

REVIEWS

Barriers to cancer pain management: a review of empirical research

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Summary. Patient-, physician-, and health care system-related barriers of cancer pain management in patients with malignant diseases are a recognized and widely investigated issue. The purpose of this review is to summarize the main findings of empirical research on these barriers in the literature. The most significant patient-related barriers were patient reluctance to report pain and adhere to treatment recommendations. Besides that, cognitive, affective, and sensory patient-related barriers to cancer pain management with opioid analgesics have been studied using quantitative and qualitative research methods. The Barriers Questionnaire and its shortened and modified versions were the most commonly used instruments in the context of research on patient-related barriers to cancer pain management. The most prominent physician-related barriers were insufficient physicians' knowledge about cancer pain management, inadequate patterns of pain assessment, and inadequate opioid prescription. The methodologies used to conduct the majority of the studies on physician-related barriers were weak. Nevertheless, physician knowledge of pain management guidelines, the quality of pain assessment and opioid prescription have been shown to be obviously better in a few Western countries. Institutional and health care system-related barriers were relevant only in countries with restrictive opioid prescription regulations. The evaluation of the influence of cultural-social-economical background on cancer pain management could probably help to obtain better insight into the problems of unrelieved cancer pain.

Introduction

The prevalence of acute and chronic pain in cancer patients is high: about 30% in patients with newly diagnosed cancer, 50-70% in patients receiving active anticancer therapy, and 60-80% in patients with far advanced disease (1). Uncontrolled pain has been reported to be an important contributing factor in a variety of studies that have assessed cancer patients who are at risk for suicide;

thus, pain management has also ethical implications (2). In the majority of cancer patients (up to 90%), sufficient pain relief can be obtained if adequate treatment, as suggested by various guidelines, is provided (3). Undertreatment of cancer pain is caused by the barriers to the use of analgesics, in particular opioids. In this respect, patient-, health care professional-related, and institutional barriers have been identified (4).

Patient-related barriers

The most significant patient-related barriers are patient reluctance to report pain and adhere to treatment recommendations. In addition, cognitive, affective, and sensory patient-related barriers to cancer pain management with opioid analgesics have been identified (5).

Effective doctor-patient communication is the cornerstone of successful pain treatment; however, poor communication between pain patients and their physicians remains a pervasive problem (6). Several studies investigated cancer patients' communication concerning their pain experience with the health care providers (7-12). Few of these studies have focused on the quality of pain communication between cancer patients and physicians. Kimberlin et al. (11) conducted focus group interviews and personal interviews with cancer patients and their families and described communication in pain management. The quality of the communication was not satisfactory. Patients wanted to be more active in the process of information exchange by expressing their own needs; they also wanted their providers to have better communication skills and to address their fears regarding cancer pain management. Berry et al. (8) analyzed audiotapes from oncologists' and cancer patients' consultations regarding cancer pain and concluded that physicians addressed mostly sensory issues leaving out the cognitive and emotional issues. The studies where the quantitative approach was used focused on the extent of pain communication (7, 9, 12, 13). The results differed depending on the questions asked or the questionnaires used. For example, 93-100% of patients talked with their providers about pain (7); 63% discussed the symptoms, including pain (13); 47% did not talk to anyone about pain relieving medications within the past 24 hours (12) or waited for spontaneous decrease of pain intensity before asking for medications (9).

Lack of adherence with the analgesic regimen was investigated to a lesser extent than pain communication. Coward et al., describing pain self-report and self-management decisions qualitatively in 20 cancer patients with bone metastases, found that more than half of them did not take pain medications by the schedules recommended by physicians (10). Miaskowski et al. found in a longitudinal study of a random sample of 65 cancer

patients that overall adherence rates for opioid analgesics prescribed on demand were much lower than for those prescribed on a regular around-the-clock regimen: 22-27% vs. 85-91%, respectively (14).

The majority of studies on patient-related barriers to cancer pain management investigated patients' cognitions about pain management generally and effects of pain medicine particularly. Systematic investigation of pain cognitions as the barriers to cancer pain management has started with the construction of Barriers questionnaire (BQ). The questionnaire consists of 27 items and covers 8 beliefs: a) fear of addiction; b) fear of becoming tolerant to the effects of analgesics; c) concern that the side effects of analgesics (drowsiness, nausea, constipation, or mental confusion) are inevitable and unmanageable, d) belief and fear that increased pain indicates a progression of the disease, e) fear of injections, f) fatalistic beliefs about cancer pain, g) belief that "good patients" do not complain about pain, h) belief that health care professionals find it annoying to talk about pain, and that this talk distracts them from treating the cancer (15). BQ in original and modified form was applied extensively for the research of barriers among cancer patients. Some researchers, however, used other questionnaires and qualitative research methods to assess patients' attitudes to cancer pain management (16-20). Findings of all these studies have shown that there were three types of patients' cognitive barriers to cancer pain management: concerns about analgesic use (fear of addiction, tolerance, and side effects), concerns about pain communication (willingness to tolerate pain, to be "a good patient", and prioritizing that physicians cure cancer instead of relieving pain), and maladaptive beliefs about possibility to control pain in general (belief that pain related to cancer is inevitable). Some other cognitive barriers, like concerns regarding family reaction to pain reports, concerns about the careers' attitudes towards the credibility of the need for opioid analgesia (20), perceived lack of planned treatment, and lack of trust in health care system (16), were identified in qualitative studies on patient-related barriers to cancer pain management. A qualitative study on patients' cognitive barriers to cancer pain management has

been performed in Lithuania as well. The study revealed patients' beliefs and fears similar to those investigated with the BQ (21).

