

Perceptions of palliative care among patients with advanced cancer and their caregivers

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ABSTRACT

Background: Early palliative care is increasingly recommended but seldom practised. We sought to examine perceptions of palliative care among patients with advanced cancer and their caregivers.

Methods: After conducting a cluster randomized controlled trial of early palliative care versus standard care for patients with advanced cancer, we approached patients and their caregivers to participate in semistructured interviews seeking to assess, qualitatively, their attitudes and perceptions about palliative care. We used the grounded theory method for data collection and analysis.

Results: A total of 48 patients (26 intervention, 22 control) and 23 caregivers (14 intervention, 9 control) completed interviews. Participants' initial perceptions of palliative care in both trial arms were of death, hopelessness, dependency and end-of-life comfort care for inpatients. These perceptions provoked fear

and avoidance, and often originated from interactions with health care professionals. During the trial, those in the intervention arm developed a broader concept of palliative care as "ongoing care" that improved their "quality of living" but still felt that the term itself carried a stigma. Participants in the intervention group emphasized the need for palliative care to be reframed and better explained by health care professionals. Participants in the control group generally considered it pointless to rename palliative care, but many in the intervention group stated emphatically that a different name was necessary in the early outpatient setting.

Interpretation: There is a strong stigma attached to palliative care, which may persist even after positive experiences with an early palliative care intervention. Education of the public, patients and health care providers is paramount if early integration of palliative care is to be successful.

Competing interests:

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Palliative care is interdisciplinary care that aims to improve quality of life for patients living with any serious illness, and their families; ideally, it begins at diagnosis and is provided concordantly with other disease-directed treatments.¹ Early palliative care is encouraged by international agencies such as the World Health Organization, which states explicitly that "palliative care is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life."² Several studies have shown that early involvement of specialized palliative care services for patients with advanced cancer improves quality of life, increases satisfaction with care and mitigates depression.³⁻⁵ Nevertheless, referrals to palliative care are typically made late in the disease course.^{6,7}

Negative attitudes toward palliative care among patients and caregivers are often cited by physicians as a reason for late referrals to palliative care services,^{6,8} and a change of name to "supportive care" has been proposed.^{8,9} Although some studies have reported on attitudes of oncologists and other physicians toward palliative care and its name,^{6,8,10-12} there has been scant research on the perspectives of patients and caregivers. Previous surveys of patients and/or caregivers have solicited opinions about either the quality of palliative care received^{13,14} or about the acceptability of the name "palliative care" versus "supportive care" for those who might be referred.^{9,15} With the exception of a study that validated a measurement tool to assess perceptions of palliative care,¹⁶ a detailed exploration of how patients

and their caregivers perceive palliative care has been lacking.

We previously conducted a cluster randomized controlled trial that compared early palliative care with usual practice in patients with advanced cancer, which showed benefits favouring the intervention group in quality of life, symptom control and satisfaction with care.⁵ After completion of the trial, we conducted qualitative interviews with participating patients and their caregivers. Our principal aim was to examine perceptions of palliative care of participants who had been randomly assigned to an early palliative care intervention or to a control group. Secondary aims included examining the probable sources of these perceptions, the potential influence of the intervention on these perceptions, and opinions about renaming palliative care.

Methods

Setting

Details of the cluster randomized controlled trial are available elsewhere.⁵ The study took place at Princess Margaret Cancer Centre, a comprehensive cancer centre in Toronto. Twenty-four medical oncology clinics from the 5 largest site groups (Lung, Gastrointestinal, Genitourinary, Breast and Gynecologic) were randomized such that patients in the clinics of the intervention group received early referral to a palliative care team (consultation and follow-up in an outpatient oncology palliative care clinic at least monthly for the 4-month trial duration, with additional visits as required) whereas patients attending clinics of the control group received standard oncology care (no formal intervention, but palliative care referral was not denied, if requested). Caregivers in the intervention group were not required to attend clinic visits but did so at their discretion. The study was approved by the University Health Network Research Ethics Board.

Participants and masking

Eligibility criteria for the trial were a diagnosis of advanced cancer, estimated survival of 6–24 months (by the primary oncologist), and Eastern Cooperative Oncology Group (ECOG) performance status of 0, 1 or 2.¹⁷ Exclusion criteria were insufficient English literacy to complete questionnaires and inability to pass a cognitive screening test.¹⁸ Primary caregivers were identified by participating patients, and were eligible for inclusion if they were 18 years of age or older, and had sufficient English proficiency to participate in an interview.

Although complete masking was impossible, patients and caregivers provided written informed

consent to participate in their own study group, without awareness of another group. Thus, those in the control group were unaware of an early palliative care arm in the trial.

Recruitment and interviews

At the end of the trial, patients and caregivers were approached in person or by telephone for participation in the qualitative study. Recruitment was purposive, with the aim of interviewing patients and caregivers from both the control and intervention groups, with a mixture of high and low scores on measures of quality of life and satisfaction with care, and participants who were older and younger, and male and female.¹⁹ Recruitment ceased when theoretical saturation of data was attained (i.e., no new information was being obtained from additional participants).²⁰ Trained research personnel conducted the semistructured interviews, which were done on an individual level, were audiotaped in a private room and lasted about 60 minutes; field notes were made after the interview. Interviews were conducted following a guide (Appendix 1, available at www.cmaj.ca/lookup/suppl/doi:10.1503/cmaj.151171/-/DC1), which included questions about participants' initial perceptions of palliative care (before the trial), probable sources of these perceptions, participants' reactions to discussions about palliative care, perceptions after participating in the trial and opinions about renaming palliative care.

