

Family physicians and cancer care

Palliative care patients' perspectives

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ABSTRACT

OBJECTIVE To explore factors that affect the integrity of palliative cancer patients' relationships with family physicians and to ascertain their perceptions of their FPs' roles in their care.

DESIGN Qualitative study using grounded-theory methods, taped semistructured interviews, and chart reviews.

SETTING Two palliative care hospital wards in Winnipeg, Man.

PARTICIPANTS A purposeful sample of 11 men and 14 women.

METHOD Qualitative content analysis of interview transcripts.

MAIN FINDINGS Cancer care is organized in a sequential, parallel, or shared manner between FPs and cancer specialists, with sequential care a common outcome if patients' relationships with their FPs wane. Cancer patients can lose contact with FPs because of patient or physician relocation, distrust over delays in diagnosis, failure to perceive a need for FPs, poor communication between FPs and specialists, and a lack of FP involvement in the hospital. People with cancer value FPs for being accessible through prompt appointments and telephone contact; for providing emotional and family support; and for referral, triage, and general medical care.

CONCLUSION Family physicians can enhance care of cancer patients. Contact with FPs can be maintained by ensuring good communication between specialists and FPs, defining a clear role for FPs, addressing concerns about delays in diagnosis, and referring patients back to FPs, particularly after hospitalization.

RÉSUMÉ

OBJECTIF Explorer les facteurs qui influencent l'intégrité de la relation des patients en soins palliatifs pour un cancer avec leur médecin de famille et déterminer leurs perceptions quant au rôle de leur médecin de famille dans la prestation des soins qu'ils reçoivent.

CONCEPTION Une étude qualitative à l'aide de méthodes fondées sur la théorie ancrée, des entrevues semistructurées enregistrées sur bande et l'examen des dossiers.

CONTEXTE Deux unités de soins palliatifs en milieu hospitalier à Winnipeg, au Manitoba.

PARTICIPANTS Un échantillon délibéré de 11 hommes et femmes.

MÉTHODE Une analyse qualitative du contenu des transcriptions des entrevues.

PRINCIPAUX RÉSULTATS Les soins oncologiques sont organisés de manière séquentielle, parallèle ou partagée entre les médecins de famille et les oncologues. Une organisation séquentielle se produit le plus communément si les relations des patients avec leur médecin de famille s'effritent. Les patients souffrant de cancer peuvent perdre contact avec leur médecin de famille en raison du déménagement de l'un ou l'autre, d'une méfiance due à un délai dans le diagnostic, du défaut de percevoir la nécessité d'avoir un médecin de famille, d'une mauvaise communication entre le médecin de famille et le spécialiste et d'une participation insuffisante du médecin de famille en milieu hospitalier. Les personnes qui souffrent d'un cancer apprécient les médecins de famille en raison de leur accessibilité caractérisée par des rendez-vous sans délai et des contacts par téléphone; de la prestation de leur soutien émotionnel et à la famille; et des services d'aiguillage, de tri et de soins médicaux en général.

CONCLUSION Les médecins de famille peuvent améliorer leurs soins aux patients souffrant de cancer. Les contacts avec le médecin de famille peuvent être maintenus en assurant une bonne communication avec les spécialistes, en définissant un rôle précis pour les médecins de famille, en réglant les préoccupations associées au délai dans le diagnostic et en aiguillant à nouveau les patients vers le médecin de famille, surtout après une hospitalisation.

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Family physicians are generally viewed as the professionals best able to provide continuous, comprehensive primary medical care to Canadians and to coordinate care when other health care providers are involved.^{1,3} The connection between patients with cancer and their family physicians, however, is often lost by the time patients need palliative care.^{4,8} One study found that, while 98% of cancer patients said they had FPs, only 31% had follow-up appointments, and only 43% reported that their FPs were involved in their follow-up care.⁵

If patients have not maintained contact with FPs, they could have difficulty finding new ones. Although a national survey of Canadian FPs in 1997 showed that 59.8% described palliative care as part of their practices,⁹ another study showed that few (13%) wanted to take on new terminally ill patients.⁶

