help as well as emotional support.
Executive Summary

This study describes the experience of caring for the terminally ill in the community. It does so by investigating the types of care used, the experiences of those involved in caregiving and bereavement, and their satisfaction with community services.

Researchers found that caregivers feel strained in many ways. Most say the people they care for are limited in the daily activities they can do. The caregivers feel confined, isolated, helpless, and exhausted. They also often have to reduce their professional work hours or stop working because of the time they must spend on care, leading to a loss of income. As a result, caregivers not only require practical help and emotional support, they also need financial help. They are not getting these kinds of help, and policies to address these needs must be developed.

The terminally ill use hospital care and palliative homecare co-ordinated by community care access centres. Most families get homecare services only immediately prior to death, though, whereas for the best care they should have access to palliative services earlier. If families could get support sooner, there would be great potential to ease the strain on caregivers. As well, early access to homecare services may decrease hospital admissions; these increase dramatically in the months just before death. Family physicians and other referring professionals should work with families to increase early access to community palliative care.

Some barriers to adequate service remain even when families are able to get community palliative care. First, services are not flexible in response to changing care needs. As death approaches, people need more care; however, delivery models give each person a
set amount of services. Second, patients lack continuity of care. Continuity is defined as patients receiving care from the same person, or at least from the same agency; staff having special training in palliative care; staff using a consistent care plan; a multidisciplinary team delivering care; and staff delivering care based on the status, goals, and expectations of the patients and their families. Some factors that case managers from community care access centres cited as barriers to this continuity are staff shortages, reduced access to specialized care, not having a family physician or having a family physician who does not make house calls, limited funding for support services, and the competitive process cities use to hire homecare agencies. In order to improve community palliative care services, these concerns need to be addressed.

One way to deal with some of these concerns is to make it easier for health providers from various disciplines to work together in teams. This would allow for holistic care and facilitate consultation between healthcare providers. In this way, expertise in palliative care could best benefit the family. To address limited staff availability, access centre case managers recommended using advanced practice nurses who have additional training or certification in palliative care to care for patients who are dying. Overall, there needs to be a mechanism to make sure care is delivered seamlessly, even when taking into account funding, accountability, and communication.

The research team also found that health providers giving palliative services might not have specialized palliative care training. To improve this knowledge among health professionals, palliative care topics should be included in the basic level curriculum of all
health professional schools. Also, financial support should be provided to health professionals for ongoing education to ensure that a range of health providers and case managers in the community have some expertise in the delivery of palliative care.

When caregivers knew that death was inevitable, they were able to prepare practically and emotionally by adopting coping strategies. Family and friends were the principal sources of informal practical and emotional support, and formal supports were clergy and family physicians. During bereavement, caregivers needed to interact with others so they could come to an acceptable understanding as to why death occurred. Family and friends played an important role in the recovery process. However, formal care providers should also be prepared to assess and treat complicated grief and bereavement-related depression.

Information for this study was gathered by telephone and home interviews with caregivers and care recipients, and through six focus groups with community care access centre case managers in Southern Ontario.
Background

The healthcare system is changing rapidly, particularly in the care of the terminally ill, which is moving from institutions to the community. Current government policy is in favour of more and better care for the terminally ill in the community (Canada, Special Committee on Euthanasia and Assisted Suicide, 1995; Hamilton-Wentworth District Health Council, 1996; Health Services Restructuring Commission, 1998; Metropolitan Toronto District Health Council, 1997). Several factors encouraged this move to dying at home, including the preference of the terminally ill and their families, recognition that medical care has limits, improvements in home-based medical technology and pharmacology, and hospital restructuring and the resulting closure of hospital beds (Sanker, 1993; Stajduhar and Davies, 1998). A growing elderly population is providing further impetus for developing home-based palliative care programs (Brown, Davies and Martens, 1990; Steele and Margaret, 1996).

During this period of transition, it is necessary to critically examine how services are delivered and how suitable they are for the terminally ill and their family caregivers. A particular gap in our knowledge is what pressures family caregivers feel when home death is central in planning care for the terminally ill. Inadequate or inappropriate support to these caregivers results in misusing costly and limited resources, adding burden to the family and contributing to prolonged grief for the survivors (Grunfeld, Glossop, McDowell and Danbrook, 1997; Hinton, 1994; Hanson, Danis, and Garrett, 1997; Fakoury, McCarthy, and Addington-Hall; 1996).