Data analysis

The grounded theory method guided data collection and analysis.^{20,21} We chose this approach because it provides a systematic yet flexible guideline for collecting and analyzing qualitative data to construct explanations, or theories, "grounded" in the views of the participants.^{21–23} All audiotapes were transcribed verbatim; accuracy was further ensured by an independent rater, who listened to the audiotape while reading and correcting the transcript. Four coders analyzed the data by using an inductive constant comparison method.²¹ This approach involved systematically reading the transcribed interviews, identifying themes and then proceeding to verify, confirm, qualify and explain these themes by comparing data within and between interviews. To ensure rigor and minimize coder bias, we reviewed and compared emerging codes and written notes at weekly team meetings. Reflexivity, or the critical examination of the researchers' influence on the research process,²⁴ was addressed using field notes, reflective writing after interviews and team discussions. We examined negative cases (i.e., examples that appeared to run counter to the

emerging propositions) to refine the themes and their interpretation.²⁵ NVivo 8 software facilitated the analytical process.

Results

We approached 85 patients and 50 caregivers for participation in the qualitative study, and 71 consented to participate: 48 patients (26 intervention, 22 control) and 23 caregivers (14 intervention, 9 control). The main reasons for declining participation were feeling unwell or caring for an unwell patient, lack of time or interest, and the palliative care content of the interview (7 control group participants). All interviews were conducted in person except for 3, which were conducted by telephone. All participants completed the entire interview.

Table 1 shows characteristics of the patients and caregivers. In the intervention group, patients had a median of 5 visits to the palliative care clinic, and caregivers had a median of 4 visits. We identified themes within each of the 5 main topics covered during the interview. The themes and representative quotations from participants in the intervention and control groups are presented in Tables 2–6. Perceptions were similar among patients and caregivers within each trial group.

Initial perceptions of the meaning of palliative care

Patients and caregivers in the intervention and control groups had strikingly consistent descriptions of their initial perceptions of palliative care, both within and between groups (Table 2). A prevailing theme was that palliative care was synonymous with death and with care in the last weeks of life. One participant stated bluntly, “There’s no real meaning besides death” (P004c; first letter refers to patient [P] v. caregiver [C]; second letter refers to intervention [i] v. control [c]). Others spoke about control of symptoms and quality of life, but always in the context of end-of-life care: “It was always associated with a good death and a good dying, but the presumption was that there was *dying* to be had as opposed to a potential lengthening of life” (P049c); “There are other things that come to mind. There’s quality of end stage of life but again that all relates to death” (P040i). Palliative care was perceived as a passive form of care, when there was “nothing else that can be done” and “no hope.” There was a strong association with being incapacitated, bedridden and incapable of self-care, and with care in “places that you never get out [of] again” (P047c). Participants also expressed uncertainty regarding the meaning of palliative care, with some qualifying their

statements by saying that they were unsure of the exact meaning of the term, and others claiming they had “no idea” of what it represented.

Sources of perceptions of palliative care

Many participants in both trial arms stated that they had previous experiences with family or friends with a terminal illness who had “gone into palliative care” (Table 3). In these situations, palliative care had generally been presented by health care professionals as an option of last resort, often apologetically: “I’m sorry, I think we’ve got to put her into palliative care” (P023i); “We can’t do anything else, he’s in palliative care” (P031i). Experiences of participants as patients within the cancer system also influenced their impressions. Some patients stated that their health care providers delayed palliative care, equating it with end-of-life care and assuring them that they were “not there yet” (P033i). Others stated palliative care had been presented to them as an alternative to further treatment: “I said, ‘I’m not taking radiation,’ and she [radiation oncologist] says, ‘Well then, you know, it’s maybe time that we set you up with palliative care’” (P004c). The media were another source of information; participants reported that palliative care was generally presented as end-of-life care in palliative care units or hospices. Still others stated that they had “always known” about palliative care or were unsure of how their impression had been formed.

Initial reactions to palliative care

In keeping with the perceptions or interpretations of the meaning of palliative care, participants in both groups described feeling “frightened” and “shocked” when palliative care was introduced (Table 4). Avoidance and resistance were common reactions, particularly in the control group: many stated that they tried not to think about palliative care, and did not want to “dwell on the negative.” Others did not feel the subject was relevant for them, because it was “far away” and they were “optimistic”; this included some patients in the intervention group who felt that they did not “qualify” for palliative care, but were willing to participate in research to help others. In the intervention group, resistance to participating in a palliative care intervention was a prominent theme, but participants also stated that their initial misgivings were allayed by an explanation of the rationale for early palliative care by their oncologist or by the research team during the recruitment process: “Well, when I hear palliative care, ... naturally, I think, ‘Oh God, I’m not long for the world,’ but then when she explained it to me ... I thought, well people should have thought of that before” (P031i).

