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Palliative care by family physicians in the 1990s

Resilience amid reform

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ABSTRACT

OBJECTIVE To explore issues family physicians face in providing community-based palliative care to their patients in the context of a changing health care system.

DESIGN Focus groups.

SETTING Small (<10 000 population), medium-sized (10 000 to 50 000), and large (>50 000) communities in Nova Scotia.

PARTICIPANTS Twenty-five men and women physicians with varying years of practice experience in both solo and group practices.

METHOD A semistructured approach was used, asking physicians to reflect on recent palliative care experiences in order to explore issues of care.

MAIN FINDINGS Five themes emerged from the discussions: resources needed, availability of family support, time and money supporting physicians' activities, symptom control for patients, and physicians' emotional reactions to caring for dying patients.

CONCLUSION With downsizing of hospitals and greater emphasis on community-based care, the issues identified in this study will need attention, particularly in designing an integrated service delivery model for palliative care.

RÉSUMÉ

OBJECTIF Examiner les problèmes qui se posent aux médecins de famille dans la prestation à leurs patients de soins palliatifs basés dans la communauté, dans le contexte d'un système de santé en évolution.

CONCEPTION Des groupes témoins.

CONTEXTE De petites (<10 000 habitants), moyennes (de 10 000 à 50 000 habitants) et grandes (>50 000 habitants) communautés en Nouvelle-Écosse.

PARTICIPANTS Vingt-cinq médecins, hommes et femmes, comptant un nombre d'années d'expérience varié de pratique en solo ou en groupe.

MÉTHODE On a eu recours à une approche semistrukturée en demandant aux médecins de faire part de leurs réflexions sur leurs récentes expériences en soins palliatifs afin de cerner les problèmes dans la prestation.

PRINCIPAUX RÉSULTATS Cinq thèmes se sont dégagés des discussions: les ressources requises, la disponibilité de soutien aux médecins de famille, le temps et l'argent à l'appui des activités des médecins, le contrôle des symptômes chez les patients et les réactions émotionnelles des médecins dans le contexte des soins aux patients en fin de vie.

CONCLUSION Compte tenu des réductions dans les hôpitaux et de l'importance accrue accordée aux soins dans la communauté, les problèmes identifiés dans cette étude exigeront une attention particulière, notamment dans la conception d'un modèle de prestation de services intégrés en soins palliatifs.

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Care for those with advanced cancer is moving out of hospitals and into communities. In Nova Scotia alone, the number of patients with advanced cancer dying out of hospital has risen by 50% in the last 10 years (personal communication from M. Pennock, Nova Scotia Vital Statistics, 1998). Forces behind the move include hospital downsizing, the projected doubling of cancer cases in Canada in the next 20 years,¹ and an expressed need for solutions to what is perceived as suffering at the end of life.²

The trend to community-based care means that the role of family physicians is crucial.³ Palliative care patients challenge family physicians' skills in many ways, including treating pain and symptoms; communicating with families in emotionally stressful circumstances; making difficult ethical decisions; and caring for very ill and dying patients at home, often with limited resources.

Patients and their families increasingly seem to want care in the community and at home.^{4,5} A home environment facilitates meaningful connection with family, normalcy (living as normally as possible despite disease), sustaining relationships, self-determination of care, and satisfaction for caregivers who provide direct care.^{5,6} Factors associated with successful dying at home have been studied in Canada^{4,5,7,8}; those more likely to die at home have higher socioeconomic status, receive care from specialized palliative services,⁴ have able caregivers (family, friends, nurses, and physicians), have manageable physical conditions, and live in adequate surroundings. We found no previous studies investigating how Canadian family physicians are responding to the shift in terminal care from hospitals to homes.

This study explores family physicians' perceptions of providing community-based palliative care to their patients in the context of a changing health care system. We hope the findings of this study will be useful for family physicians, policy makers, and program planners in considering resource allocation and delivery of care in the future.

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Methods

The study used focus groups to provide an opportunity for participants to discuss community- and home-based palliative care and to describe their perceptions of this aspect of their practice.⁹

Recruitment. Focus groups were held in communities purposefully chosen to represent small (<10 000 population), medium-sized (10 000 to 50 000), and larger (> 50 000) centres. At each location, someone from the local palliative care or hospice organization provided a list of family physicians who used or did not use palliative support services for their patients. In communities where no palliative care supports were available, physicians were chosen at random from a list provided by the Nova Scotia College of Physicians and Surgeons.

