Original Article

Factors That Hinder and Facilitate Cancer Patients' Knowledge About Pain Management—A Qualitative Study

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Abstract

Context. Pain management education may improve pain control for some patients, whereas individual differences exist.

Objectives. To evaluate possible critical components, facilitators, and hindrances for improved knowledge about pain management, in not hospitalized adult oncology patients with pain from bone metastasis participating in a pain management intervention.

Methods. This substudy is a qualitative evaluation of the PRO-SELF Pain Control Program, tested in a randomized controlled trial. During six weeks, 87 participants in the intervention group received tailored coaching encounters by a trained oncology nurse. Three encounters for each patient were audio recorded. The encounter between patient's with the largest ($n = 12$) and lowest ($n = 8$) change in knowledge about pain management from before to after the intervention was transcribed verbatim and analyzed with qualitative content analysis.

Results. The critical components of the intervention were repetition of information, struggling with resistance, use of peer experiences, and keeping track of variations. Facilitators of improvement were patients' trust and preparedness to try new procedures, the patient's self-awareness and body awareness, and taking active role in own care. Difficulties in processing complex information, culturally conditioned behaviors, fear, and lack of knowledge were the most important barriers to the success of the intervention.

Conclusion. Education in pain management in cancer patients requires repeated information, allowing time for overcoming resistance related to dysfunctional beliefs and fear. To facilitate the patient's involvement in their pain management, tailored and person-centered education is needed. J Pain Symptom Manage 2019;57:753–760. © *2019 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.*

Key Words

Cancer pain, PRO-SELF Pain Control Program, interview, barriers, facilitators

Introduction

Numerous barriers can hamper cancer patients' ability to manage their pain. These barriers can be related to health-care professionals, the patient, or the health care system.[1] Patient education has been reported to be an important strategy to overcome these barriers.[1] However, the relationships between education and pain outcomes are unclear.[2,3] Three systematic reviews of educational interventions for cancer pain have been reported[2–4] and concluded that patient-based educational interventions can result in modest but significant benefits in the management of cancer pain,[2] that cancer pain educational interventions can improve pain outcomes,[4] and that patient-based educational programs may result in improvements in relevant patient-reported outcomes.[3]

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The most recent review[3] concluded that the interventions offered were heterogeneous and that improvement of pain management was seen in less than one-third of studies and in fewer than 20% of all included patients. Therefore, more in-depth knowledge about education and information about improved knowledge of cancer pain management are of great importance to improve pain management in cancer patients.[2]

The PRO-SELF Pain Control Program consists of patient education, skills building, and nurse coaching.[5] In a Norwegian replication of the PRO-SELF study,[6,7] significant decreases in pain intensity scores and in hours per day in pain, as well as an increase in the total dose of opioids, were found for both the intervention and the standard-care group, while patients in the PRO-SELF group had significant increases in knowledge scores compared with the control group.

Research on factors that influence knowledge about cancer pain management is scarce and inconsistent. Earlier research in cancer patients have shown that being white and having higher levels of trust were predictors of increased knowledge,[8] older patients were shown to have more barriers to cancer pain management,[9] and being younger, female, and African-American, as well as being better educated and being married were associated with higher information needs over time.[10] Of note, cancer diagnosis and stage were not significant predictors of a patient's knowledge of pain management. Although a large number of descriptive, cross-sectional studies have evaluated barriers to cancer pain management,[9,11–14] few have gone into detail about the barriers related to education of the patients. To overcome difficulties that commonly arise when transferring evidence into practice, the characteristics of the evidence, together with the barriers to and facilitators of change, should be explored.[15]

Therefore, in this qualitative study, we were interested in gaining deeper insights about possible critical components and facilitators of and hindrances to improvements in knowledge about pain in cancer patients after a pain management intervention. This knowledge is important for better tailoring interventions that fit different patient characteristics and needs.

Methods

The present study is a substudy of PRO-SELF Pain Management in Norway [ClinicalTrials.gov as NCT00760305]. The Regional Committee for Medical and Health Research Ethics approved the study.

