

Original Article

Can Cancer Patients Influence the Pain Agenda in Oncology Outpatient Consultations?

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Abstract

Pain in cancer patients is common, yet it is often inadequately managed. Although poor assessment has been implicated, how patients contribute to this process has not been explicated. This study aims to uncover patients' contributions to discussions about pain during oncology outpatient consultations. Seventy-four medical encounters were observed and audiotaped. Verbatim transcriptions of pain talk were examined using conversational analysis. Thirty-nine of 74 patients talked about pain with 15 different doctors during consultations for follow-up or active treatment. Patients' talk about pain varied consistently according to how pain talk was initiated. In 20 consultations where pain was put on the agenda by patients, they used communication tactics that emphasized their pain experiences, seemingly to attract and maintain their doctors' attention. These tactics appear necessary, as the cancer treatment agenda restricts opportunities for patients to have supportive care needs addressed. On the other hand, in 19 consultations where doctors elicited information about pain, patients used communication tactics that minimized their pain experiences, seemingly to conceal potential disease progression or recurrence, the very focus of these specialist consultations. Where cancer was implicated as the source of pain, chemotherapy or radiotherapy was offered, and where cancer was suspected, referrals for investigations were made. Two of the 20 patients appeared to influence the treatment-focused agenda and were given referrals to pain clinic rather than further cancer therapy as initially recommended. J Pain Symptom Manage 2010;39:268–282. © 2010 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.

Key Words

Pain, pain assessment, cancer patients, oncology consultations, palliative care, conversational analysis

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Introduction

Pain in cancer patients is common,¹ can occur at any stage within a patient's cancer journey,² and is often feared more than dying from cancer itself.³ Further morbidity can result from unrelieved pain, including depression and anxiety, deep venous thrombosis or pneumonia because of restricted activity, noncompliance with recommended treatments, or inability to complete treatment protocols.⁴ Lack of adequate pain control in cancer patients is a persistent problem² and can produce catastrophic effects on family members and the patients themselves.⁵ Although proper pain management should have the highest priority for those who routinely care for cancer patients,⁵ it is often inadequately managed.^{2,3,6} Indeed, a substantial percentage of cancer patients receive analgesics that are inadequate in type or potency to manage their pain.²

Regular and systematic assessment is the cornerstone of effective pain control,^{7,8} whereas poor assessment is predictive of undertreatment.⁹ Indeed, nurses and doctors themselves cite deficient assessment as a major factor related to suboptimal cancer pain management,^{10,11} despite interventions to improve this situation.¹² Poor agreement between professional and patient assessments of symptoms is a recurring concern.^{13–17}

Proper assessment should always be linked with appropriate documentation. Weber and Huber¹⁸ report inadequate documentation of important aspects of cancer pain in a large outpatient hematology and oncology department, which they argue may have had a major negative impact on the quality of cancer pain treatment; the contrast with detailed documentation related to cancer and its treatment led the authors to conclude that clinicians must not have perceived pain to be important, and items that are not perceived to be important will not be assessed properly.¹⁸

Although pain management is an integral part of the total management of cancer,¹¹ it has been found that the main focus during consultations is on disease and treatment,¹⁹ and this "treatment agenda" restricts opportunities to assess and address patients' supportive care needs.²⁰ We have found that oncology clinicians limited their explorations of pain to that which might indicate the need for cancer

therapy, focusing their questions on the onset, location, and duration of pain.²¹

Although it appears that pain and its management have been given too little attention by health professionals, cancer patients and their families also provide barriers to effective pain control. Patients have expressed reluctance to complain of pain or to take analgesics because of anticipated side effects, fear of addiction,²² or because they feel it is a sign of personal weakness,²³ even when they are experiencing significant pain.²⁴

Although poor communication among health care providers has been identified as another important issue for cancer pain management,²⁴ little consideration has been given to patients' contributions *during interactions* with professionals, particularly within an oncology setting.^{25,26} In this article, we explore how patients in oncology outpatient clinics contribute to discussions about pain. Our goal is to uncover how cancer patients influence the pain management agenda to provide a more complete understanding of the processes involved.

Methods

Data Collection

Data were collected over a five-month period using nonparticipant observation in the oncology outpatient department of a large teaching hospital, where patients receive radiotherapy and/or chemotherapy. Consultations between 74 different cancer patients and 15 different doctors were observed and audiotaped. The sample was achieved by randomly selecting one of seven participating consultant oncologists' clinic sessions and then approaching consecutive patients on the clinic list during the period of recruitment. Ninety-six percent of patients approached gave written informed consent to participate in the study. There were 43 female and 31 male patients ranging in age from 24 to 84 years (mean = 55.65 years; standard deviation [SD] = 16.19 years). Interactions between professionals were also observed outside of consultations during clinic sessions. Pertinent observations from these consultations and interactions as well as informal discussions with professionals were recorded in field notes and used to provide context when interpreting the observed consultations.