Timely and appropriate community services are necessary to support the terminally ill and their family caregivers, particularly in light of the downsizing of Canada’s hospital sector. There is a lack of strong evidence regarding the use and effects of community palliative care and bereavement support services. Of the limited research done to date, most has been conducted in the United States and the United Kingdom. Very little primary research dealing with palliative care support has been done and supported in Canada (Viola, Moher, Coyle, Grunfeld, Ross et. al., 1998). A proper assessment is required to understand the role of homecare and its place in supporting death in the home.
The goal of this study, funded jointly by the Canadian Health Services Research Foundation and the Ontario Ministry of Health and Long-Term Care, is to describe the type of formal and informal care used by the terminally ill and factors associated with care and service satisfaction. Study objectives include:

- describing the pattern of informal and formal care used by the terminally ill and their caregivers;
- describing family caregivers’ reactions to providing care, bereavement, and bereavement care; and
- determining the factors which influence family caregivers’ and the terminally ill’s satisfaction with community services.

Information gained from this study will help us develop recommendations to 1) improve current services reported to be useful by family caregivers and the terminally ill; 2) develop new services based on need; and 3) plan for profession-specific specialities to meet anticipated needs due to hospital restructuring, population growth, and increasing disease rates.

This report outlines study methods and measures employed in this study. We provide a description of caregivers and older family members who are typically referred to community care access centres for palliative care. We identify documents that are being written based on the findings of this project and that will be posted on the project’s web site. Finally, we summarize dissemination and provider partnership practices that transpired during the course of the study.

Study design

The goal of this study was to systematically collect and synthesize information that would provide a complete description of care of the terminally ill in the community. The use of several different information sources allowed us to address a broad range of issues and to develop converging lines of inquiry. Five primary sources provided data: telephone interview surveys with family caregivers; in-depth home interviews with
caregiver/care recipient pairs; in-depth home interviews with caregivers in bereavement; focus groups with community care access centre case managers; and analysis of the Ontario Ministry of Health and Long-Term Care’s databases. Each component is described below.

1) Caregiver telephone survey

Family caregivers participated in a telephone interview twice: when the terminally ill person was designated as palliative by a community care agency and six months later. In the event that the patient died during the study period, the caregiver participated in a bereavement interview held three months after the death.

Sample

To be included in the study, the terminally ill people had to be 50 years or older at the time of designation, residents of the catchment area of the participating access centre, and designated as palliative by the participating access centre. The family caregivers had to be residents of the catchment area of the participating access centre and able to communicate well in English. Study locations were the catchment areas of six access centres: Hamilton (urban base); Brant (urban/rural mix), Haldimand-Norfolk (rural base), Waterloo Region (urban/rural mix), Wellington-Dufferin (urban/rural mix), and Windsor-Essex (urban/rural mix).

Procedure

Case managers from the access centres or staff from the visiting nursing agencies identified potential caregiver participants, described the study to them, and obtained their consent to give their names and contact numbers to the researchers. An information letter was left with the family, or the investigators mailed the letter seven days before making telephone contact. The letter informed the potential caregiver participants about the study and advised them that they would receive a telephone call unless they contacted the investigators to decline participation. Participants who were contacted by phone were reminded of the letter and invited to participate in the study. The phone call also gave
potential participants an opportunity to ask questions about the study. If a respondent agreed to participate, a convenient time was arranged for an interview.

Palliative care specialists provided training to the telephone interviewers on issues related to grief and bereavement. A palliative care specialist was available to the interviewers in case they experienced a stressful interview. If an interviewer identified caregivers in distress, the interviewer asked for permission from the caregiver to contact someone in a community care agency who could help them. After the caregivers participated in the interviews, the investigators sent thank-you letters. In the event that the care recipient had died, the caregiver also received written condolences from the investigation team.

**Interview schedule**

The interviewers collected data on patient and caregiver characteristics. The patient characteristics were sex, age, marital status, diagnosis, living arrangements, functional dependence, pain, pain management, stated preferred place of death, and place of death. Formal services used by the patient were also recorded. The caregiver characteristics were sex, education, employment status, self-report of health status, caregiving experience, and social support networks.

The Caregiver Strain Index (Robinson, 1983) was used to assess the experience of caregiving. Caregivers responded “yes” (1) or “no” (0) to 13 items representing various areas where caregivers feel strain (for example, physical, personal, family, or financial). Total scale scores ranged from 0 (no strain) to 13 (high strain). The internal consistency of the index is high (0.86). Construct validity of the measure was also supported by correlating total index scores with care recipient characteristics, caregivers’ subjective views of the caregiving situation, and the emotional well-being of caregivers (Bradburn and Caplovitz, 1965; McNair, Lorr, and Droppleman, 1971).

