

Needs of cancer patients in palliative care during medical visits

Qualitative study

Dominik Melhem MD CMFC(SP) Serge Daneault MD PhD FRCPC

Abstract

Objective To explore the needs of cancer patients in palliative care and to determine how care providers, including family physicians, could meet these needs more fully.

Design Qualitative study performed using semistructured interviews.

Setting Palliative care departments (ambulatory and intrahospital).

Participants Twelve patients with a diagnosis of cancer deemed to be in the palliative phase, who had already received either chemotherapy or radiation treatment.

Methods The interviews were recorded and transcribed. They were then coded and categorized to identify and define themes describing the participants' experience. Data were collected until new interviews no longer yielded new categories of results.

Main findings Study participants primarily needed the expertise of their physicians, but they also needed reassurance by means of clear information about their disease, its treatment, and the prognosis delivered over the course of patient-physician visits, and by means of various measures that could act as safety nets. Participants needed to be heard without being judged. In terms of follow-up care, the oncology nurse navigator was just as important as the physician and could stand in for him or her to meet most relational needs and share and explain information on the disease.

Conclusion Non-family physician specialists cannot meet all of the patients' complex needs; throughout the palliative phase, non-family physician specialists need the support of a family physician and an oncology nurse navigator. Each care provider must be made aware of the patient's needs and ensure that they are met, to the best of his or her ability. Failing to do so might exacerbate the loneliness and anxiety experienced by terminally ill patients.

EDITOR'S KEY POINTS

- Patients with cancer have needs beyond medical expertise. They need respect and validation of their experiences, they need to be listened to without judgment, and they need reassurance.
- To optimize patient care, non-family physician specialists should enlist the support of a family physician or an oncology nurse navigator early in the process. The nurse navigator can stand in for the physician to meet most relational needs and share and explain information on the disease.
- Overall, patients had positive impressions of the health care system, despite seeing deficiencies. Patients were grateful for the presence of the nurse navigators, who had frequent contact with the patients. Some patients felt hope when they knew in advance what the other treatment options were in the event that their current treatment failed.

This article has been peer reviewed.
Can Fam Physician 2017;63:e536-42

La version en français de cet article se trouve à www.cfp.ca dans la table des matières du numéro de décembre 2017 à la page 945.

In Canada, family physicians provide a large proportion of palliative care services to patients at home and in the hospital.¹⁻³ However, several studies report that physicians are not always comfortable having end-of-life discussions with their patients.⁴ Good communication needs to be focused on the needs of the patient.^{5,6} For this reason, the College of Family Physicians of Canada believes that a patient-centred approach and communication skills are core competencies for family physicians.⁷ Patient-centred approaches have been associated with a greater sense of satisfaction and control among patients, better adherence to treatment, a decrease in symptoms, and a decrease in costs to the health care system.^{8,9}

Several patient-centred approaches have been described. Nonviolent communication (NVC), as proposed by Marshall Rosenberg, is based on the Sanskrit principle of *ahimsa*, embraced by Gandhi and meaning “to do no harm.” The NVC approach starts by identifying the needs of the individual, because these needs are the source of behaviour.¹⁰ This is done with the idea that acknowledging an individual’s needs is therapeutic in itself. In the process of treating incurable patients, we are constantly confronted with symptoms that do not respond to our treatment approaches. Nonviolent communication does not require care providers to meet all of a patient’s needs; it invites them to act with compassion and to at least acknowledge these needs and offer comfort. To our knowledge, there has only been one study on the use of NVC in the health sector.¹¹ This study revealed that NVC leads to an increase in empathy in nurses.

Some authors are of the opinion that, by failing to sufficiently take patients’ needs into account, the health care system actually contributes to their suffering.¹²⁻¹⁴ In this study, we seek to answer 2 questions. First, is there a group of priority needs that all palliative care patients have and that need to be addressed during medical follow-up? And, second, how could we respond more fully to the needs of these patients?

The objective of this study was to explore the needs of cancer patients in palliative care and to determine how care providers, including family physicians, could meet these needs more fully.

