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Developing Effective Cancer Pain Education Programs

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Abstract

Pain is prevalent, burdensome, and undertreated in individuals with cancer across the disease trajectory. Providing patients and family caregivers psychosocial support and education to manage cancer pain is a core component of quality care that can result in significant clinical benefit. In this review, we (1) outline an approach for developing and assessing the effectiveness of education programs for adults with cancer pain; (2) discuss considerations for tailoring programs to the needs of diverse populations and those with limited health literacy skills; (3) describe the resource needs and costs of developing a program; and (4) highlight innovative approaches to cancer pain education. We conclude with recommendations for future research and the next generation of educational interventions.

Keywords

pain; education; cancer; oncology; pain management; symptoms

Introduction

Cancer-related pain is prevalent across the cancer trajectory. A review of 52 studies found that pain affects 59% of cancer patients on anticancer treatment, 64% of patients coping with advanced-stage or metastatic disease, and 33% of survivors post-treatment [1]. For more than 30% of cancer patients, pain was moderate to severe in intensity [1, 2]. Although there are guidelines regarding the management of cancer pain [3**], pain control among cancer patients and survivors is suboptimal, with as many as 50% undertreated for their pain [4] and greater than 70% of advanced cancer patients expected to have unrelieved pain as a symptom at the end of life [5].

Reducing the pain and suffering of cancer patients is essential to delivering quality care. Pain experienced by adults with cancer affects quality of life [6], physical functioning [6–8], roles and social functioning [6], concentration [7*], and mental health [8]. Pain often co-occurs with additional symptoms, such as fatigue, sleep disturbance, loss of appetite, and anxiety [6, 7*, 9, 10]. If pain is accompanied by depression, its deleterious effects on quality of life and disability are amplified [11]. Moreover, pain in cancer patients is associated with high costs and extensive utilization of health care [12, 13]. For patients receiving care in outpatient clinics, monthly costs (in 2011 US dollars) were, on average, \$107–\$120 for analgesics and medical visits and \$82 for indirect costs, including over-the-counter medications, complementary medicine, and counseling. Including the costs of hospitalization, which occurred in about 8% of patients, the average expenditure was \$1,209 per month per patient [12]. Cancer patients who report pain also report financial difficulties [6].

The effective management of cancer pain includes pharmacological and non-pharmacological approaches [3**, 5, 14]. Nociceptive pain, resulting from tissue injury or impending injury, is typically localized, and is responsive to opiate medications. Neuropathic pain, resulting from injury or malfunction of pain nerves or the central nervous system, often due to chemotherapy treatment, tends to be chronic and does not respond well to opioids. It may be partially ameliorated by anti-convulsant or anti-depressant medications. In the treatment of pain, one should be cognizant of the complexity of the pain experience for cancer patients and survivors. This complexity rests in the combination of anatomic and physiologic disruptions that drive nociceptive and neuropathic pain syndromes and in the interplay of educational, psychological, social, economic, and spiritual factors that frame the pain experience and contribute to “total pain.” For this reason, education and psychosocial support for cancer patients and their families have become a standard component of cancer care [3**]. Three recent meta-analyses have demonstrated efficacy of educational and/or psychosocial interventions on various outcomes, including decreasing pain intensity [15**, 16**, 17**]. Thus, health care providers need a framework for developing education programs relating to cancer pain.

In this report, education programs for cancer pain are defined as “information, behavioral instructions, and advice in relation to management of cancer pain” [15**]. To be useful for healthcare providers developing and/or delivering education programs for cancer pain, we first describe the essential components of a program and models from the literature. We then

provide practical guidance for developing a program and for assessing how well it works, and describe well-validated assessment tools that may be used for this purpose. We conclude with recommendations for advancing the science of education programs for cancer pain.