Focus groups were cofacilitated by two members of the research team. Participants were asked to reflect on changes in the health care system in Nova Scotia and to describe what worked well and what could be done differently to enhance care for patients at the end of life. Additional areas of inquiry centred on needs and availability of resources, how interdisciplinary care works in the community, and what physicians thought they needed to know for providing end-of-life care.

Analysis. Focus groups were audiotaped and transcribed. Transcripts were read independently by three members of the research team and analyzed for emerging key words and phrases. Two researchers then grouped words and phrases into larger categories. These categories were checked against those developed independently by a third team member. Areas of overlap and difference were explored until all the key words and phrases were accommodated in a category and saturation was achieved. The categories became the basis for a coding structure within QSR NUD*IST,¹⁰ a software program designed for text analysis.

The study was approved by the Research Ethics Committee of Dalhousie University's Faculty of Medicine.

Main findings

Twenty-five physicians participated in five focus groups. Six physicians were from small centres, nine from medium-sized centres, and 10 from larger centres. Seven were women, 17 were in group practice, and 13 were certificants of the College of Family Physicians of Canada. Ages ranged from 32 to 63 years, and number of years in practice ranged from 7 to 37.

Discussions indicated that physicians, patients, and families had faced great challenges in the changing care environment. Much discussion centred on how to provide high-quality palliative care in the community and at home. Issues discussed were grouped into five categories (**Table 1**): resources, family support, time and money, symptom control, and physicians' emotions.

Table 1. Themes that emerged from focus group discussion

RESOURCES

- Timely access to adequate home care
- Access to hospital admission when needed
- Access to drugs and equipment
- Support for interdisciplinary health care teams
- Access to special expertise in palliative care

FAMILY SUPPORT

- Families' availability to patients
- Families' agreement with treatment goals
- Family members' physical and emotional personal resources for coping

TIME AND MONEY

- Physicians' time to spend with patients and families
- Physicians' remuneration for this time in various settings (office, home, hospital)

SYMPTOM CONTROL

- Need to ensure minimal pain and other symptoms
- Methods to overcome patient and family barriers to adequate symptom control
- Accessibility of focused literature resources

PHYSICIANS' EMOTIONS

- Personal reactions to providing such care
- Emotional responses to angry families
- Satisfaction with provision of good care

Resources. Home-based services, according to participants, should be coordinated, timely, and adequate: "... because what you've got is a grieving family, and what... they want is simplicity. They want somebody to tell them how it should be done." Rapid response to changing needs was also highlighted.

But when it comes to the point they really can't do it anymore, they'd like to be able to get someone in there quickly.... When it comes to the crunch, they really usually need someone in, you know, that day or that afternoon.

The variation in services available in light of differing needs was also an issue. "One day a week of home care seemed inadequate for someone who is unable, or just barely able, to get herself to the washroom."

Timely access to in-hospital care was described by many as necessary for a variety of reasons. A family's willingness to care for someone at home can be supported "as long as they [the family] know they [the doctors] can come up with a bed." Another physician said, "One of the things that helps people at home is the knowledge that, if things do get out of control, you can get them in [to hospital]". One urban physician suggested that perhaps the shift from institutional care to community care had been so great that patients *had* to die at home. "It's almost impossible for somebody to die in a hospital any more."

Participants rejected this hospital versus home dichotomy and suggested instead the need to facilitate continuity between the two sites. Hospital care was seen as necessary for acute symptom control, for family respite, and for terminal care when patients or their families could not cope with death at home.

A need for access to drugs and equipment was mentioned by several physicians. Actually finding the drugs required for symptom control did not seem to be a problem. Pharmacies were generally perceived as helpful and cooperative, even after hours if needed. Paying for the drugs, on the other hand, was an issue for some patients. "There's the odd person that kind of goes without once in a while because they don't have access to money to provide for themselves." Drugs are not currently an entitlement under Homecare Nova Scotia.

We asked for comments on the role of interdisciplinary teams in providing end-of-life care. Participants said that one thing that made a positive experience was the existence of knowledgeable and cooperative team members. They expressed concern about "isolated islands of concern and care." These "islands," symbolic of fragmentation of care, were seen as not being good for patients.

