The role of cancer nurses in cancer-related pain management in Europe

Palliative Care & Social Practice

2023, Vol. 17: 1–12

DOI: 10.1177/26323524231216996

Johan de Munter, Nikolina Dodlek, Ani Khmaladze, Sara Torcato Parreira, Helena Ullgren, Rik de Man, Floris A. de Jong and Wendy H. Oldenmenger

***Abstract*:** Cancer pain is a common symptom in patients with cancer and can largely affect their quality of life. Pain management is important to minimize the impact of pain on daily activities. Cancer nurses are significantly involved in all steps of pain management and contribute to the success of therapy through their knowledge and expertise. While they generally play an important role in the screening, assessment, diagnosis, treatment and follow-up of patients and their (pain) symptoms, this varies from country to country in Europe. An important aspect is their role in educating patients and their families about what pain is, what impact it can have, how it can be treated pharmacologically or non-pharmacologically and what effects or problems can occur during treatment. While there is a great discrepancy between education and training opportunities for cancer nurses in different European countries, there is a continued need for education and training in pain management. Cancer is increasingly becoming a chronic disease, and the management of pain in cancer survivors will be crucial to maintain an adequate quality of life. With this, the crucial role of cancer nurses is becoming even more important.

Keywords: cancer-related pain, multimodal pain management, nursing, pain management, quality of life

Received: 13 April 2023; revised manuscript accepted: 7 November 2023.

Correspondence to:
Wendy H. Oldenmenger
Erasmus MC Cancer Institute, University Medical Center Rotterdam, P.O. Box 5201, 3008 AE Rotterdam, The Netherlands
w.h.oldenmenger@erasmusmc.nl

Johan de Munter
UZ Ghent, Ghent, Belgium

Nikolina Dodlek
UH Center Osijek, Osijek, Croatia

Ani Khmaladze
Caucasus Medical Centre, Tbilisi, Georgia

Sara Torcato Parreira
CUF Tejo Hospital, Lisbon, Portugal

Helena Ullgren
Department of Oncology and Pathology, Karolinska Institute, ME Head & Neck, Lung & Skin Cancer, Karolinska Comprehensive Cancer Centre, Stockholm, Sweden

Rik de Man
Mundipharma Pharmaceuticals B.V., Leusden, The Netherlands

Floris A. de Jong
Exact Sciences, Baar, Switzerland

Introduction

In 2020, 19.3 million people worldwide were diagnosed with cancer, and with the global prevalence of cancer steadily increasing it is estimated that 28.4 million people will be newly diagnosed with cancer in 2040.[1] Depending on the type of cancer, for many patients, pain is often one of the first symptoms that ultimately leads to a cancer diagnosis, and the incidence of pain continues to increase with disease progression and even more during cancer treatment.[2,3] The International Association for the Study of Pain defines pain as 'an unpleasant sensory and emotional experience associated with, or resembling that associated with actual or potential tissue damage'.[4] This definition emphasizes that pain is subjective as experienced by the patient and that pain is present whenever perceived as such by the patient. A survey of patients with cancer in Europe found that 56% suffered from moderate to severe pain at least monthly[2] and a systematic review estimated a prevalence of pain in 55% of patients during cancer treatment and in 66% in the advanced stages of the disease.[3] In addition, cancer pain remains a challenging symptom even after treatment is completed, with a prevalence of 20–50% in cancer survivors.[3,5] This applies equally to all age groups.[6]

Causes of cancer-related pain include not only the tumour and metastases, which inflame or erode bones, viscera or nerves, but also pain related to tissue or nerve damage caused by anticancer treatments such as surgery, chemotherapy and radiation or pain experienced in connection with diagnostic procedures such as biopsies.[7–9] Patients with cancer may suffer from acute and chronic pain syndromes simultaneously and can experience painful symptoms at multiple sites.[10] Suffering from cancer pain may not only have