Data Analysis

The audio recordings of the consultations were transcribed verbatim using modified conventions of conversation analysis^{27,28} (Appendix). The transcriptions were initially subjected to content analysis, during which we identified sequences of explicit talk about pain and bodily discomfort within these consultations. This talk was characterized by the use of words, such as “ache,” “sore,” “tenderness,” “pressure,” and “pain.” Discussions about analgesics and cancer treatment for pain also were selected. Collectively, these sequences are referred to as *pain talk*, and subjected to conversation analysis.

Conversation analysis is a generic approach to the analysis of social interaction and seeks to provide a theoretical and empirical analysis of how human interaction is produced and organized.²⁹ The basic unit of analysis is a turn of talk that may be a full sentence, a set of sentences, or a single word or utterance.³⁰ Although these turns are not allocated in advance, they are normatively prescribed (e.g., only one person speaks at a time and a question predicts an answer). However, this turn-taking system is limited to “ordinary” conversation. The study of institutional talk²⁷ recognizes the influence of the institution and context of the interaction, where utterance type and speaker identity are more constrained.³¹ Key features of institutional talk imply that, compared with ordinary conversation, there is a reduction in the range of interactional practices available to participants and locations where interactions occur plus a specialization of remaining ordinary conversational practice. This means in medical encounters that, although a doctor’s question requires an answer from the patient, having answered that question, the patient is *not* free to initiate a new turn of talk. These restrictions are often perceived to be troublesome, especially for lay participants.³²

Results

Sample: Cancer Patients and Doctors

Thirty-nine of the 74 (53%) patients (95% confidence interval: 40.8–64.4) talked about pain at some point during their interactions with the doctor (26 female and 13 male patients, aged 29–84 years, with mean = 58.95

years and SD = 14.08 years). The most common cancers were breast cancer (12), lung cancer, (6) and multiple myeloma (5). Twenty-three patients were attending follow-up clinics, 13 were receiving active treatment, and three were having their initial postdiagnosis consultation with an oncologist. Companions were present during 24 of 39 visits. Consultations in which pain talk occurred were unequally distributed across the 15 doctors. Four consultants (oncologists) were responsible for 22 of 39 consultations (56%). The remaining 17 consultations were conducted by consultants, registrars (oncology residents), and clinical assistants (general practitioners [GPs] contracted by consultants).

Amount of Pain Talk

The proportion of turns at talk during consultations involving pain talk ranged from 3% to 69% (mean = 22%; SD = 15%). Thus, about a quarter of consultations is taken up with talk about pain issues.

How Pain Talk Is Initiated

Most consultations (26 of 39) began by doctors asking patients “How are you?” Nearly all patients (23 of 26) responded to this question as a social greeting rather than a clinical assessment, with replies, such as “Fine, thank you” or “Not too bad.” However, four patients then proceeded within that same turn of talk to report problems with pain as is shown here:

Patient: Fine, still a bit sore where I had the operation...

In only three consultations did patients reply immediately to doctors’ “How are you?” with reports of pain:

Doctor: How are you?

Patient: Well, I’ve still (.) got (.) a lot of pain.

Once the consultation was opened, talk about pain could be presented by patients or companions or be elicited by doctors. Patients volunteered pain talk in 20 consultations, and on two occasions, patients’ companions initiated pain talk. Doctors initiated pain talk for the remaining 17 interactions.

Structure of the Pain Talk Sequences

Much of what patients say about their pain is constrained by the structure of medical interviews and by their doctors' interruptions. Patients respond to clinical cues provided by clinicians' questions. Consequently, their descriptions of pain are remarkably brief, usually limited to 10 words or less and focus on the physical domain. Patients only infrequently mention their social context or include psycho-emotional aspects of their pain, as illustrated in the following excerpt:

Patient: I did a silly thing yesterday. You know I've got this arthritis and I do take care, I really do... yesterday I WAS overtired. You see when I come in here [oncology department] I don't sleep well. [laughs]

Doctor: Yes.

Patient: ...But what I did, I fell asleep in front of the television and my head went down. You know that gel that Doctor [GP] ... it's cured that [painful neck]...

Doctor: It's quite wonderful... I can't remember which jelly you've got...

Patients' Objectives for the Consultation Agenda

When medical encounters are structured by doctor-centered³³ rather than patient-centered³⁴ questions, there is limited opportunity for patients to openly influence the process of defining problems and determining treatment outcomes. Consequently, they must draw upon techniques to achieve their own objectives for consultations.³⁵ As will become clear in the following sections, the nature of patients' talk about pain varies consistently according to how pain talk was initiated. First, we consider patients who originated the topic of pain during their oncology outpatient appointments and who appear to either seek their doctors' acknowledgment of their distress or attempt to influence the consultation agenda. Next, we consider patients whose companions or doctors instituted pain talk and, in contrast, who appear to be working to conceal their pain or diminish its significance. Further analysis reveals the ways in which patients attempt to achieve these objectives.