Previous research has identified several key dimensions of family physicians' involvement in cancer care. These include effective communication with patients^{8,10-13} and specialists,^{4,14} clear role definition,^{4,15-17} and skill and confidence in cancer care.¹⁸ Much of this research reflects the views of physicians themselves. There is less information from cancer patients' perspective on FPs' place in their care, or on their perceptions of why these connections continue or dissolve. There is evidence that the quality of relationships with FPs is correlated with cancer patients' quality of life, but no qualitative exploration of why.¹⁰ This study aimed to discover factors that affect the integrity of the patient-FP relationship in cancer care and to explore how cancer patients perceive FPs' roles in their care.

METHOD

Approach and setting

Given the lack of previous exploration of patients' views of FP involvement in cancer care, we took a

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grounded-theory approach. This qualitative method is suitable for discovering patterns in complex human experience and for generating hypotheses.

Participants were identified from palliative care inpatient wards in two hospitals in Winnipeg: Riverview Health Center and St Boniface General Hospital. Both wards focus on symptom control at the end of life; most patients are admitted with very advanced disease. About one quarter of patients are discharged home; the rest die in hospital. Due to limited community support for terminally ill people, only about 10% of deaths from each ward occur at home. Difficulty in identifying FPs to provide follow-up care after discharge is common. Patients on both wards are cared for by a few physicians with special training and experience in palliative care.

The first author spent about 4 weeks on each ward during the summer of 1997 doing most of the data collection, with a final week of interviewing in the spring of 1998. This time was spent observing ward rounds, getting to know staff, identifying and interviewing participants, having conversations in patient lounges, and reviewing charts.

Sampling and design

This study arose from a concern that hospitalized terminally ill patients were not in contact with their FPs. Accordingly, a homogeneous sampling technique was chosen to explore the particular experience of these patients. Because terminally ill patients are very vulnerable, ward staff were asked to indicate which patients were well enough to participate. Two to 3 days weekly were spent at each hospital, and all suitable patients were approached. Inclusion criteria included a score of 24 or more on the Folstein Mini-Mental State Examination (MMSE) and fluency in English.

Individual semistructured interviews were chosen as the most appropriate method to achieve an in-depth understanding of participants' experience while respecting their frailty. Conducted by the first author using an interview guide (**Table 1**), they lasted approximately 30 minutes. Visiting family members were invited to be present, but were asked to hold their comments until the end of the interview. Ethics approval for this project was obtained from the Committee on Use of Human Subjects of the Faculty of Medicine at the University of Manitoba.

Analysis

Interviews were tape-recorded and transcribed verbatim. The method of thematic content analysis was modified from Burnard.¹⁹ Transcripts were initially coded

Table 1. Sample questions from interview guide

Since your diagnosis, have you had a family physician who has been involved in your care?

When did you start seeing your FP? How did you choose this FP? What was your relationship like before your diagnosis?

How was your FP involved in diagnosing your cancer?

How did your relationship change after your diagnosis?

What did your FP do for you that was useful? Is there anything that you would have liked him or her to do differently?

What was the communication like between your specialists and your FP?

What types of things do you see your FP for now?

How able is your FP to handle problems that might come up now?

independently by the first two authors using open coding in the margins of the transcripts. Emerging themes were identified and were tested on subsequent transcripts and eventually grouped into larger categories. Data collection continued concurrently with data analysis, with the two analysts meeting weekly. A sample size of 20 to 30 was initially chosen,²⁰ and after 22 interviews we believed that saturation was achieved. This belief was confirmed with analysis of three further interviews, which generated no new themes.

Trustworthiness of the findings was enhanced by use of verbatim transcriptions and at least two researchers for all stages of data analysis (triangulation of investigators). The high level of saturation achieved in category development and the frequency and structure of data analysis meetings further enhanced trustworthiness. Member checking, where participants give feedback about the preliminary analysis, was impractical given the short life expectation of study participants.

