

Patient empowerment in cancer pain management

An integrative review

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Abstract

Background: Pain in patients with cancer is underestimated in prevalence and severity, although more than half of the patients with cancer experience pain. Whereas empowerment has been highlighted as central to success in nonmalignant pain management, empowerment has not been well studied in cancer pain management. The lack of an overview of the existing literature hampers the comparison of results across different studies and implementation of the research findings in everyday cancer pain practice.

Aim: To provide an overview of the literature and give recommendations on patient empowerment in cancer pain management. The questions guiding this review are a) What does patient empowerment in cancer pain management comprise? b) How is the concept of patient empowerment operationalized in literature on cancer pain management? c) To what extent are empowerment-based interventions effective in improving cancer pain management?

Study design and methods: An integrative review was conducted to develop understanding of empowerment and empowerment related concepts within pain management for patients with cancer. This method includes both empirical and theoretical publications. Databases PubMed, CINAHL and PsycINFO were searched for relevant publications from 1990 to April 2012. Two researchers independently reviewed each citation for inclusion and data on patient empowerment in cancer pain management were extracted and categorized for analysis.

Results: The final selection resulted in 26 papers eligible for review. None of the publications gave an exact definition of patient empowerment in cancer pain management. Various empowerment-related concepts were mentioned in literature. All concepts considered relevant were categorized as ‘self-efficacy’ or ‘patient participation’. Self-efficacy was more extensively studied than patient participation in cancer pain management. Interventions that comprised education seemed most successful in improving pain management and coping skills training may have additional effects. An intervention in which the main informal caregiver was involved in education and training also showed additional positive effects on patient self-efficacy and pain measures. No additional effects were found for coaching or interventions comprising education that was customized to the individual patient. However, more research in this area of healthcare is necessary to substantiate the findings.

Conclusion: Patient empowerment comprises the combination of active patient participation in and self-efficacy for cancer pain management. Education and training in pain management skills may improve patient empowerment. Since cancer patients experience specific barriers to pain management, it seems important that an educational intervention addresses all common barriers to cancer pain management and encourages patients’ active participation in their pain management. Future research should develop educational and skills-training interventions to increase active participation of cancer pain patients to self-manage their cancer pain.

Introduction

The incidence and prevalence of cancer is high and still increasing [1-3]. In Europe, pain occurs in 56% of the patients with cancer [4-7]. A review by Deandrea et al. [8] revealed that nearly one out of two cancer patients received inadequate pain management. Pain management has been defined as “taking care of or handling the pain, including pain relief and pain modulation (i.e. adjusting or softening the pain)” [9-11]. The impact of pain in patients with cancer differs from the impact of pain in patients with non-progressive diseases, since cancer pain is often associated with progress of the disease and fear of dying [12, 13]. The main focus of both the patient and physician is on cure or life prolongation and less on symptom management [12, 14].

Experiencing pain has a negative influence on quality of life [15-17]. Quality of life can be defined as: “the individuals’ perception of his or her position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns” [18]. Responses to pain are shaped by the interaction between biological, psychological and social variables [19-21], and increased pain levels have been associated with more psychological impairment [20]. Moreover, psychological interventions have shown to be able to modulate pain in cancer patients [12, 13, 22-24]. Therefore, attention for psychological factors in a multidimensional approach towards pain in cancer patients is important.

Cancer pain patients experience specific barriers to report pain and using pain medication, as many fear side effects or addiction to medication [14, 17, 25]. Patients also do not want to disappoint their physicians or distract them from treating the disease [14, 26]. In addition, physicians experience barriers to cancer pain management [27, 28]. Barriers to discussing pain may be due to knowledge deficits and their attitudes towards pain medication [27, 28]. Physicians should systematically ask cancer patients about pain and patients should become more empowered to talk about their pain with their physician in order to achieve successful pain management [14, 29].

The psychological concept *patient empowerment* is seen as an important element in achieving successful pain management [30]. Empowerment is a concept described in many contexts and for different levels of society (e.g. individual, organizational and community empowerment) [31, 32]. In healthcare, empowerment has been gaining more attention since the paradigm shift from provider centered to a patient-centered approach, in which the patient is seen as being responsible for his own choices and their consequences [30, 33-37]. Despite the assumed importance of patient empowerment, there is lack of a clear definition in the literature [30, 37, 38]. An early definition of patient empowerment is: “the discovery and development of one’s inherent capacity to be responsible for one’s own life” [33], which agrees to a large extent with many other definitions and descriptions [27, 30, 35-41]. Empowerment can be viewed as a process (inter- or intra-personal) or outcome [30, 35] and is unique to the individual patient [27, 30, 42, 43].

Patient empowerment has been labeled as central to success in chronic pain management, since it is associated with gaining control over pain [40]. Given the complexity of pain [44] and the paradigm shift in health care [30, 34, 45, 46], an empowered patient may have a better chance of successful cancer pain management [22, 30, 45, 47-49]. Although, it is not clear what patient empowerment encompasses for cancer pain management.

We tried to obtain more clarity on patient empowerment in the context of cancer pain. The questions guiding our research were a) What does patient empowerment in cancer pain management comprise? b) How is the concept of patient empowerment operationalized in literature on cancer pain management? c) To what extent are empowerment-based interventions effective in improving cancer pain management? In the present integrative review we aimed to gain more insight in the role of patient empowerment in cancer pain management and provide recommendations for improving cancer pain management through patient empowerment.

