The PRO-SELF© Pain Control Program improves family caregivers' knowledge of cancer pain management

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Abstract:

Background:
The majority of cancer treatment is provided in outpatient settings. Family caregivers' (FCs') knowledge and beliefs about pain and its management are critical components of effective care.

Objective:
This study's aim was to evaluate the efficacy of a psychoeducational intervention, compared to control, to increase FCs' knowledge of cancer pain management.

Intervention/method:
FCs of oncology outpatients were randomized together with the patients into the PROSELF © Pain Control Program (n=58) or a control group (n=54). FCs completed a demographic questionnaire and the Family Pain Questionnaire (FPQ) at the beginning and end of the study to assess their knowledge about pain and its management. The intervention consisted of nurse coaching, home visits, and phone calls that occurred over 6 weeks.

Results:
One hundred and twelve FCs (60% female) with a mean age of 63 years (SD 10.7) participated. Compared to FCs in the control group, FCs in the PRO-SELF© group had significantly higher knowledge scores on all of the single items on the FPQ, except for the item "cancer pain can be relieved", as well as for the total FPQ score.

Conclusion:
The use of a knowledge and attitude survey like the FPQ, as part of a psychoeducational intervention provides an effective foundation for FC education about cancer pain management.

Implications for practice: Oncology nurses can use FCs' responses to the FPQ to individualize teaching and spend more time on identified knowledge deficits. This individualized approach to FC education may save staff time and improve patient outcomes.

Introduction

Unrelieved pain remains a significant clinical problem and one of the most feared consequences of cancer.[1] The majority of cancer treatment is provided in outpatient settings. Therefore, both patients and their family caregivers (FCs) are required to make numerous judgments and choices on a daily basis about how to achieve optimal pain control. Their judgments and choices are based on information and instructions provided by clinicians, the needs of the patient, and FCs' knowledge and attitudes about pain and its management.[2] Adequate knowledge is the foundation that FCs need to develop required caregiver skills and to be able to seek guidance from clinicians when needed.[3] Information and a better understanding of the pain management regimen give FCs more confidence and a higher level of comfort to assist patients to achieve optimal pain management.[4]

To improve FCs' perspectives on pain management, it is important to increase their ability to participate in pain management and enable them to assess pain and to help patients take adequate doses of analgesics.[3] Achieving optimal pain control requires collaborations among patients, their FCs, and clinicians. FC education is a critical component of pain management because misconceptions and lack of knowledge can result in inadequate pain control.[5, 6]

Across several studies,[7-11] FCs reported numerous barriers, negative attitudes, and misconceptions regarding cancer pain management. Some of the most significant barriers included fears of addiction, concerns about opioid–induced side effects, and a belief that increased pain indicates disease progression.[7-9] As a result of these negative attitudes and misconceptions, FCs may encourage patients to take lower doses and withhold doses of analgesics, which results in inadequate pain control.

Of note, FCs reported both confidence and willingness to participate in cancer pain management. However, at the same time they reported distress and some difficulty in performing the necessary tasks.[3] This finding emphasizes the need to increase FCs' ability to take part in cancer pain management.

However, only three intervention studies were identified that evaluated the effects of educational programs to improve FCs' knowledge and attitudes about cancer pain management.[12-14] For one intervention study that provided a brief pain education program to 64 cancer patients and their FCs,[12] improvements in knowledge and positive beliefs about cancer pain management were found in both patients and their FCs.[12] However, the intervention did not affect the long-term outcomes of pain intensity, interference because of pain, adequacy of analgesics used, or pain relief.

In a more recent randomized clinical trial (RCT) that included 161 patients and their FCs,[13] both groups' attitudes about analgesic use and patients' pain outcomes were measured at baseline, five weeks, and nine weeks after the educational intervention. While patients in the intervention groups (patients alone, patients and FCs) had significant decreases in attitudinal barriers at 9 weeks compared to controls, no decreases in attitudinal barriers were found in their FCs. The authors did not offer any explanation why FCs‘ attitudinal barriers did not decrease over time.