Patient-Initiated Pain Talk

During pain talk sequences, clinicians appear to be limiting "nonessential" pain talk while concentrating on the "right kind" of pain.²¹ Thus, doctors focus their enquiries about pain solely in areas that might indicate the need for cancer treatment. Of course, patients are not necessarily aware of their doctor's restrictive focus. Consequently, they must withstand clinicians' efforts to dispense with problems perceived not to be relevant to this specialist care focus if they are to put and keep additional pain issues on the consultation agenda. Twenty patients instigated pain talk, and this was primarily aimed at gaining acknowledgment of their distress. However, in two cases, it seems that the patients attempted to be more assertive and did not simply acquiesce to the doctors' attempts to adhere to his/her doctor's agenda.²¹ Patients who introduced the topic of pain and emphasized their pain experiences did so using one or more communication tactics:^{36,37} 1) using emphasizing language; 2) expressing worry; 3) using technical medical language; 4) "recycling" the topic of pain; and 5) interrupting their doctor's turn at talk. Importantly, these tactics were wholly absent from pain talk excerpts where doctors and companions initiated pain talk.

Using Emphasizing Language. Although it may seem unremarkable that cancer patients experiencing pain would express worry or use emphasizing language, in the context of these tightly controlled consultations, these episodes stood out, and we identify them as communication tactics as exemplified in the following excerpts. In an apparent attempt to portray their pain problems as serious and in need of attention,³⁸ patients use language and expressions that accentuate the intensity, severity, and negative impact of pain on their lives. The following 70-year-old patient with breast cancer described the location of her pain and stressed that it was horrible. When the consultant twice attempts to change the focus of discussion, the patient emphasizes the negative effect of her distress, although the doctor does not acknowledge this. Ultimately, the focus of the consultation shifts after the question in the final line in the following excerpt:

Patient: Horrible [pain] you know, and er (.) I don't know whether it is um (.) what the cause of it ... but when I try, when I get up, I've got pain all the way down to here.

Doctor: Hmmm.

Patient: ...But of course when I am doing this awful retching I am really, I am really hurting here.

Doctor: Mmm.

Patient: It is really (.) you know (.) [speaking quietly—not heard]-

Doctor: Have you got a list of your medication at the moment?

Patient: Yes, I went to the doctor er (.) he phoned up on um (.) I wasn't supposed to see you 'til NEXT Thursday [speaking quietly—not heard].

Doctor: Have you got any headaches or anything like that?

Husband: [overlaps with patient]/

Patient: /Well very slight () not a lot of headache no ... I have never felt as bad as this in my entire life.

Doctor: And the pain anywhere well apart from the back?

Expressing Worry. Possibly to justify attention to their pain problems, some patients overtly express worry or concern,³⁸ particularly about the meaning of their pain, for example, does it signify disease recurrence? These were the only patients to make a disclosure of an emotional nature. In the next example, a 73-year-old patient with a gynecological cancer expressed worry in response to the consultant's "How are you?" Later during the interaction, she articulated further concern in response to the doctor's query about her abdomen. This concern was then re-expressed at the end of the consultation; however, these cues were not picked up by the clinician. Consequently, her worries were neither fully disclosed nor did the patient receive any reassurance from the consultant as the topic shifts from pain to bowel function, and there is no further pain talk during the interaction.

Doctor: How are YOU?

Patient: Well, I am fairly well, thank you. I have been having (this little pain). And I do worry about, you know what it is sometimes. Don't tell me. The one thing I don't want to know, is how big it is [tumor]. Because/

Doctor: /Tell me FIRST, how you are? So you, there's not much change in the situation for the time being?

Patient: No I can't say there is.

Doctor: Right. So you have got little niggling pain from time to time but nothing more than that?

Patient: No nothing else.

...

Doctor: Tummy doesn't swell?

Patient: My TUMMY doesn't.

Doctor: Doesn't it?

Patient: No I feel it is permanently swollen down there.

Doctor: But do you get discomfort from that?

Patient: From my tummy?

Doctor: Mmm.

Patient: No.

Doctor: No?

Patient: I have a few little pains. () three operations, I thought something might be leaking or something/

Doctor: /What about your bowels? Are they working pretty well?