Method

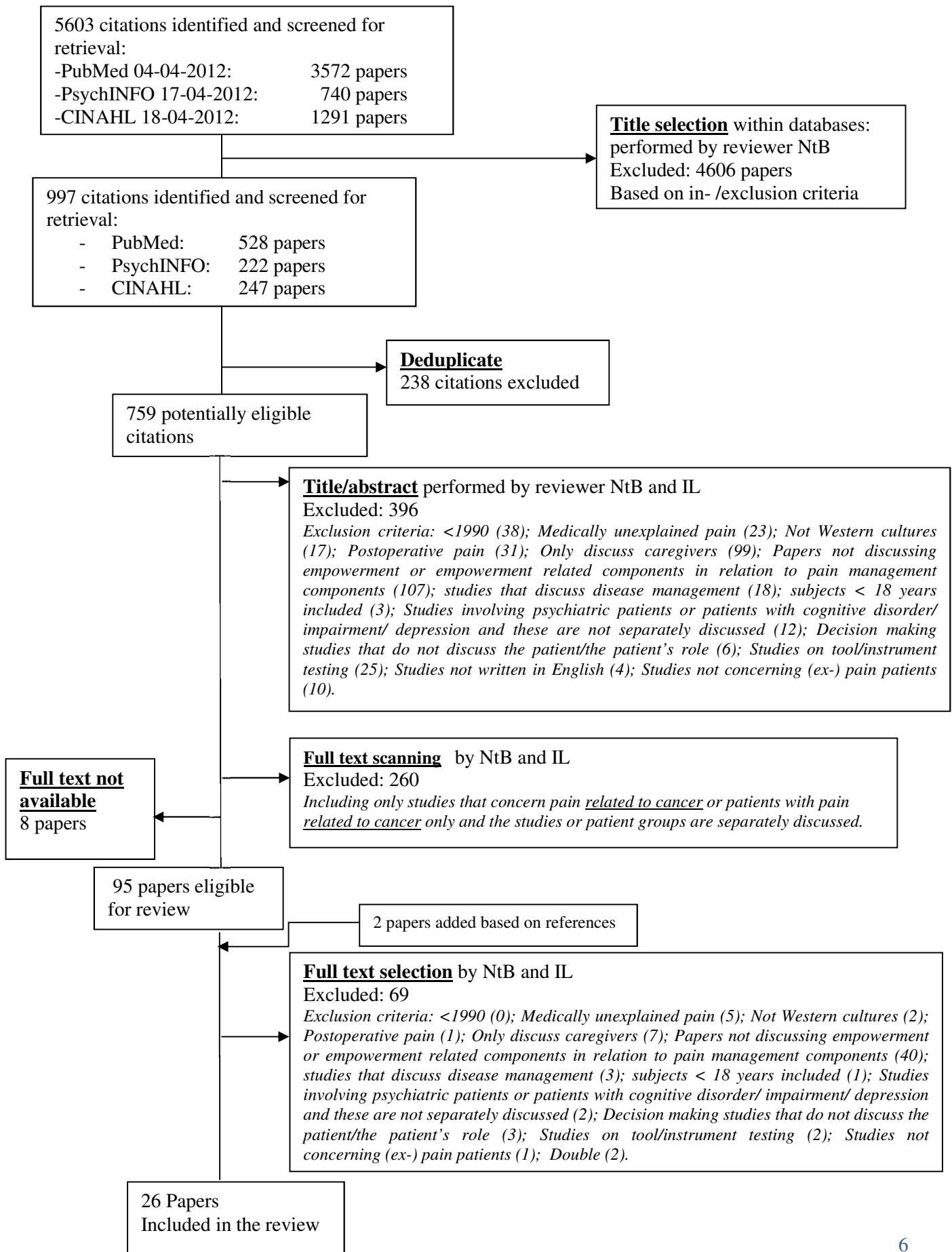
An integrative review was performed, since this approach allows for the inclusion of findings from diverse methodologies to be applied to clinical practice and evidence-based practice initiatives [50]. For this review the databases PubMed, CINAHL and PsycINFO were searched for relevant publications.

A preliminary search with the search terms *empowerment* and *pain management* resulted in a limited number of articles. Next we searched for the MESH terms related to empowerment: self-efficacy, mastery, self-control, control, self-esteem, self-concept, self-perception, internal-external control, decision making, and used empowerment as additional search term. This search was not limited to 'patient empowerment', since papers may discuss empowerment of patients without using the term patient empowerment. These terms were combined with pain management related MesH terms: pain measurement, analgesia, pain therapy, pain prevention & control and American society for pain management nursing. Additional search terms included: pain prevention, pain control and pain assessment.

This search resulted in 5603 citations. Deduplication and selection based on title identified 997 citations to further assess for eligibility. After title selection, two reviewers (NtB and IL) individually performed the next selection steps. Discrepancies were discussed and a third reviewer (YE) was consulted when necessary. Based upon abstracts we selected studies using the following criteria; published between 1990 and April 2012 and discussing empowerment or empowerment related components in combination with pain management or pain management related components, in which pain related to cancer or patients with pain related to cancer was separately discussed. Excluded were studies: published < 1990, not concerning pain (management) or involved patients <18 years, on medically unexplained pain (e.g. fibromyalgia), including patients with a psychiatric or cognitive disorder/impairment or depression which were not separately discussed; postoperative pain, conducted in non-western cultures, which concern decision-making but do not discuss the patient's role, discuss disease management, discuss caregivers only, not written in English and studies concerning testing of a tool/instrument were also excluded.

Abstract selection and full text scanning resulted in 95 papers eligible for review. Full text selection resulted in 24 articles included in the review for evaluation. Based on reference search of the selected papers, two articles were added to our sample. The final sample for this integrative review resulted in 26 publications, including 21 empirical and five theoretical papers. The article selection steps are shown in figure 1. Relevant findings were extracted using self-developed data-extraction forms. Subsequently, the findings were compared and analyzed for the purpose of this review.