Description of the Primary Study

In total, 179 adult oncology outpatients with pain from bone metastasis participated in the PRO-SELF intervention study. Details of the PRO-SELF intervention are provided in the study by West et al.[5] In brief, patients in the PRO-SELF intervention group received tailored coaching by an oncology nurse who was specially trained in the intervention (PRO-SELF Nurse [PSN]). The PSN visited the patients in their home at weeks 1, 3, and 6 and conducted telephone interviews at weeks 2, 4, and 5. The dialogue between the nurse and the patients concerned patients' knowledge on pain management and their perception about pain, as measured using the Pain Experience Scale (PES),[16] at baseline and six-month follow-up. The dialogues were tape-recorded for each home visit. The patients completed a diary every evening during the six-week period describing their pain and pain relief for that day. The patients reported their pain intensity and analgesic medications daily, and about side effects for each week.[5] For more detail about the intervention, see Appendix A and the study by West et al.[5]

Qualitative Study Methods

The digitally recorded verbal interactions between the PSN and patients during three coaching sessions in the patients' homes were used for the qualitative evaluation of the PRO-SELF intervention.

PES scores were used to select the participants in the present study. The PES contains 13 items that measure an individual's knowledge about pain and its management as well as an individual's perception of their pain experience.[16] The knowledge portion of the PES contains nine items that address knowledge about addiction, drug dependence, frequency of drug administration, scheduling of drug administration, and side effects associated with opioid analgesics. Each of the nine items is rated using an 11-point numeric rating scale (NRS) that ranges from "disagree" to "agree." The total sum of PES scores ranges from 0 to 90, where higher scores indicate a more accurate knowledge in pain management.[16] Changes in the PES scores (from enrollment to the end of the study) for the patients in the intervention group ($n = 87$) were calculated. To capture as much variation as possible in the patients' understanding of pain management, we selected patients with the highest (≥ 15, $n = 12$) and lowest (<15, $n = 8$) changes in PES scores.

Data Analysis

The dialogues during the encounters were transcribed verbatim and analyzed using qualitative content analysis following a direct deductive approach.[17] In the analysis, we focused specifically on the patient-nurse interactions.

Three prespecified categories—1) *critical function components*, 2) *hindrances to improvement*, and 3) *facilitators of improvement* in pain management—were identified as crucial for uptake of evidence into practice[15]

and allowed us to identify the most active components of the intervention. The analysis contained the following steps:

1. An operational definition for each of the categories and a coding scheme that organized the data into categories were developed.[17]
2. The transcripts were read several times to get a sense of the whole.[18,19]
3. Sequences of patient-nurse conversations were selected as the meaningful unit for analysis.[20]
4. Open coding was used, meaning that meaningful units were labeled with a code related to the predefined categories when reading it.[17,18] The code "hindrance to improvement" was, for example, written in the margin when a patient described their fear or misunderstanding of medication management.

Each category was then reviewed, and the content was divided and grouped into subcategories that corresponded with and/or exemplified the three predefined categories. The identified categories were found in both the high- and low-improvement groups. Results from all patients in each category are presented and illustrated with quotes.

Results

Participant Characteristics

The characteristics of the participants are presented in Tables 1 and 2. Half of the patients in the high-improvement group (50%) and 75% of those in the low-improvement group were male. At enrollment, patients in the low-improvement group had an average PES score of 63% (range 54–91); patients in the high-improvement group had an average PES score of 50% (range 39–79).

Critical Components of the Intervention

Critical components of the coaching intervention were represented by the following subcategories: *repetition of information and struggling with resistance*; *helping patients understand their situations by teaching about peer experiences;* and *keeping track of variations* in perceived pain.

Repetition of Information and Struggling With Resistance. After the PSN described the rationale for a PES item, she stopped and listened to the patient's answer. Then, she repeated the same information exactly the same way or with slight variations in the wording. Resistance and cultural beliefs were met by repeated presentation of information by the PSN. In some cases, patients expressed that they had got new insights about pain management.

Patient (P): Yeah, but I'm sort of old school. I was brought up not to take any medications until you're right in the midst of it.