Developing an Education Program for Cancer Pain

Essential Components

A recent analysis of major evidence-based clinical practice guidelines for cancer-related pain concluded that educational interventions need to: (1) address barriers to pain management by dispelling myths/misconceptions about pain and pain management, particularly with regard to addiction and tolerance to pain medication; (2) promote involvement of patients and family caregivers in education about pain and its management; and (3) use appropriate teaching materials, particularly for patients with low-literacy and for whom English is a second language [14]. Similarly, in the most extensive systematic review and meta-analysis of cancer pain educational interventions to date, Cummings et al. recommended that programs focus on knowledge, skills, and attitudes about pain and pain management and use pre-constructed education materials [16**]. Efficacious patient education programs have also emphasized communicating with healthcare providers about pain and enhancing pain-related coping skills (e.g., self-monitoring, problem solving, and changing maladaptive cognitions about pain) [18*, 19*, 20, 21*, 22, 23]. Moreover, in recognition of the complexity of the pain experience in cancer patients, Cummings et al. [16**] recommended that programs be developed and delivered by a multidisciplinary team of content experts.

Most of the effective educational interventions for cancer pain consist of individualized, face-to-face coaching sessions, usually 30–60 minutes in length, and sometimes involving a video or digital videodisc (DVD) presentation with written materials or booklets [16**]. Table 1 describes some of the emerging programs for cancer patients that have been effective and may offer ideas for those who are designing a new cancer patient education program.

In summary, the essential components of an educational program for cancer pain are delineated in guidelines for management of cancer pain,[3**] and interventions related to these guidelines have improved pain-related outcomes. Below we provide guidance on developing educational programs for adults with cancer that are shaped by characteristics of the disease, the patient, and the context of each patient's life.

Designing Programs across the Cancer Continuum

Newly diagnosed or patients in treatment—The varying experiences of patients across the cancer continuum make it necessary to tailor cancer pain education programs to the phase of survivorship. For newly diagnosed patients, the ability to process and retain information is usually compromised [24], and many patients struggle to make treatment decisions [25]. From the patient's perspective, treatment decisions may take priority over management of pain and other symptoms. Patients and family members may be reluctant to mention pain to their physicians because of concern that it will distract the physician from the treatment of the cancer [26, 27]. Therefore, pain education programs at this phase should

allow for opportunities for repetition of information and offer reassurance that treatment for cancer and optimal symptom management can coexist. Providers must also be mindful that preferences for information and level of involvement in making medical decisions are dynamic and thus should be continually assessed and honored [28].

Patients who have completed primary treatment—Unlike patients in treatment who have regular contact with healthcare providers, post-treatment cancer survivors may have fewer opportunities to present their concerns about pain and/or participate in education programs for cancer pain. Although some oncology clinics are starting to provide post-treatment survivors with “survivorship care plans” (i.e., a summary of treatments received, surveillance plans, and recommendations for preventing/addressing late effects and chronic effects of cancer, such as pain) [29, 30], many survivors do not receive such care plans and are completing treatment without an adequate understanding of how to manage symptoms, and when to seek care. Moreover, it may be unclear who is responsible for pain management, placing cancer survivors at risk for poor control of pain [29].

During this phase of survivorship, pain symptoms may raise concerns about recurrence [31, 32] which can be distressing and a potential barrier to seeking care. Once primary treatment is completed, pain education programs should address the patient’s understanding of chronic pain symptoms and provide guidance on when it may be necessary to access care. Because post-treatment survivors may not have frequent healthcare visits, innovative ways to deliver education programs for cancer pain may be needed. A promising approach used by Kroenke and colleagues (2010; see Table 1) improved pain and depression outcomes in adults with cancer using automated home-based symptom monitoring coupled with telephonic education and symptom management from a nurse care manager [33*].

Near the End of Life—More than 403,000 cancer patients are expected to die with unrelieved pain in the United States in 2012 [5]. Patients with advanced cancer have been shown to benefit from educational interventions in recent clinical trials [21*, 34*]. Interventions in this group need to be of low burden and demonstrate effects quickly [15**]. Educational interventions in the setting of advanced cancer may need to address analgesic adverse effects, which may increase as patients become frail and death draws near. Patients may benefit from early referrals to a palliative care service for pain and symptom management, as well as from having health care providers who can skillfully address the effects of psychosocial issues (e.g. existential issues, fear of dying, need for autonomy and control) on symptom management and remain cognizant of the shifting treatment goals of the patient [35].

Involving Family Members in the Education Program for Pain

Family members are frequently involved in helping to manage cancer pain (e.g., by discussing pain management with the care recipient and healthcare providers, by administering pain medications) [36]. More than 40% of caregivers (most of whom were family members) report receiving no instruction in managing their loved one’s pain [37], and many report feeling hesitant to disclose the patient’s pain to the oncologist. Family caregivers who were hesitant to report pain also reported fear of distracting the oncologist

from treating the cancer, fear of addiction to opioids, and fatalism in regard to pain relief [38].

