

Palliative care on Manitoulin Island

Views of family caregivers in remote communities

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abstract

OBJECTIVE To describe family caregivers' experiences with palliative care services in rural communities.

DESIGN Qualitative study.

SETTING Manitoulin Island, Ont.

PARTICIPANTS Thirteen family caregivers of 12 deceased patients who had received palliative care services.

METHOD Twenty-five family caregivers were recruited by mail and local newspaper. Eight were excluded because they lived off the Island or were too recently bereaved; one declined an interview; and three were excluded by researchers. Initial contact was by telephone; those retained (13 people) were interviewed at home. Interviews were conducted by the same researcher using a semistructured interview guide. All interviews were audiotaped and transcribed, and content was analyzed.

MAIN FINDINGS Three interwoven themes were identified: access to services, quality of services, and support and caring. Hospital and community-based services were accessed with ease at the local level; difficulties were noted when accessing services in tertiary care centres. Participants were generally grateful for and pleased with services received. Two areas of concern raised by participants were communication and pain and symptom control. Participants suggested to the Ministry of Health ways to improve rural palliative care services. More public funding for in-home palliative care services was identified as a priority.

CONCLUSION Participants thought good services and supportive care at the local level made up for difficulties in accessing and using palliative services in tertiary care centres. Community spirit and culture were seen as making situations more bearable.

résumé

OBJECTIF Décrire l'expérience de prestataires de soins familiaux avec les services de soins palliatifs dans les collectivités rurales.

CONCEPTION Une étude qualitative.

CONTEXTE L'île Manitoulin, en Ontario.

PARTICIPANTS Treize prestataires de soins familiaux à des patients, maintenant décédés, ayant reçu des services de soins palliatifs.

MÉTHODOLOGIE Vingt-cinq prestataires de soins familiaux ont été recrutés par l'entremise de la poste et du journal local. Huit ont été exclus parce qu'ils vivaient en dehors de l'île ou que leur deuil était trop récent; une personne a refusé l'entrevue et trois autres ont été exclues par les chercheurs. Le contact initial s'est fait par téléphone; les personnes retenues (13) ont été interviewées à leur domicile. Les entrevues ont toutes été menées par le même chercheur, qui a utilisé un guide d'entrevue semi-directive. Toutes les entrevues ont fait l'objet d'un enregistrement sonore et d'une transcription, et leur contenu a été analysé.

PRINCIPAUX RÉSULTATS Trois thèmes étroitement liés se sont dégagés: l'accès aux services, la qualité des services ainsi que le soutien et le réconfort. Sur le plan local, il s'est révélé aisé d'accéder aux services hospitaliers et communautaires; des difficultés ont été éprouvées lorsqu'on accédait aux services dans des centres de soins tertiaires. Les participants manifestaient généralement de la gratitude et de la satisfaction à l'endroit des services reçus. Les participants ont relevé deux principales préoccupations, soit la communication ainsi que le contrôle de la douleur et des symptômes. Les participants ont suggéré au ministère de la Santé des façons d'améliorer les services de soins palliatifs en région rurale. On a identifié comme priorité une augmentation des fonds publics accordés aux services de soins palliatifs à domicile.

CONCLUSION Les participants estimaient que les bons services et le soutien réconfortant sur le plan local compensaient les difficultés dans l'accès et le recours aux services de soins palliatifs dans les centres de soins tertiaires. L'esprit et la culture communautaires étaient considérés comme des facteurs rendant les situations plus supportables.

This article has been peer reviewed.

Cet article a fait l'objet d'une évaluation externe.

Can Fam Physician 2000;46:1301-1307.