Access to experts in palliative care was seen as important by both rural and urban physicians. "[Without the] palliative care team, I wouldn't be able to do it" (ie, provide home-based palliative care). Rural physicians commented on their ability to call "experts" to discuss problem-solving strategies.

Family support. Families available to patients, who agreed with patients' personal treatment goals, were not cure oriented, and had the physical and emotional resources to cope with death at home were seen by physicians as key to facilitating home-based care of dying patients. Physicians saw having the desire and capacity to support a dying person at home as a desirable trait in family members: "The big thing [is that family members] were interested, and weren't afraid... of looking

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after this person and the fact that their family [member] or loved one was dying.”

Physicians described the critical role of patients' families who participated in decisions about care. A family was thought to be “very supportive of her and her decisions around [her] choice of staying at home, despite the fact that she was very distressed.” Another family physician acknowledged that informal caregivers might have been “anxious” about their loved one's desire to stay at home, but nevertheless “everybody wanted the death to happen at home.”

While some families accept the terminal phase and provide support and care, in others “there's a lot of anger, bitterness.” Contact with families far apart from terminally ill patients, either emotionally or geographically, can also be difficult for family physicians. Sometimes, such families want “extreme measures taken, and it's hard to deal with them over the phone or there's conflict within the family.” Still other families:

Just can't handle the stress of it or they don't want to, or they're just not prepared or equipped to deal with the stress of watching somebody dying and slowly going downhill. They're more comfortable in the hospital setting.

Family anxiety over patient distress could shape the tenor of decisions or their implications:

The [patient's] wife... needed reassurance that what she was doing was the right thing, you know. Quite often, especially since family members would start to question it and say, “well, why don't you take him to the hospital?” Well, there was no need to take him to the hospital. He wanted to stay home. She was coping quite well, and basically it was coming out of the family's anxiety that there was somehow, something the hospital could provide, something nonspecific... but somehow he should be there. Well, he didn't need to be there. And she did very well. But there was a lot of pressure on her, and I think without any other support to tell her that she was doing okay, she would have caved in likely and felt bad about herself.

Overall, family physicians saw family support as the foundation for successfully keeping patients at home.

Time and money. Home-based palliative care places new demands on family physicians. Each focus group discussed the time spent on palliative care and the question of adequate compensation for that care.

I often get a call from the patient, and then I can spend hours... trying to track down resources, trying to make arrangements... there's just a myriad of things that I could spend several hours in a day, and I have done that, and I've not billed a blessed thing for it.

One important point was that an adequate framework for compensation enhances the ability to deliver home-based palliative care. One participant said, “It does make you feel a lot more comfortable spending the time, though, if you can bill for it.” Another participant suggested, “I would never hesitate to talk to somebody, but afterwards...I think there's a bit of resentment going on, because you didn't bill for that or should have.” Nevertheless, the physician “never denied anybody service” because of the inability to bill for time. Concern for the patient and family remained paramount, despite time constraints and inadequate billing options: “Actually, at the time, I don't even think about [billing]. I'm more concerned about the family.”

Symptom control. Pain and symptom control were discussed only infrequently in terms of shaping a positive experience. One participant acknowledged strongly that:

My number one priority in a patient with palliative care is no pain.... [T]he primary goal is to make sure that they are comfortable, and yet hopefully lucid enough that they can enjoy some of the time left.

Support for effective symptom control is found in the narratives around what shapes negative palliative care experiences. Participants specifically mentioned pain and symptom relief when recounting negative experiences. Three discrete issues were identified: the clinical challenge of ensuring adequate control, the fact that some patients were “uncomfortable” with the medications provided (those who avoided medications posed a particular challenge), and family members' expressed concern over giving too much medication with the result that “they're quite hesitant and reluctant to do anything.” Participants also described a need for rapid, easy access to symptom control strategies through pocket manuals or other brief, focused literature resources.

Physicians' emotions. Emotions described by participants can be broadly categorized as anger or blame, guilt, and reward. Physicians reported that anger or blame directed at them arose from questions about

diagnosis, quality of care, or existing family dynamics. One participant captured some of the emotion:

I guess sometimes when you get all these mixed feelings, you know, you kind of feel a failure as a physician because you've done everything you can; really you've done your best.