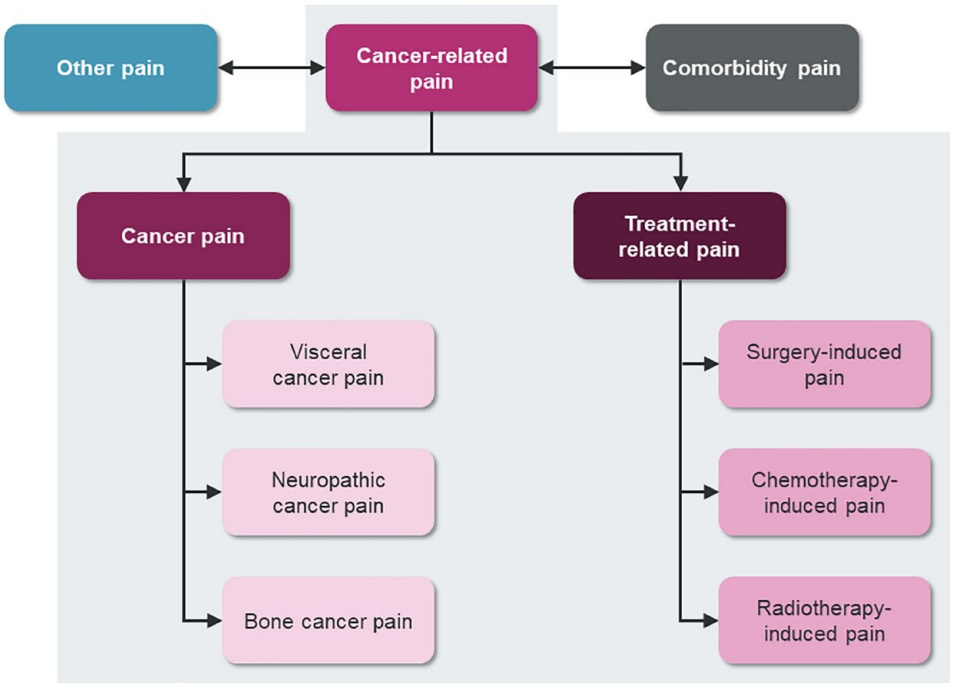

Figure 1. Cancer-related pain.
Cancer-related pain can be classified as cancer pain, caused by the tumour or its metastases, or treatment-related pain, that represents all types of pain due to an anti-cancer therapy. Visceral cancer pain is caused by damage to visceral organs by the tumour or its metastases, while neuropathic pain is caused by damage to the central or peripheral nervous system. Bone pain is thought to be a mixture of different pain classes.[20] Treatment-related pain can be distinguished according to its cause into surgery pain, chemotherapy-induced pain and radiotherapy pain. The intensity of cancer-related pain is influenced by many other factors, including any other pain that may occur in the patient, such as comorbidities or independent pain.

physical consequences, such as sweating, nausea or fatigue, but is also associated with psychological sequelae, such as anxiety and depression as well as a reduction in patient quality of life, and has a social impact for affected patients, independent of their age.[11] Such interference with daily activities can in turn worsen cancer pain, limit coping skills and cause fatigue, anxiety, depression and mood disorders.[11–13]

However, it is important to note that pain in patients with cancer is not synonymous with cancer-related pain (Figure 1).[7] A comprehensive clinical examination is needed to distinguish between cancer pain, cancer treatment pain and pain due to co-morbid conditions, and to identify the type of underlying pain in order to treat it appropriately.[14] Safe, effective and evidence-based management of cancer-related pain is a cornerstone of comprehensive cancer care.[9,14–17] Advances in the early detection, diagnosis and treatment of cancer enable patients to survive longer, and an increasing number of healthcare professionals consider cancer to be a disease for which a chronic course can be achieved.[18] This means that comprehensive pain management must also be continued for a longer period of time and is essential for patients to maintain an adequate quality of life, especially since one in five working-age cancer survivors suffers from chronic pain.[19] This requires a multidisciplinary approach to the management of pain in cancer survivors, in which community nurses and general practitioners play an important role, especially once a patient has been cured of cancer, but may still experience chronic pain.

Cancer nurses play a key role in the management of pain and are often the single point of contact for information and education, coordination of care, screening and assessment of signs and symptoms, and administration and follow-up of pharmacological and non-pharmacological interventions. In addition, cancer nurses are often more accessible to patients to openly discuss their signs and symptoms and related concerns. They also have an important role to play in