RESEARCH

Palliative care on Manitoulin Island

The definition of palliative care is still evolving.^{1,2} It is widely accepted that it is active, compassionate care primarily directed toward improving quality of life for people and families facing life-threatening illness¹ and that it is delivered by interdisciplinary teams with family physicians playing a pivotal role.^{3,4}

The Ontario Ministry of Health (OMH) recognizes that development of palliative care services has been hampered by a lack of public policy and financial support. In 1992, the OMH announced funding for four palliative care initiatives directed at interdisciplinary service providers, family physicians, volunteer visiting programs, and pain and symptom management teams across the province.⁵ Ontario's community-based home care services, including palliative care, were recently restructured and are now offered by Community Care Access Centres (CCAC).⁶

Few researchers have investigated palliative care in rural settings; existing studies were mainly carried out in other countries.^{7,9} A recent study on delivery of palliative care by a CCAC noted discrepancies in services between urban and rural settings, with rural clients finding access to care more difficult.⁶ The authors of a very recent study, undertaken for Health Canada, reported that little was known about palliative care services in rural Canada and suggested that there is a need to better understand how rural palliative care services are offered. They proposed a rural model of palliative care.¹⁰

While existing palliative care studies undertaken in rural Canada have mainly focused on the views and needs of professionals,^{10,12} there is also a need to ascertain the views of patients and their families. While some interviews with families have been reported,^{13,15} we found no Canadian study that specifically examined how rural clients viewed palliative care services. Qualitative research has been suggested as the best approach for exploring clients' perceptions of palliative care.^{13,14,16} This qualitative study aimed to describe family caregivers' experiences with palliative care services in rural communities.

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METHODS

Manitoulin Island, situated near the northern shores of Lake Huron, is the largest freshwater island in the world, with an area of 2766 km². It has a population of approximately 12 000; about one third live in First Nations* communities. The closest tertiary care centre is in Sudbury, Ont, 130 km away. Some Islanders, however, live more than 250 km from Sudbury. At the time of the study, publicly funded home care services were provided to the entire non-Native population by a single agency (Home Care). Private nursing agencies offered limited services in some parts of the Island. No formal group of health care providers was specifically responsible for palliative care services. A small group of palliative care volunteers worked informally in one region of the Island. One hospital provides services at two sites.

Ethical approval for this study was obtained from the Ethics Committee of Laurentian University in Sudbury.

To recruit participants, the local Home Care case manager identified deceased clients who had received home care services in the 3 years before the study. Letters of invitation were sent to 50 people who had cared for these clients. Articles in the two local newspapers also invited potential participants to contact the researchers directly. The 25 family caregivers who responded were contacted by a researcher: one declined an interview and eight others were excluded because they either lived off the Island or were too recently bereaved.

We used purposive sampling to choose participants. The inclusion criteria that guided final selection were representation from the three main geographic areas of the Island, different relationships to the deceased, different medical diagnoses, and different cultural backgrounds. The final sample consisted of 13 people from the families of 12 deceased clients.

All interviews were carried out in participants' homes by the same researcher, who used a semi-structured interview guide. Questions were asked about the deceased client and his or her illness, the family's experience with health services, effectiveness of and gaps in health services, and experience with health professionals and others.

Participants' interviews were audiotaped and transcribed verbatim. Using a qualitative research approach, interview content was analyzed by two

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*First Nations and Native are used throughout this article to refer to the original inhabitants of Canada and their descendants.

researchers separately in a systematic and objective way for recurring themes.¹⁷⁻¹⁹ The researchers then reviewed their findings together and agreed on the most common themes. A third researcher subsequently independently verified the identified themes and related quotes for consistency and relevance. Three general themes emerged from the data.

FINDINGS

Profiles of participants and deceased patients

Average age of deceased patients was 68 (range 53 to 82); all but one had cancer. Half died at home, half in hospital. Only one deceased patient was from a First Nation. Seven study participants were spouses of the deceased clients; other participants were children, grandchildren, and one friend. One couple were interviewed together. Eleven of the 13 participants were women.

Emerging themes

Three complex and interwoven themes emerged: access to services, quality of services, and support and caring. Access to services and quality of services are closely linked. The supporting and caring theme can be viewed as interwoven with the other two themes.

Access to services. Participants described their experiences with physicians, hospitals, community health care agencies, and informal community resources while their family members were terminally ill. They described the ease as well as the difficulties encountered in accessing services.

Access to Island hospital services was viewed as dependable and available when necessary.