METHODS

We chose to conduct in-depth interviews and use qualitative analysis to develop a detailed picture of patients’ experiences.^{15,16}

Study population

This study was conducted in the Centre hospitalier de l’Université de Montréal in Quebec, comparable to most

large North American hospitals. After the study received the approval of the research ethics board, physicians working in ambulatory palliative care clinics and oncology nurse navigators at the hospital were asked to identify patients who would qualify for the study. Patients were considered for inclusion if they were older than 18 years of age, were in the palliative phase of cancer, and had received at least 1 radiation or chemotherapy treatment. Patients were excluded if they could not communicate in French or English or had dementia or a severe psychiatric disorder that was not being managed.

Data collection

A member of the research team contacted the patients who had been identified and confirmed that they were interested in taking part (only 1 patient declined to participate at this stage); the researcher then arranged patient interviews. Participants were advised that they would also be invited to take part in a focus group to validate the study observations.

The semistructured interviews began with open-ended questions about memorable experiences that the participants had had during medical follow-up care, in terms of their needs, feelings, and expectations.

Data collection and analysis were performed concomitantly. A sampling approach aligned with our theoretical objectives¹⁷ was used progressively so that we could avoid recruiting patients of the same age, sex, and diagnosis, and so that we could expand the breadth of patient experiences included. At the same time, the questionnaire was refined by adding more detailed questions so that we could explore the content more fully and validate concepts that emerged from our concomitant analysis. Thus, questions were added to the initial questionnaire. The care providers and study participants then validated the patient needs model by means of 2 focus groups.

Data analysis

The data were analyzed in 3 phases.¹⁵ The first phase consisted of open coding of units of transcribed text, hewing as closely as possible to the participants’ own words. The second phase consisted of more in-depth coding and the definition of more abstract categories. The third and final phase consisted of a thematic analysis to identify links among the categories and to identify the concepts. Coding was done independently by the 2 researchers, who compared their results while actively looking for contradictions. Any divergence identified (<5%) was discussed to arrive at a consensus. Saturation was achieved when new interviews no longer added new categories of results (D. Willms and N.A. Johnson, unpublished manuscript, 1999). The qualitative data were analyzed using QDA Miner, version 4.1.27.¹⁸

FINDINGS

The 12 participants who made up the final sample had been seen by physicians in an ambulatory palliative care clinic (**Table 1**). When a patient had a family physician, he or she was sent back to this physician unless the complexity of the case required joint follow-up by the family physician and the specialized team. Participant comments supporting our observations are provided in **Table 2**.

Themes

Patients need medical expertise, but they also have other needs. The participants reported that they readily trusted their physicians' clinical competence; however, they believed that purely biomedical care was not enough and that their psychological, social, and spiritual needs had to be considered as well. Some physicians did not take these other needs into account.

Patients need respect and validation of their experiences.

The participants reported that, particularly when they felt vulnerable and emotionally overwhelmed, they needed their physicians to take the time to validate their suffering and to give them permission to suffer. When this happened, a relationship of trust emerged. When it did not, the participants felt frustrated and lonely. Several participants mentioned that a gentle approach was important when the physician was sharing bad news.

Patients need their physicians to listen without judging.

There was a close relationship between the need for respect and the need to be heard. The participants wanted their physicians to be "present" and "nonjudgmental" as they listened. This particular need cannot be delegated, as it is critical to providing patients with the best possible expertise. The participants related that they were constantly interpreting their physicians' body language for signs of attentive listening. Eye contact and sitting, rather than standing, were 2 examples of attentiveness cited.

Table 1. Study participants

PSEUDONYM	SEX	AGE, Y	CANCER DIAGNOSIS	EDUCATION, Y	PROFESSION	TIME BETWEEN DIAGNOSIS OF UNTREATABLE CANCER AND INTERVIEW, MO	CHARACTERISTICS OF PHYSICIAN ASSIGNED TO PALLIATIVE CARE
Homer	M	57	Stomach—metastasizing	15	Buyer	9	Geriatrician with 32 y experience
Yvette	F	54	Esophagus—metastasizing	NA	Receptionist	16	Family physician with 16 y experience
Ginette	F	58	Hard palate	12	Educator	2	Family physician with 44 y experience
Manon	F	58	Colorectal—metastasizing	10	Seamstress	86	Family physician with 16 y experience
Diane	F	67	Rectum—metastasizing	15	Clinical research technician	17	Family physician with 16 y experience
Élise	F	78	Thyroid	9	Nutritional aide at a hospital	87	Family physician with 9 y experience
Gino	M	73	Prostate—metastasizing	9	Sales manager	12	Geriatrician with 32 y experience
Joe	M	78	Esophagus	8	Truck driver	59	Family physician with 44 y experience
Ray	M	64	Lungs—metastasizing	8	Day labourer	23	Family physician with 44 y experience
Maria	F	86	Breast—metastasizing	3	Clothing manufacturer	61	Family physician with 44 y experience
Victor	M	58	Prostate—metastasizing	19	Accountant	89	Geriatrician with 32 y experience
Chayo	M	81	Lungs—metastasizing	15	Nurse	1	Family physician with 9 y experience