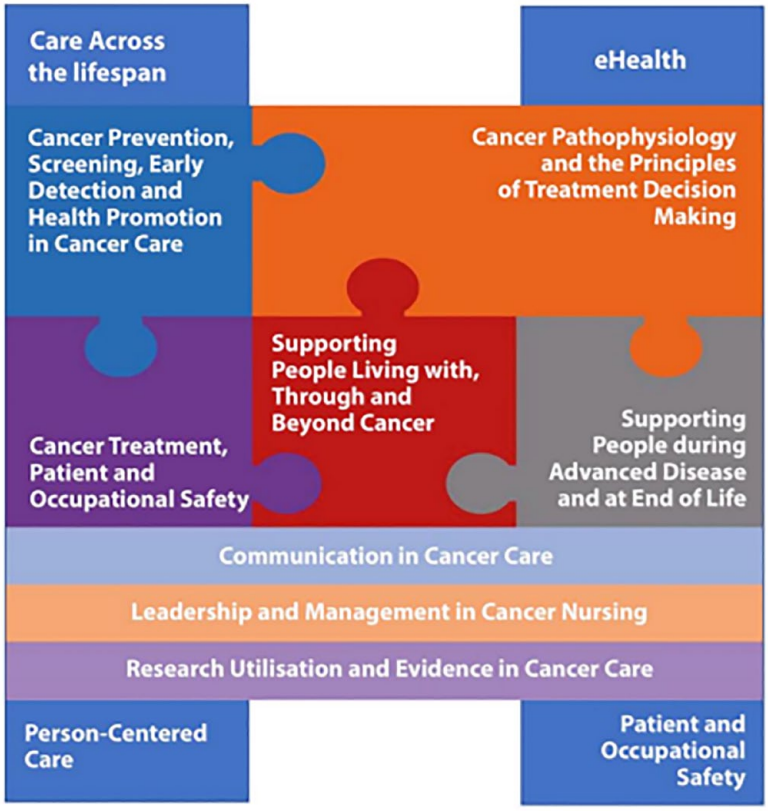

Figure 2. The EONS Cancer Nursing Education Framework.
The overall purpose of this EONS Cancer Nursing Education Framework is to provide guidance regarding the fundamental knowledge, skills and competencies required by nurses who care for people affected by cancer as part of multi-professional teams across Europe.
EONS, European Oncology Nursing Society.

patient safety, as nurses are often the last line of control in pain management.[21]

Cancer nurses play a central role in the care of patients and are the largest group of healthcare professionals caring for patients with cancer. The aim of this narrative review is to highlight the contribution and impact of cancer nurses in the management of cancer-related pain. We aim to provide insight into methods and approaches nurses use to support patients with cancer-related pain.

Methods

Papers published in English were identified through an extensive literature search of PubMed using the following search terms: 'oncology nurs*', 'cancer pain', 'nursing', 'pain management' and 'pain assessment' from 2009 until 2022.

Articles were also identified through grey literature searches. Authors who were representatives of six European countries identified any remaining articles not picked up by the search or reference list search. The final overview of references was generated on the basis of relevance for the broad scope of this review.

The role of nurses in cancer care

According to the European Oncology Nursing Society, cancer nurses are nurses who have completed specialized training with specific qualifications after which they have both the authority and full responsibility to provide the necessary care to patients with cancer. This care is based on evidence-based research and practice, continuous specialized education and training, and ethical and personal skills and competences. Cancer nurses have full responsibility for all nursing services provided under their direction and the associated patient outcomes in all areas of cancer care as is summarized in Figures 2 and 3.