The nurses and the doctors in the [local] hospital were absolutely wonderful. They would respond no matter when we called... if we just wanted questions answered, if we wanted to admit her. There were never questions of whether there would be room or not. They always made room.

Participants recognized the benefits of having tertiary care centres in Sudbury, but access issues, such as distance, travel time, separation from families, and limited access to professionals, were identified.

They're distant in Sudbury. They're very far away. If you have a problem, to get in touch with one person that you

know there, that you could ask the question of, is very difficult and you can't exactly run in.

Transportation is tough for people from the Island. Getting her there... it was pretty hard on her; the whole thing was really very hard on her, to travel that far.

Participants also spoke of the accessibility of their local Island doctors. Many local doctors did home visits, and these were appreciated: "The doctor was good, he was exceptionally good; he would just come and visit. He even cried when he left that morning." Other participants did not request home visits and were not offered them: "I've always thought housecalls would really pay, especially for someone like her."

Nearly all reported using Home Care for nursing and homemaker support, and these services were generally accessed with relative ease: "I didn't have to make any calls. The Home Care coordinator set everything up for us. She was always here when she was supposed to be."

Some participants reported difficulties in getting adequate nursing care either because of cost or because there were not enough nurses. This difficulty was especially evident when a patient's illness worsened. One participant reported not using Home Care services because she did not know how to access the service. "I probably would have appreciated a nurse to come in, but I wasn't sure how to get her here. I wasn't sure who to call."

Many participants relied on other community resources, such as friends, local pharmacists, and palliative care volunteers: "There's this sort of underground thing of these little night angels [palliative care volunteers] that do this, and it's remarkable." "The pharmacists, the grocery store, the church, and the community people were very supportive with their visits, from ordering from small grocery stores to the pharmacists' calling and giving me information."

Quality of services. Participants offered their opinions on the quality of services received and their suggestions for improvement. They were generally grateful for services received and reported that services were provided in a professional and confidential manner.

The staff at the local hospital were described as always being available and responsive: "Anyway, then we got to the hospital, and they just laid out the red carpet. They just brought everything and did everything, so kind." Staff at the tertiary care cancer treatment centre were also viewed as being helpful:

RESEARCH

Palliative care on Manitoulin Island

"The nurses were wonderful; the doctors were semi-wonderful, because they were too busy really."

At times, coordination among services caused difficulties for some families.

She'd be discharged from the hospital on a Friday afternoon, and we'd get this call saying.... You can pick your mother up in an hour.... It hadn't been coordinated with Home Care. Just all of a sudden they decided, home you go!

Many participants described how home nursing care and support from homemakers and palliative care volunteers gave them respite time and kept them going: "That was the best part of all, being able to go upstairs and sleep and know that he was safe, or somebody was watching him." It also enabled them to keep their family members at home.

I know what a comfort it was for him: being with his family, in a loving family. I know what it was like for us as a family, having the love and caring of nurses and support staff and everybody. I [wish] I could make sure that there was even one person who could get the same, because maybe some people are falling through the cracks here.

Participants were generally able to grant their family members' wishes to die either at home or in hospital. Some felt that staying at home prolonged patients' lives.

I do think, partially because we had the luxury of him being at home and dying at home, that basically prolonged his life. I really believe that, it was easier to do, to pay attention to details, so he got several more months out of that.

In one case, a participant reported not being able to grant a wish to die at home because of the cost.

She asked us to support her at home. In fact she begged us to support her at home.... We could have kept her at home to the end if we would have been able to bear the cost. She actually died in the hospital.

Two areas of care were of particular concern to participants. The first was related to pain and symptom control. Some reported that pain was well managed: "She had good pain control, but there were times when she was quite reluctant to take medications." A few felt differently: "One concern that I had,

that everyone wasn't as familiar with the [morphine] pump as I thought they should be."

Some also spoke of problems controlling other symptoms, such as poor appetite, nausea and vomiting, depression, anxiety, and sleep disorders.

I know the doctor was loath to use sedatives or tranquilizers or sleeping pills, but I think that his emotional needs and sleeplessness and anxiety could have been addressed, even partially. I brought it up here locally and brought it up in Sudbury, and I got nowhere. No, it's like it's not a very important issue.