Figure 1. Article selection



Results

1. Components of patient empowerment

In our selection of 26 articles, empowerment or a derivative (e.g. empowers) was mentioned in ten publications [22, 23, 51-58]. However, none of these used a definition or description of the concept. After extracting all relevant information from the included publications, all mentioned empowerment-related concepts could be categorized into two groups: *self-efficacy* and *patient participation*.

1.1 Self-efficacy

As definition of self-efficacy (SE), we used the following: “the personal conviction that one could successfully perform certain required behaviors regarding a specific situation or task” [59-61]. In the area of pain management self-efficacy is seen as the individual's perceived capacity to deal with or handle the pain [62, 63]. Of many concepts the definitions overlap to such a large extent, that for this review we discuss them altogether as ‘self-efficacy’. Table 1 gives an overview of the concepts mentioned in the articles and the measurement instruments used. Overall, in the included articles there were three types of self-efficacy: SE for (components of) pain management, SE for communication and SE of the caregiver to help the patient.

Self-efficacy (or a related concept) in relation to cancer pain management was discussed in 19 out of 26 papers [22, 25, 48, 51-56, 58, 64-72], including one theoretical [55] and eighteen empirical studies [22, 25, 48, 51-54, 56, 58, 64-72]. Five publications presented information on one extensive intervention; the Cancer Health Empowerment for Living without Pain (Ca-HELP) study [48, 52, 53, 58, 73], and three publications discussed the influence of the caregiver on the relation between self-efficacy and pain management [66, 68, 69]. In chapter 2 we will discuss the findings on self-efficacy in relation to cancer pain management.

1.2 Patient participation in pain management

The second group of categorization was ‘patient participation’. We defined patient participation in pain management as “efforts performed by the patient in order to decrease pain levels or to improve functioning despite pain” [23, 25, 74]. Various forms of patient participation in pain management have been mentioned in the selected articles; patient communication with their healthcare provider [26, 55, 57, 64, 75], shared decision-making [29, 73] and active use of coping strategies (i.e. pain management) [23, 25, 74]. Table 1 gives an overview of the articles and the used concepts.

The importance of active participation of the patient in management of their pain was discussed in ten out of 26 articles [23, 25, 26, 29, 55, 57, 64, 73-75]. Four of these studies were theoretical [23, 29, 55, 75] and seven empirical [25, 26, 57, 64, 73, 74]. Findings will be discussed in chapter 3.

2. Self-efficacy and cancer pain management

The literature indicates that for patients who experience pain due to cancer, the conviction of being able to modulate pain (i.e. self-efficacy for pain management) is important in order to actually achieve change in pain experience or improve functioning despite pain. All included studies (n = 19) agree that there is a negative relation between self-efficacy and cancer pain severity [25, 48, 51-56, 64-72, 74]. High levels of self-efficacy appeared to be related to low pain scores. For instance, in their literature review on disparity in quality of cancer pain management, McNeill, Reynolds and Ney [55] emphasize that self-efficacy for managing cancer pain may influence pain related outcomes and treatment effectiveness. Moreover, improved communication and addressing economic and sociocultural environmental factors that influence cancer pain management should enhance self-efficacy [55]. Vallerand, Hasenau, Templin and Collins-Bohler [22] studied disparity in cancer pain management between black and white patients. They found that the difference in self-efficacy for pain management between the two groups was the only factor explaining disparity in pain intensity and pain interference with function. Valeberg et al. [72] categorized a group of cancer pain patients in two groups by pain severity ratings (high and low), and found that the lower the self-efficacy score was; the more likely a patient was to experience high pain intensity levels [72]. A longitudinal study on pain in cancer patients treated with bone marrow transplantation showed significant associations for pain management self-efficacy and active pain coping (i.e. pain management) [70]. Additionally, self-efficacy for pain management measured before transplantation was found to be a strong predictor of pain experience and pain report in the first 24 days after transplantation [70]. Correlations between patient self-efficacy for pain management and pain levels varied from low to moderate (-0.13 to -0.36) [25, 48, 54, 68, 70]. Yet, the direction of this relationship is not evident. Contributing factors in this relation have been examined and will be discussed next.

Barriers to pain management experienced by the patient influence the relation between self-efficacy and pain management. Negative relations have been found between barriers and cancer pain management [67, 72]. In the earlier described study on differences between patient groups with high and low pain scores, patients in the high pain intensity group experienced more barriers to pain management [72]. Mosher et al. [67] studied pain management and self-efficacy for coping with cancer (i.e. pain management SE), including pain management, in a group of breast cancer patients. They found that the pain management SE subscale 'self-efficacy for seeking and understanding medical information' was negatively associated with greater barriers to pain management [67]. Vallerand et al. [22] proposed that increasing knowledge of and reducing barriers to pain management may increase self-efficacy and therefore decrease disparity in cancer pain management for different population groups. Combining these findings, we assume that patients with higher self-efficacy are better able to overcome barriers and be active in using strategies to decrease pain and/or improve functioning.

In addition, barriers and self-efficacy levels may affect pain management efforts of the patient, like compliance to the prescribed treatment. Valeberg et al. [71] hypothesized that inadequate adherence with analgesic regimen could be a reason for unrelieved pain in cancer patients, and investigated factors influencing oncology patients' adherence. They found that higher adherence scores were associated with lower self-efficacy for physical function, higher average pain intensity and higher pain relief scores [71]. According to the authors, patients with lower self-efficacy for physical function may be more motivated to do something about their pain and therefore improve adherence to medication [71]. Lin [25] found that self-efficacy for pain management was inversely correlated with pain, and positively related with pain management efforts. The latter was positively related with pain outcomes [25]. This may reduce pain levels and improve self-efficacy for pain management. It is likely that improved self-efficacy for pain management may enhance pain management efforts, like adherence to medication, resulting in better pain management.