F—female, M—male, NA—not available.

Table 2. Excerpts of participants' comments, by theme

THEME	COMMENTS
Patients need medical expertise, but they have other needs as well	<ul style="list-style-type: none"> • I come from a family of family physicians, so I tell myself that if he is a physician, he has the skills to be doing what he is doing (Victor) • The approach with the patient—for sure it's important. It's maybe even a priority (Manon) • A feeling that I didn't trust her—that she was too stiff. My illness, my lungs. She would say: "You have this. You have that. I'm going to give you some pills." Give me some pills? It was sort of like I was going to be my own guinea pig. Do it yourself, because I'm not coming back here (Ray) • Empathy is very important. And the desire to help. That can do miracles. The way you approach people. Coming to your patient when you are stressed and tired ... or greeting your patient with a beautiful smile (Chayo)
Patients need respect and validation of their experiences	<ul style="list-style-type: none"> • The main thing is to go slow. The patient is already suffering enough. He's suffering—sometimes more than you would think (Ray) • The physician sat down and then she said to me: "I don't have good news. Are you ready to listen to me?" (Chayo) • She gave me the information, but the information was catastrophic. It wasn't like, "It could be this. It could be that, which is the worst-case scenario. Otherwise, it could be like this, or this, or this." I didn't get the scale. I got the catastrophe. I had no control over the situation. She was in the driver's seat (Diane) • "We could always do an infiltration." "It hurts so much, just the idea of having a needle inserted. Forget it. Not right now. Maybe later, but not right now." "Okay." That's how I knew she was listening: If that's how you are feeling, no problem (Diane) • But I wasn't alone. I had my partner with me. I didn't necessarily need to talk. Sometimes, there's nothing to say (Homer)
Patients need their physicians to listen without judging	<ul style="list-style-type: none"> • She listened. She closed her eyes to not be influenced by the stoic side—you know, this is how it's going to be. And she listened. She said, okay. She took in what I said. She didn't interpret it (Diane) • I don't know how the courses are taught Yeah, so maybe it's the prejudices we have in our society—judging people by how they look—which is part of belonging to a society. But maybe it can be done differently (Diane) • "No, I'm listening to you. I can repeat what you said to me, word for word." [the doctor] I said to him, "You're not listening to me. You're looking at me, but with your eyes. You're not listening to me" (Manon) • When you are speaking to someone who is avoiding eye contact, it's not—for me, personally—that's not a good sign (Manon) • She asked me questions. She really asked questions. Then she asked me to describe. She really listened to me—to what I was saying. It was, like, "That doesn't matter, maybe it's a little" "So it's wacky, whatever!" [Laughter.] It was, like, "Go for it!" [Laughter] So that created some trust between us (Manon)
Patients need reassurance	<ul style="list-style-type: none"> • You're all alone in his office. He tells you that you have cancer. And I'm thinking, maybe it would be better to wait until I bring someone with me (Gino) • I was happy that she called when my partner was there. For me, that's important. Probably because I have one more person fighting for me—because it's a fight every day (Victor) • I can't talk the way I'm talking with you. It's rare. Even with my doctors. It's either my wife or my daughter who does the talking (Ray) • He's the one who told me about Dr R. He encouraged me. He told me there were treatments. That they caught it early. That it wasn't too late (Gino) • I appreciate that. That if it didn't work, there were other things they could do. That I wasn't being sentenced to being in pain for all eternity (Diane) • The one who gave me the information—I really thought he was smart. He talked to me for an hour and a half. We were both surprised that he gave me that [expletive] information (Joe)