FINDINGS

Participants

Demographic and medical information was collected from the charts of the 11 men and 14 women who participated. Time from diagnosis to interview ranged from less than 1 month to 12 years, with a mean of 2.6 years. Diagnoses included 11 primary cancer sites, the most common being breast and lung cancer. Age of participants ranged from 28 to 84 years, with a mean of 58 years. Three had lived in rural areas at some point in their cancer care, but only one was currently living outside Winnipeg. Of the 25 patients, 19 had FPs

before the diagnosis. Nine patient-physician relationships dissolved between time of diagnosis and the interview, and nine new relationships were established.

Themes

Patterns of care. Participants described three patterns of care that represented increasing levels of involvement by FPs: sequential care, parallel care, and shared care. In sequential care, patients received virtually all of their care from specialists after diagnosis. "I didn't see [my FP] much at all, because I got handed over to the surgeon pretty well ... and then to ... the oncologist." At the end of active treatment, some participants returned to their FPs for follow-up care. Others saw palliative care specialists as best able to meet their needs.

In parallel care, FPs continued to follow patients, but were seen as managing non-cancer medical problems and providing encouragement. Cancer and palliative care were seen as the exclusive role of specialists. "[The FP is] still looking after the diabetes. ... One kind of doctor does this; he does that: [to] each their own.":[Symptom control is] not in her hands.... You leave that... to the specialists. She's just a family physician."

In shared care, participants saw their FPs as having a role in discussing their treatment alternatives, referring to new specialists, and assessing and managing their cancer symptoms, as well as in taking care of their other medical and emotional needs. Shared care often began with a statement of intent. "[My FP] said that he would be involved, that I would be seeing him, and if I was too sick to come, he would come and see me."

Integrity of patient-FP relationships. Several themes emerged that were perceived as contributing to a weaker connection with FPs, creating a pattern of medical care more often experienced as sequential than parallel or shared.

Relocation: Contact was affected by changes in the physician's practice and by patient and physician relocation. "About 3 or 4 months into my chemotherapy, [my FP] decided to cut down her hours, and she's just practising 2 hours a week." "[My FP] was headhunted by the Americans."

Weak connection before diagnosis: Some participants had no strong relationship with FPs before diagnosis. This was especially true for young, previously healthy patients. "I would use the [walk-in] clinics to go to if there was any reason that I needed to see a doctor."

Distrust or anger over a delay in diagnosis: Delays threatened trust or ended a relationship, especially if patients thought their doctors had not been thorough. Even when participants were uncertain whether or

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not there had been an undue delay, their uncertainty on this point created distance and hesitation.

I've had nothing against him. I don't wish to see more of him because there is nothing really [pause]... We can sit there, and I could say to him, "Why didn't you do this?" or "Why didn't you send me there sooner?" There is no way of going back.

Lost test results, errors in charting, and a feeling of being rushed or dismissed were interpreted as signs of a lack of thoroughness, and were often connected with concerns about delay in diagnosis.

Well, I think he misdiagnosed. I had a lot of bleeding [in my urine], and he prescribed an... infection medicine. I had taken in a blood [clot] sample;... he just threw them in the garbage, instead of... sending them off at least to have them analyzed, and I find that down the road I had... cancer.

Needs met better by specialists: Some participants saw little reason to see FPs, because most of their health problems required the expertise of cancer specialists, who often handled other minor medical problems as well. "Sometimes bladder infections could be caused by your pills that you're taking, so a lot of times [the oncologist] took care of it anyway."

Communication problems between physicians: Cooperation and timely communication between FPs and specialists were important if FPs were to be viewed as important in patients' care. Both were often perceived as absent. "[My FP] wasn't let in on a lot of things that were happening. ... She phoned three times once to get the results of a scan." "[Physicians] did not seem to want to get together and talk. Each had their little area."

Lack of hospital presence: Extended hospital stays and lack of hospital privileges led to erosion in the connection with FPs. It's not helpful... when doctors do not have privileges at certain hospitals.... I think she would have liked to have helped me more,... but there wasn't the facilities for her to put me in the palliative care [in her hospital]. I was having my chemo. He really wasn't [around], because as I say, I was too sick. I was kept in the hospital. I would assume that he would have gotten reports from the cancer doctor.