In summary, improving pain management self-efficacy may lead to lower pain levels through overcoming barriers and performing more pain management efforts. Education on pain management, including informing about pain medication, may be a step towards better pain management through increasing self-efficacy. Publications on several interventions adopting this assumption were included and will be discussed next.

2.1 Interventions on self-efficacy

Overall, the selected papers on interventions regarding self-efficacy in cancer pain patients described interventions including patient education on pain management, pain management skills training and coaching. These methods have been implemented in various ways. Below we will discuss what has been found in this area of research so far.

The majority of interventions to improve self-efficacy in cancer pain management included education on pain management [51], often combined with coaching [48, 52-54, 58, 64]. For example, an intervention by González Barón et al. [51] was found to increase self-efficacy for pain management. The intervention included a questionnaire in which pain management strategies like increasing medication and distraction were suggested [51]. Another intervention performed in this area was the Cancer Health Empowerment for Living without Pain (Ca-HELP) intervention; a randomized controlled trial testing a tailored (i.e. customized) education and coaching intervention [58]. The intervention aimed to enhance pain communication self-efficacy (i.e. the confidence in the ability to communicate effectively about pain) and pain management self-efficacy (i.e. the confidence in the ability to achieve control over pain) to encourage pain-related communication and pain control behaviors, resulting in pain control [58]. Additionally, improved pain control was expected to be a positive reinforcer for pain management self-efficacy [58]. Patients in both the 'intervention' and the 'control' group received an information booklet and three follow-up interviews by phone. In the intervention group knowledge was assessed, misconceptions corrected and the patients were educated about pain self-management and communication and were trained in patient-physician

communication. The Ca-HELP intervention was effective in improving communication self-efficacy for both groups, but improvements were larger in the intervention group [53]. Improved communication self-efficacy was not associated with decreased pain severity and showed only small temporary benefits on pain-related functional impairment [53]. Post-intervention pain management self-efficacy was significantly related to subsequent pain severity [48], and was also found to be one of the mediators for the relationship between tendency to adhere to healthcare-provider recommended treatments and decreased pain severity [52]. However, gains in pain management self-efficacy were similar for both groups [53]. Therefore, it was likely that the positive findings on communication and pain management self-efficacy were mostly due to providing a booklet with information on pain control, which patients in both groups received [53]. In another education and coaching intervention, by Kurtz, Kurtz, Given & Given [54], all patients received written information on pain management, and telephone coaching by a nurse for eight weeks [54]. In addition to the negative correlation found between self-efficacy and pain at all time points; this coaching intervention resulted in a modest increase of self-efficacy levels during the intervention, which was not sustained at the follow-up interview six weeks afterwards [54]. No long-term effects of either coaching or education were found in a video education intervention for socioeconomic disadvantaged patients [64]. Intervention group patients watched a video on pain report and management, the control group watched a video on nutrition for cancer patients and a research nurse coached both groups directly after watching the video and within three days after [64]. The intervention group improved in communication about their pain, resulting in short term improvements on correspondence between patients' reported levels of pain and physicians' estimations [64]. For all patients, levels of pain control self-efficacy were low and only small short term increases in pain management self-efficacy and decreases in pain intensity were found for both groups. These effects may be the result of temporary increased attention to pain report and pain medication during the time the intervention took place [64]. The interventions suggest that education on pain management may contribute to improving patient empowerment. Individualized education, coaching and improving communication did not show additional effects on pain management directly. However, improved communication may result in increased knowledge on pain management, and improve pain management self-efficacy. Although, the moderate effects of the interventions performed so far suggest that more factors need to be addressed to improve pain management through patient empowerment.

The second technique that was used to improve self-efficacy and cancer pain management is training of pain management skills [51, 56, 65, 66, 68, 69]. In addition, effects of involving the main informal caregiver in training have been studied [66]. Training of pain management skills and involving the main caregiver in pain management may show positive results on self-efficacy and pain management [51, 56, 65, 66, 68, 69]. Anderson et al. [65] studied if training pain management skills through listening to and following instructions from audiotapes would influence self-efficacy and cancer pain. Patients were randomly allocated to a control group receiving no intervention or one of

the three cognitive-behavioral intervention groups; relaxation, distraction and listening to positive mood statements [65]. Except for temporary immediate pain reduction, their audiotape interventions had no significant effects on pain control self-efficacy or pain [65]. Porter et al. [66, 68, 69] investigated the effect of involving the main informal caregiver in training pain management skills in lung cancer patients. Besides the finding that patients with high levels of self-efficacy reported lower levels of pain, patients also reported lower pain levels when the informal caregiver's self-efficacy for helping the patient was high [68, 69]. When the patient's self-efficacy for pain management level was low, caregivers often overestimated this, and these patients reported higher pain scores [69]. These patient self-efficacy scores reported by patients and caregivers were less discrepant when patients had higher self-efficacy, and in this situation both patient and caregiver reported lower patient pain levels [69]. In the 14-session telephone based intervention tested by Porter et al. [66], patients were trained in various pain management strategies and their caregivers received training in how to help the patient manage pain. The 'control' group patient-caregiver combinations received educational coaching sessions. Patients in both groups improved in self-efficacy and pain ratings. The education intervention resulted in higher self-efficacy for patients who had an early stage of lung cancer, and patients in a more advanced stage of disease benefited more from the pain management skills training [66]. In their review on non-invasive interventions for lung cancer patients, Rueda, Solà, Pascual & Subirana Casacuberta [56] also concluded that enhancing coping skills strategies could contribute to improving the patient's self efficacy for pain management [56]. Although the amount of research is limited, the studies imply that practical training of various pain management skills may have positive effects on pain management if patients are free to choose a strategy to apply.