PSN: Exactly, so now that's what we need to learn some more about … that you don't wait … 'no, the pain isn't too bad now so I think I'll wait … '

P: Okay

PSN: You see, the reason the pain medications have to be taken at regular times is that we want to keep the levels of pain medication in the blood stable.

P: Yeah

PSN: And it's really important because then you will always keep that stable concentration.

P: And that's … I hadn't thought much about that before. Thanks for telling me about this.

(High PES score)

The PSN took the patient's description of a particular behavior as the starting point for improving pain management and provided the rationale for following the instructions about pain medication. This approach requires that the nurse have a high

Table 1
Demographic and Pain Characteristics of Participants ($N = 20$)

	High Improvement, $N = 12$	Low Improvement, $N = 8$	Total Sample, $N = 20$
Sex			
Male, *n* (%)	6 (50)	6 (75)	12
Female, *n* (%)	6 (50)	2 (25)	8
Age, mean (range)	65 (45–80)	69 (57–83)	8
Diagnosis			
Breast cancer, *n* (%)	6 (50)	1 (13)	7
Prostate cancer, *n* (%)	5 (42)	4 (50)	9
Other, *n* (%)	1 (8)	3 (37)	4
Cohabitant, Yes, n (%)	8 (67)	4 (50)	12
Education			
University/College, *n* (%)	5 (42)	6 (75)	11
Secondary, *n* (%)	7 (58)	2 (25)	9
Average pain level, mean (range)	5 (4–6)	3 (1–5)	4 (1–6)
Worst pain level, mean (range)	7 (5–8)	4 (2–6)	6 (2–8)
Hours in pain/day, mean (range)	13 (4–24)	6 (1–16)	4 (1–24)

Table 2
Overview of Participants ($N = 20$)

	Sex	Age	Cancer Diagnosis	Cohabitation	Education	PES Score 1	PES Score 2	PES Difference	PES Score Group
1	F	78	Breast	No	University/College	43	74	+21	High
2	M	76	Prostate	Yes	University/College	56	70	+14	Low
3	M	82	Prostate	Yes	University/College	54	64	+10	Low
4	F	51	Breast	Yes	University/College	59	87	+18	High
5	F	64	Breast	Yes	Secondary	39	71	+32	High
6	M	73	Prostate	Yes	Secondary	43	73	+30	High
7	F	73	Breast	Yes	Secondary	69	90	+21	High
8	M	83	Prostate	No	University/College	57	67	+10	Low
9	M	80	Prostate	Yes	Secondary	57	78	+21	High
10	M	60	Other	No	University/College	59	64	+5	Low
11	M	79	Other	No	Secondary	43	93	+50	High
12	F	54	Breast	Yes	University/College	58	94	+36	High
13	M	62	Prostate	Yes	Secondary	40	78	+38	High
14	M	59	Prostate	Yes	University/College	56	57	+1	Low
15	F	57	Other	No	University/College	79	83	+4	Low
16	M	71	Colon	Yes	Secondary	54	60	+6	Low
17	F	45	Breast	No	University/College	51	96	+45	High
18	M	61	Prostate	Yes	University/College	54	89	+35	High
19	M	63	Prostate	No	Secondary	39	82	+43	High
20	F	63	Breast	No	Secondary	91	94	+3	Low

F = female; M = male; PES = Pain Experience Scale.

level of competence, skills, and sensitivity to assess the patient's educational needs.

Helping Patients Understand Their Situations by Teaching About Peer Experiences. A critical component of the PRO-SELF encounter was to use the patient's own experiences. Such communications were filled with confirmations from patients, such as *No, I've tried that myself, tried exactly that.* Likewise, the provision of examples of how other patients in the same situation managed to control their pain increased the patient's hope and motivation to follow the nurse's advice. The patient whose conversation is presented below had a low initial knowledge of pain management but made great improvements over time.

P: My shoulder hurts all the time so I don't exercise, I can't bring myself to go out and exercise and that makes me feel, you know, it sort of makes me tired mentally.

PSN: In my opinion, you know, I think you should switch to a stronger medication. Just for the time being. Lots of these patients, especially women, they do a lot of training, and it's pretty clear that they get more out of their day and their exercise when they've taken pain medications.