Even FPs who came to the hospital as visitors could not treat their patients. "Not here, they won't let her touch anything, which I find is really stupid."

Roles of FPs in cancer care

Being accessible: Family physicians' offers of access and time were both helpful and symbolically important

as a sign of commitment to patients. "I don't know how much more supportive she can be, when you say, 'You can phone me at any time. ...' Lots of times she's able to tell me what to do or she'll write me a prescription over the phone." "[The FP] left a message with her receptionist that any time I called, I was to be put through. She would return calls as soon as she was able, sometimes in the evening."

Participants saw telephone access as particularly important, as it helped to reduce their anxiety, assisted in problem solving at home, and ensured that serious problems received medical attention. Many FPs also offered prompt office appointments, but home visits were rare and patients believed that few doctors did them.

Providing support: Participants viewed FPs as providing warmth, encouragement, and emotional support. "With your family doctor you are able to discuss the smaller problems, your feelings, I guess. You don't with a specialist." "She's a pillar of strength and encouragement.... She's right behind me, you know."

Familiarity was an important aspect of this support, but years of previous contact were not necessary for its development. The crisis of having cancer could create a sense of familiarity and trust relatively quickly between doctor and patient. "[I have] so much faith in her now. Before, she was just another doctor that I was learning to know."

Patients appreciated it when FPs attended to the needs of family members and answered their questions. "He's helping my kids... to get them through this. ... Actually I wish there was more time with the whole family. ... You know, like sit down and talk about it, what we can't seem to get out of the specialists, because it's a colder atmosphere."

Providing referral, triage, and general medical care: Some participants were impressed with the speed and efficiency with which their FPs arranged for testing and referrals once the cancer diagnosis was suspected. "He's fantastic. ... He set everything in motion." "I'm happy with the specialists that [the FP] got. [She's a] pretty good link."

Family physicians performed a triage function, evaluating the significance of new symptoms and making referrals as needed. The lack of this help was lamented by one participant. "I got completely lost ... by not having a family doctor, because you ... have to have a specialist for every last little thing."

Participants with unrelated medical problems noted their need for their FPs' help, as they did not want to bother their specialists about such problems. Relatively few noted a substantial role for their FPs

in providing information about their cancer or in managing cancer-related symptoms or medications. For most, the FPs' role in such matters was minor. "[The FP] did a couple little things for us when [the oncologist] was away... that involved an injection into the tummy of a particular drug."

DISCUSSION

Although erosion in patient-FP relationships has often been described as a problem in cancer care,^{5,7,21} this study provides the first insight from patients' perspectives into the factors at play. Many of these spring from the changing primary care environment in Canada, which has featured physician shortages and relocations, FPs working fewer hours, and withdrawal of urban FPs from hospital work.²² In addition, some participants did not perceive a clear role for FPs. This was especially true when physicians appeared less than competent or out of the communication loop with specialists and when no comorbidity required their assistance.

The roles of FPs in cancer care described here reflect those in other studies of patient-FP relationships in general.^{23,24} A similar emphasis on providing psychosocial support to patients with cancer has been noted in studies of FPs.^{25,26} These participants made relatively little mention of a role for FPs in providing information about cancer and treatment choices or in cancer follow up and symptom control. Family physicians themselves perceive these as important roles they play in cancer care.^{25,26} This discrepancy could reflect an unrealistic self-appraisal on the part of FPs, as well as the particular experience of the urban and hospitalized sample of this study.

Re-establishing ties with FPs to facilitate discharge from a palliative care unit is often difficult. Strategies that serve to maintain involvement of FPs throughout cancer care could increase the likelihood of patients' entering the palliative care phase with that relationship intact. Shared care²⁷ and parallel care feature a more active relationship between patients and FPs. Such a relationship is desired by FPs²⁶ and oncologists,¹⁴ and we hypothesize it would better meet the needs of cancer patients. Some FPs, particularly rural ones, want to be involved in cancer treatment under the supervision of oncologists (shared care), while others prefer providing support and help with non-cancer-related problems (parallel care).²⁶ The shared-care model is often used in provision of oncology services to rural areas, with excellent outcomes.²⁸ In palliative care, a model of greater FP involvement has been implemented in Edmonton, Alta, and demonstrates shared care.²⁹

Both shared and parallel care require good communication between FPs and specialists, something many participants noted as lacking. Family physicians want information about the nature and potential side effects of cancer therapies, about prognosis, and about what patients have been told.²⁶ Face-to-face or telephone contact is perceived as more effective than written reports, and is particularly important for role negotiation between physicians.