In conclusion, both theoretical and empirical studies reveal that self-efficacy seems important in cancer pain management. Interventions performed in this area of research imply that education on pain management will be most effective to improve self-efficacy, and practical training of pain management skills could enhance effects. However, the lack of randomized controlled trials in this research area makes that it cannot be excluded that effects of time influence this relation. Although some studies in our selection claim to be an RCT, no study used a *real* control group (i.e. a group receiving no intervention). More research on the relation of self-efficacy and cancer pain management is necessary in order to develop effective interventions and reduce the burden of pain in cancer patients.

3. Patient participation and cancer pain management

Besides the influence of self-efficacy on pain management, active involvement of the patient in finding and performing strategies to manage cancer pain appeared to contribute to patient empowerment. As previously discussed, patients often experience barriers contributing to inadequate cancer pain control, often caused by misconceptions about tolerance, addiction or management of side effects. These barriers retain them from communicating their pain to others [26]. In their paper on ethics and pain management, Cain and Hammes [75] state that no cancer patient should live with unrelieved pain because of fear of side effects. They stress the importance of patients' active involvement in their pain management, to prevent discrepancy between physicians' assumptions regarding patients needs and patients' actual wishes, values and needs, and receive adequate treatment [75]. Shared decision-making in the communication between patients and their physicians, in which the physician helps the patient to (re)shape values regarding decision making on pain management, was mentioned as the most useful for arriving at the treatment option that is in the patient's best interest [29, 55]. Communication on pain is an essential first step towards pain management.

The commonly assumed difference between cancer pain patients and other pain patients did not seem to hold in the psychological area of pain management. Lin [25] compared pain management strategies in cancer pain patients and low back pain patients, and found that their coping efforts and pain descriptions were comparable [25]. Arraras, Wright, Jusue, Tejedor & Calvo [74] compared cancer pain patients with a group of pain patients with various pathologies and found comparable pain levels in both groups. However, the cancer pain patients in their sample performed more pain management efforts [74]. Regarding the psychological component of pain and pain management, the found similarities imply that cancer pain patients may also benefit from pain management strategies applied by other pain patients.

3.1 Interventions on patient participation

Interventions performed on patient participation included (psycho)education, psychotherapy, cognitive-behavioral therapy and coaching, in order to improve communication about pain and to motivate patients to be actively involved in influencing their pain. Results will be discussed next.

Since pain consists of an objective and subjective component, Thomas and Weiss [23] stated that effective cancer pain management should consist of both pharmacological and non-pharmacological interventions. Therefore they studied the three most common non-pharmacological methods performed by mental health professionals to influence cancer pain (i.e. psycho-education, psychotherapy and cognitive-behavioral therapy). They concluded that psycho-education could enhance patient participation in pain control strategies by improving medication adherence and decrease pain levels [23]. Supportive psychotherapy and cognitive-behavioral therapy may reduce pain through managing stressors. In addition, they concluded that patients are more open to mental health services than physicians realize, especially if referred by their oncologist [23]. A multidimensional approach towards cancer pain would be in the patients' best interest.

Enhanced communication about pain with the healthcare provider and improved shared decision-making may result in better pain management, when this results in improved knowledge on how to influence pain. Oliver et al. [57] conducted a tailored coaching intervention in which patients were educated about pain management and were encouraged to communicate with their doctor about pain. ‘Control group’ patients received standardized education. Intervention group patients significantly improved on several pain measures, control patients did not. Since both groups had equal knowledge gains, the authors conclude that the improvements in pain control were likely due to improvements in active patient participation in shared-decision making, self-efficacy and medication adherence [57]. Data of the previously described Ca-HELP study were used to explore the underlying mechanisms. The intervention aimed to help patients more effectively discuss their pain-related questions, concerns, and preferences with physicians. The oncology visits were audiotaped if agreed upon and the recordings were coded for patient’s active participation and the level of physician effort to involve patients in the consultation and decision-making [73]. They found that patients with more pain interacted more active through shared decision-making, resulting in more information given by the physician [73]. However, although the Ca-HELP intervention was effective in improving communication self-efficacy [53] and communication [73], this was not directly related to pain outcomes [48]. The data on the previously described video education intervention by Anderson et al. [64] indicated that communication temporarily improved in the intervention group, who watched an instruction video on the use of a pain rating scale and how to communicate with providers about pain. Also, their pain management was temporarily improved [64].

In conclusion, (psycho)education and communication may result in improved patient knowledge on ways to manage pain, which may improve self-efficacy for pain management and efforts to influence pain, resulting in lower pain levels. Although, the limited amount of studies in this research area and the lack of randomized controlled trials weaken these conclusions.

Discussion

Patient empowerment seems to be an umbrella term for many concepts, including self-efficacy and forms of active patient participation. In cancer pain management, it is likely that empowered patients have higher self-efficacy levels and fulfill an active role in their pain management. Although the literature on patient empowerment in cancer pain management is limited, interventions that improve knowledge on cancer pain and pain management strategies, through education and training of pain management skills, seem most successful to enhance patient empowerment and cancer pain management. Involving the patient's main informal caregiver in the empowerment process may have additional positive effects. Enhancing patient empowerment may result in better cancer pain management. Yet, the underlying relations have not well been studied so far.