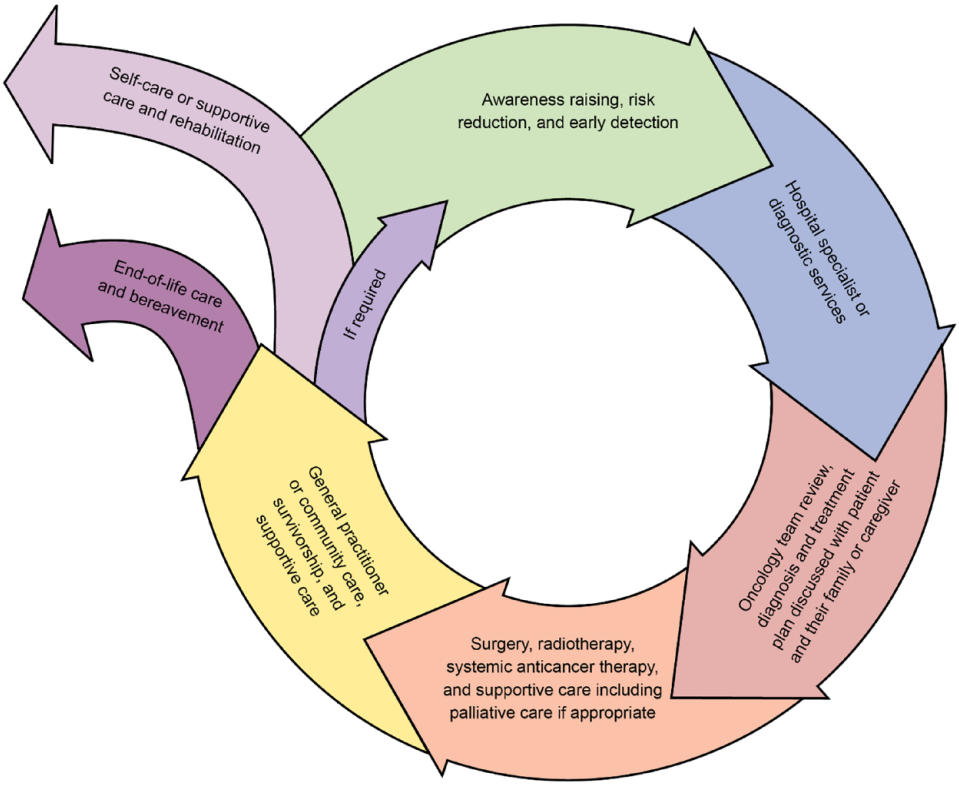

Figure 3. The role of cancer nurses in cancer pain management.
Source: Reprinted from Young *et al.*,[21] with permission from Elsevier.

Not only the training of cancer nurses but also their autonomy varies widely across Europe. For example, while nurses in some countries are authorized by specific qualifications to prescribe drugs, this may not be the case in other countries. As an example, Supplemental Table 1 gives an overview of the variation in educational qualifications from countries across Europe. The role of nurses has evolved considerably over the past century. Whereas in the past cancer nurses worked at the bedside with few technological advances, today they are largely advanced professionals and leaders responsible for all areas of cancer care, from prevention and early detection to survivorship and end-of-life care, as shown in the cancer care continuum (Figure 3). The cancer care continuum is also a useful framework to illustrate the contribution of cancer nurses at different stages and especially their contribution in pain management.

Not only their role in cancer care, but also their general role, is based on a professional partnership with patients, their families and other healthcare professionals, the latter recognizing their expertise in cancer and pain management and being ready to discuss specific therapeutic strategies with them as part of an interdisciplinary team. They are not only the first point of contact for patients, but often also the professionals who spend the most time with patients and families; for this reason, they are able to build a professional relationship of trust with patients and their families.[22] The communication skills of nurses are based on their training and, together with the relationship of trust between nurses and patients, form a very good basis for correctly assessing the patients' pain, as patients are often more open towards them than towards other healthcare providers. This enables them to support patients professionally throughout their cancer journey and fulfil a role as a professional advisor to patients. The trust placed in nurses by society is also evident in the latest annual Gallup ratings of various professions.[23]

Cancer nurses are usually involved in all steps of cancer pain management, but their role varies from country to country and also among different institutions within a given country. Generally,

nurses are responsible for pain screening, assessment, patient education and monitoring, while their role in other steps of pain treatment varies. For example, specialist nurses are allowed to prescribe medicines in the Netherlands and the United Kingdom, whereas in most other European countries this right is reserved for physicians.[24]

The role of cancer nurses in pain management

Cancer nurses play an important role in the screening, assessment, diagnosis, treatment and follow-up of patients and their (pain) symptoms. To fulfil these responsibilities, advanced pain assessment skills are required, as well as strong clinical judgement to assess the patient's needs, determine the cause, develop and manage the care plan and evaluate the outcome of treatment.[22] In addition, nurses should be familiar with non-pharmacological treatment options, understand the pharmacological properties of analgesics used for pain management, be aware of possible synergistic adverse effects/risks and monitor and manage patients' symptoms appropriately.[22] Furthermore, nurses provide care and support appropriate to the patient's particular psychosocial context.[25]

Cancer nurses are an important part of the patient's interdisciplinary pain management team and are in an excellent position to conduct and document a thorough pain assessment at every patient encounter. This permanent monitoring starts before treatment, continues throughout the course of treatment, and is also carried out after treatment as part of long-term monitoring and treatment evaluation. Through frequent contact with their patients, they also represent a central point of contact for patients and families and can be the first to recognize patients' fears about their disease and the associated treatments. Coordination of cancer care also includes referral to more specialized healthcare professionals or services when needed.

Pain assessment tools

As pain can occur at any stage of cancer, regular pain screening and accurate pain assessment when pain occurs is an essential cornerstone of nursing practice and treatment.[22] Numerous unidimensional and multi-dimensional tools are available for pain assessment. Regular monitoring using simple unidimensional tools is the 'gold standard' and should be performed at every opportunity with patients.[9,14,17] The best known and most widely used unidimensional tools for responsive patients are the numeric rating scale, the visual analogue scale and verbal rating scale.