There is now an opportunity to shift the approach to cancer pain education, which has traditionally focused on the individual with pain, by adopting a “family-centered” approach, as highlighted in a recent review of guidelines for management of cancer pain [14]. This approach recognizes that family members are involved in care and are participants in decisions regarding the patient. Family-centered care respects the culture, values, beliefs, perspectives, and choices of the family members who are instrumental to the care of the patient.

Developing Programs for Those with Limited Health Literacy Skills

Only 12% of American adults have proficient health literacy skills [39]. Education programs for cancer pain should engage patients with diverse health literacy skills. Health literacy is people’s “knowledge, motivation and competencies to access, understand, appraise, and apply health information in order to make judgments and make decisions in everyday life concerning health care, disease prevention and health promotion to maintain or improve quality of life during the life course” [40]. Some views include the ability of individuals to orally communicate about health [41], the latter particularly relevant as inadequate communication with health care providers is a common barrier to care for cancer patients [42].

Recommendations are available for assessing health literacy and designing educational materials to meet the needs of individuals with diverse health literacy skills [43–47]. Strategies for addressing literacy through verbal communication and printed materials include use of conversational and peer language and use of the active voice. Information should be limited to what is needed at the time. The focus should be on specific steps and actions the patient can take rather than on presenting facts and statistics.

To assure that patients of all literacy levels benefit, educational materials should be pretested with the intended audience. Pre-testing provides information regarding the acceptability of the materials and allows the developer to assess comprehension, determine the degree to which patients believe the materials have relevance for them, evaluate cultural considerations, establish if there is enough information to accomplish the suggested behaviors, and determine if it motivates them to act [48].

Developing Cancer Pain Education Programs for Diverse Populations

It is important to tailor pain education programs to serve cancer patients of all backgrounds and across the cancer continuum. Table 2 provides some practical approaches to address typical challenges faced by providers who care for adults with cancer-related pain. Below we provide some additional considerations for working with two populations: (1) older cancer survivors, and (2) minority populations.

Older Cancer Survivors—Special consideration may be needed to deliver education programs on cancer pain to older cancer survivors. Adults with metastatic cancer who are age 70 years or older are 2.4 times more likely than younger patients to receive inadequate

pain management [49]. Further, older age appears to influence attitudes towards pain and analgesics. Factors such as poorer knowledge about taking analgesics, reluctance to communicate with medical staff, poorer performance status, and being more likely to live alone suggest that older patients require more support in the management of their cancer pain and education tailored to their needs [50]. It is also likely that older cancer survivors are also managing multiple comorbidities, including illnesses associated with their own constellation of pain symptoms.

Minority Populations—Racial/ethnic disparities across the pain continuum are pervasive. Black, Asian, and Hispanic cancer patients are undertreated for pain [51, 52]. Black cancer patients have greater pain intensity, pain interference, and disability [6, 53] and in contrast to white cancer patients, black cancer survivors often do not experience pain relief even after consultation with supportive care [54].

Barriers to pain management type, ranking, and number may differ for demographic groups [52]. Stoicism is apparent in Hispanic and African American cancer patients, suggesting that, for some demographic groups, a report of lack of pain does not necessarily indicate an absence of pain [55]. Similarly, lack of reporting pain is associated with stoicism, fatalism, and concern that pain will be a burden to family among Chinese American cancer patients [56]. Culture also influences the patient-provider relationship. In some cultures, for example, the physician raises the important issues and introduction of a different topic (e.g., pain) would suggest that the patient was questioning the clinician's judgment on what was important [57].

To ensure that programs and materials reflect cultural considerations, it is important to involve the patient population and/or relevant stakeholders (e.g., caregivers) in program development. Lasch and colleagues [58] engaged minorities in the development of multicultural education materials for cancer pain and gleaned many insights. For example, Latino focus group participants indicated that they would be more likely to comply with a treatment that is described as “important” versus one that is framed as “helpful.” Latino participants also shared that concepts such as “control and prevention” were less understandable to Latinos. Using phrases such as “keep it from coming back,” “make better,” or “help this” would be more effective [58]. In sum, delivering care to diverse populations requires careful exploration of the pain experience, including cultural considerations, throughout the cancer journey.