Using Technical Medical Language. Although the use of technical terminology or "medical jargon" is usually the preserve of health professionals, within this group of pain talk sequences, many patients use anatomical terms to name parts of their bodies and clinical labels for various conditions. Most patients when discussing their pain medications identify the analgesics they are taking by their proprietary names, and indeed, some patients

use the word “tumor” in reference to their pain. It appears that these patients use other jargon and knowledge about their conditions to demonstrate an “egalitarianism” of knowledge, to justify seeking their clinicians’ attention.³⁹

In the following example, an 80-year-old man with lymphoma used technical medical language to support his question, which his consultant answered ambiguously. Apparently not satisfied with this explanation, he reintroduced the topic and made the suggestion, albeit mitigated, that further clinical investigations might be appropriate. However, the clinician refuted this suggestion and dispensed with the topic by introducing the physical examination.

Doctor: Any nausea, vomiting, or abdominal pain?

Patient: No, no. I feel my eyes are not right. Could be all sorts of things I suppose, but I think we looked at sinuses before, but they were all right. I am on repeat sinus inhalations which keeps them clear. But um, they both feel achy and that one I always suspected, that’s the one I had the tumor on.

Doctor: Yes.

Patient: And I was just wondering, were they were all right?

Doctor: Well, I mean I think that as far as we can ascertain there’s no (evidence of) lymphoma there. So I think that and that you have got some lymphoma in your abdomen and in your um, mainly in your abdomen, but I wouldn’t want to treat that unless there were specific problems.

...

Doctor: ...But I think we’ll probably see you in three months’ time, and if there are problems in the interim, significant weight loss, significant sweats or fevers, then I would be happy to see you earlier, or if you pop up some glands.

Patient: Yes, yes. I did phone half way through this break and wonder if there was, because of the discomfort with my eye, or both eyes actually, whether a scan would be appropriate, but the nurse said, if you don’t hear otherwise/

Doctor: /No, I don’t think so, I think that it is unlikely that we’re going to see a recurrence in your sight, but I think that if you start to get any protrusion of the eye, then I think, or any swelling around the eye, that we don’t see at the moment, then I think it would be worthwhile thinking about that. Let’s put you on the bed, a sec.

“Recycling” the Topic of Pain. In contrast to patients’ attempts to capture their doctors’ attention within the confines of the structure imposed on consultations by doctors, some tactics produce, however briefly, their own structure to the interaction. Clinicians briefly considered patients’ complaints of pain and then, sometimes abruptly, changed the focus of discussion.²¹ However, there were patients who appear not to be satisfied with the attempted resolution, which is made apparent when they “recycle,”⁴⁰ that is, reintroduce the topic of pain at later points in their consultations. Through complaining persistently, including drawing upon physical sensations that only they could perceive, these patients seemingly attempt to demonstrate just how debilitating their suffering is and therefore worthy of being heard as legitimate.³⁵

After complaints of excessive tiredness and menstrual bleeding, the registrar attempted to begin the physical examination but was interrupted by this 51-year-old breast cancer patient as she introduced a third problem, pain. The doctor explored her pain by determining its precise location.

Doctor: ...I think we’ll have a little look at the uh-/

Patient: /Yeah, that’s another thing. I’ve been getting the pain again, and I don’t like that. (.) On that side. I had that (1) I had it this morning actually.

Doctor: Right, let’s have a look.

Patient: I can’t see anything.

Doctor: Will you put your head down a bit more.

Patient: It’s just that sharp pain like I had before. (2)

Doctor: Can you pop this [pullover]? Thank you. You show me where the pain is.

Patient: Well, it's just over there somewhere. I can't really pinpoint where.

Doctor: Right. (If I hurt you, just say). [examining]

Patient: Yeah, there. (7)

Doctor: Any more?

Patient: No.

Doctor: So it really is just up there?

Patient: Yeah. Up there.

After this examination, the doctor, uncharacteristically for these consultations, enquires about the patient's social context. Consequently, he attributes her problems to her difficulties in her family life. In the following excerpt, the doctor attempts to bring the consultation to a close with instructions and a decision against further tests. Although not openly disagreeing with the doctor, the patient "recycles" her pain by introducing a more "objective" aspect, which effects further discussion if not a satisfactory resolution.

Doctor: Yes, my feeling is that you should persevere with the Arimedex for another couple of months, and come and see us again.

Patient: Yes.

Doctor: Would that be all right?

Patient: Yeah, yeah.

Doctor: And I don't think I want to do any more tests today.

Patient: No (2) but that (.) spot, that didn't show up on the bone scan or anything did it?

Doctor: No, no.

Patient: Well last time I saw Dr [consultant] he said something about the bone scan.

Doctor: [looking through patient's notes] ... It certainly didn't show up on the '93 one. (3) How often, how many times a day do you get this pain?

Patient: Well, there's no particular time. I mean, I woke up one morning with it. It was really hurting me. I don't know if that woke me up, or, I just you know, like I say I

had it this morning when I was in the bath. Because Dr [GP] told me once it might be the way I move because after surgery they cut through the nerve endings.