For patients who are unresponsive or otherwise limited, there are many other tools available, such as Face, Legs, Activity, Cry, Consolability (FLACC) Scale or the Rotterdam Elderly Pain Observation Scale (REPOS).[26,27] Once pain management is initiated, patients' pain should be reassessed at appropriate intervals to confirm adequate pain control and to monitor for adverse events.[22] However, as unidimensional tools do not capture psychological or social components, a more detailed assessment using a multi-dimensional tool should be carried out once pain has been identified by regular monitoring.

The concept of 'total pain' considers that pain also has physical, psychological, social, emotional and spiritual components. The combination of these elements is believed to result in a 'total pain' experience that is individualized and specific to each patient's particular situation.[28] Taking this framework into account, it has been proven that pain is often associated with other processes, which in turn strongly influence pain.[29]

Multi-dimensional pain instruments allow assessment not only of the pain itself, but also of other key features of pain, such as affective, cognitive, social and spiritual dimensions. Common tools for assessing these factors are the Brief Pain Inventory – Short Form and the McGill Pain Questionnaire.[30] These should be used when monitoring with a unidimensional instrument has revealed that the patient is in pain to document the pain and its impact on social, psychological and other Quality of Life aspects. This is particularly necessary as pain, through its social, psychological, spiritual and other dimensions, has a significant impact on patients, their families and leads to a deterioration in the quality of life of patients and those closely related to them.[29] A second measurement with the same multi-dimensional tool should be performed when an evaluation of treatment after pain management has been initiated and established.[31]

Pain management

As diagnosis, stage of disease, response to pain and interventions, and personal preferences vary

from patient to patient,[31] a tailored approach to each patient is key to managing cancer pain. In this context, a multimodal approach to pain management has been adopted for several years and treatment decisions are made by an interdisciplinary team including experts from different disciplines, such as oncologists, nutritionists, palliative care specialists, anaesthesiologists or even cardiac specialists, and are tailored to the needs of the patient. In most European countries, cancer nurses are full members of these interdisciplinary teams and nurses appreciate the interprofessional approach that prevails in the treatment of cancer patients. Because nurses are usually in close contact with patients and their caregivers, they often serve as advocators for the patients within interdisciplinary teams.[21]

Patient education

An important aspect of their work is to educate patients and their families about what pain is, what its physical consequences can be, how it can be treated pharmacologically or non-pharmacologically and what side-effects or problems can occur during treatment. The latter are monitored, assessed and managed by nurses.[32,33] Educating patients is a crucial part of nursing and cancer care, including pain management.[32] Patient education may include when to use each medication, what outcomes to expect, potential risks associated with a specific medication and how to use follow-up systems such as patient diaries or apps. An important aspect of appropriate pain management is to ensure patient safety. Opioid medications, for example, are associated with some very common side-effects such as dry mouth or constipation. Patients should be educated on how to manage such side-effects. It should be emphasized that the goal of pain management is not just to provide pain relief, but also to maximize daily functioning while minimizing pain interference.

Patient education – support for self-management

As part of patient education, cancer nurses can also provide patients with options for self-management of pain. Self-management can be defined as 'patient engagement in health-promoting activities, interaction with healthcare providers, adherence to recommendations, monitoring of physical and emotional status, making autonomous decisions and management of role function and relationships'.[34] Pain self-management is the patient's ability to manage pain using cognitive and behavioural strategies; this includes knowledge, skills, and psychosocial, relational and informational support in performing health behaviours.[35]

According to a systematic review by van Dongen *et al.* from 2020, self-management can be assigned to seven different domains:

(1) medicine and pharmacology (e.g. self-medication with painkillers), (2) lifestyle (e.g. use of complementary and alternative medicine), (3) psychology (e.g. keeping a diary), (4) social support (e.g. participation in support groups), (5) knowledge and information (e.g. obtaining treatment information), (6) navigation and coordination (e.g. financial planning) and (7) medical decision-making (e.g. participation in advance care planning).[36]

While there is some evidence for the effectiveness of self-management approaches, the results of these approaches are very heterogeneous in different studies, and overall, not all patients benefit. Because of their knowledge of individual patients, nurses are probably best placed to discuss with patients and their caregivers which of these self-management measures are appropriate for patients.