Finally, in a small feasibility study that tested a brief DVD-based educational program with a booklet that reinforced the information provided in the DVD, fifteen patients with advanced cancer and ten FCs participated.[14] FCs' knowledge scores improved by 42% from the beginning to four weeks after the intervention. The greatest improvements were found in the items that addressed beliefs about addiction to medication, saving medicine until the pain is worse, and giving analgesics regularly.[14] As only ten FCs were included in this study and the participants were not randomized, it is difficult to draw definitive conclusions about the efficacy of the DVD based educational intervention.

Findings from only two studies suggest that educational programs increase FCs' knowledge of pain management.[12,14] Given the paucity of research on the efficacy of pain management interventions for FCs of oncology patients, the purpose of this study was to evaluate the efficacy of a psychoeducational intervention (i.e. the PRO-SELF© Pain Control Program[15]) compared to control care to increase FCs' knowledge and attitudes regarding cancer pain management.

Methods

Sample and Settings

This study is part of a large RCT that evaluated the efficacy of the Norwegian version of the PRO-SELF© Pain Control Program (PROSELF© PCP-N) compared to a control group in improving cancer pain management. A total of 179 oncology outpatients with bone metastasis were recruited from a university-based cancer center and were asked to identify the person most involved in their care (i.e., their FC). These FCs were invited to participate in the study. All FCs were adults ($\geq$18 years old) who were able to read, write, and understand Norwegian. One hundred and twelve FCs agreed to participate and provided written informed consent. The Regional Committee for Medical and Health Research Ethics (REK) approved the study. The Protocol ID is 158707/V10 and it was registered on ClinicalTrials.gov as NCT00760305.

Instruments

FCs completed a demographic questionnaire about age, gender, living arrangements, education, and employment status.

FCs' knowledge about cancer pain management was measured by a modified version of the Family Pain Questionnaire (FPQ).[16] The FPQ contains 9 items that measure an individual's knowledge about pain and its management. These 9 items address knowledge about addiction, frequency of analgesic administration, scheduling of analgesic administration, and side effects associated with opioid analgesics. The drug dependence item was deleted from the original FPQ because dependence and addiction have the same meaning in the Norwegian language. An item about the association between pain and disease progression was added because it was included as a barrier to cancer pain management in a questionnaire developed by the American Pain Society's Quality of Care Committee.[17] Each of the items was rated on an 11 point numeric rating scale (NRS) that ranged from "disagree" to “agree”. Some items were reverse coded so that each item is scored to reflect the degree of correctness.[16] Scores for each of the items were summed and converted to a 100% scale to create a total FPQ knowledge score. Higher scores on each item indicate a more correct response. The FPQ has well-established validity and reliability.[16, 18]

Patients medical records were reviewed for disease and treatment information including cancer diagnosis, treatments, and radiographic evidence of bone metastasis. They completed a demographic questionnaire about age, gender, education, and employment status.

The Karnofsky Performance Status (KPS) scale was used to evaluate patients’ functional status[19] and has well-established validity and reliability[20]. KPS scores ranged from 10 (“fatal processes progressing rapidly; moribund”) to 100(“normal, no complaints; no evidence of disease”).

Data Collection Procedures

Patients were randomized after completing the enrollment questionnaires into either the PRO-SELF© (n=87) or control (n=92) groups. FCs were assigned to the same group as the patients (i.e., PRO-SELF© (n= 58) or control group (n=54)). FCs in the control and PRO-SELF© groups completed the FPQ at the beginning and at the end of the study to assess their knowledge about cancer pain management.

Intervention for the PRO-SELF© and control groups

The Norwegian version of the PRO-SELF© Pain Control Program was adapted from the work of Miaskowski and colleagues.[15] In brief, patients and their FCs in the PRO-SELF© group were contacted by a specially trained oncology nurse. The nurse visited their home at weeks 1, 3, and 6 and conducted telephone interviews at weeks 2, 4, and 5. At the week 1 visit, the PRO-SELF© nurse conducted an academic detailing session that addressed the identified knowledge deficits based on patients’ and FCs’ responses to the individual items on the FPQ.[21] At weeks 2, 4, and 5, the PRO-SELF© nurse contacted patients or their FCs in the intervention group by phone and reviewed the patients’ pain intensity scores and pain medication intake. During these sessions, the educational content of the PRO-SELF© Program was reinforced and patients and FCs were coached about how to modify their pain management plan or how to contact their physicians to improve pain outcomes. At weeks 3 and 6, the PRO-SELF© nurse made home visits where the educational material was reinforced and additional coaching about pain management took place.