Continued on page e540

Table 2 continued from page e539

Overall, cancer patients are satisfied with the health care system despite the gaps	<ul style="list-style-type: none"> • The health care system—they're doing their best. They're doing what they can. They can't do more without more tools (Ray) • I would never criticize the health care system. First of all, I added up the cost and I said to him, just the cost of that drug, that treatment, plus the cost of Xgeva [denosumab], plus the hormone therapy and my implant, which I still have, that's \$50 000 a year. Who am I to complain? I'm fortunate. I'm one of the lucky ones (Victor) • So on weekends? On Friday from 12 o'clock on? Forget about it. Don't have a problem between Friday noon and Monday morning. Forget about it. Go to emergency. And when you go to emergency, you're dealing with people who don't know you—who haven't read your medical record. Reading an entire medical record takes time. Emergency departments are overflowing. It's like there's something missing (Diane) • She left the office. We were in her office and she was trying to reach the radiologist for my results. They didn't have time. She went right to their office. She came back. Really efficient. I couldn't believe it (Diane)
Vital importance of the oncology nurse navigator	<ul style="list-style-type: none"> • Right now, I find Julie [the nurse] more reassuring than [the doctor] ... because I have more communication with Julie than with Dr R. (Gino) • My nurse navigator. And Dr D. She's amazing. They communicate so well with each other. That helps too (Homer) • Eventually, I decided on Friday to call [the nurse]. What an amazing team. On her voicemail, Julie said that they would respond to messages left after 3 PM the next day. I called at 3:15 PM. We were in the car, doing our grocery shopping, and she called back (Victor)

Patients need reassurance. The participants reported a need for reassurance. Some wanted advance notice of bad news so that they could ask a friend or family member to accompany them to the appointment—a role that could also be played by the oncology nurse navigator, who could help the patient by completing the physician's answers and asking more questions to arrive at a better understanding of the disease.

The participants felt reassured and relieved when their physicians explained realistic alternatives to treatment, should it fail. They saw this as a safety net that enabled them to hold on to some measure of hope.

Finally, the participants reported that they needed their physicians to ensure that the participants understood the disease, the prognosis, and the treatment. This starts with something as simple as ensuring that the patient does not have a hearing problem and checking to make sure that he or she has understood. Two male participants, who described themselves as people who did not ask a lot of questions, said that they wished health professionals would take the initiative of providing them with more information. One reported that he felt great relief when his family physician sat down with him and his wife and gave them additional information.

Positive patient perceptions of the health care system. Overall, cancer patients are satisfied with the health care system, although they do see deficiencies. Our study participants understood the limits of the system. They believed that there was a lack of resources and that it would not be reasonable to ask for more than they received. One participant said he was grateful

to the system for spending tens of thousands of dollars on his care. In a similar vein, delays and wait lists were perceived to be acceptable.

Importance of the oncology nurse navigator. Quebec has had oncology nurse navigators for a number of years. The participants were grateful for the presence of these health care professionals, who had much more frequent contact with patients. Nurse navigators can reassure patients and answer their questions, without necessarily contacting the physicians. The participants' expectations of their health care professionals can be found in **Table 3**.¹⁹

DISCUSSION

Patients with cancer have needs beyond medical expertise. To optimize patient care, non-family physician specialists should enlist the support of family physicians or nurse navigators early in the process. American studies^{20,21} have itemized care deemed essential. All of our study participants had access to an oncology nurse navigator and a palliative care physician. Realistically, in the current medical context, there will not be a nurse navigator for every palliative care patient, which is why the family physician's involvement throughout the care process is so important.^{22,23} Several participants in our study reported that they did not have enough information after their diagnosis and that they would have benefited from seeing a family physician shortly after their oncology appointment.

We observed that patients quickly trusted their physicians' medical competence. The literature indicates that