Doctor: That's right yes.

Patient: And I thought, well that makes a lot of sense.

Doctor: Yes. They also do sometimes slightly damage the bone when they get it [tumor] out.

Patient: Oh they do? Because I always feel like it is the tip of the ribs there.

Doctor: But it's not getting any worse is it?

Patient: Well no. I can't even describe it. It's sort of like. It, it's sudden, and then it goes.

...

Doctor: So it's other problems really, isn't it? [referring to son with severe mental health problems]

Patient: Mm. Hmm.

Interrupting Their Doctor's Turn at Talk—Patients' Attempts at Asserting an Agenda. Although it is not uncommon for doctors to regularly interrupt patients' pain talk,²¹ it is unusual for patients to exhibit such behavior.⁴⁰ However, two patients did interrupt their doctors' turns at talk to change the topic to their pain or did persevere in continuing their talk about pain. In other words, they did not relinquish the floor when interrupted by their doctors, an uncharacteristic patient behavior.⁴¹ In doing so, they were actively, if unconsciously, exerting control over the emerging pain discourse⁴² in an apparent attempt to reveal their suffering and influence clinicians' decision making related to their distress.

In the following excerpt, a 62-year-old woman with ovarian cancer indicated that she preferred to avoid further chemotherapy, which prompted a discussion of radiotherapy as a third option. This option was supported by the patient's interruption shown in the excerpt; however, her son requested more information about chemotherapy. The patient again interrupted the consultant's answer with an apparent cue for an emotional

disclosure, which the doctor acknowledged but did not explore. The patient then attempts to expand on her perceptions but is interrupted by her doctor who is offering a fourth option, a referral to Pain Clinic.

Patient: What happens if I choose not to do either [of the two chemotherapy regimes offered]?

Doctor: That's fair enough as well. I mean, there's no straight, straight answer because as I said, you may have response in 30% of the case. But I cannot GUARANTEE that ...

...

Son: Is that radiotherapy [third option put forward]?

Doctor: Yeah. But that's not going to (1)/

Patient: /You see I can actually pinpoint where the pain is/

Doctor: /Right. I mean that's not going to get rid of the problem but that will be you know if you were not keen on having ah, chemotherapy, I think you might I mean you could that's another option.

...

Son: (5) If you tried the tablets first, would you then try the Taxol later?

Doctor: We can. We can but it's not likely to, our experience in THIRD line (1)/

Son: /Yeah/

Doctor: /are very disappointing. So that what you have to be aware of/

Patient: /I think it's quality time you're looking for, really.

Doctor: That's as well.

Patient: I mean I'm very dispassionate about/

Doctor: /I mean there is an option obviously, you have problem with ah, analgesic, I mean, Co-proxamol is not very strong but you have problem to tolerate it, Co-proxamol.

...

Doctor: So maybe what I could do in the first instance, is to refer you/

Patient: /Yeah/

Doctor: /our pain control people/

Patient: /Yeah/

Doctor: /who are expert in trying to control pain/

Patient: /I see/

Doctor: /to see if they can play with medication/

Patient: /Uh-huh/

Doctor: /or other things to try to control your pain (0.5) a bit better. (0.5) Okay?

Patient: (1) Uh-huh.

Doctor: Because if it wasn't for the pain, at the MOMENT, you're not too too unwell.

Patient: Uh-huh.

Doctor: And there is no (.) I mean we don't HAVE to jump into treatment NOW. (1) Right? You still/

Patient: /So I have time to think about it?

Likewise, a referral to the Pain Clinic came after cancer treatment is offered to a patient who complains that his current analgesia, dihydrocodeine, is inadequate.

Patient: But I've still got this/

Doctor: /The pain/

Patient: /back pain and leg pain which appears to be linked together.

Doctor: Right, OK.

Patient: And I've gone on to dihydrocodeine.

Doctor: Yes.

Patient: You know, I was taking Co-proxamol.

Doctor: Yes.

Patient: And that seems to be OK as long as I take it.

Doctor: Right.

Patient: But I end up running out of pills in the middle of the night as it were, because you can only take a limited number.

Doctor: Right, yeah.

This excerpt is followed with the doctor providing options for management of the pain, including radiotherapy, and changing his clodronate to pamidronate, drugs used to treat painful bone lesions in multiple myeloma and breast cancer. However, the patient's persistence resulted in a referral to the Pain Clinic at the end of the consultation in spite of the doctor's preference for providing cancer treatment.

These two medical encounters appear to be aberrant occasions. Although all of the patients who introduced the topic of pain use communication tactics to grasp their doctor's attention and gain acknowledgment of their distress, these two patients not only manage to influence the consultation agenda, their actions affect the apparently desired outcome. Interestingly, in both cases, the patients appear to favor symptom management rather than further cancer treatment.