Participants did not openly express feelings of inadequacy when it came to palliative care. Rather, they perceived obstacles as external to their competencies. One rural participant noted:

I'm fairly comfortable with palliative care. I find it one of the more rewarding experiences that I've had in my practice in the last 5 years. I felt I made a difference.

Another participant echoed this sentiment, adding that "To get somebody a good death is, I think, one of the best things you can ever do."

Physicians participating in this study have clearly articulated important issues requiring attention in order to support patients who wish to die at home. The role of the family is critical, it seems, to the success of this endeavour. Family physicians must support patients directly by ensuring adequate symptom control and by putting practical help and equipment in place in the home. Just as important, though, if not more so, is finding ways to support family members

to take on this role. **Figure 1** depicts our concept of the support structure.

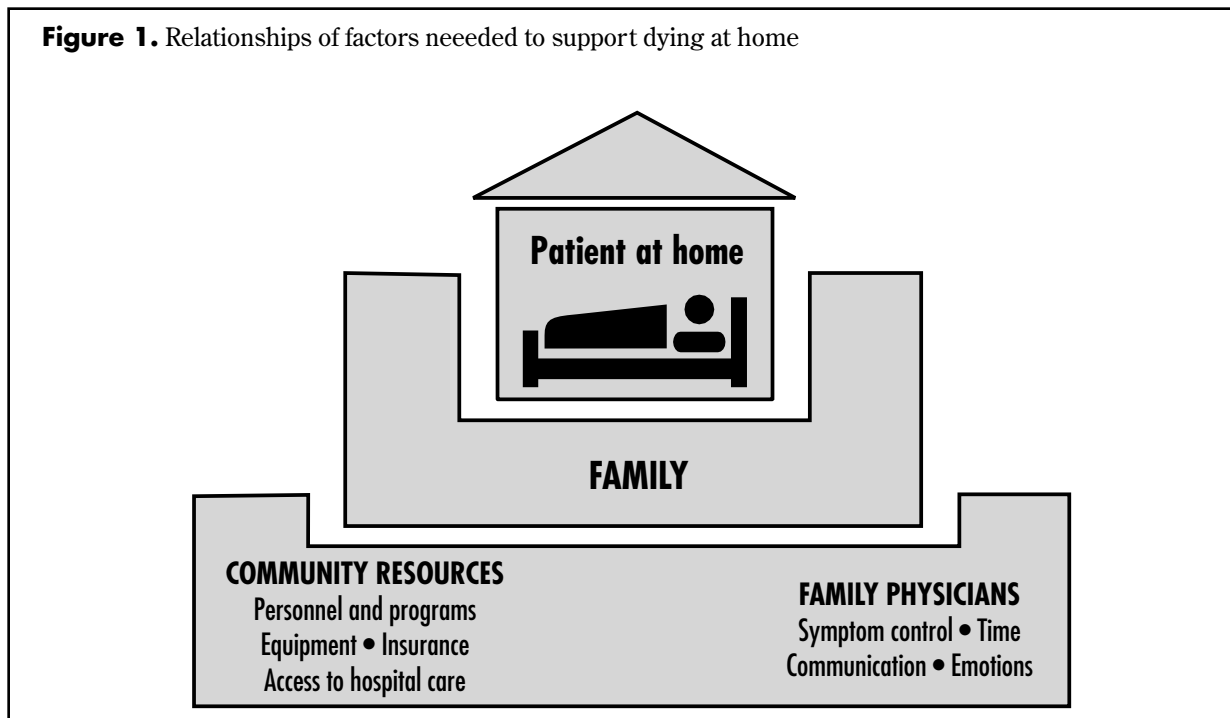
Discussion

Community and home care of dying people has always been part of most family physicians' practice. What is changing is that home is the setting for longer periods during terminal care and more people are dying at home. Participants in this study told of the challenges they face in getting timely access to adequate "amounts" of home care services, including nurses and personal care workers. They expressed some frustration with what seems to have become a "forced choice" for families to have their dying family members stay at home. Choice of location of care seemed to them to have become more based on the functions of hospitals than on the needs of patients and families.