Perceptions after receiving early palliative care

Participants in the control group described no difference between perceptions of palliative care

before and after the trial. In contrast, among those in the intervention group, fear was generally replaced after contact with the palliative care team by a “more comfortable” attitude toward palliative care and a broadened under-

Table 1: Baseline characteristics of 48 patients and 23 caregivers

Characteristic	Patients, no. (%) [*]		Caregivers, no. (%) [*]	
	Intervention <i>n</i> = 26	Control <i>n</i> = 22	Intervention <i>n</i> = 14	Control <i>n</i> = 9
Age, median (range), yr	61 (51–83)	65 (41–82)	61 (38–71)	57 (40–80)
Sex, female	19 (73.1)	10 (45.5)	8 (57.1)	8 (88.9)
Married or in a common-law relationship	15 (57.7)	14 (63.6)	14 (100)	8 (88.9)
Living situation: alone (patient); with patient (caregiver)	7 (26.9)	5 (22.7)	13 (92.9)	7 (77.8)
Ethnic origin, European [†]	26 (100)	20 (90.9)	14 (100)	9 (100)
Education level				
Postsecondary [‡]	24 (92.3)	18 (81.8)	10 (71.4)	6 (66.7)
High school	2 (7.7)	3 (13.6)	3 (21.4)	1 (11.1)
Less than high school	0	1 (4.6)	1 (7.1)	1 (11.1)
Missing	0	0	0	1 (11.1)
Employment status				
Retired	14 (53.9)	12 (54.5)	7 (50.0)	4 (44.5)
Employed	7 (26.9)	4 (18.2)	6 (42.9)	3 (33.3)
Unemployed	3 (11.5)	0	1 (7.1)	2 (22.2)
Disability	2 (7.7)	6 (27.3)	0	0
Tumour site [§]				
Lung	4 (15.4)	5 (22.7)	3 (21.4)	1 (11.1)
Gastrointestinal	7 (26.9)	8 (36.3)	6 (42.9)	4 (44.5)
Genitourinary	3 (11.5)	4 (18.2)	1 (7.1)	2 (22.2)
Breast	6 (23.1)	1 (4.6)	3 (21.4)	2 (22.2)
Gynecologic	6 (23.1)	4 (18.2)	1 (7.1)	0
ECOG performance status at baseline [§]				
0	10 (38.5)	7 (31.8)	5 (35.7)	3 (33.3)
1	16 (61.5)	13 (59.1)	9 (64.3)	6 (66.7)
2	0	2 (9.1)	0	0
Active chemotherapy at baseline [§]	22 (84.6)	20 (90.9)	10 (71.4)	8 (88.9)
Relationship to patient				
Spouse or partner	–	–	12 (85.7)	7 (77.8)
Son or daughter	–	–	1 (7.1)	2 (22.2)
Other family member	–	–	1 (7.1)	0
No. visits to palliative care clinic, median (range)	5 (4–5)	0 (0–0)	4 (0–8) [§]	0 (0–0)

Note: ECOG = Eastern Cooperative Oncology Group.

^{*}Unless stated otherwise.

[†]The 2 participants of non-European ethnicity were Southeast Asian and South Asian.

[‡]Includes college, university, vocational/trade school and other.

[§]For tumour site, ECOG performance status and active chemotherapy, values indicated for caregivers are those of the patients for whom they were caring.

[§]Only 1 caregiver had no visits to the palliative care clinic, with all others attending twice or more.

standing of it being “more of a long-term [situation],” with the palliative care team being an “advocate for health care” (Table 5). Participants described a sense that the inclusion of the palliative care team was the “new normal,” stating that their contact with the team had removed its stigma, had increased their “quality of living”

and had given them confidence that they would have resources to cope. However, many participants still felt uncomfortable with the term palliative care in relation to themselves, especially when discussing their care with others, who might think they were imminently dying. Some chose to relabel the care they were receiving as