Doctor- or Companion-Initiated Pain Talk

In contrast to the wide range of communication tactics used by the 20 patients who sought doctors' acknowledgment of their pain, the range of different tactics used by the 19 patients who sought to conceal or diminish pain was smaller and the tactics more subtle. As done earlier, we illustrate each of these tactics with excerpts from only one of the consultations where it is exhibited.

As the focus of the oncology center is cancer management, during consultations, doctors predominantly sought evidence to make cancer treatment decisions.⁴³ Within pain talk sequences, they sought to identify the "right kind" of pain that may be amenable to cancer therapy. To do this, clinicians asked questions from their "mental checklists."²¹ They appeared to be using a heuristic specific to the different cancer contexts: lymphoma patients were questioned about "lumps and bumps," fever and sweating, whereas patients with pelvic tumors were asked about abdominal pain, swelling, and bowel function. In this group, doctors introduced the topic of pain by eliciting information directly from patients. Perhaps, to conceal potential cancer recurrence or progression, these patients use language that minimizes their pain experiences in response to their doctors' enquiries. Their pain talk includes the following

communication tactics that diminish the significance of their pain and its effect on their lives: 1) denying pain; 2) using depreciatory language; 3) hesitation; and 4) attributing pain to noncancer causes.

Denying Pain. Given that all pain talk within this group was originated by others, the easiest way for patients to avoid talking about pain, which might signify disease recurrence or progression, is to deny its presence when questioned. Three patients deny experiencing pain; however, these patients were not reporting a genuine absence of pain but seemed to be using a tactic to avoid talking about their pain experiences, as they later admit to experiencing pain.

The following excerpt is from an initial oncology consultation with an 81-year-old woman with a visible breast cancer. After the opening of the encounter, the patient claimed not to have pain, and the physical examination ensued. However, after the doctor's inspection of the tumor, he again inquired about pain. It is then that she not only admitted to its presence but also volunteered that it was worsening. The patient was subsequently advised to have radiotherapy.

Doctor: Okay. Do you have any pain at all?

Patient: Not to complain of, no.

...

Doctor: But you are getting pain around there [breast mass] are you?

Patient: Yes. It does seem to be, not getting better it is getting worse if anything.

Using Depreciatory Language. In contrast to the group of patients who initiate talk about pain and work to emphasize the intensity, severity, and negative effect of their pain, these patients use language that diminishes the significance of their pain experiences. Here, the consultant verbally probed a 53-year-old man with a renal carcinoma twice before he admitted to experiencing discomfort. This disclosure results in the oncologist's further pain-related queries, a physical examination, and a subsequent recommendation for a chest x-ray to rule out cancer recurrence.

Doctor: Hello how are you?

Patient: Not too bad.

Doctor: Fine. So what has happened since we saw you last time?

Patient: Nothing.

Doctor: Nothing. Right. Nothing bad? No change?

Patient: Yeah, well a little slight ache that is all.

Doctor: Ache where?

...

Doctor: ...Are you taking any pain killer for that?

Patient: No no.

Doctor: So it is not bad enough?

Patient: No no.

Doctor: So it is not bad enough to take pain killers. Okay. ...we will send you for a chest x-ray to make sure to make sure the problem is still under control.

Hesitation. When questioned about pain or analgesics, more than half of these patients respond in a hesitant manner, which serves to lessen the negative effect of their expressions of discomfort. Elsewhere, during their consultations, these same patients speak without hesitation. In the following excerpt, this 70-year-old woman with metastatic renal cancer very hesitantly replied to the consultant's query about pain using language that minimized her pain experience.

Doctor: ... Apart from the tummy getting a bit harder, are there any other (.) problem like pain (.) or-

Patient: Umm, it's feeling a bit (.) a bit sore. ()/

Doctor: /Yeah, right, okay.(1) I'll have a little look at you [examines]... Is it sore only when I touch it, or is it always a bit sore?

Patient: It's a wee bit sore ().

Attributing Pain to Noncancer Causes. As patients are aware that pain is associated with

cancer, both at its primary and metastatic sites,⁴⁴ they may attribute their pain to a cause other than cancer, seemingly to disguise potential evidence that may indicate their cancer has returned or their condition has worsened. Five weeks before the current consultation, this 45-year-old man chose to consider further the offer of chemotherapy for his newly diagnosed lung cancer. Worsening pain prompted his return to the outpatient clinic but not before a visit to his GP who changed his analgesics. In the following excerpt, although not suggesting that his pain is not from his tumors, he volunteered an explanation of habituation and mediation rather than progressing cancer for his increased pain. Chemotherapy was commenced after this encounter.