Table 3. Participants' expectations of their health care professionals

HEALTH CARE PROFESSIONAL	EXPECTATION
Family physician	<ul style="list-style-type: none"> • Relieve uncomfortable symptoms • Support the oncologist by validating the patient's understanding of his or her disease and, if necessary, providing additional information, especially about the prognosis • Ideally, being involved right from the day the cancer is diagnosed, particularly if there is no nurse navigator (the case for approximately 40% of Quebec patients in 2010¹⁹) • Ensure the patient is prepared for bad news by suggesting he or she bring someone to the appointment • Listen; be "present" and do not judge during follow-up care • When it is realistic to do so, reassure the patient so that he or she can feel hopeful • Be proactive and expedite tests and appointments when appropriate because the nurse does not have the same influence as the physicians have in this area • If the patient does not have a nurse navigator, be prepared to take more time to listen to the patient's need for reassurance • When delivering bad news or when the patient is in distress, take at least a few moments to allow the patient to feel the feelings. For example, spend a few moments in silence • Be as available as possible, particularly when the nurse navigator is not there (evenings and weekends) to avoid unnecessary trips to the emergency department • Be proactive in cooperating and communicating with other care providers
Oncologist	<ul style="list-style-type: none"> • Make diagnoses, propose treatment, and provide care • Ensure the patient receives all of the necessary information on his or her disease, treatment options, and prognosis • Ensure the patient is prepared for bad news by suggesting he or she bring someone to the appointment • Listen; be present and do not judge during follow-up care • When it is realistic to do so, reassure the patient so that he or she can feel hopeful • Be proactive and expedite tests and appointments when appropriate because the nurse does not have the same influence as the physicians have in this area • If the patient does not have a nurse navigator, be prepared to take more time to listen to the patient's need for reassurance • When delivering bad news or when the patient is in distress, take at least a few moments to allow the patient to feel the feelings • Be proactive in cooperating and communicating with other care providers
Nurse navigator	<ul style="list-style-type: none"> • Ensure that the patient really understands his or her disease, ideally by being there right after he or she hears the diagnosis. Consult the oncologist or family physician if the patient needs a physician's expertise • Follow the patient, ideally from the moment of the diagnosis of cancer • Provide the patient with emotional support; validate his or her feelings; refer the patient to other professionals as needed • Listen attentively; be present; do not judge during care • Ensure the patient is comfortable • Be proactive in cooperating and communicating with other care providers

patients initially feel "social" trust in the medical institution, which trains its physicians to high standards of care. Patients then develop "interpersonal" trust on the basis of the physician's interpersonal skills, rather than his or her clinical competence.²⁴ For this reason, needs not related to medical expertise take on great importance.

Reassurance is one such need. Patients want to be reassured when it is realistic to do so. In our study, some patients felt hope when they knew in advance what the other treatment options were in the event that their current treatment failed. This has been found to be true in other studies as well.²⁵⁻²⁷

Being heard in a nonjudgmental, respectful manner is also important. A physician who listens attentively will be better able to select care based on the patient's needs and

values.^{25,28} Attentive listening can also result in a better "therapeutic presence,"²⁹ which is linked to better quality of care.^{30,31} Failure to acknowledge or respect the patient's experience is often a source of suffering and solitude for patients.³² Previous studies have noted that empathy and attentive listening gradually decrease as medical training progresses.^{33,34} The causes of this problem are multisystemic. Increasingly, faculties of medicine are attempting to alter their curriculum to remedy this problem.^{35,36}

Limitations

Because we used a qualitative research method, our observations are not generalizable to the overall population; however, the composition of our sample makes it possible to draw comparisons with other similar

institutions. Because our study only included cancer patients in palliative care, caution must be exercised in extrapolating the results of this study to patients with treatable cancers. Our selection process might also have weakened the strength of our study results; the patients selected might not be representative of patients who do not have access to palliative care physicians or oncology nurse navigators. We suspect that our participants would have had higher expectations of their non-family physician specialists had they not had access to these professionals. In spite of this, we believe that our study conclusions apply to family physicians who offer their patients palliative care. Other studies are needed to more clearly define the role of family physicians and oncologists in the treatment of advanced cancers in the absence of a palliative care physician or an oncology nurse navigator. Finally, as Kendall et al suggest, results for patients with cancer might not apply to patients with terminal, noncancer diseases.³⁷

Conclusion

Despite the many positive aspects of palliative care for patients with cancer—oncology nurse navigators, for example—many improvements in service delivery could be made. In addition to care from oncologists and nurses, patients with untreatable cancers who have just received their diagnoses would benefit greatly from having a family physician able to deliver palliative care. In more challenging cases, the addition of a physician specializing in palliative care might benefit the patient. Close cooperation and communication between care providers is essential to meet the complex needs of such patients. This study confirmed that these are very vulnerable patients who have needs beyond pure medical expertise. They need to be heard, supported, informed, and reassured when it is possible to do so. They need validation of their experience. The simple act of naming a patient's need communicates empathy and can bring relief. Each care provider has a responsibility to ensure that the needs of their patients are heard and addressed.