Assessing the Effectiveness of an Education Program for Cancer Pain

All patients with cancer should be screened for pain during the initial evaluation, at regular follow-up intervals, and whenever new therapy is initiated [3**]. Because health care providers often underestimate patients' pain severity [57], the standard of care for measurement is patient self-report. Suggestions are offered in the National Comprehensive Cancer Network (NCCN) Adult Cancer Pain Clinical Practice Guidelines for pain assessment in those unable to verbally report pain [3**]. Consistent with the current emphasis on measurement-based care [59], we suggest a brief and targeted assessment using standardized measures to facilitate personalized care, track patient progress, guide treatment

adjustments, and evaluate how well a pain education program is working. The measures we suggest below are brief; can be scored in less than one minute; are available at no cost for health care providers; and are valid and responsive to intervention effects. Consistent with expert consensus regarding caring for or investigating pain [60, 61], we recommend serial assessment of: (1) pain severity and functional interference, and (2) patient ratings of global improvement and satisfaction.

Brief Pain Inventory

The Brief Pain Inventory (BPI) was developed to assess cancer-related pain and has also been validated for use in primary care and other clinical populations [62–65]. The BPI includes subscales for *severity* and *interference*. Four items assess pain severity (currently, least, worst, and average) during the past week on scales from 0 = *no pain* to 10 = *pain as bad as you can imagine*. The severity subscale is scored as the mean of the 4 items. An additional seven items assess pain-related functional interference across different domains (i.e., general activity, mood, walking, normal work, relations with other people, sleep, and enjoyment of life) rated from 0 = *does not interfere* to 10 = *interferes completely*. The interference subscale is scored as the mean of the seven interference items. The BPI has demonstrated internal consistency (Cronbach’s alpha = 0.77–0.91), has been validated in more than 36 languages, and is responsive to both pharmacologic and behavioral pain interventions [62]. The measure is available online at: <http://prc.coh.org/pdf/BPI%20Short%20Version.pdf>

If a shorter measure is needed, a three-item version of the BPI has shown strong initial psychometric performance [66]. This abbreviated measure, known as the PEG, includes one severity item (average **P**ain) and two functional interference items (interference with **E**njoyment of life and **G**eneral activity). For each scale, the total score is the average of the items.

Patient-Reported Improvement

A retrospective global rating of improvement provides a patient-centered approach to assessing change that is clinically meaningful [67]. Most global ratings are based on the Patient Global Impression of Change scale (PGIC) [68], which is advocated for use by the Initiative on Methods, Measurement, and Pain Assessment in Clinical Trials (IMMPACT) committee [60]. The PGIC is a single-item rating by patients of their improvement with treatment on a 7-point scale that ranges from 1 = *very much improved* to 7 = *very much worse*. A related approach that has been used in a recent cancer pain and depression clinical trial involves asking, “Overall, since starting the program, would you say that your pain is *worse, about the same, or better?*” Those rating their pain as *better* are then asked if their pain is a *little better, somewhat better, moderately better, a lot better, or completely better* [33*].

If discordant results emerge between the global rating and the BPI or PEG, this provides clinically useful information. For example, the BPI/PEG may suggest improvement in pain whereas the patient globally assesses his or her status as *about the same*. If this occurs, the provider is encouraged to explore reasons for the discrepancy from a biopsychosocial

framework (e.g., comorbid physical or psychological conditions). Although retrospective global ratings are subject to varying degrees of recall bias depending upon length of the recall period, current severity of symptoms, and other patient- and disease-specific confounding factors,[69] they have face validity, are generally more sensitive than serial symptom assessments, and correlate strongly with patient satisfaction with treatment [67]. Notably, satisfaction with cancer pain management operated as a significant mediator between barriers to analgesic use and analgesic adherence in a recent randomized controlled trial [70].