Doctor: ...So what's been happening?

Patient: (1) I had that little bit of pain, eh one weekend and it just/

Wife: /[sitting upright] Come on. Not a little bit of pain. You had a LOT of pain over the weekend... he's just been given whole new set of tablets ...

Doctor: ...And who changed those, your own doctor?

Patient: Yeah ... Because the time barrier got (.) usually with the other tablets, the time barrier got shorter ... I was in a lot of pain. (2) Whether I'm gettin' used to the tablets, I don't know.

Doctor: Hmmm.

Although doctors prevailed and ultimately uncovered patient pain during these encounters, patients were actively contributing, albeit in a subtle manner, to the consultation by using communication tactics that diminish the impact of their expressions of pain.

Discussion

A barrier to pain management identified in the literature is patient difficulty communicating with health care professionals.¹⁰ We explored how cancer patients talked about their pain in outpatient clinics. Through direct observation and audio recording of consultations and subsequent analysis of pain talk in detailed verbatim transcriptions, we found patients

using particular communication tactics when talking to clinicians about their pain. These relevant communication tactics appear to be used to achieve their objectives related to pain within the challenging structure of consultations, where doctors maintain “interactional control.”⁴⁵

What is most striking from these data is that, of the 39 of 74 consultations in which pain is discussed at all, in only two encounters did the patient appear to influence the outcome of the consultation. It is notable that it was only through the use of exceptional communication tactics,⁴⁶ interrupting doctors, and persisting when interrupted by their doctors, were they offered a different, previously unmentioned, treatment option—referral to the pain control clinic. In both cases, this was linked with the patient explicitly declining further disease-modifying treatment in favor of a palliative approach. In neither case did the clinician appear to fully explore the pain control options available or even the “next rung” on the World Health Organization’s pain ladder⁴⁷ before suggesting that the patient be seen by pain specialists.

Using a conversation analysis approach provides a transparency to analytic claims. Readers are able to see for themselves whether what is claimed is apparent in the talk and whether it is transferable to another locale. The aim of this study was to identify what processes related to talk about pain were taking place within oncology outpatient clinics. Therefore, although the sampling techniques used do not allow generalizing to the entire cancer patient population, these findings can be considered practices that are possible across similar settings.⁴⁸

Pain is a common and feared symptom of cancer.^{49,50} In cancer patients, pain is often interpreted as an indicator of their condition and a sign of recurrent or progressive illness.^{44,51,52} It is, therefore, likely that patients experience anxiety related to cancer whenever they develop an unexplained pain or existing pain worsens.⁵³ This anxiety appeared to be manifested in patients’ behavior. As people differ in how they cope with anxiety, it is certainly possible that cancer patients’ anxiety about pain is variously manifested in how they actually talk about their pain during consultations with their cancer doctors. The pain talk we

observed formed two distinctly different and mutually exclusive groups. Within each group, patients’ behavior was exhibited in two consistent but disparate ways, which may reflect two different mechanisms for coping with anxiety. For example, some patients appear to cope with anxiety by trying to avoid finding out that the pain they are experiencing heralds disease progression or cancer recurrence and, hence, do not initiate it as a topic.⁴⁴ Neither do they attempt to amplify their experiences once their pain has been uncovered by clinicians. Indeed, it seems that some patients attempted to minimize its occurrence altogether. On the other hand, some patients may cope with their anxiety by having clinicians openly address their problems and concerns and, therefore, draw their doctors’ attention to their pain by introducing it onto the consultation agenda and working to keep it there.

Talk about cancer patients’ pain and its treatment predominantly occurred during interactions with consultant oncologists. Previously reported underestimation of pain severity could be the result of doctors basing their assessments on their wider clinical experiences and subsequent expectations¹⁷ rather than the patient in front of them. Inadequate communication between professionals and their patients about pain experiences could represent another major factor interfering with the provision of adequate pain control. Furthermore, practitioners prescribe and administer analgesics based on their perception of the pain their patients experience⁵⁴ and not necessarily on what patients directly report. If doctors initiated pain talk, it would appear that they were anticipating, based on clinical experience, that patients’ conditions would likely warrant pain. Although the patient is the best source of information for the treatment of pain, physicians often use clinical judgment in the interest of time.²²

As clinicians asked questions according to what appeared to be a preset agenda or “mental checklist,” which patients were not empowered to disturb,²¹ doctors were able to maintain overall control of the content and sequence of pain talk.⁵⁵ This meant that the patients had extremely limited opportunities to introduce onto the consultation agenda any ideas or concerns that were important to

them or information they felt might be useful for their doctors. Similarly, Kimberlin et al.²³ report patients and carers going to great lengths to get the attention they felt they needed from doctors. This included exaggerating needs with the belief that this was the only way to get clinicians who otherwise "... never got interested in the pain part of it ... (p. 571)" to address perceived needs in a satisfactory and timely manner.