Table 2: Representative quotations about initial perceptions of palliative care

Theme	Control group	Intervention group
Death, end of life	<p>What comes to mind is bedridden, death bed, finality. (P062c)</p> <p>Well, “they’re preparing me to die.” That’s about it. (P056c)</p> <p>Plots waiting. That’s what I think it is. (P017c)</p> <p>Terminal meaning that that’s the end of the road. (C057c)</p>	<p>You know, that’s just helping people prepare to die. (P043i)</p> <p>The care that you receive when you’re dying, when you’re dying. That’s what comes to mind. (P034i)</p> <p>It means death to me. It does. The end. (C068i)</p> <p>Well, when you think palliative care, you think the person’s on death row. (C055i)</p>
Comfort care	<p>It just seems to me of keeping the patient comfortable if they’re in pain, try to give them something to look after the pain. That’s about it. (P069c)</p> <p>I would only assume that it’s an attempt to make the patient feel as comfortable as they can, or as can be arranged, until the end. (P020c)</p> <p>I thought, what the heck is that? Then I realized they’re just trying to keep you comfortable until you die. Can’t ask for any more. (P056c)</p> <p>It’s to make sure that you’ve gone with dignity, painless and comfortable, comfort. (C064c)</p>	<p>Just they take you off medication and put you on just comfort care. (P008i)</p> <p>Our impression, or my impression at least of palliative care, was sort of keep them doped, keep them comfortable, make them as comfortable as you can before he goes. (P013i)</p> <p>I understand what it’s all about is keeping the person as comfortable as possible as they go through the end of their days, because whatever they’ve got is not going to be cured and they’re not going to survive or they’re not going to be healed and palliative care is all about keeping them comfortable and allowing them to die in dignity. (C035i)</p>
No more choices, nothing left to do	<p>This is it, no more choices. (P049c)</p> <p>There’s nothing and it’s end-of-life, like you’ve reached the end of anything that can be of any help to you. (P041c)</p> <p>Because when it comes to palliative, they’re always sad that they didn’t help, that all is over. (P048c)</p> <p>The stage of palliative care, hope is kind of more or less gone. (C070c)</p>	<p>Well, the basic one is the psychological one that, “Now I’m going into palliative care, which basically means there’s no hope for me whatsoever and that I have very little time left.” (P015i)</p> <p>Dying, end of life, nothing left to do. (P025i)</p> <p>But in most cases, you don’t see palliative care, or anyone in palliative care, until you have come to the point where they’ve told you there’s nothing else to be done. (P014i)</p>
Loss of autonomy	<p>Well, I guess what comes to mind is that the end is near and that you’re in a situation where somebody else has to take care of you. (P037c)</p> <p>It just sounds old and sick and helpless. (P065c)</p> <p>Basically they are so sick they cannot do more than that, just stay there and to wait for the end. (P050c)</p>	<p>I guess palliative care is when you’re pretty much at that stage where you can’t take care of yourself any more. (P045i)</p> <p>When you think palliative care, you think bedridden, unable to look after yourself on any level. (P040i)</p> <p>That’s about it really. Not doing anything, just laying in bed and waiting. (P023i)</p>
A place to die	<p>No, no, I knew what palliative was. ... I knew exactly. I said, “Well, palliative is, oh God, where people go to hospital to die.” (P047c)</p> <p>I guess that’s the house where people are who don’t get well any more. (C059c)</p> <p>Well, to me, palliative care is the place where you go to die. (C064c)</p>	<p>I knew there was such a thing as palliative care but I just always thought of it as there are places where people go for palliative care when it’s known that they have 2 months to live or 3 months to live or 1 month or whatever the magic numbers are and whatever the situation is. (C035i)</p> <p>And it’s a place to die. But they make you as comfortable as possible and of course, nobody likes to think of pain and I guess they give you the very best painkilling treatments that are possible. (P023i)</p>
Unsure of meaning	<p>I don’t even know the exact definition. Is it for someone who’s dying? (C039c)</p> <p>First and foremost, I never knew what palliative care was to be honest. I never looked it up in the dictionary or, I did nothing and we don’t have this care back home. (P052c)</p> <p>Scares me a bit. ... Even though I don’t really know what it is. I don’t know really what it is. (C059c)</p>	<p>It’s like a foreign language, palliative care, yeah, but I didn’t really have any connection to what it was. I just had an idea that it was when people were dying they had palliative care. (P034i)</p> <p>What does it mean? Is it Greek for something or Latin for something? (P045i)</p> <p>I didn’t even know what palliative care really meant. (P002i)</p>

“symptom control” or to refer to their palliative care physician as their “medication specialist” or “pain specialist.” Others stated flatly that they felt palliative care was not the correct term for the care they were receiving. Palliative care tended to remain a term that “emotionally has a lot of weight to it.”

Renaming or reframing palliative care

Participants in the intervention group stated strongly that the end-of-life association of palliative care did not represent the care they had received

and that this “disconnect” was problematic (Table 6). A prominent theme was that palliative care should be explicitly rebranded: “That shell of meaning that surrounds palliative care has to somehow change” (P015i). Participants suggested public education, poster campaigns and routine involvement of palliative care at diagnosis as options for destigmatizing palliative care: “When you get it right from the get-go you just think, ‘Okay, they’re part of the team. That’s great’” (P010i). Direct explanation by an oncologist “educated on palliative care,” who could present it in a nonthreatening

Table 3: Representative quotations about sources of perceptions of palliative care