Oncologists struggle with the sheer number of FPs they deal with, the lack of patient updates from FPs, and the variability of FPs' interest in providing cancer care.¹⁴ Family physicians need to be able to articulate to patients and specialists the kinds of help they are able to provide. For most, this would include assessment of new symptoms and appropriate referral, emotional support to patients and families, ongoing supervision of other medical problems, and ready accessibility (particularly by telephone). Some FPs are also willing to review treatment options, respond to symptoms arising from the cancer or its treatments, and provide follow-up care. This clarification of roles should be done early and revisited periodically, and should respect the preferences of patients, FPs, and specialists.

Hospitalization should be recognized as a serious threat to patients' connection with the many FPs who no longer have hospital privileges. Establishing follow-up appointments with FPs after discharge should be a priority of hospital-based physicians caring for such patients.

Finally, a diagnosis of cancer involves some delay for most patients. Feelings of doubt and anger that often arise from such delay can strain patient-physician relationships.¹⁰ Physicians might do well to explore patients' feelings about this issue, as an honest exchange of views could reconcile and mend a relationship that otherwise would be lost.

Limitations of this study include having mainly urban participants in an inpatient palliative care service. Such people could have very different experiences with their FPs from those at home or in rural communities. Further study should explore the experiences of a wider sample and test the applicability of the themes we have identified.

CONCLUSION

Cancer care may be organized as sequential, parallel, or shared care between FPs and cancer specialists; sequential care is common if patients' relationships with FPs wane. Cancer patients lose contact with FPs

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because of patient or physician relocation, distrust over delays in diagnosis, lack of a perceived need for an FP, poor communication between FPs and specialists, and a lack of FP involvement in the hospital. People with cancer value FPs for being accessible through prompt appointments and telephone contact; for providing emotional and family support; and for referral, triage, and general medical care. Future research needs to validate these findings on a larger patient population. ❖

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Contributors

Dr Norman did the original literature search and collected all data. She was the primary author of the written report submitted to the University of Manitoba, of the original submission, and of revisions to this manuscript. **Dr Norman** and **Dr Sisler** wrote the original research proposal and submission to the ethics committee and analyzed all transcripts. **Dr Sisler** revised the Results and Discussion sections. **Dr Norman**, **Dr Sisler**, and **Dr Harlos** prepared the Methods section. **Dr Hack** helped choose the methods, advised on data collection, and acted as a third reviewer of emerging themes and categories. He made several important revisions to the article. **Dr Harlos** provided the original idea for the study, helped with data collection, and reviewed and commented on each draft of the article.

Competing interests

None declared

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Editor's key points

- Palliative care patients reported a spectrum of family physician involvement in their care, from minimal care after referral to an oncologist to parallel, committed, complementary care during the final stages of illness.
- Patients perceived barriers to FP involvement including poor communication between physicians, lack of hospital privileges, and limited practices.
- Palliative care patients highly valued what involved FPs offered: accessibility, medical backup, and emotional support to patients and families.

Points de repère du rédacteur

- Les patients en soins palliatifs ont rapporté une gamme d'interventions du médecin de famille dans leurs soins, allant de soins minimaux après l'aiguillage vers l'oncologue à des soins parallèles, dévoués et complémentaires durant les phases terminales de la maladie.
- Les patients percevaient des obstacles à la participation des médecins de famille, notamment une mauvaise communication entre les médecins, l'insuffisance de privilèges hospitaliers et les limites dans la pratique.
- Les patients appréciaient vivement ce que les médecins de famille impliqués offraient: l'accessibilité, le soutien médical et émotionnel aux patients et à la famille.

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