P: No, that's true

PSN: They all hurt somewhere, in an arm, or a knee, or a hip

P: Yeah, I understand, they can't manage it without taking medication.

(High PES score)

Keeping Track of Variations in Perceived Pain. The patient's daily pain assessments gave both the PSN and the patient a systematic overview of variations in pain related to activities, medication use, and interventions used to manage pain. The diary complemented the coaching sessions by reminding the patients to maintain a regular schedule; it helped them to become aware of early signs and of the resources needed to efficiently manage their pain. This increased level of awareness was part of the learning process.

PSN: Please describe how much your pain journal has helped.

P: Oh, I think it's been really useful because it forced me to sit down and think a bit about how I had been feeling. And then I know why I've gone from 10 to 3, for example (on the pain severity score). I don't know how you would keep track of it otherwise.

(High PES score)

Facilitators of Improvement

Facilitators of improvement during the coaching intervention were *trust and preparedness to try new procedures; patient's self-awareness and body awareness;* and *patients taking an active role in their own care.*

Trust and Preparedness to Try New Procedures. The PSN's coaching was a critical component as the coach became familiar with the patient's attitudes and behaviors and repeated the advice from previous visits. When information from different sources was consistent, patients had the confidence to trust the advice and follow the PSN's instructions and try new routines.

P: I've figured out that no matter which doctor it is … and now I've been at three hospitals … it's exactly the same.

Doctors are always ready to hand out the paracetamol (acetaminophen) and they consistently tell me it's much better to take them according to a schedule.

PSN: Yeah, I would also recommend that ….

P: … so we keep it in check. Well, I'll try doing that, then.

(High PES score)

Some patients pointed out that they made a conscious decision to trust the information and then by testing the advice they realized that it worked. *What has helped me the most was that I have learned to take the analgesics around the clock.* Such an attitude was a facilitator for improvement.

Patients' Self-Awareness and Body Awareness. Some patients learned to know when the concentration of the pain medication decreased, which helped them to take another dose before the pain became too severe. Knowledge of how their body worked and awareness of their own weaknesses and strengths facilitated the patient's learning how to manage their pain:

P: And, um, trying to handle a pain like that … it's pretty intense when it comes along, but then it's gone again in a tenth of a second. I learned to sort of just sit still for the short time it lasted … move with caution.

(High PES score)

Patients who were aware of their fears and the underlying reasons for them were in a better position to battle against their "demons."

Patients Taking an Active Role in Their Own Care

Knowledgeable patients who took an active part in their own care had good control over their pain and knew what to do if they needed help. This behavior was observed in patients with good initial knowledge and in patients with high levels of improvement. These patients considered themselves competent to take care of themselves at home.

PSN: Um, how can we help you manage the pain better? How can the health care staff …

P: No, no. I think, as I said, it's the other way around and I've had incredibly good help.

PSN: Hmm

P: and I get … I mean, I ask questions, and then I get answers.

(High PES score)

Active patients obtained information from different sources (e.g., internet, friends, journals, books, clinicians). They described how they adjusted their medications and their behaviors based on their needs. For example, if children were going to visit, they took a nap and increased their pain medication so they were able to interact with the visitors. They tested and critically evaluated the advice that they received from the PSN and other sources and supplemented this information with their own self-care methods that they knew were effective.

Hindrances to Improvement

The most common barriers to the success of the intervention were *difficulties with being able to process complex information; assumptions, beliefs, and attitudes about pain management*; and *fear and lack of basic knowledge about the illness and treatment.*

Difficulties With Being Able to Process Complex Information

This analysis found that some patients had difficulties in understanding complicated explanations about pain medications and pain management and how to apply the information in their daily lives. Some patients confused chronic pain and breakthrough pain. Others followed the advice literally in a nonfunctional way: for example, one patient reported that he/she set the alarm clock for 4 AM to exactly follow the advice to take medication at regular intervals, without reflecting that this disturbed his/her night sleep.