Additional Measures Of Interest

Patients with pain often have other symptoms (e.g., depression, anxiety, constipation, nausea, fatigue, sleep disturbance) that need to be controlled to facilitate optimal pain control [3**]. Brief, validated, and no-cost measures to assess depression and anxiety in adults with cancer are the 9-item Patient Health Questionnaire depression scale (PHQ-9)[71] and the 7-item Generalized Anxiety Disorder anxiety scale (GAD-7) [72]. Both measures ask patients to rate how often they have been bothered over the past 2 weeks by various problems on a 4-point Likert scale from 0 = *not at all* to 3 = *nearly every day*. Each is available in two-item versions, and together they make up the brief PHQ-4, which is valid for use in medical populations [73]. The PHQ-9, GAD-7, and PHQ-4 are validated in Spanish and numerous other languages. These measures and the scoring instructions are available at no cost at: <http://www.phqscreeners.com/>.

If reducing barriers to pain management is the focus of a pain education intervention, an outcome measure that may be used is the Barriers Questionnaire (BQ). Although originally developed as a 27-item measure [74], a 13-item version (BQ-13) has recently been shown to be valid, reliable, sensitive to change, and psychometrically equivalent to the longer version for adults with cancer [75]. The BQ-13 includes seven items that measure barriers related to pain management and six items related to the side effects for analgesics. Patients are asked to respond to each item according to a six-point Likert scale from 0 = *do not agree at all* to 5 = *agree very much*.

A recent examination of additional outcomes that patients with chronic pain consider important to measure includes enjoyment of life, well-being, fatigue, and sleep disturbance [76]. Providers may consider assessing these outcomes in evaluating how well cancer-related pain educational programs are working.

Considerations of the Cost of a Pain Education Program

A pain education program will vary in resource needs and cost depending on the intensity of the program, the size and type of the patient population (in treatment, in survivorship, at end of life) and the delivery channel. Face-to-face interventions will include one or more full time positions for oncology nurses or other nurse-physician specialists to conduct in-person education sessions and follow-up phone sessions with pain assessments. However, this personnel cost may be lower if lay health workers are employed instead (Table 1) [19*]. In a study comparing psychologist-led and lay-led interventions to reduce back pain, the lay-led intervention cost \$100 per patient served and the psychologist-led intervention cost \$210 per

patient; however, the psychologist-led intervention also had slightly better outcomes [77]. The cost of the program will include phone charges and other costs of space, computers, and educational materials. Cost of shipping will need to be considered if materials need to be mailed to patients, particularly if in-person sessions are not part of the program or for survivors who may not visit the provider on a regular basis. No-cost cancer pain education materials (e.g., booklets, DVDs) are available through the National Cancer Institute (NCI) [78] and American Cancer Society (ACS); [79] however, if program developers prefer to create materials specific to their program, production costs will need to be considered. Interventions that involve technology such as MP3 players [80] will need to consider the cost of such technology and associated programming.

During program development, resources may be needed to assure that the intervention is appropriately tailored to the target population. Thus, time of multidisciplinary content experts will be necessary to develop the curriculum, and to gather, select, and modify materials as needed. In the case where focus groups are utilized to verify the specific education needs of a population, costs of focus group moderators, incentives for participants, and analysis of the data must be considered. Finally, personnel time will be needed to create databases or filing systems to keep track of patients, encounters, and pain assessment results. Technology may provide a way to capture information in a streamlined way with minimal burden on the healthcare team or the patient. For example, using a tablet connected to a wireless network, cancer patients can complete a symptom severity screening scale as they wait for their appointment. A report reflecting current symptoms as well as symptoms from previous visits is generated and provided to the clinician and included in the patient's medical record. This approach was received well by both physicians and patients in two recent trials [81, 82].

Conclusion

Based on two recent meta-analyses [15**, 16**], findings from other emergent studies [19*, 21*, 22, 33*, 83*] and clinical practice guidelines [3**], cancer pain educational interventions should be an essential part of daily clinical practice. Further research is needed to identify patients who may or may not obtain the most benefit [15**], determine the influence of factors such as provider expertise and patient learning styles [84], establish the optimum timing of education interventions in relation to pain intensity [15**], maximize cost-effectiveness in the implementation of interventions, evaluate use of multi-media approaches, and identify the mechanisms of action in improvement in cancer pain and coping due to educational interventions. Research is also needed to establish how best to involve family members in education programs for cancer pain. Involving caregivers in educational interventions has had mixed effects in past clinical trials [23, 85]. Understanding the reach of programs (e.g., do programs appeal to the intended patient population) is also important. To date, whites, females, and those recruited from medical facilities comprise the majority of program participants [17**].