The 10-item modified Barthel Index (Collins, Wade, Davies, and Horne, 1988) was used to assess the patient’s functional dependence. This instrument assessed 10 activities that covered personal care and mobility. Within each activity the respondent rated the activity
on a three-point scale, depending on whether the care recipient could perform the task independently, with some assistance, or not without help. The overall score ranged from 0 (independent) to 20 (high dependence). Where the care recipient required assistance the respondent indicated who provided assistance. Categories included the respondent (caregiver), other family members, friends or neighbours, unpaid volunteers, and paid healthcare workers.

Recording how many services the care recipient used was modelled after the interview protocol used in the Canadian Study of Health and Aging (1994). Interviewers reviewed a comprehensive list of services with the respondents. If a respondent reported using a specific service within the four weeks before the interview, the interviewer completed a structured interview that recorded whether there was a waiting list, if they paid for the service, if the service was reliable, if it met the family’s needs, and if they were satisfied with the amount and quality of help received. If the patients had not received the services, respondents were asked for reasons why they did not use them.

**Selected findings**

Five hundred and thirty individuals agreed to participate in the study. Figure 1 outlines participation rates. In this study component findings will be drawn from the first interview with caregivers (N = 373). In this sample the average age of the care recipients was 70 years (SD = 9.45) and the average age of the caregivers was 62 years (SD = 12.06). Other characteristics of the study group are shown in Table 1.
Figure 1
Flow of caregiver participants through telephone survey component of the study, showing the sample size in each interview component.

Table 1.
Characteristics of study population (N = 373)

<table>
<thead>
<tr>
<th>Care Recipient Characteristics</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex (percentage female)</td>
<td>147 (39.4)</td>
</tr>
<tr>
<td>Diagnosis (percentage with cancer)</td>
<td>348 (93.3)</td>
</tr>
<tr>
<td>Sex (percentage female)</td>
<td>281 (75.3)</td>
</tr>
<tr>
<td>Relationship to Care Recipient</td>
<td></td>
</tr>
<tr>
<td>Spouse</td>
<td>284 (76.1)</td>
</tr>
<tr>
<td>Child</td>
<td>62 (16.6)</td>
</tr>
<tr>
<td>Extended family</td>
<td>27 (7.2)</td>
</tr>
<tr>
<td>Lived with Care Recipient</td>
<td>340 (91.2)</td>
</tr>
<tr>
<td>Not employed outside the home</td>
<td>227 (60.9)</td>
</tr>
<tr>
<td>Education of Caregiver</td>
<td></td>
</tr>
<tr>
<td>Elementary completed</td>
<td>132 (35.4)</td>
</tr>
<tr>
<td>Secondary completed</td>
<td>157 (42.1)</td>
</tr>
<tr>
<td>College completed</td>
<td>37 (9.9)</td>
</tr>
<tr>
<td>University completed</td>
<td>41 (11)</td>
</tr>
</tbody>
</table>
Most caregivers (332 or 89 percent) reported that the care recipient had some problems functioning. The number of caregivers providing assistance in specific functional activities was as follows: bathing, 225 (60 percent); dressing and undressing, 198 (53 percent); mobility, 183 (49 percent); and toileting, 62 (17 percent).

Two hundred and thirty-five (63 percent) respondents reported that caregiving was confining; 164 (44 percent) caregivers reported that caregiving was a physical strain; and 114 (32 percent) caregivers reported that they had to adjust their work arrangements to assume caregiving responsibilities.

Employment adjustments included quitting their job, reducing time worked, and taking a leave of absence from work. Ninety (24 percent) respondents reported that caregiving was a financial strain, either because of lost income or the costs of medications, responding to special dietary needs, and purchasing or renting equipment.

2) In-depth home interviews with caregiver/care recipient pairs
A qualitative research strategy was used to examine the family caregiving experience.

Sample
Study participants were recruited for face-to-face interviews over a six-month period in 2001. Participants (spouses or adult children looking after a terminally ill family member plus the care receiver) were drawn from the population of 373 caregivers who had participated in the caregiver telephone survey. Family pairs were deliberately selected from the telephone survey sample to ensure maximum variation in the caregiving experience so the research team could document differences in the caregiving experience.
Procedure

After the telephone interview, selected caregivers were invited to participate in a face-to-face interview. The project co-ordinator called those who expressed an interest in this part of the study and who gave their permission to be contacted. Upon contact, interested caregivers were informed that they and the care recipient would be interviewed separately in their home. If they were willing, a home interview was scheduled.