Assumptions, Beliefs, and Attitudes About Pain Management

Patients' attitudes toward pain and use of drugs (e.g., normalization of pain and being ashamed for not being strong enough) as well as their assumptions and beliefs (e.g., becoming addicted to pain opioids) were the most difficult obstacles to improvement. Some patients shared that it was "normal" to have pain when you have cancer and that you just have to be strong and endure the pain. They described that they were ashamed to ask for strong pain medications or tranquilizers. Others expressed guilt and wondered why they were afflicted with this disease, despite their healthy living and sound eating habits. In some cases, patients described that their next of kin were frightened by the patient's illness and by seeing them affected by the medication.

P: Y'know, I think, I think it's embarrassing to ask sometimes.

PSN: Of course.

P: … But I feel a bit, like sinful in some way, I mean when I sort of beg for it, then maybe he or she is thinking 'Oh, that's the way it is,' like I'm awfully eager to get myself some drugs.

PSN: Yes, I understand.

P: Because I have some, y'know, prejudices against these medications.

(Low PES score)

Although the PSN provided evidence-based information that cancer patients often received too low a dose of pain medication, that patients should take their medications around the clock, and that patients with cancer pain should not be worried about becoming addicted to opioids, the patients' behavior did not change.

Fear and Lack of Basic Knowledge About the Illness and Treatment

Another hindrance to improvement was the patient's fears and lack of basic knowledge about their disease and its treatment. This ignorance made them open to hearsay and myths that formed their beliefs and assumptions and was a major hindrance to receiving treatment.

Fears of death, the loss of control, and becoming dependent on drugs occupied many patients' thoughts and controlled their actions. Because of a lack of basic knowledge about their illness and of how their pain medication worked, patients made their own assumptions about the mechanisms. In cases where the fear was grounded in misunderstanding and a lack of knowledge, the coaching by the PSN could bring the patient a new understanding.

P: So when I feel better I skip the pills because I don't want to, um … trigger my system.

PSN: But then it comes back again.

P: Yeah, then it comes back. But I thought that if you started taking analgesics, your body would eventually sort of get so used to them that you would always have to … right when you had severe pain, you would have to increase the dose. So that's why I think it's better to just put up with minor pain.

PSN: Yeah, I understand, but it's actually the other way around.

P: Okay.

PSN: It's precisely the opposite.

P: Well, there I learned something new.

(High PES score)

Discussion

This study is one of the first to describe the hindrances to and facilitators of improvements in knowledge about pain management after an educational intervention. The PSN's coaching was mainly based on the patients' knowledge deficits. One of the strengths of the PRO-SELF program is the use of academic detailing[21] to determine the patients' basic level of knowledge and motivation as a basis for their education. Repetition of information is a key component of academic detailing,[21] and one of the key principles in learning.[22] The repetition of information in a permissive atmosphere was a crucial element in this study, allowing a patient to test new behaviors. Other components were the use of *the patient's own experiences, experiences from peers and metaphors* that facilitated the reconstruction of patients' beliefs about pain medication.

The last subcategory within critical components was *keeping track of variations of perceived pain*. The use of a daily pain diary forced patients to sit down and think about their pain and reminded them about keeping to a regular schedule of analgesics. The use of a pain diary has been shown to help patients to cope with their pain in a home setting[23,24] and is recommended as one strategy to overcome barriers to cancer pain management.[1] Schumacher et al.[23] found that 91% of patients in a home setting found the pain management diary useful because it heightened their awareness of the pain experience, provided a guide to self-care behaviors, facilitated communication, and enhanced their sense of control.