Patients and their FCs in the control group were given a booklet about Cancer Pain Management developed by an oncologist at Oslo University hospital. In addition, they were contacted with the same frequency as patients and their FCs in the intervention group. The focus of the visits and phone calls was on monitoring patients' level of adherence with completing the pain management diary.

Data Analysis

Descriptive statistics and frequency distributions were generated on FCs' and patients' demographic characteristics. Independent Student t-tests or Chi Square analyses were performed to evaluate for differences in demographics between FCs and patients in the PRO-SELF© and control groups. Descriptive statistics and frequency distributions were generated on patients' clinical characteristics. Independent student t-tests or Chi Square analyses were performed to evaluate for differences in clinical characteristics between patients in the PRO-SELF$^©$ and standard care groups between patients in the PRO-SELF$^©$ and standard care groups.

Mixed model analyses, with tests of a group x time interaction were performed to determine whether any differences existed over time in individual item or total FPQ scores between FCs in the PRO-SELF© and control groups. The test of the interaction determined whether changes in individual item or total FPQ scores, from the beginning to the end of the study, were significantly different between the PRO-SELF© and control groups. In addition, within each treatment group, changes from the beginning to the end of the study in individual item and total FPQ scores were evaluated for statistical significance using mixed model tests of the simple effects. All calculations used actual values. Adjustments were not made for missing data. Therefore, the cohort for each analysis was dependent on the largest complete set of data across groups. A p-value of < 0.05 were considered statistically significant. All analysis was performed using SPSS Version 18.0.

Results

Sample Characteristics

As shown in Table 1, no statistically significant between group differences were found in any of the demographic characteristics. In terms of the patient groups, no between group differences were found for demographics or clinical characteristics, except for the KPS score. The control group had statistically significant higher KPS scores at the time of enrollment (Table 2). A more complete description of these patients is found elsewhere.[21]

Differences in baseline FPQ knowledge scores

At the beginning of the study, except for the item ”cancer pain can be relived”, no statistically significant differences were found for any of the individual items or total FPQ knowledge scores between FCs in the PRO-SELF© and control groups. For this FPQ item, FCs in the PRO-SELF© group had a significantly higher mean score (8.5, SD 1.5) than FCs in the control group (7.8, SD 2.0, p=.03).

Changes in FPQ knowledge scores over time

As shown in Table 2, statistically significant group x time interactions were found for all of the single items and FPQ total scores, except for the item “cancer pain can be relieved”. Compared to the control group, FCs in the PRO-SELF© group had significant increases in their knowledge for all single items, as well as for the total score. An examination of the simple effects within each group revealed improvements in scores for all individual items except “Treatments other than medicines (such as massage, heat, and relaxation) can be helpful for relieving pain”, as well as for total FPQ score only for FCs in the PRO-SELF© group.

Discussion

This study is the first to evaluate the effects of a psychoeducational intervention to improve knowledge and attitudes about cancer pain management in a sample of Norwegian FCs of cancer patients with pain from bone metastasis. Overall, the PRO-SELF© group scored significantly higher scores at the end of the study compared to the beginning, with significant improvements in eight of the nine items on the FPQ. The FCs who received the intervention increased their overall knowledge of cancer pain management by 21% over the course of the intervention. However, their total score at the end of the study was only 76%, which suggests that additional improvement in knowledge could occur.