Two trained members of the research team conducted the individual interviews in the pair’s home. At the start of the interview, the interview team met with both members of the pair to explain the purpose of the interviews and why they were being conducted separately (so that each person could freely express his or her views about giving or receiving care). After obtaining oral and written consent, each interviewer conducted an audio-taped interview separately with each person. After leaving the home, the interviewers held a debriefing session in which they described aspects of the pair and the home that might provide contextual cues to help interpret the information received during the interviews.

Audio tapes of each interview were transcribed to create verbatim written accounts. The interviewers cleaned the tapes (compared the audio-taped and written versions of each interview) and made corrections as needed. To preserve participant confidentiality and anonymity, all identifying information captured on tape was removed from the transcripts.

Interview schedule

Two parallel versions of an interview guide were developed for care recipients and caregivers. Topics for the semi-structured interview included 1) perceptions on formal services (what worked well, what did not work well, what was missing from services accessed, and what should be changed); 2) informal support (who provided what type of assistance, what type of support was most appreciated, what was missing from the support received, and what should be changed); and 3) the caregiving experience (what aspects of caregiving were most satisfying, most difficult, and most unexpected, as well
as advice for new palliative caregivers). Prior to conducting the interviews, the interview
guides were tested with two care-receiver/caregiver pairs recruited through a local
hospice care agency. This testing led to revisions to the protocol and interview questions.

**Selected Findings**

Twelve family pairs participated in this component of the study. By inviting family
caregivers to discuss their experiences and points of view, we can learn what home-based
palliative caregiving is like for spouses and adult children.

- This study component identified many of the negative reactions to caregiving
  reported elsewhere in the literature, including exhaustion, isolation, and
  helplessness in watching the decline of the family member.

- Participants identified positive aspects of caring for a family member. These
  include the opportunity to strengthen the relationship, the discovery of emotional
  strength, and the identification of previously unknown abilities.

- When asked to provide advice for new caregivers, participants readily came
  forward with a number of suggestions that ranged from taking good care of
  oneself to being flexible and willing to take on whatever caregiving brings.

3) **In-depth home interviews with caregivers in bereavement**

A qualitative research strategy was used for face-to-face interviews over a six-month
period in 2001 around issues of bereavement and bereavement care for family caregivers.

**Sample**

Participants (spouses or adult children looking after a terminally ill family member) were
drawn from the population of 207 bereaved caregivers who had participated in caregiver
telephone survey. Family caregivers were deliberately selected from the telephone survey
sample to ensure maximum variation in the bereavement experience and document the differences in bereavement situations.

**Procedure**

After the telephone interview, selected caregivers were invited to participate in a face-to-face interview. The project co-ordinator called those who expressed an interest in this part of the study and who gave their permission to be contacted. The project co-ordinator explained the in-home interview portion of the study to them and scheduled a home interview.

A trained member of the research team conducted the interviews in the caregiver’s home. The interviewer explained the purpose of the interview, obtained oral and written consent, and then conducted an audio-taped interview with the family caregiver. Audio tapes of each interview were transcribed to create a verbatim written document. The interviewers cleaned the tapes (compared the audio-taped and written versions of each interview) and made corrections as needed. To preserve respondent anonymity and confidentiality, all identifying information captured on tape was removed from the transcripts.

**Interview schedule**

Topics for the interview included the caregivers’ current situation, how they were coping, and the types of support they were receiving. The interview also explored how the care recipient died, including place of death and appropriateness of place of death.

**Selected Findings**

Twelve family caregivers participated in this portion of the study. The results of this study component describe bereavement reactions among a sample of adults who were caregivers for older adults.
• In discussing bereavement, a number of caregivers explained that they had known for some time that the death of their loved ones was inevitable. This knowledge had enabled them to prepare both practically and emotionally, adopting coping strategies specific to their needs.

• Caregivers who appeared to have more trouble coping were younger participants in their 50s and 60s.

• Caregivers received their primary informal emotional and practical support from friends and family members. Clergy and family physicians were the primary sources of formal emotional support.

4) Case managers’ perspectives on continuity of care for terminally ill patients and their families

The purpose of this feature of the study was to explore the views of community care access centre case managers about what leads to the best continuity of care for palliative care patients and their families.

Sample

Focus groups were employed that included case managers from six access centres: Brant, Haldimand-Norfolk, Waterloo, Wellington-Dufferin, Niagara, and Halton. The investigators obtained approval from the executive directors of the centres before asking their staff members to participate in the focus groups.