Our review provides guidance regarding the development and delivery of educational programs to manage cancer pain. Health care providers are also encouraged to acquire and use available evidence-based clinical practice guidelines, such as those from the NCCN

[3**], which outline the core messages to be conveyed to patients and family caregivers about cancer pain. Educational materials consistent with these guidelines (e.g., booklets, DVDs, web-based information) are available as previously mentioned, through the ACS and NCI and can be readily incorporated into the design of any developing program. In using these materials, providers should remain mindful of their patient population and consider tailoring or adding supplemental material to optimize relevance and effectiveness in diverse populations. Providing ongoing assessment and education is the standard of care in the treatment of cancer-related pain [3**], and with the incorporation of topics reviewed here, health care providers have the potential to greatly reduce pain and suffering and improve quality of life in their cancer patients.

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Table 1
 Innovative and Emerging Models for Delivering Cancer Pain Education Programs

Randomized Trials			
Reference	Participants	Intervention	Findings
Kravitz et al., 2011 [19]	<ul style="list-style-type: none"> At least moderate pain severity or interference Mixed cancers N = 265 	<ul style="list-style-type: none"> Single face-to-face session up to 1 hour Compared tailored education and coaching (aimed at reducing pain misconceptions and enhancing skills and self-efficacy for communicating with physicians about pain) to enhanced usual care (provision of basic information about cancer pain management) Delivered by trained lay health educators Participants followed for 12 weeks 	<ul style="list-style-type: none"> ↑ Pain communication self-efficacy Temporary ↓ pain-related interference No effects on pain intensity
Kroenke et al., 2010 [33]	<ul style="list-style-type: none"> At least moderate levels of pain and/or depression Mixed cancers N = 405 	<ul style="list-style-type: none"> Patients from 16 community-based urban & rural oncology practices Compared telephone-based centralized symptom education and management (at least 4 calls during first 3 months) to usual care Included automated home-based symptom monitoring which guided care provided by nurse-physician specialist team Nurse care manager logged mean of 157 minutes direct telephone time per patient in the intervention group (mean of 11 calls) during the 12 month trial 	<ul style="list-style-type: none"> ↓ Pain intensity ↓ Depression severity Majority of patients found nurse care manager calls and automated symptom monitoring at least moderately helpful (82% and 73%, respectively)
Oldenmenger et al., 2011 [21]	<ul style="list-style-type: none"> Advanced stage + at least moderate pain Mixed cancers N = 72 	<ul style="list-style-type: none"> Compared a multi-modal intervention (consultation with a pain specialist and tailored pain education from a palliative care nurse who also provided weekly phone-based monitoring of pain and side effects) to standard care 8-week follow-up 	<ul style="list-style-type: none"> ↓ Pain intensity + interference ↑ Analgesic adherence ↑ Pain knowledge Pain management adequacy did not differ between groups
Thomas et al., 2012 [83]	<ul style="list-style-type: none"> At least mild pain Mixed cancers 90% male N = 318 	<ul style="list-style-type: none"> Three-group design comparing pain education (video and pamphlet), coaching (video and pamphlet + 4 telephone sessions of motivational interviewing to address pain management attitudes), and usual care Delivered by advanced practice nurse 6-month follow-up 	<ul style="list-style-type: none"> ↓ Pain interference and ↑ mental health in coaching group compared to education or usual care groups
Smith et al., 2010 [22]	<ul style="list-style-type: none"> Breast cancer patients with persistent and moderate pain N = 89 	<ul style="list-style-type: none"> Compared a single 30-minute pain education/communication skills training session (i.e., myths/misconceptions about pain and analgesics; communicating with healthcare providers about one's pain and doing in-session role plays; monitoring pain and in-session practice using a pain diary) to attention control 	<ul style="list-style-type: none"> ↓ Pain barriers No significant effect on pain relief, adequacy of pain management, distress, or quality of life

Randomized Trials			
Reference	Participants	Intervention	Findings
		<ul style="list-style-type: none">• Delivered by interventionists with training in psychology, public health, or health education• 12-week follow-up	