Some patients often seek to minimize symptoms, which could reflect a worsening of their overall clinical condition.⁵⁴ Indeed, it appears that cancer patients could successfully conceal pain, an important marker of underlying pathology, if the topic is not intentionally pursued. Perhaps, this is not an issue with oncologists who are specifically looking for indicators of need for further cancer treatment; however, analgesia was not necessarily provided or even discussed.²¹ Therefore, by only focusing on cancer control or ablation and not on pain management per se during consultations, it is unlikely that past reports of inadequately controlled pain in cancer patients will improve.

A number of alternatives to this situation exist. It is now widely recognized that palliative care has a crucial role in the care received by patients and carers throughout the course of the disease and should be delivered in conjunction with anticancer and other treatments.⁵⁶ For this to be realized in practice, cancer clinicians will need to broaden the focus of the consultation agenda to include pain and other symptom management.

Another option might be better utilization of multidisciplinary team members, in particular, specialist cancer nurses. Indeed, U.K.-published guidance from the National Institute of Clinical Excellence⁵⁷ advocates a team approach to the provision of supportive care, such as symptom control. However, for symptom management to be seen as more than an "optional extra," increased resources, better organizational support and guidance, and monitoring of achievements need to be implemented.²⁰

Finally, GPs may become more active in symptom management for cancer patients. However, GP colleagues have reported anecdotally that they infrequently see patients who are being followed up in oncology outpatient clinics. If patients come to see them because of pain, they may provide patients with analgesic

prescriptions "to tide them over" until their next appointment with the oncologist or request that the patient's appointment be brought forward. Even if there was universal agreement that GPs should be the professionals responsible for managing pain in cancer patients, the situation may not spontaneously improve. GPs admit having difficulty managing some pain problems,^{14,58} and there have been reports of pain in cancer patients being inadequately controlled by them.⁵⁹⁻⁶³ Clearly, training opportunities in symptom management would need to be provided for and used by GPs. However, with the changes in the way the General Medical Council regulates medical practice in the United Kingdom, one might expect that the introduction of revalidation will have impact in the way cancer pain is managed across all settings of care.⁶⁴

Observations such as ours can expose what happens in consultations but do not reveal the intentions underlying those behaviors. Future research needs to uncover intent and the behavior. Furthermore, to investigate the hypothesis that differences between groups may be because of anxiety, future work should explore antecedents to the observed behavior, such as levels of anxiety and diagnostic groups.

Poor or absent pain assessment has been identified as one of the major reasons for poor pain management.⁹ We have observed how this is constructed during outpatient consultations. Assessment of pain is not simply overlooked, but its exploration is actively resisted by some doctors unless they are suspicious that there may be need for additional cancer therapy.²¹ If health professionals do not give patients permission and opportunities to discuss issues related to pain, patients will continue to be restricted in their ability to influence the pain agenda and may continue to suffer unnecessarily.²²

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Appendix

Guide to Simplified Transcriptions^{27,28}

Punctuation: “,”; “.”; “?”	Represents how speech is heard: comma indicates very brief pause; full stop indicates voice dropped at end of statements; question mark indicates rising intonation at end of statement
Pt: Trouble round my back ... You know, Dr: Do you open your bowels normally? ...	Ellipses within lines indicate omitted words Ellipses between lines indicates break in talk
Dr: Do you get any chest pain at all? Pt: Not really, it's just a/ Dr:/Is it keeping you awake? Pt: No. Pt: But I've still got this/ Dr:/The pain/ Pt:/back and leg pain ...	Forward stroke at end of one line and beginning of next indicates second speaker has interrupted first speaker Forward strokes at the beginning and end of second speaker's line and at the beginning of first speaker's subsequent line indicates overlapping talk where first speaker continues to make point
Hu: she has got a lot more pain.= Dr: =You've got MORE pain?	= at end of one line and beginning of next indicates no pause between speakers; letters or words in upper case indicates emphasis used by speaker
Dr: How is er (.) the breast?	Full stop in brackets indicates pause less than one second in length
Dr: I'm coming round behind you. (8) If it's uncomfortable ... Pt: It's um (.) still pretty hard, (pressing) ... feels as if it is () ...	Number in brackets indicates length of pause in seconds Speech in brackets not clearly heard. Empty brackets indicates indecipherable speech
Dr: It [radiotherapy] stopped it [bone pain]?	Text in square brackets was not spoken but added for context or clarity
Pt: No:o. As usual it's not too bad today.	Colon between letters or duplication of letters indicates prolongation of word or letter sounds
Dr: Do you ever get headaches before or is that-?	Dash at end of line indicates speaker did not complete sentence