Of paramount importance, it seems, is the need for family physicians and community resources to provide families with the practical and emotional support to undertake caring for dying patients at home. If families do not feel able to do this or are not supported, failure is likely.

Issues identified by participants and the concept of support for patients that emerged from this study will need attention in development of integrated service delivery models for palliative care in Nova Scotia and, likely, in other Canadian settings. Provincial health systems will need to develop policy to improve access

Figure 1. Relationships of factors needed to support dying at home



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to resources outlined in **Table 1**. This must include financial support for equipment and medications and salary support for required personnel. Just as important, however, is the prospective design of delivery models that facilitate timely access to resources.

Models for palliative care service delivery will also need to demonstrate ways to enhance support for family members caring for their dying. Such support will include not only practical support (eg, equipment, drugs) but more importantly, strategies to enhance the confidence and competence of families to deal with death at home. An integrated service delivery model should prepare all health care professionals to provide this kind of support.

The issue of forced choice of location of care came up unexpectedly. As hospital beds have become fewer, family physicians in some communities think that hospitals will not offer anything that could not otherwise be obtained in the community. Understanding families' and health care providers' perception of this is important if we are to facilitate community care and also respect patient choice in location of death.

In constructing new delivery models, attention must be paid to adequacy of remuneration in community settings. Home care billing codes do exist in Nova Scotia; perhaps physicians are not using them. Strategies to help family physicians share care with other team members might reduce the stress they feel in trying to make time for dying people in the midst of the rest of their practice.

It is also clear that strategies to help family physicians cope with the emotional load of caring for dying patients might help to sustain their long-term commitment to this type of care.

The findings of this study represent an attempt to identify "transition issues" for family physicians, families, and patients as care for dying people moved in great part from hospitals to homes. These transition issues arose as health care was reorganized during the latter half of the 1990s.

Limitations. The five focus groups had an average of five participants each, making them somewhat smaller than ideal. This might have limited the scope of discussion. In addition, the facilitators were known to most participants, and this might have dissuaded participants from making negative comments about specialized palliative care resources.

Conclusion. We must design programs that provide access to the resources patients and families need in a timely fashion, and we must pay special attention to

Editor's key points

- In this qualitative study, family physicians providing palliative care in patients' homes wanted better resources and support, such as easier access to hospitals, better drug coverage, and the backup of experts in the field.
- Families of dying patients needed a range of support from minimal reassurance to management of serious conflicts.
- Most participants thought they spent a great deal of time on palliative care and were not adequately paid for it.
- Symptom control was an important goal; expert help and tools, such as pocket references, were seen as very valuable.
- Providing palliative care was both demanding and highly rewarding.

Points de repère du rédacteur

- Dans cette étude qualitative, les médecins de famille qui dispensaient des soins palliatifs à domicile voulaient de meilleures ressources et un plus grand soutien, comme un accès plus facile aux hôpitaux, une meilleure couverture en matière de médicaments et l'accès aux ressources auxiliaires d'experts dans le domaine.
- Les familles de patients en fin de vie avaient besoin de soutien de divers ordres, allant du simple réconfort à la gestion de conflits majeurs.
- La plupart des participants étaient d'avis qu'ils consacraient beaucoup de temps à la prestation de tels soins et qu'ils n'étaient pas rémunérés suffisamment pour ce faire.
- Le contrôle des symptômes revêtait beaucoup d'importance; l'aide d'experts et des outils comme des aide-mémoire de référence étaient jugés utiles.
- La prestation de soins palliatifs était à la fois exigeante et immensément satisfaisante.

issues of support for families caring for dying patients. For physicians providing palliative care, we must find ways to provide timely information on symptom control, to remunerate their activities appropriately, and to sustain them emotionally during their tasks. ❖

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Education in Dalhousie University's Faculty of Medicine.

Contributors

Dr Burge led the design and conduct of the study and participated in the qualitative analysis and development of the discussion.

Drs McIntyre, Cummings, Kaufman, and Pollett participated in study design, development of the focus group guide, and review and critical reflection on the data. **Drs McIntyre, Cummings, and Pollett** helped facilitate the focus groups. **Dr Twohig** was involved in data analysis. **Drs Burge, Twohig, and McIntyre** were principal writers of the first and subsequent drafts of the paper.

Competing interests

None declared

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