For some participants, the second area of concern was communication about the diagnosis and course of illness. Some thought information was lacking and, for a few, information was shared in an insensitive manner.

Mom was waiting to talk to the doctor, who is very difficult to catch.... She did catch him coming off the elevator, and he grabbed a newspaper, and he did a very basic outline of the body, and went, "It's here and here and here and here and here, 6 months." And this was at the nursing station. But he left it up to Mom to tell Dad.

Some participants spoke of not knowing what to say to their dying family members and not knowing what to expect when death approached.

So part of that fell on my shoulders, to reassure her that she was a good person... that she need not be afraid of dying. Just acknowledging her fears and for her to be able to talk about her fears was important.

I think that somebody along the way should have said, "This is what could happen." You know, when you get to that stage where a person dies, there is no benefit in not knowing. The family needs to know what it's going to look like.

Participants also shared the emotional turmoil they experienced while watching their family members die and their feelings afterward. Some acknowledged the support they received after the death, while others suggested that bereavement help would have been beneficial to them.

There was a great deal of support for him emotionally but none for me. I'm sure that there were services that were available that I could have taken advantage of if I had known about them,... someone to sit and talk to for

an hour once in a while. I ended up writing a journal just to express my feelings.

Support and caring. Participants often referred to the genuine support and caring shown to them and their dying family members by care providers. This was especially evident when they were asked to reflect on how different it might have been had they been living in an urban area. Island care providers were described as being closer to them, fully committed, and always willing to help and be there for them: "I was just carried along on this little blanket of love.... There's not the busyness that you find in the city. People have time to take time."

I'm quite sure that in the city we would have been lost in the shuffle. I think we got a lot of small-town touches that made the whole thing bearable. You're not just a number. It's the fact that everybody knows of somebody or knows them. It just seems to take health care that extra step where there's a face on the patient and with the face there is a family.

Participants also spoke of the kindness and compassion shown to them before and after the death.

The nurse was very good. She stayed at the very end, gave Mom a bath, and some of the other things that so made it easier. She actually came to the funeral. The funeral director came in... and he very lovingly wrapped and covered my mother in a warm blanket and I thanked him after because... it's the end of November and even though we know the person is dead, it was very thoughtful that he wrapped her and treated her with kindness. Then after he had her wrapped in a blanket, and they had a very appropriate procedure to do it, he then picked her up in his arms and carried her out.

Care providers in tertiary care centres, even though helpful, were perceived as not having the same personal touch. They were seen as busier, and they did not know the patients.

Well, having been in [a city] hospital, I know you can pretty well die before you get a nurse, right? Here the nurses and doctors are all on first-name basis with the patients and their families. And if they have nothing to do at the moment, they will drop in and say, "Hi, how are you doing?" They are just much more friendly and much more available.

DISCUSSION

Participants were grateful for and generally satisfied with palliative care services. Family palliative caregivers' reluctance to be critical is a recognized bias in palliative care research.²⁰ It is also possible that participants were not aware of the latest advances in care of the terminally ill, and this might have influenced their perceptions of the care received.

Participants spoke of supportive and caring professionals and others who helped them through the terminal illness trajectory, and expressed a belief that living in a rural community gave them a special connectedness with local health care providers and the community. The unique spirit of rural communities has been noted to be an important element that should be preserved and enhanced in development of rural palliative care.¹⁰

Overall, family physicians were perceived as supportive and involved. A Canadian urban study has reported increasing reluctance among family physicians to be involved in palliative care,²¹ but in other settings, with support of palliative care teams, family physicians continue to provide services with confidence.^{3,4,22} Participants who had been supported by palliative care volunteers found this support to be very helpful. The role of volunteers in supporting families of terminally ill patients is well documented^{5,23,24} and has been suggested as a core element of rural palliative care.¹⁰

Difficulty accessing care

Some participants reported difficulties in accessing home care services due to lack of funding or because they were not aware of existing services. Other studies in rural settings support these findings.^{6,10} Appropriate home care support helped families care for their family members at home even until death if that was desired. Some participants reported that being cared for at home prolonged patients' lives. At least one participant was not able to grant a dying wish for death at home because she could not afford nursing care. Our findings support the suggestion that Canada has a two-tiered home care system when it comes to place of death: those with financial resources (eg, private insurance) are better able to keep family members at home,²⁵ especially when illness is prolonged.