Theme	Control group	Intervention group
Health care system experience: caring for family, friends	<p>The nurse looking after him took him on another floor. That’s where the palliative are. “People are here to die,” or “they’ll never get out of here,” or something like that. (P047c)</p> <p>My father-in-law was in the palliative care unit before he died of lung cancer, and so it was in palliative care nothing is done to sort of advance anything. It’s just make you as comfortable as possible until you die. (C030c)</p> <p>I know a lot of people in [residential hospice]. That is totally palliative care. ... People in there never come out. That’s how I look at it. I presume that’s more or less the fact of life or whatever. (C057c)</p>	<p>My ex-husband actually died. ... He died in 3 months. But for the first period, they were treating him and then they said, “We can’t do anything else, he’s in palliative care.” (P031i)</p> <p>Yes, when my wife passed away. Three years ago she had a massive stroke. ... Was taken to the hospital of course. ... She couldn’t speak. She was paralyzed. She couldn’t talk. She couldn’t swallow. She couldn’t do anything. Just lay there. And after 3 weeks the nurse said, “I’m sorry, I think we’ve got to put her into palliative care.” Of course I started questioning, “what the heck is that?” So found out all about it and so on and that’s when I heard. (P023i)</p> <p>[My mother] was frail and she was ... so anyway, with the palliative care, that’s where it came up during the last week of her life I heard about that. (C067i)</p>
Health care system experience: own cancer care	<p>Well, palliative care was introduced to me by a doctor that didn’t know my case very well, and that specific doctor said, “Well, you know, speak to Palliative Care,” and it was like someone had hit me. I was shocked. To me that means I have 6 months to live. (P004c)</p>	<p>The very first time that one of these home nurses came to my house, right, she said ... “You’re not in palliative care, like you’re dying of anything, are you?” And I just looked at her, I remember just saying, “Oh, is that what that means?”, I said. (P002i)</p> <p>When I first went to see the oncologist, she told me that sooner or later I would meet the palliative care team, and then reassured me that, “Oh no, that won’t be for a long time.” ... So she, herself, had that same association somehow in there, so as not to panic the patient. (P014i)</p>
Media, films	<p>It definitely, in the media, is associated directly with kind of end-of-life, so that’s always hard. (P036c)</p> <p>Yeah, there was this movie about a woman with ovarian cancer and she goes into palliative care, yeah. You know, and I think, really, when I think of it some of the images that I’ve seen in the media have influenced how I feel about palliative care. (P004c)</p> <p>I feel that it’s portrayed [in the media] in a very dramatic way. It’s joyless. I think, if done properly, it can be an opportunity for a tremendous amount of joy. At least that’s my goal with [patient]. (C019c)</p>	<p>I think it maybe was just a newspaper article about some important person who had passed away. And they just mentioned that they died in the palliative care department or whatever they call it, of such-and-such a hospital. (P016i)</p> <p>Well, I think in general it’s just from reading generally because there’s various places that have palliative care units and usually those as far as I know that’s when patients are in really in their last stages and can’t be on their own anymore and I guess they have to be where the medication has to be administered often and regularly and maybe they can’t even get up. (P026i)</p> <p>It’s probably articles I’ve read that people maybe were at the end of life and they were in some kind of hospice, which was referred to as palliative care. (C046i)</p>
Unsure where	<p>I don’t know where the devil I first heard it. (P056c)</p> <p>I have no idea. I mean I’ve always known about palliative care existed. (P037c)</p> <p>I have a sort of a concept, but where it came from I have no idea. (P020c)</p> <p>It’s just sort of a word that popped up and it’s just been there. (C039c)</p>	<p>I just think I knew palliative, I just knew the word associated in my mind with care that you would get when you were at the end of your life, when you need that intense care. I think I just knew that. (P010i)</p> <p>Well I knew it existed just from hearing about it, I mean, in the world. (P025i)</p> <p>If it’s urban legend or myth or whatever, it’s in my head so that’s what I thought. (C044i)</p>

way as “part of the treatment package,” was considered by participants to be more helpful than relying on written material. A related theme was that palliative care should be renamed if provided early: “I think you have to really think about a name that would outline what you’re trying to do. You’re not trying to help someone in their last days” (P007i). None who advocated for a name change offered a

more suitable name (“Greater minds than mine can come up with a snappy little title” [P034i]), but when the name “supportive care” was suggested, it was met with approval.

Participants in the control group generally saw no purpose in renaming or reframing palliative care but also did not find it relevant to their own situation. They were unaware of the concept of

Table 4: Representative quotations about initial reactions to palliative care

Theme	Control group	Intervention group
Shock and fear	<p>I don’t know, because it’s a bit of a surprise to hear that related to you, so it’s sort of a jolt, a wake-up. (P041c)</p> <p>It would be like you’re sitting here and someone says, “Your house burned down!” Like, what does that mean? (P004c)</p> <p>I said, “No, no, I’ll fight it. I’m not going to go for this palliative care.” It scared me, it did scare me. (P052c)</p>	<p>To us at least, it was a bit of a shock. ... we had a preconceived idea of what it was, which was clearly wrong. (P013i)</p> <p>I was very surprised when ... I thought, “Oh my God! I’m sicker than I thought.” (P031i)</p> <p>The word is extremely frightening because it’s like we can’t do anything for you. We’re putting you in palliative care. (P025i)</p>
Resistance to palliative care*	<p>If palliative care is ... “We’ve got to get into some palliative care,” I’m going to say, “Whoa.” I hope I never hear that. I like to think of it like a candle. You burn ... life should be like a candle, burn bright, flicker once or twice and go out. That’s what I want to be, a candle. (P069c)</p> <p>That’s one of my, I don’t know if it’s a fault or whatever, but my husband used to say I’m an ostrich; I put my head in the sand. I don’t deal with it, I’m fine. You don’t want to deal with it unless you really have to. (P065c)</p> <p>I’d have to be ... if I were an awful lot worse where I thought I was going to be a burden to my family or something like that, then I might bring it up. ... Other than that, I would do almost anything before I did that. (P060c)</p> <p>I think because we haven’t, we don’t look there, we don’t go there, we don’t dwell on the negative part of that. I guess, to me, in a way it’s a bit of a negative. (C070c)</p> <p>You’d never get him into palliative care first of all [laughter], but I think it would have to be ... I don’t know. He would be a difficult case. ... like something would have to completely debilitate him before he would even consider the option of palliative care. (C030c)</p>	<p>It’s like we don’t like it. It’s like that’s about dying, death. I’m not doing that, thank you. I think yeah, that would be my initial response to it. (P066i)*†</p> <p>Well, I knew that palliative care was out there someplace, but obviously it was something that I was trying to avoid. [Oncologist] was good enough to be able to say that, “Maybe you should think about palliative care in a little different way, and this would be useful.” So, it was actually the doctor who put the positive spin on it rather than the negative consciousness that I had of it. (P015i)*†‡</p> <p>They mentioned palliative care and I went, “No!” You know? You know, “I’m not ready for that.” And then, she went further to explain that it was — the approach wasn’t meant to be, to put them in the end of life care, it was just same as me ... study, early intervention. (P025i)*†‡</p> <p>Right away I thought, “This is great, this isn’t what I thought it was at all.” It was good. ... They explained it right away. Maybe if I had gone away thinking that, “Oh, I have to meet up palliative care,” then maybe I would have had time to think about it and maybe I would have been more nervous about it. But, because they did it right away, there was no waiting, big waiting and time for you to think up things. (P010i)*‡</p>
“Not relevant for me”*	<p>Never really thought of it, to tell you the truth, because in my head I’m optimistic. (P020c)</p> <p>I don’t expect to be in that predicament for a long time coming yet. It’s very foreign to me. I don’t think about it much. (P065c)</p> <p>No, we never discussed it, but I have no doubt that we may one day, we will one day. But, as long as it’s far, far away. (P017c)</p> <p>I think that it’s that I haven’t really been that sick in the sense of being debilitated and you know what? I don’t even know the stages of cancer. I think I know I’m at the top where it’s not operable and all of that but it’s not at the stage where like I’m going to leave soon. We don’t know and I think maybe because of that, nobody has ever really brought it up nor have I or maybe partly, because I don’t want to. I don’t know. I haven’t thought about it till now. (P037c)</p>	<p>I went, “Well, okay. I’ll help the research,” but thinking to myself, “I don’t qualify. It’s not for me.” (P043i)*†</p> <p>Well that was my initial reaction to it, I thought, “palliative care?” Because I always think of it as someone in their last, you know, in the last few weeks of life. ... But when they started to explain that perhaps it was useful, I, as you know, like to talk so the idea of having someone to sort of unburden to, I thought that was a good idea. So I was very willing to participate. (P031i)*†‡</p> <p>So, that’s how I was introduced to palliative care. ... It was presented to me primarily as a method, a sourcing of pain control and the pain I had been experiencing in my ribs was significant enough that while I could live with it, it was fatiguing. (P024i)*‡</p>
<p>*For these themes, intervention group quotations include both †examples of initial reactions and ‡examples of how these reactions were mitigated by explanations from their treating oncologist or from members of the research team who introduced the trial.</p>		