Emotional changes of cancer patients hindering adequate pain treatment are defined as affective patient-related barriers. Despite the fact that cancer pain patients have been shown to have a high prevalence of mood disorders (22), the emotional changes were not studied in the context of barriers to pain treatment to the same extent as cognitive factors. There were only few surveys, where affective factors were taken into account (15, 23-25). In different studies, different psychological, or affective, factors were in the focus of interest, e.g., anxiety (24), depression (23), mood fluctuations (15), and stress (24, 25). The association between affective and cognitive factors has consistently been demonstrated in cancer patients' settings: depression, negative mood, and stress were associated with maladaptive beliefs about pain control and concerns about the use of pain medications. This suggests interdependency of attitudinal and emotional factors.

One of the major challenges in treating pain with opioids is to achieve the best obtainable balance between analgesia and side effects. Side effects of opioids might be defined as sensory patient-related barriers to cancer pain management in case they hinder pain medication use. Empirical research of barriers to cancer pain therapy showed that approximately 20-75% of the respondents reported that they were bothered by side effects of pain treatment (7). The results of the studies examining the relationship between pain medicine adherence and sensory barriers consistently showed that prior experience of side-effects or severe current side effects prevented cancer patients from analgesic use, despite moderate to severe pain (26). This consistency support the notion that patients prioritize symptoms, and that the outcome of the treatment is better if patients' priorities are taken into account (27).

Physician-related barriers

Physician-related barriers to cancer pain management were studied by questionnaire methods (physicians' self-reporting) and drug prescribing reviews (objective methods to assess the pain management situation). However, the methodologies

used to conduct the majority of these studies were quite weak: very few of the questionnaires used were properly validated; studies did not evaluate physicians' knowledge, but rather asked their opinions regarding what they perceived as barriers. Nevertheless, the findings of the studies are analyzed with respect to adequacy of opioid prescription, physicians' patterns of pain assessment, and their general knowledge of cancer pain management (28).

According to the WHO standards, the first choice for moderate-to-severe pain should be strong opioids, administered orally on an around-the-clock basis and by long-acting formulations. Rescue medications for breakthrough pain as well as medications to counteract the most common opioid side effects (e.g., constipation, nausea, sedation) should be prescribed concomitantly. The opioid dose should be continuously adjusted based on the patient's individual reactions in terms of pain relief and severity of side effects (29).

In the majority of surveys on the adequacy of opioid prescription to cancer pain, up to 50% of physicians reported prescribing opioid analgesics for moderate-to-severe cancer pain (30-33). Considerably fewer surveys showed a preference for strong opioids by more than 80% of physicians (34, 35). The lowest percentage of physicians (20%) choosing strong opioids for moderate-to-severe cancer pain was found in Italy (36) and the highest (97%) in Denmark (37). Most often respondents reported using morphine as the drug of choice (30, 33, 35). The oral administration of strong opioids was usually recommended (38), with the exception of physicians in West Africa, where oral opioids were not available (39). In Italy, the percentage of respondents who reported preferring the oral route (48%) was almost the same as those who preferred administering opioids intramuscularly (46%) (36). Eighty to ninety percent of western physicians were familiar with sustained released formulation, and more than 90% preferred "around the clock" schedules (40). The percentage of respondents reporting adequate prescription of rescue medications was much lower (on average about 55%) (35, 41). Results regarding management of side effects of opioids were even worse: only 30% or less of physicians reported routinely prescribing laxatives and antiemetics (35). Overall adequacy

of physicians' recommendations for cancer pain management varied from 16.5% to 95% of respondents choosing correct answers (30, 32, 34, 37, 42, 43), with the best recommendations coming from respondents in the United States, Canada, and Denmark and the poorest ones from respondents in Korea. The most pronounced failures were revealed in the management of neuropathic pain cases and in the choice of efficient doses of opioids (31, 44).

Inadequate pain assessment was reported as one of the main barriers to cancer pain management by 20-80% of respondents (32, 42, 44). The majority of physicians did not evaluate the types of pain and did not use instruments to measure pain intensity, but among those who reported using pain measurement instruments clinically, the visual analog scale (VAS) or verbal rating scales (VRS) were most popular and used in 70-80% of cases, while more comprehensive pain measurement instruments, including psychological and health-related quality of life measures (e.g., McGill Pain Questionnaire, Brief Pain Inventory), were used only occasionally (39, 45).