Given the relation between pain and quality of life [12, 16, 24, 25, 27, 42, 76, 77], improving cancer pain management by enhancing patient empowerment may result in improved quality of life. Improving quality of life should be the focus of cancer treatment [16]. Despite the specific underlying cause of cancer related pain, cancer pain patients may not need to be approached differently than patients with other pain related diseases, since reactions to pain are comparable [25]. As mentioned before, empowerment can be viewed as a process or outcome [30, 35]. Self-efficacy (i.e. sense of control) seems to reflect the outcome of patient empowerment. This review shows substantial evidence for the negative relation between self-efficacy and cancer pain [25, 48, 52-55, 66-70, 72, 74, 78], and enhancing self-efficacy of cancer patients may lower pain levels. The process of empowerment encompasses the active participation of patients in their pain management, for instance by discussing pain and pain treatment with the physician and learning and performing pain management strategies. However, the effects of empowerment-based interventions on pain management were quite small and often temporary. Also, no study used real control groups (receiving no intervention) so the effects found may have been due to time.

Interventions should address sociocultural environmental factors and include nonpharmacological pain management strategies. Since much pain can be attributed to the physical dimension [70], the use of pain medication is a major component of cancer pain treatment. Yet, psychological barriers to pain management experienced by cancer pain patients [14, 17, 25] are inversely related to analgesic use [17], resulting in less use of one of the main cancer pain management strategies: use of pain medication. However, pain levels and behavioral responses were found to be comparable to non-cancer pain patients [25, 74]. This may explain why nonpharmacological interventions are also effective in empowering cancer patients [23]. They can help to overcome psychological barriers, and to improve skills to handle pain. The studies by Porter et al. [66, 68, 69], in which the main caregiver of the patient was involved, show that the social environment may influence pain and pain management.

Introducing various pain management strategies gives the patient options to be actively involved in deciding on his/her pain management, and may therefore improve empowerment [51, 55]. Since every individual has different wishes, needs and values in life, both pain and quality of life are subjective and uniquely experienced by every patient. Knowledge levels and preferences for pain management strategies differ for each person as well. Training of a pain management strategy that does not appeal to the patient has shown to be ineffective [65], and education with standard material may be ineffective when offered to specific groups [64]. In addition, in cancer pain management it is important that interventions address the specific barriers experienced by cancer pain patients.

Despite the continuing lack of a clear definition, our findings on the content of patient empowerment in cancer pain management are in accordance with publications on patient empowerment in patients with other chronic pain conditions; patient empowerment contains self-efficacy and acquiring or reinforcing psychosocial skills [30, 79]. As stated by Aujoulat [30], patient empowerment is not disease or treatment specific [30]. Although cancer patients were not included in their study, their findings were similar; this indicates that empowerment in cancer pain patients might be comparable with empowerment in other pain patients.

Our findings match to a great extent with previous findings on patient empowerment, and therefore strengthen existing knowledge on patient empowerment in cancer pain management. However, some limitations of study should be taken into account. A major limitation when studying patient empowerment in cancer pain management was the fact that empowerment encompasses many concepts, even when placed in the specific context used in this study. Since the definitions of many psychological concepts have comparable descriptions, for the purpose of analysis of the findings these concepts were combined and labeled as 'self-efficacy' and 'patient participation' in this study. A limitation for the intervention studies was the lack of a possibility to have a 'real' control group, receiving no intervention, since it is ethically not approved to withhold patients from standard treatment. In addition, patients should always voluntarily participate in an intervention, resulting in selection bias. This may have influenced findings. Also, findings of this study may not be globally generalizable, since only studies conducted in western countries and written in English were included. However, various countries and several cultural groups were included in the studies, making the studies generalizable for western countries.

We chose for the integrative review method, as this is the only literature review approach that allows the combination of diverse methodologies [50], in a field in which hardly any RCTs or controlled trials are available. Results of the analysis add to the growing evidence on the importance of patient empowerment in pain management.

In conclusion, patient empowerment can be viewed as the patient's sense of control over pain and pain-related functional restrictions due to cancer or cancer treatment, or the process through which this can be enhanced. Enhancing patient empowerment may result in better cancer pain management. Education on pain management, including improving knowledge of medication and pain management strategies, may enhance self-efficacy levels and patient's active participation in efforts to communicate their pain and engage in activities to reduce it. More research should be undertaken on how to improve cancer pain patients' knowledge about pain management and their pain management skills.

Author contributions

This research was performed for the purpose of master thesis of IL, and serves as amplification of the PhD research of NtB. IL contributed to this research during an internship at Radboud University Nijmegen Medical Centre (RUNMC). NtB and IL were responsible for the data collection. IL performed data analysis and drafting of the manuscript. ET, SD, YE and NtB made critical revisions to the paper and supervised the study.