early palliative care, equated palliative care with end-of-life care, thought that renaming palliative care would be euphemistic and found the name “supportive care” too vague. In the intervention group, this opinion was less common, held by

caregivers or older patients with a pragmatic, “realistic” attitude to end-of-life care: “Well, I’ll be 80 in June and I feel that if I haven’t thought about dying at this stage I’d better smarten up a bit” (P028i).

Table 5: Representative quotations about perceptions after receiving early palliative care

Theme	Intervention group
More comfortable attitude toward palliative care	<p>I certainly don’t now see it as I’m in the final box or the chamber. He’s [palliative care physician] given me some hope, which is wonderful. I mean, I’m not hopeful or have any (or maybe way deep, deep down inside) wishes that things would be different, but I think he’s given me some alternatives. (P045i)</p> <p>I think the more you know about something, the less scary or the less worrying. You’re more comfortable. I think the more contact that we have with people like [palliative care team], it’s just, it’s more normal. ... Our “normal” now includes coming to the hospital; he goes and gets his CT scans, he goes to oncology, he also goes and sees [palliative care physician] and palliative care. That’s the norm. It’s just a part of what happens when you go to [the hospital]. (C046i)</p> <p>Yeah, I think it has given me confidence that hey, these guys really care. ... Yeah, things are going to be okay. Yeah. I don’t know what more I can say. Yeah, it’s given me confidence. (P023i)</p> <p>Well, my first reaction, as I say, to the word is, “Oh my God.” But when I realized that I really wasn’t going to die in 2 or 3 weeks and so this was something that was very, very helpful. So I, I could see the benefit to it and so then I sort of changed my attitude to palliative care. (P031i)</p>
Broadened definition of palliative care	<p>I think the same thing as everyone else, “Oh, palliative care, I must be at the end.” But, I’ve come to learn that’s not the case — it’s an ongoing care and I’m very grateful to have it when I am feeling well and feeling strong and able to do things. (P010i)</p> <p>Yeah, that, in fact, it’s not just end-of-life it’s the whole symptom management, potentially through the whole ... through all phases it is available, and I didn’t know that. (P001i)</p> <p>I see that it now comes on in an earlier stage of my treatment. ... Earlier stage, rather than palliative care as in when they’re no longer treating you. So this is palliative care while they’re still treating you. (P008i)</p> <p>Because that’s right; it’s about the quality of living. And what you can do to help with that quality of living. ... And if anyone mentioned it, if anyone said, “It’s just about dying,” I would know now to say, “No. Palliative care is not dying. It’s living. It’s living the best you can with what ... the issues you’re dealing with, sort of.” Yeah. So I learned. (C003i)</p>
Team useful but name problematic	<p>It’s just one of those ... it’s like anybody who has been raised with certain values or beliefs. Palliative care, in my mind, has always been final stages. Now I know intellectually, rationally, palliative care is not final stages, but emotionally I still carry that term as, perhaps a slightly fearful term. (P024i)</p> <p>[My impression has changed] of what the team does, yes, but not what palliative care is. What the team does, yes, and that’s why they should change the name. [laughter] (P043i)</p>
Avoiding the term “palliative care”	<p>I don’t think I even refer to it as palliative care. That palliative word, not liking it, still not liking it, still haven’t adjusted to it. I just say I’m seeing [palliative care physician]. I see so many doctors there. They’re like, “Okay, that’s nice. Are you okay, relatively speaking?” It’s like yeah. I don’t even refer ... I don’t use that palliative word — the P word. (P066i)</p> <p>Well, I think just in my own head, just to make me feel more comfortable, I referred to her as my “medication specialist” as opposed to my “palliative care doctor” versus my “oncologist,” right? ... [To others] I say that I’m seeing my “medication specialist.” Sometimes if they ask a little more, then I will say that she is actually in the palliative care department but they branch out a little bit and they deal with people like me. ... Why? Because if I told people I was seeing a palliative care doctor, they would think I was going to die in a few weeks or months. (P040i)</p> <p>I mean, I would feel much more comfortable saying I’m going to the pain-control clinic. I say, “Oh, well, that’s cool.” You got pain, you get treatment for the pain. ... I’m trying to kid myself into saying, “You’re not really in palliative care. You’re just doing pain control, which is cool.” That’s kind of a deception that when the day is done I say you’re in palliative care, that’s exactly what palliative care means. (P024i)</p> <p>I don’t tell people I’m seeing somebody in palliative care. I just, I say, “Oh one of the doctors at [hospital] told me this or that” or “Oh, one of your team doctors?” “Yeah, yeah, one of the team doctors.” I don’t ... I don’t talk about it. ... They may just get so scared they walk away and so it’s best not to say anything. (P022i)</p> <p>I’ve never mentioned to any of my friends that I’m in palliative care. I think they’d go into shock. Or to the family. I think, to the best of my knowledge, they all have the same understanding that I had. (P013i)</p>
The care I received is not palliative care	<p>I don’t think I’ve had palliative care yet, because I’m not on my last legs, not by any stretch of the imagination. (P007i)</p> <p>Palliative care [is] not, to me, sort of what we’ve had, because we’ve really, we’re so into the early part of it. (C061i)</p> <p>Somehow, it still doesn’t really change my feeling about palliative care because I think she [palliative care physician] gave me wonderful care. Somehow I can’t equate what I experienced with her as palliative. (P040i)</p>