Dr Melhem is a family physician practising in Beloeil, Que. **Dr Daneault** is Associate Professor in the Department of Family and Emergency Medicine in the Faculty of Medicine at the University of Montreal in Quebec.

Contributors

Dr Melhem conducted this study during a 1-year fellowship in palliative care at the Centre Hospitalier de l'Université de Montréal. He was involved in every stage of the research: defining the research question, conducting a review of the literature, recruiting and interviewing study participants, analyzing the data, and writing this article. **Dr Daneault** acted as his mentor and guide for every stage of the research, performed part of the data analysis, and helped to revise the manuscript in preparation for publication.

Competing interests

None declared

Correspondence

Dr Dominik Melhem; e-mail dominik.melhem@gmail.com

References

- Shang M, Jancarik AS. *Soins palliatifs et de fin de vie en centres hospitaliers. Recension de pratiques*. Longueuil, QC: Agence de la santé et des services sociaux de la Montérégie; 2014.
- Ministère de la Santé et des Services sociaux. *Politique en soins palliatifs de fin de vie*. Quebec city, QC: Ministère de la Santé et des Services sociaux; 2010.
- Bédard C, Major D, Ladouceur-Kégle P, Guertin MH, Brisson J. *Soins palliatifs de fin de vie au Québec: définition et mesure d'indicateurs. Partie 1: population adulte (20 ans et plus)*. Quebec city, QC: Institut national de santé publique du Québec; 2006.
- Ambuel B, Mazzone MF. Breaking bad news and discussing death. *Prim Care* 2001;28(2):249-67.
- Lobb EA, Kenny DT, Butow PN, Tattersall MH. Women's preferences for discussion of prognosis in early breast cancer. *Health Expect* 2001;4(1):48-57.
- Ngo-Metzger Q, August KJ, Srinivasan M, Liao S, Meyskens FL Jr. End-of-life care: guidelines for patient-centered communication. *Am Fam Physician* 2008;77(2):167-74.
- Working Group on the Certification Process. *Defining competence for the purposes of certification by the College of Family Physicians of Canada: the evaluation objectives in family medicine*. Mississauga, ON: College of Family Physicians of Canada; 2010.
- Stewart M, Brown JB, Weston WW, McWhinney IR, McWilliam CL, Freeman TR. *Patient-centered medicine. Transforming the clinical method*. 2nd ed. Abingdon, UK: Radcliffe Medical Press; 2003.
- Little P, Everitt H, Williamson I, Warner G, Moore M, Gould C, et al. Observational study of effect of patient centredness and positive approach on outcomes of general practice consultations. *BMJ* 2001;323(7318):908-11.
- Rosenberg MB. *Nonviolent communication. A language of life*. 2nd ed. Encinitas, CA: PuddleDancer Press; 2003.
- Nosek M, Gifford E, Kober B. Nonviolent communication (NVC) increases empathy in baccalaureate nursing students: a mixed method study. *J Nurs Educ Pract* 2014;4(10):1-15.
- Daneault S, Lussier V, Mongeau S, Hudon É, Paille P, Dion D, et al. Primum non nocere: could the health care system contribute to suffering? In-depth study from the perspective of terminally ill cancer patients. *Can Fam Physician* 2006;52:1574-5. Available from: www.cfp.ca/content/cfp/52/12/1574.full.pdf. Accessed 2017 Oct 17.
- Cassel EJ. The nature of suffering and the goals of medicine. *N Engl J Med* 1982;306(11):639-45.
- Arman M, Rehnsfeldt A, Lindholm L, Hamrin E, Eriksson K. Suffering related to health care: a study of breast cancer patients' experiences. *Int J Nurs Pract* 2004;10(6):248-56.
- Charmaz K. *Constructing grounded theory. A practical guide through qualitative analysis*. London, UK: Sage Publications; 2006.