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Table 1. Findings*Self-efficacy and patient participation in cancer pain management*

Author(s), year	Study design	Aim	Participants/ Subjects	Concept of Self Efficacy	Measurement instrument	Relevant outcomes
[22] Vallerand 2005	Cross-sectional	Examine perception of control over pain on disparities in pain, symptom distress and functional status in white and black patients.	n = 281, various cancer types	Perception of control over pain	Item of the perceived Control Scale (One item)	Perception of control over pain predicts pain intensity and pain interference with function, and was the only identified factor causing disparity between the groups.
[25] Lin 1998	Cross-sectional	Explore the differences between chronic cancer pain and chronic low back pain with respect to the use of coping strategies to manage pain and self-efficacy for attenuating pain and pain outcomes.	n = 173, 85 low back pain, 88 various cancer types	Self-efficacy	Modified Coping Strategy Questionnaire (CSQ)	Perceived self-efficacy was inversely correlated with pain outcomes, and positively related with use of coping for both groups. Behavioral responses to pain were comparable.
[48] Jerant 2011	Experimental (RCT)	Examining relationships between self-efficacy for communicating with physicians and pain control self-efficacy and subsequent pain severity among cancer patients.	n = 244, various cancer types	Pain control self-efficacy, communication self-efficacy	Three items of the chronic pain self-efficacy scale, modified Perceived Efficacy in Patient-Physician Interactions scale (PEPPI)	Post-intervention pain control SE was significantly related to subsequent pain severity, communication SE was not.
[51] Gonzalez Baron 2006	Experimental	Test efficacy of a tool for identifying threatening symptoms for patients and evaluate incidence of pain in the suffering.	n = 73, various cancer types	Personal and psychosocial resources to face threats to integrity	Self-developed instrument	Coping strategy users report less suffering, related to pain. The intervention helps to identify and diminish threatening psychosocial symptoms and empower personal and psychological resources, relieving suffering.

[52]	Jerant 2011	Experimental (RCT)	Explore relationship between adherence tendency and pain severity.	n = 224, various cancer types	Pain control self-efficacy, communication self-efficacy	Three items of the chronic pain self-efficacy scale, modified Perceived Efficacy in Patient-Physician Interactions scale (PEPPI)	Post-intervention pain control self-efficacy was one of the mediators for the relationship between tendency to adhere to healthcare-provider recommended treatments and pain severity.
[53]	Kravitz 2011	Experimental (RCT)	Determine effectiveness of a tailored education and coaching intervention to reduce pain misconceptions and enhance communication self-efficacy.	n = 258, various cancer types	Pain control self-efficacy, communication self-efficacy	Three items of the chronic pain self-efficacy scale, modified Perceived Efficacy in Patient-Physician Interactions scale (PEPPI)	The tailored education and coaching intervention increases communication SE, but not pain control SE, compared to enhanced usual care. Improving communication SE has small benefits on pain-related impairment, but not on pain severity.
[54]	Kurtz 2008	Experimental	Investigate the relationship between personality traits and ability to control pain and fatigue in patients involved in a symptom control intervention.	n = 214, various cancer types	Mastery (= sense of control)	Pearlin Mastery scale	Mastery was negatively correlated with pain. Greater mastery leads to a reduction in severity of pain.
[55]	McNeill 2007	Theoretical	Examination of poverty-related and racial and ethnic disparity in cancer pain management.	n = 1, prostate cancer	Perceived control	-	Perceived control may influence pain related outcomes and treatment effectiveness. Assessment is the crucial point in pain management. Improving communication and addressing environmental factors that influence pain management can enhance self-efficacy.
[56]	Rueda 2011	Systematic review	Assess the effectiveness of non-invasive interventions delivered by healthcare professionals in improving symptoms, psychological functioning and quality of life in lung cancer patients.	n = unknown, lung cancer	Self-efficacy	Various	The promotion of coping skills strategies could contribute to improve the patient's self-efficacy. Interventions should aim to increase the patient's understanding of their illness and its meaning, to increase their ability to be active participants in therapy.

[58]	Kravitz 2009	Theoretical	Description of a study testing the effectiveness of a tailored education and coaching intervention on cancer pain severity, pain related impairment, and quality of life.	various cancer types	Pain control self-efficacy, communication self-efficacy	Three items of the chronic pain self-efficacy scale, modified Perceived Efficacy in Patient-Physician Interactions scale (PEPPI)	Pain management SE may promote less pain and functional impairment. Communication SE leads theoretically to more assertive interactions with the physician, more effective clinical interventions, and better outcomes.
[64]	Anderson 2004	Experimental (RCT)	Evaluate the efficacy of a video education intervention for underserved minority patients.	n = 97, various cancer types	Perceived control over pain	Pain control scale of the Survey of Pain Attitudes	Underserved minority patients have low levels of perceived control over pain. Education on controlling cancer pain showed short-term improvements pain scores.
[65]	Anderson 2006	Experimental (RCT)	Effectiveness of cognitive-behavioural audiotape interventions in reducing pain and improvement in overall pain control through this.	n = 59, various cancers	Perceived ability to perform coping behaviors	Outcome Expectancy and Self-Efficacy (OESE)	No significant effects of the cognitive behavioral interventions on perceived self-efficacy with regard to pain were found.
[66]	Porter 2010	Experimental (RCT)	Test the efficacy of a caregiver-assisted coping skills training protocol for lung cancer patients.	n = 233, lung cancer	Self-efficacy	Modified self-efficacy scale	Both the coping skills training intervention and the education/support intervention improved patient self-efficacy and worst pain ratings. The education intervention resulted in higher self-efficacy for patients who had an early stage of lung cancer, and patients in a more advanced stage of disease benefited more from the pain management skills training.
[67]	Mosher 2010	Cross-sectional	Examine the interrelations of self-efficacy for coping with cancer, perceived barriers to pain management, distress, and pain outcomes in breast cancer patients.	n = 89, breast cancer	Self-efficacy for coping with cancer	Revised Cancer Behaviour Inventory (CBI)	Lower self-efficacy for seeking and understanding medical information was associated with barriers to pain management, overall self-efficacy for coping with cancer was not.