Physicians' general knowledge about the principles of cancer pain management varied a lot: from 25-30% (46) to almost 100% (41) of physicians reporting knowledge of WHO recommendations. Specifically, physicians had inadequate understanding of the concept of tolerance to opioids, addiction, respiratory depression, and the phenomenon of tolerance to side effects (40, 47). Knowledge about the efficacy of different routes of opioid administration was satisfactory among western physicians, but a crucial deficit of knowledge in this area was observed among Taiwanese doctors (48). Lack of the knowledge of opioid dosing, including equianalgesic conversion tables and supplemental doses for breakthrough pain, existed among western physicians as well (49). The main reported problems among western physicians were insufficient pain relief, unmanageable side effects, opioid dosing, pain assessment in the elderly, patient follow-up, management of breakthrough pain, and psychological support to cancer patients (36, 37, 50).

Institutional barriers

In many countries, institutional barriers cover health care system-related barriers, such as complicated bureaucratic regulations governing the

supply, regulations of prescription and administration of opioids. There are also problems related with continuity of care, when the patient is seen by a number of different physicians across a number of different health care settings with no one capable or willing to take responsibility for the overall pain management (51). However, institutional barriers are relevant only in countries with restrictive opioid prescription regulations, including Lithuania (52). Furthermore, it was shown that changes of legal requirements concerning opioid prescription had less influence on the outcomes of pain treatment if compared with patient- or physician-related barriers (53).

Conclusion

Patient- and physician-related barriers have a remarkable negative influence on the quality of cancer pain management. Among patient-related barriers, inadequate adherence to pain medicine, insufficient extent and quality of pain communication as well as maladaptive patients' beliefs regarding pain and pain medications should be noticed. The latter barrier negatively affects both pain communication and medication adherence. However, clearer definitions of pain communication and pain medication adherence as well as validated instruments to assess these latter factors are lacking. The same might be said about the instruments assessing physician-related barriers. Nevertheless, it seems that both cognitive (e.g., knowledge, attitudes) and behavioral (e.g., pain assessment and opioid prescription) elements of physician-related pain management are obviously better in a few countries (e.g., some states in the United States, Australia, Denmark). Therefore, the evaluation of the influence of cultural-social-economical background would probably help to obtain a better insight into the problems of unrelieved cancer pain and to develop more effective interventional and educational programs for cancer pain management.

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Onkologinių ligų sukelto skausmo mašinimo kliūtys Empirinių tyrimų apžvalga

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Raktažodžiai: onkologinių ligų sukeltas skausmas, malšinimo kliūtys, pacientai, gydytojai, medicinos etika.

Santrauka. Su pacientais, gydytojais ir sveikatos priežiūros sistema susijusios onkologinėmis ligomis sergančiųjų skausmo malšinimo kliūtys yra aktuali ir pasaulinėje mokslinėje literatūroje plačiai tyrinėjama problema.

Šios apžvalgos tikslas – apibendrinti svarbiausius minėtų kliūčių empirinių tyrimų duomenis. Literatūros analizė parodė, kad svarbiausios nuo paties paciento priklausomos kliūtys yra paciento nenoras pranešti apie skausmą bei netikslus skausmą malšinamuju vaistu vartojimo rekomendacijų laikymasis. Be to, naudojant tiek kiekybinius, tiek kokybinius socialinių mokslų tyrimo metodus, buvo tiriami individualūs pacientų psychologiniai ir kognityviniai, emociniai ir fiziologiniai veiksnių, nepalankiai įtakojantys onkologinių ligų sukelto skausmo valdymo eigą. „Kliūčių klausimynas“ bei jo sutrumpintos ir modifikuotos versijos – dažniausiai taikoma tyrimo priemonė nuo pacientų priklausomų skausmo malšinimo kliūčių tyrimo kontekste. Šis klausimynas skirtas psychologinių ir kognityvinių nuo paciento priklausomų onkologinių ligų sukelto skausmo kontrolės kliūčių tyrimams. Pagrindinės nuo gydytojo priklausomos kliūtys yra nepakankamos gydytojų žinios apie onkologinių ligų sukelto skausmo malšinimo principus, nepakankamas skausmo įvertinimas bei Pasaulinės sveikatos organizacijos onkologinių ligų sukelto skausmo valdymo rekomendacijų neatitinkantis opioidų skyrimas. Daugelio nuo gydytojo priklausomų kliūčių studijų metodika, deja, buvo nepakankamai validi. Nepaisant to, nustatyta, jog tiek gydytojų skausmo malšinimo principų žinios, tiek skausmo vertinimo bei opioidų skyrimo kokybė akivaizdžiai buvo geresnės atskirose Vakarų šalyse. Nuo sveikatos apsaugos sistemos priklausomos kliūtys aktualios tik tose šalyse, kuriose galioja opioidų skyrimą ribojantys įstatymai. Todėl tikėtina, jog kultūriniai, socialiniai ir ekonominiai veiksnių įtakos onkologinių ligų sukelto skausmo malšinimo kokybei tyrimai galėtų padėti geriau suvokti onkologinių ligų sukelto skausmo masto priežastis.

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