- Hutchinson SA. Grounded theory: the method. In: Munhall PL, Oiler Boyd C, editors. *Nursing research. A qualitative perspective*. 2nd ed. New York, NY: National League for Nursing Press; 1993. p. 180-212.
- Glaser BG, Strauss AL. *The discovery of grounded theory: strategies for qualitative research*. Chicago, IL: Aldine Publishing Company; 1967.
- QDA Miner, version 4.1.27. Montreal, QC: Provalis Research; 2016.
- Institut de la statistique du Québec. *Enquête québécoise sur la qualité des services de lutte contre le cancer 2013. L'infirmière pivot en oncologie et l'expérience patient*. Quebec city, QC: Institut de la statistique du Québec; 2013.
- Temel JS, Greer JA, Muzikansky A, Gallagher ER, Admane S, Jackson VA, et al. Early palliative care for patients with metastatic non-small-cell lung cancer. *N Engl J Med* 2010;363(8):733-42.
- Lowery WJ, Lowery AW, Barnett JC, Lopez-Acevedo M, Lee PS, Secord AA, et al. Cost-effectiveness of early palliative care intervention in recurrent platinum-resistant ovarian cancer. *Gynecol Oncol* 2013;130(3):426-30. Epub 2013 Jun 14.
- Aubin M, Vézina L, Verreault R, Fillion L, Hudon E, Lehmann F, et al. Family physician involvement in cancer care follow-up: the experience of a cohort of patients with lung cancer. *Ann Fam Med* 2010;8(6):526-32.
- Aubin M, Vézina L, Verreault R, Fillion L, Hudon E, Lehmann F, et al. Family physician involvement in cancer care and lung cancer patient emotional distress and quality of life. *Support Care Cancer* 2011;19(11):1719-27. Epub 2010 Sep 30.
- Pearson SD, Raeke LH. Patients' trust in physicians: many theories, few measures, and little data. *J Gen Intern Med* 2000;15(7):509-13.
- Daneault S, Dion D, Scotte C, Yelle L, Mongeau S, Lussier V, et al. Home and noncurative chemotherapies: which affects the other? *J Clin Oncol* 2010;28(13):2310-3. Epub 2010 Mar 1.
- Daneault S, Lussier V, Mongeau S, Yelle L, Côté A, Scotte C, et al. Ultimate journey of the terminally ill. Ways and pathways of hope. *Can Fam Physician* 2016;62:648-56.
- The AM, Hak T, Koëter G, van der Wal G. Collusion in doctor-patient communication about imminent death: an ethnographic study. *BMJ* 2000;321(7273):1376-81.
- Kuuppelomäki M, Lauri S. Ethical dilemmas in the care of patients with incurable cancer. *Nurs Ethics* 1998;5(4):283-93.
- Chochinov HM, McClement SE, Hack TF, McKeen NA, Rach AM, Gagnon P, et al. Health care provider communication: an empirical model of therapeutic effectiveness. *Cancer* 2013;119(9):1706-13. Epub 2013 Jan 22.
- Tannen T, Daniels MH. Counsellor presence: bridging the gap between wisdom and new knowledge. *Br J Guid Counc* 2010;38(1):1-15. Epub 2010 Jan 5.
- Chochinov HM, Hack T, McClement S, Kristjanson L, Harlos M. Dignity in the terminally ill: a developing empirical model. *Soc Sci Med* 2002;54(3):433-43.
- Stanley P. The patient's voice: a cry in solitude or a call for community. *Lit Med* 2004;23(2):346-63.
- Hojat M, Mangione S, Nasca TJ, Rattner S, Erdmann JB, Gonnella JS, et al. An empirical study of decline in empathy in medical school. *Med Educ* 2004;38(9):934-41.
- Bellini LM, Shea JA. Mood change and empathy decline persist during three years of internal medicine training. *Acad Med* 2005;80(2):164-7.
- Murray J. Development of a medical humanities program at Dalhousie University Faculty of Medicine, Nova Scotia, Canada, 1992-2003. *Acad Med* 2003;78(10):1020-3.
- Divinsky M. Stories for life. Introduction to narrative medicine. *Can Fam Physician* 2007;53:203-5 (Eng), 209-11 (Fr).
- Kendall M, Carduff E, Lloyd A, Kimbell B, Pinnock H, Murray SA. Dancing a different tune: living and dying with cancer, organ failure and physical frailty [abstract OP 002]. *BMJ Support Palliat Care* 2015;5(1):101-2.