Procedure

Initial contact with the case managers took the form of a letter from the research team informing them about the focus groups and asking them to participate. The project coordinator followed the letter with a telephone call to focus group candidates. This call served the purposes of describing the objectives and format of the focus group session,
answering questions, and getting agreement to participate. Once the participants agreed, the project co-ordinator scheduled a time to conduct the focus group.

A critical incident approach was used to find factors associated with good or poor continuity of care. The strength of this technique is that it seeks information on both the positive and negative aspects of care provision from those closely involved — in this instance, access centre case managers. Transcripts from the focus groups were analysed in INVIVO and analysed inductively by the research team to identify key themes.

**Interview schedule**

Focus group questions examined how participants conceived the notion of continuity of care for the study population. Respondents were asked to provide details of incidents where “continuity of care could have been better” and where “continuity of care went particularly well.” Respondents were encouraged to make detailed descriptions of the incidents they selected so that factors that contributed to good or poor continuity of care could be identified. Finally, participants were asked to suggest strategies that could improve continuity of care for the study population.

**Selected findings**

Thirty-eight case managers participated in six focus groups representing six community care access centres located in south-central Ontario. The following themes emerged:

- Good continuity of care was provided if the family received care from the same staff person or the same agency; if the service provider had specialized training in palliative care; and if a consistent care plan was delivered by a multidisciplinary team based on the status, goals, and expectations of the patients and their families.

- Poor continuity of care was associated with staff shortages; not having a family physician or having a family physician who did not make house calls; the absence of specialized care; limited funding for support services; and the competitive
process that cities use to hire homecare agencies for professional services, supplies, and equipment.

5) Service use during the last year of life

One of the objectives of this project was to identify patterns of formal service use and factors that predicted formal service use. These findings will help the team develop recommendations to 1) improve current services; 2) develop new services based on need; and 3) plan for profession-specific specialties to meet the needs or anticipated increases in need due to hospital restructuring, population growth, and increased disease rates. To accomplish these objectives, it is necessary to understand current patterns of use. This knowledge serves two functions. First, it helps to place the qualitative component of the study, aimed at informal care giving, within a context of formal service use. Second, it serves to measure changes in availability, access, and use resulting from hospital restructuring.

Method

The sample for this study included all those people who lived in Brant, Haldimand-Norfolk, Halton, Hamilton, Niagara, Wellington-Dufferin, or Waterloo counties of Ontario at the time of their death in 1996. Combined, these counties have a population of approximately 1.7 million people. The study was limited to those persons who had lung cancer, prostate cancer, pancreatic cancer, female breast cancer, and colon cancer as underlying causes of death. This was done to minimize subject variation and to focus on those conditions that might reasonably be expected to benefit from palliative care.

Data

Data for this record linkage study came from four sources: vital statistics for 1996; hospital discharge abstracts; day procedure abstracts; and homecare administrative files for the years 1995 and 1996. Each of these databases resides in, and was accessed through, the Ontario Ministry of Health and Long-Term Care’s provincial health planning
database, often referred to as the provincial data warehouse. The vital statistics file contains information abstracted from individual death certificates. The fields of interest for this study included the deceased’s county of residence, date of birth, gender, and cause of death. Hospital discharge abstracts and day hospital procedures contain, among other information, the county of residence, gender, postal code, date of birth, reason for admission, dates of both admission and discharge for each episode, as well as a unique patient identifier that is common among the databases. The identifier is shared with the homecare database, along with the person’s gender and place of residence (Table 2).

<table>
<thead>
<tr>
<th>Variable</th>
<th>Vital Statistics</th>
<th>Inpatient Discharge</th>
<th>Hospital Day Procedures</th>
<th>Homecare Services</th>
</tr>
</thead>
<tbody>
<tr>
<td>Date of birth</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Date of death</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Sex</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Residence</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Primary diagnosis</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Personal ID</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
</tbody>
</table>

*Shaded areas indicate data used for linkages

**Inclusion criteria**

Patients eligible for this study were residents of central-west Ontario with colon, prostate, lung, female breast, and pancreatic cancer (collectively these diagnoses will be referred to as “sentinel conditions”), in which a subsequent death resulting from cancer occurred during 1996. Abstract data from the Canadian Institute for Health Information were available for each patient for the 12 months prior to death. A patient record was included for further analysis if the service record matched the vital record on all three qualifiers (date of birth, gender, and place of residence). Homecare records were included if they shared a personal ID number with either an inpatient or day surgery record.
Selected findings

Number of deaths from sentinel causes

In 1996 a total of 2,237 deaths from one of the five sentinel conditions were registered in the region. There were no duplicate deaths recorded that matched on place of death, gender, date of birth, and date of death.