[68]	Porter 2008	Cross-sectional	Examine self-efficacy for managing pain, symptoms, and function in lung cancer patients and their caregivers, and associations between self-efficacy and patient and caregiver adjustment.	n = 152, lung cancer	Self-efficacy	Modified self-efficacy scale	Patients with high levels of self-efficacy have lower levels of pain and symptoms, and higher levels of physical and functional wellbeing. Significant proportions of the variance are explained by the caregiver's self-efficacy level.
[69]	Porter 2002	Cross-sectional	Examine the degree of correspondence between lung cancer patients and their family caregivers in their perceptions of the patients' self-efficacy for managing pain and other symptoms of lung cancer.	n = 30, lung cancer	Self-efficacy	Modified self-efficacy scale	High patient self-efficacy was associated with low symptom severity. When caregivers perceived patients to be high in self-efficacy, both rated lower levels of patient's symptoms.
[70]	Syrjala 1995	Longitudinal	To examine the fit of a model of biomedical, physical functioning, psychological functioning, and social variables in predicting treatment-related pain intensity in cancer patients.	n = 358, various cancer types	Self-efficacy	One self-created item	Pre-treatment self-efficacy and active coping style were significantly negatively associated with mouth pain experienced after bone marrow transplantation.
[71]	Valeberg 2008	Cross-sectional	Describe oncology outpatients' level of adherence with an analgesic regimen and evaluate the effects of selected demographic variables, pain characteristics, barriers to pain management, and self-efficacy.	n = 174, various cancer types	Self-efficacy	Chronic pain self-efficacy scale	Higher adherence scores were associated with lower SE scores, higher average pain intensity, higher pain relief scores, and the use of strong opioid analgesics.
[72]	Valeberg 2008	Cross-sectional	Determine a pain severity cut point (CP), using average pain intensity, and determine differences in the groups on various characteristics.	n = 210, various cancer types	Self-efficacy	Chronic pain self-efficacy scale	Self-efficacy significantly contributes to higher pain scores. High pain intensity was associated with lower self-efficacy scores and barriers to pain management.

Author(s), year	Study type	Aim	Participants	Concept of Patient Participation	Measurement instrument	Relevant outcomes
[23] Thomas 2000	Review	Explain the basic principles behind three nonpharmacological interventions and discuss relevant research studies.	n = 944, various cancer types	Actively participate in pain control strategies	Various	Psychoeducational interventions can decrease reported pain levels through education of pharmacological issues and empowers patients to actively participate in pain control strategies. Supportive psychotherapy and cognitive-behavioral therapy can reduce pain through managing stressors.
[25] Lin 1998	Cross-sectional	Explore the differences between chronic cancer pain and chronic low back pain with respect to the use of coping strategies to manage pain and self-efficacy for attenuating pain and pain outcomes.	n = 173, low back pain (85), various cancer types (88)	Use of coping strategies	Modified Coping Strategy Questionnaire (CSQ)	The most frequently used coping strategies were almost the same between low back pain patients and cancer pain patients, and were positively correlated with pain outcomes.
[26] Coward 2000	Cross-sectional	Describe meanings related to the pain experience and individual meaning and management of pain in patients with cancer and metastatic bone pain.	n = 20, various cancer types	Communication with healthcare provider	Audiotaped interviews, questionnaires	Misinformation regarding tolerance and addiction, communication about pain and management of side effects cause barriers to pain management. Active patient involvement in communication on pain may help overcoming these barriers.
[29] Jansen 2001	Theoretical	Defend a model on the importance of active participation of the patient in the decision making process for adequate pain treatment.	patients with cancer related pain and AIDS related pain	Shared-decision making	-	Patient participation in the decision making process is necessary for successful pain management.

[55]	McNeill 2007	Theoretical	Examination of poverty-related and racial and ethnic disparity in cancer pain management	n = 1, prostate cancer	Communication with healthcare provider , collaboration	-	Pain management must be a collaborative process, with good communication and trust between healthcare providers and patients.
[57]	Oliver 2001	Experimental (RCT)	Evaluate the effect of an individualized education and coaching intervention on pain outcomes and pain-related knowledge.	n = 67, various cancer types	Communication with healthcare provider	Pain and impairment measures	Short-term education alone to improve effective communication with doctors is not sufficient to reduce pain intensity for minority patients with low levels of perceived control over pain.
[64]	Anderson 2004	Experimental (RCT)	Evaluate the efficacy of a pain reduction intervention for underserved minority patients.	n = 97, various cancer types	Communication with healthcare provider	Pain Management Index (PMI)	Instructions on how to communicate better with the physician do not result in significant additional benefits regarding pain levels.
[73]	Street 2010	Experimental (RCT)	Examine the effect of a tailored education-coaching intervention to help patients more effectively discuss their pain-related questions, concerns, and preferences with physicians.	n = 148, various cancer types	Active patient participation behavior, shared decision-making	Audio-recorded consultations	Patients with more baseline pain interacted more active with physicians through shared decision-making, resulting in more information given by the physician.
[74]	Arraras 2002	Cross-sectional	Compare pain management strategies and pain related behaviours of patients with cancer and other diseases.	n = 118, various cancer types (51) and non-cancer (67)	Activities to control pain	Cuestionario de Formas de Afrontamiento (CEA), Escala Multidimensional de Locus de Control del Dolor	The two groups had comparable levels of pain severity, negative coping style and low internal locus of control. Interventions to encourage active coping and activity levels are important.
[75]	Cain 1994	Theoretical	Explore underpinning ethical principles and extensions of principles for pain control in cancer care.	cancer pain patients in general	Communication with healthcare provider	-	No cancer patient should live with unrelieved pain because of fear of side effects. Caregivers' assumptions regarding patients' wishes, values and educational needs often lead to rejection of therapy or acceptance of therapy with loss of control over one's destiny. Patients should be involved in the discussion on pain management.

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