The need to travel to tertiary care centres for specialty services was a challenge for participants. Not only was traveling itself difficult for sick people and

RESEARCH

Palliative care on Manitoulin Island

Key points

- This qualitative study examined family caregivers' experiences with palliative care services in rural communities.
- Access to care was generally good for local services, but was less good for more remote, tertiary care services.
- In two areas quality of care was considered less than ideal: pain management and communication regarding diagnosis and management.
- Rural families generally felt they had received warm, kind, and supportive care from local health care providers.

Points de repère

- Cette étude qualitative examinait l'expérience de prestataires de soins familiaux avec les services de soins palliatifs dans des communautés rurales.
- L'accès était généralement aisé en ce qui avait trait aux services locaux, mais était plus difficile dans le cas des services de soins tertiaires dans des centres plus éloignés.
- Deux aspects dans la qualité des soins ont été jugés sous-optimaux: la prise en charge de la douleur et la communication concernant le diagnostic et le traitement.
- En général, les familles rurales étaient d'avis qu'elles avaient reçu des soins chaleureux, empreints de gentillesse et réconfortants de la part des dispensateurs de services de santé locaux.

those who were transporting them, it also meant separation from family and unexpected costs. This barrier to accessing services^{6,10} has been reported previously, and, for our participants, palliative care included diagnosis and treatment in tertiary care centres. This finding supports the broader view of when palliative care begins, a view held by the Canadian Palliative Care Association¹ and other groups.²

Two main concerns

Participants indicated two main areas of care that could be enhanced: pain and symptom control, and communication. These have been noted in other studies as important concerns for families.^{13,15,26} Professionals have also identified a need for more knowledge and skills in these areas of care.^{6,11,12} Communication and pain and symptom control are core concepts of palliative care

and have been recognized as such by OMH Palliative Care Education Initiatives.⁵ Some professionals from Manitoulin Island, including physicians, have participated in the education initiatives, but little is known about how the knowledge and skills gained have influenced practice.²⁷

In developing a rural model of palliative care, MacLean et al¹⁰ have suggested a need for specialist support in pain and symptom control. We do not know how well the current Palliative Care Pain and Symptom Control Team, responsible for a wide geographic area, is meeting the needs of professionals and families on Manitoulin Island. Delivery of health care services in rural areas requires providers to be generalists, which poses a challenge to developing expertise in any particular area, including palliative care. Training and supporting local people with a special interest in palliative care, so that they can be used as resources, might be a useful strategy.

Limitations

A few limitations to our study might have influenced the findings. Some of those who did not respond to the invitation to participate might have been dissatisfied with the care they had received and, because of the small community, did not want to jeopardize future relationships by criticizing local providers. Recall bias might have played a role because of the time lapse between the deaths and the interviews. Our participants might not have been wholly representative of Islanders needing palliative care. These issues, as well as the perspectives of both care providers and families, need to be explored further.

Conclusion

Participants were generally grateful for and satisfied with the palliative care services they received in rural communities. Health care providers developed a special caring relationship with them, a reflection of rural community spirit. Relief of pain and other symptoms and communication with physicians were the two main areas identified as needing improvement. The unique problems of palliative care delivery in rural areas raise questions about how effective OMH palliative care initiatives have been in meeting needs. A recent study on palliative care in rural Canada¹⁰ begins to address the special needs of rural care providers and families. The findings of our study support their emerging model of rural palliative care¹⁰ and the need for flexibility in funding and delivering palliative care. ♦

Research

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Acknowledgment

This study was funded by the North Region Sudbury Area Office of the Ontario Ministry of Health's Long-Term Care Division. A full report and recommendations based on findings were submitted to them.

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