Hindrances to improvements in knowledge after the intervention included *difficulties in processing complex information*. Making sense of new complex information about cancer pain management involves activation of mental models and making inferences from earlier experiences via inner communication or through interaction and communication with others.[25,26] Patients were commonly ill informed about when to take their medication and the value of taking the medications around the clock. High level of stress and uncertainty may further hinder patients understanding of the complex information that is provided. A review concluded that one of the most frequently mentioned barriers for patients pain management is knowledge deficiencies and misconceptions regarding pain.[27]

Assumptions, beliefs, and attitudes were identified as the greatest obstacles to improvement of knowledge; for example, it was hard to convince the patients that they should take the prescribed dose of analgesics and not stop because of a fear of becoming addicted. This is consistent with the results reported by Schumacher et al.[28] who found that 10% of the sample declined to increase their analgesic use despite having moderate to severe pain. Other studies have shown that patients' previous experiences with cancer pain management were one of the main reasons why pain management was not successful.[29] These findings indicate that a small subset of patients with cancer pain

might need alternative pain management strategies to augment their education about opioids.[28]

The analysis revealed that among *facilitators for improvement during the intervention* was a *trusting preparedness to try new procedures*. A long-term relationship between the PSN and the patients was important for building trust over time, which made patients more confident about following the PSN's advice. This was especially important for patients with dysfunctional beliefs such as a fear of taking analgesics regularly. Other facilitators of patients' attention to advice were repetition of the same advice by different health-care providers. However, more insight is needed into the patients' decision-making process about pain management.[29]

Patients' self-awareness and body awareness about sensations and the normalization of body processes were other facilitators for pain management. The patients were advised about the importance of knowing how their body works and knowing their own body was important for facilitating learning how to manage pain. This is seldom described in the literature on cancer pain management, but it seems reasonable that patients knowing their own body would increase their self-confidence and feeling of trust. One important factor here is that it is very likely easier for patients to listen to their own body when they are calm and not overanxious.

One final facilitating factor was for patients to *actively take part in their own care*, which is consistent with basic principles in the PRO-SELF intervention.[5] Active patients obtained knowledge from different sources, and they found information themselves. They critically evaluated the information they obtained from the PSN. The total information needs of cancer patients are high, and a low education level is significantly associated with higher information needs over time.[10] Even if our participants had a relatively high education level, they might find it extremely demanding to function effectively in the role of self-management of pain medication. This requires a high level of confidence and skills including understanding about the body or bodily processes, which might be quite different from all their prior education.[30]

Limitations

This study has several limitations. First, these data are drawn from a subsample of all patients undergoing the PRO-SELF intervention, and the results cannot be generalized to all cancer patients. The analysis was performed by one of the researchers (M. E.); to reduce the risk of researcher bias permeating the analysis, the categories and written summaries of findings were shared periodically between team members. This procedure is consistent with the established rigor of qualitative research,[31] allowing peers to arrive at a common understanding (consensus) of the fit between the emerging codes and categories and the raw data.

Conclusion

In coaching conversations in which improvements in pain medication management occurred, the critical components of the intervention were the repetition of information and struggling with resistance to change; helping patients understand their situation by teaching about peer experiences; and keeping track of variations. Facilitators of improvement during the coaching intervention were trust and preparedness to try new procedures; the patient's self-awareness and body awareness; and patients taking an active role in their own care. The most common barriers to the success of the intervention were difficulties with being able to process complex information; assumptions, beliefs, and attitudes about pain management; and fear and a lack of basic knowledge about the illness and treatment.

Even if we have some knowledge about what is most important for the patients in cancer pain management, it is of great value to individualize the support when meeting the patients in their homes. Further research to identify the factors that hinder and facilitate patients' knowledge about pain management is required.

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Appendix A. Details About the PRO-SELF Intervention

At the week 1, 3, and 6 visit, the PSN met patients and family caregivers in their homes. At week 1, the nurse conducted an academic detailing process that explored the patient's knowledge deficits that were identified based on the patient's responses to the individual items on the PES.[1,2] The educational information was then tailored to meet the specific needs of each patient.[3] In addition, the PSN reviewed pain scores and pain medications, coached the patients about pain-related issues and about management of side effects, and instructed them how to complete the diary and the side-effect checklist. At weeks 3 and 6, the educational material was reinforced and patients were asked additional questions as required to assist with specific problems and meet their individual pain management needs.

At weeks 2, 4, and 5, the PSN contacted patients in the intervention group by phone and reviewed their pain intensity scores and analgesic intake. During these sessions, the educational content of the PRO-SELF Pain Control Program was reinforced and patients were advised about how to modify their pain management plan or how to contact their physicians to improve pain outcomes.

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