The change of 21% in this study is larger than the 10% reported by Wells and colleagues,[12] but lower than the 42% increase reported by Capewell et al..[14] Reasons for these differences may be attributed to differences in the duration and extent of the interventions. For example, patients and FCs in our study were coached for 6 weeks by a specially trained oncology nurse whereas in the study by Wells and colleagues[12] the intervention was delivered in a single session. In contrast, Capewell and colleagues provided patients and FCs with a DVD and educational booklet. While they did not report the number of hours FCs watched the DVD, it is possible that the larger increase in knowledge scores in this study was related to increased use of the DVD.[14]

Another reason for the differences in results across studies is the instruments used to evaluate knowledge. In the study by Wells et al. study,[12] only four items from the FPQ was used and results for the single items were not reported. In the study by Capewell et al.,[14] data from patients and FCs respond to the FPQ were aggregated due to the small number of FCs in their study (n=10).

Consistent with previous studies,[8, 10, 22] the item with the lowest score at baseline in both groups of FCs was “It is better to give the lowest amount of pain medicine early on so that larger doses can be used later if pain increases". However, as noted in two other studies,[12, 14] FCs in the PRO-SELF© group had the second largest increase in this item. This finding suggests that the PRO-SELF© intervention had a positive effect on FCs' attitudes towards the development of tolerance.

Both groups of FCs in this study reported a fear of addiction at enrollment (see item 3). Of note, this item had the largest improvement (an increase of 3.3 points) in the intervention group. When the intervention nurse provided education and coaching on this topic, she compared cancer patients' need for pain medication with patients with other chronic conditions who required routine administration of medication to manage the condition (e.g., use of insulin in patients with diabetes). The nurse emphasized the difference between psychological addiction and physical dependence and the need to avoid rapid reductions in the dose of opioid analgesics to prevent withdrawal symptoms. While the knowledge of FCs in the PRO-SELF© group increased, the relatively low scores at the end of the intervention points to a need for further education and coaching on this topic. Fear of addiction may result in under-medication as many patients rely on their FCs to administer their analgesics or need encouragement from their FCs to take their pain medication.[7]

Even though FCs in the intervention group increased their scores by 3.2 points on the item "Pain medicine should be given only when pain is severe", scores on this item remained relatively low. The reasons why many FCs think that pain medicine should be given only when pain is severe is not entirely clear. One reason may be that they fear that patients will become addicted to the analgesics. Another possible explanation could be related to worries that higher doses of analgesics will not be available when the pain becomes more severe. Clinicians should educate both patients and FCs on these points and explain that pain control is more easily achieved when the pain is less severe. FCs who understand the need for upward titration of opioids and the lack of a ceiling effect for opioids are more likely to assist patients to improve pain management.[22]

The FPQ item with the lowest score at the end of the study was ”If pain gets worse it means that the cancer is getting worse”. This result is not surprising because increased pain may be a result of disease progression for some patients. Fear of cancer progression may be a barrier to adequate pain management if FCs are reluctant to admit that the cancer is progressing and that higher doses of analgesics are needed.[8, 10, 11] The intervention nurse discussed the connection between pain and disease progression with the FCs who scored low on this item. However, the fact that this score remained relatively low suggests that this topic requires more discussion in FCs of patients with advanced cancer.

The only item on the FPQ that did not demonstrate a significant group x time interaction was “Cancer pain can be relieved”. While FCs in the PRO-SELF© group scored significantly higher on this item at the end of the intervention, FCs in both groups scored highest on this item at enrollment. This finding suggests that most of the FCs had prior knowledge about this point.

Some limitations of our study need to be acknowledged. The sample was primarily Caucasian, and well-educated which limits the generalizability of the study findings. In addition, the etiology of cancer pain was limited to only bone metastasis. Therefore, these findings may not be generalizable to patients with other types of cancer-related pain. Although the PRO-SELF© program was designed for patients and FCs with an eighth-grade reading level, the intervention may need to be modified for individuals with lower levels of education.

Implications for Clinical Practice

As FCs’ and patients’ knowledge are the foundation for developing necessary skills to seek assistance from clinicians, the use of a questionnaire, like the FPQ, provides an effective foundation for FCs’ education about cancer pain management. Oncology nurses can use FCs’ responses to this questionnaire to individualize their teaching and be able to spend more time on areas with identified knowledge deficits. This individualized approach to FCs’ education may save staff time and improve patient outcomes.

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