Note: CT = computed tomography.

Interpretation

In this study, patients with advanced cancer and their caregivers described palliative care as carrying a negative stigma associated with death and with care at the very end of life, which provoked fear and avoidance. Participants' perceptions often originated from interactions with health care professionals. During the trial, those in the intervention arm developed a broader, positive conception of palliative care but still felt that the term itself carried a stigma. Participants in the intervention group emphasized the need for palliative care to be reframed and better explained by health care professionals. Partici-

pants in the control group generally considered it pointless to rename palliative care, but many in the intervention group stated emphatically that a different name was necessary in the early outpatient setting.

Previous surveys have described attitudes to palliative care of the public and of health care workers. A recent survey of 1000 American adults documented that only 24% were familiar with the term palliative care, whereas 86% were familiar with the term hospice care.²⁶ In a qualitative study in Northern Ireland involving 50 members of a group reporting on health and social care issues, palliative care was conceptualized mainly as terminal care.²⁷ Other surveys have solicited opinions of

Table 6: Representative quotations about renaming or reframing palliative care

Theme	Control group	Intervention group
No point in renaming	<p>It's kind of not one of my favourite words. ... It's like a janitor's a janitor instead of a, what do they call it? Maintenance engineers. You can change the name, but it's still the same topic, same influence. (P062c)</p> <p>What are they going to call it, a hula dance? [laughter] It's as good as anything, what the heck. ... That's what it is. An operation is still an operation. I don't care what you call it. Same with this, this is a progression toward death and that's all there is to it. (P056c)</p> <p>For example if you changed palliative to another name, the same name is going to have a stigma like palliative. Even if you change it to something that is a very nice name ..., it's still not going to change people from thinking because once they're into that thing of taking the medicines or whatever, the name doesn't matter. (P052c)</p>	<p>What is it by any other name? Be realistic. (P023i)</p> <p>It doesn't make any difference to me. "Palliative care" I think in the general population means death. "Supportive care" would mean different at the beginning, but would turn into that. (C055i)</p> <p>I don't know what else you could call it. No matter what you call it, it's not an easy topic to discuss and it's not an easy thing to go through, so I don't think the name really has that much effect. (C071i)</p> <p>Because I think I can be realistic and that is the end. We are all going to die. I think it's more difficult for others to accept that. (C068i)</p> <p>What's another word to give it that's going to have that meaning? Palliative care is end of life care. (P025i)</p>
	Intervention group	
Palliative care should be renamed	<p>Palliative care to me, it stigmatizes a little bit. "You're here because you're going to die," and that's not why you're here necessarily. It's that, plus, but you may not so there are some other things that we can do for you. It's other things that don't come out in the name, palliative care. I think it needs to be broadened because I think the work [palliative care] do is broader than that. (P043i)</p> <p>When a person is dying and is receiving palliative care, I think it's appropriate to have that name attached to the kind of care that they're being given. But when they're not dying, maybe you need another name. (P040i)</p> <p>I think it's, it's imprinted in my mind that palliative care is people dying. And I think it would be hard to shake that because I think that's what most people — you're going to find, you know. ... Yeah, I think you have to change the name to — for this part of the study — for people to change their perception. (P031i)</p> <p>I think you have to really think about a name that would outline what you're actually trying to do. You're not trying to help somebody in their last days. (P007i)</p>	
Reframing palliative care	<p>I don't know how you do it, but if somehow the medical profession could explain to the public better what palliative care is, it takes some of the fear and the stigma away from it, the negative stigma away from it, that it isn't necessarily the last 3 weeks of your life kind of thing, when you're doped up and don't know anyone's around. If it could be better explained, I think it would take a lot of the fear and shock away, certainly from my generation. Now, maybe younger people — although I've never heard my kids say anything different. (P013i)</p> <p>I would prefer actually the oncologist speaking to me one-on-one about it where they could sit down and say, "Don't get me wrong. This is not because you're dying tomorrow or in the near future but it will help you cope through the stages that you will go through." ... so, I would rather have a relatively experienced, educated oncologist, educated on palliative care say to me, "Maybe you should try this!" (P033i)</p> <p>It has to have this notion that it's going to be help ... and the help that it's going to give you is probably going to be able to help you live longer. You're still going to die in the process somewhere along the line, but there has to be some kind of a more ... a way of being able to describe palliative care as something that is there to be able to help you to continue living as long as you possibly can. (P015i)</p> <p>But I think maybe we should have ... and as I've told you ... I think, a kiosk or something downstairs or a little office, "Symptom management palliative care for anybody." I don't know, make it less traumatic. (P022i)</p>	