Hospital admissions

Of those dying from one of the five sentinel conditions in 1996, the record linkage identified 1,113 individuals admitted to hospital in 1995/1996 that matched a recorded death on all three key variables (that is, residence, gender, and date of birth). Among the 1,113, 1,070 had an admission within their last year of life. Together they accounted for a total of 1,525 hospital visits, for an average of 1.42 each in the year prior to death (Figure 2). The majority of those visits were in the last few months preceding death (Figure 3).

Figure 2: Number of hospital admissions by individuals in the year prior to death

<table>
<thead>
<tr>
<th>No.</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
</tr>
</thead>
<tbody>
<tr>
<td>Admissions</td>
<td>746</td>
<td>232</td>
<td>68</td>
<td>21</td>
<td>3</td>
<td>1</td>
<td>1</td>
</tr>
</tbody>
</table>
Homecare

Five hundred and twenty-seven of those who died in 1996 from one of the sentinel conditions and were identified from either a hospital admission or day surgery event had an admission to homecare in the year prior to death. During that time they accounted for a total of 998 total homecare admissions for an average of nearly two (1.89) admissions per person. As was the case with hospitalizations, most of these homecare admissions occurred in the last months of life (Figure 4).
**Further Publications**

Further analysis of this data is planned and ongoing. As papers are developed abstracts will be placed on the project’s web site.

Anticipated papers will address the following issues:

1) **Care of the seriously ill in the community: Study methods and patterns of caregiving**

This report will provide an overview of the objectives and design of a research program that investigated care of the terminally ill in the community. The focus of the report will be on describing the nature of informal caregiving among those palliative care patients enrolled in five community care access centres in Ontario.

2) **Care of the terminally ill in the community: Linkages between formal and informal caregivers**

Care of the terminally ill is represented by two principal systems of care. Although extensive research documents the extent of care from informal and formal sources, very
little theoretical or empirical work has been done to examine the linkages between these systems of care. The objective of this paper is to develop our understanding of those transactions that occur between the family caregiver and the formal community care system when providing homecare to the terminally ill person.

3) **Satisfaction with service delivery**

The purpose of this paper is to identify predictors of family caregivers’ satisfaction or dissatisfaction with community services used by palliative-care, community-dwelling seniors.

4) **Accuracy of reported health service use among caregivers of the terminally ill**

Understanding the pattern of service use among the terminally ill is fundamental to efforts to improve the quality and efficiency of services. The purpose of this report is to analyse the accuracy of family caregiver reports on community services used by a terminally ill family member.

5) **The burden of caregiving**

This paper will examine the burden of caregiving reported by caregivers of the terminally ill. Predictors of caregiver burden will be identified.

6) **Social networks among family caregivers**

Over the last decade, support networks in which family caregivers are anchored in the community have received increasing attention. This paper examines the types, structures, and predictors of informal social networks among bereaved family caregivers.
Linkage and Exchange

1) Stakeholder/partnership building

All participating stakeholder agencies were represented at a March 30, 2000 gathering. The purpose of this gathering was to provide the history surrounding the study, an overview of the research timelines, and to discuss practice issues.

2) Agency contact

Frequent contact was maintained with liaison personnel at each of the participating agencies to address recruitment issues, track client status, and provide study update information. Several presentations were made at these agencies concerning recruitment and study progress.

In addition, we created and distributed “Certificates of Research Participation” to nurses, case managers, and agencies. This recognition met the College of Nurses of Ontario’s reflective practice requirement for nurse case managers. Educational bursaries were provided to agencies to acknowledge the ongoing commitment of nurses and case managers.

As part of partnership building with our participating agencies, we examined how to foster positive and productive collaborative relationships. This took the form of qualitative interviews with executive directors (n = six) and front line staff (n = nine). The interviews explored themes around the benefits and obstacles for community agencies participating in research projects. The data have been analysed and a journal submission is imminent.

3) Newsletters

Two newsletters were circulated bi-annually to regional, provincial, and national planning, research, and provider organizations.
4) Magazine feature


5) Web site

The newsletter was placed on the St. Joseph’s Health System Research Network web site, thereby promoting wider distribution and awareness of the study.

6) Presentations


7) Published journal abstract