physicians and nurses, who tended to associate palliative care with terminal care,^{10,12} voiced confusion about the role of specialized palliative care,^{10,12} and felt the term palliative care decreased hope and caused distress in patients and families.⁸ Our study contributes the important perspective of patients and their caregivers, including those who received early palliative care.

There may be several reasons for the confusion surrounding the term palliative care. Palliative care has evolved relatively quickly from an initial mission centred on terminal cancer care²⁸ to one urging that “the principles of palliative care should be applied as early as possible in the course of any chronic, ultimately fatal illness.”²⁹ The 1990 WHO definition of palliative care that stressed its relevance for “patients whose disease is not responsive to curative treatment”³⁰ was changed in 2002 to underscore improvement in quality of life, prevention as well as relief of suffering, and early proactive intervention.² However, definitions of palliative care are inconsistent, even to some extent within the palliative care literature and among palliative care organizations.^{31,32} Among referring physicians there is variable awareness or acceptance of the new broadened definition of palliative care, with many continuing to equate palliative care with end-of-life care.^{8,11,12} In our study, participants’ perceptions of palliative care were derived in large part from contact with the medical system. It is therefore important that physicians and other health care professionals are familiar with the broadened definition of palliative care and are able to explain it to their patients.

The stigma associated with palliative care relates to a larger societal stigma associated with death;³³ however, patients and their caregivers were generally able to speak openly about the terminal nature of their disease or that of their loved one. They understood that the cancer was incurable, but there was variability and mixed emotion in their coming to terms with this. Most patients were still receiving cancer treatment and hoped that this could forestall death. In this transitional stage of illness,³⁴ many did not feel ready for the term palliative — which in their minds was associated with being bedridden with weeks to live — to be applied to them or their loved ones.

Rebranding and renaming palliative care were proposed by participants in the intervention group as ways to address the discordance between the early palliative care they had received and their persistent association of the term palliative care with end-of-life care. Similar results have been reported in surveys where participants were randomly assigned to different program names and descriptions to rate their impressions. In these studies, participants responded more favourably to

a program called “supportive care,” rather than “palliative care,” regardless of the description of that service.^{9,15} At least 1 oncology palliative care service reported earlier outpatient referrals after such a name change,³⁵ although oncologists did not perceive that they had changed their referral practices.³⁶

Strengths and limitations

Strengths of our study include the large qualitative sample and the inclusion of both patients and caregivers. Owing to the cluster randomized design, with masking of groups to each other’s existence, we were able to obtain opinions of both those who had experienced an early palliative care intervention and of those who had no knowledge of this intervention.

Limitations of this qualitative study relate primarily to generalizability.²⁵ The study took place at a single centre with an established palliative care clinic.³⁷ Similar to the larger trial,⁵ participants were highly educated; this was particularly the case for participants in the intervention group. Almost all patients were of European background. Despite purposeful sampling, women were overrepresented in the intervention group for patients and in the control group for caregivers. The participants interviewed may have had more favourable attitudes to palliative care than others receiving care for advanced cancer. Indeed, there were 7 patients in the original trial⁵ and 7 in this qualitative study who declined participation because of the palliative care content of the intervention or interview.

Conclusion

Patients and their caregivers in both trial groups perceived palliative care to have a negative and frightening association with death, hopelessness and dependency. Although this perception changed for participants in the intervention group, many continued to feel a stigma associated with the term palliative care and felt that rebranding or renaming palliative care could be helpful.

Our findings have important implications for practice and policy. They show the persistence of the definition of palliative care as end-of-life care in the minds of patients and their caregivers, despite an international change in that definition more than a decade ago. A name change may be considered, but would achieve nothing without a fundamental shift in the manner in which palliative care is practised and portrayed. Physicians should be aware that the manner in which they communicate information about palliative care affects perceptions of its meaning and decision-making about receiving such care. From a policy perspective, it is evident that broad-based education is necessary

to ensure a more widespread understanding of what palliative care represents and entails.

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