Patient education – support for patient adherence to pain medication

One of the reasons why patients with cancer suffer from unrelieved pain may be inadequate adherence to prescribed analgesics.[37] Among patients with cancer-related pain, rates of adherence to prescribed analgesics range from 0% to 92% in different studies. This wide variability in reported adherence rates may be due to differences in the definition of adherence and/or measurement of adherence (questionnaires, diaries or electronic devices).[37] The most important way to improve patient adherence to therapy is to provide patient-specific information about the benefits and risks of therapy. For this reason, patient pain education programmes have been developed to reduce patient concerns and increase patient adherence.[37] Cancer nurses should address factors influencing analgesic adherence behaviour over the entire pain management journey beginning from initiation of care up to treatment itself and follow-up.[38] Support for treatment adherence is mostly offered in nurse-led consultations where the principles of motivational interviewing and

patient coaching are applied. Other obstacles exist on the part of the patients, such as fear of the side-effects of the medication, lack of education about the importance of adherence to therapy and fear of medication dependency. To pre-empt potential concerns from patients and their families about opioid treatment, it is also recommended to discuss a withdrawal plan before starting opioid treatment in cancer patients.

Barriers to pain management

Despite numerous guidelines and recommendations, barriers to good control of cancer-related pain persist, and it is often inadequately treated for a variety of reasons.[39] Uncontrolled or inadequately treated pain can lead to physical and emotional impairment that increases the suffering of patients as well as their families, thereby reducing quality of life.[40] There is evidence suggesting that pain management in cancer care can positively impact quality of life and quality of death.[40,41] Some of the obstacles to achieving effective pain management include insufficient support and patient education, inadequate assessment and communication.[42–44] Furthermore, patients often have inadequate knowledge and fearful attitudes about analgesia. This lack of knowledge has been associated with reluctance to take pain medication, lower treatment adherence and thus higher pain intensity.[32,45] Other barriers to successful pain management may include the patient's culture, personal experience-based views and family or social influences.[46] Additional reasons include the fact that pain is often not adequately considered by medical staff during regular oncology treatment, patients are reluctant to address pain, and lack of access to prescriptions of appropriate and timely analgesia.[47,48]

How to overcome these barriers

A patient-centred approach to communication and proper education is particularly important to reduce barriers to optimal treatment.[49] In the absence of understanding the type and extent of the problem, pain management can be a major issue for patients with cancer and their healthcare providers. To reduce barriers to adequate pain management, it is necessary to identify them.[48] Awareness of the specific issues allows for the provision of information to patients with cancer pain and addressing their concerns about pain and analgesia. These can be effective interventions that can support self-management and lead to better treatment outcomes.[50] In coaching interventions with patients, cancer nurses should find out the reasons for refusal, allay the patient's fears, fill gaps in knowledge and work out solutions together with the patient. The patient should be given space to express his or her concerns, and both short-term goals and a longer-term strategy for the modification of attitudinal barriers and for improving pain management should be developed with the patient.[51] Individual concerns should be addressed, considering the patient's individual conditions and needs.

To break down barriers, cancer nurses are in a privileged position, as they spend a relatively large amount of time with the patients and their relatives. They often know them best of all healthcare providers and can therefore contribute significantly to the success of pain management through targeted and tailored communication.

Non-pharmacological pain management

Although pharmacological treatments are the cornerstone in the management of cancer-related pain, the use of other modalities and procedures can often improve outcomes.[14] Patients and healthcare professionals often underestimate the impact of cancer pain on psychological distress and do not appreciate the potential benefits of psychological treatments and non-pharmacological interventions. Healthcare professionals should strive to understand how each patient copes with pain and support the patient in developing pain management skills.[52] However, it is up to the nurse to select the interventions for each patient based on appropriate assessment and the patient's preference. A meta-analysis of nurse-led non-pharmacological pain interventions found that although these interventions had low long- to moderate short-term effects, they significantly reduced patients' pain, improved their knowledge of pain management, reduced barriers to pain management and pain coping, and improved other physical and emotional symptoms.[53]

Treatment follow-up

Even after cancer treatment is completed, patients may suffer from pain, and cancer nurses continue to play an important role in the patient's history of illness and/or pain. With their specialized knowledge and expertise, they ensure appropriate follow-up and monitor patients' well-being and the success of pain management. However, outpatient

pain management for patients with cancer-related pain is often inadequate due to communication barriers between patients and professionals and infrequent contact.[54] This is especially a problem when patients have different concerns and misconceptions about pain and analgesics. Better communication about their pain with professionals can help to improve pain management.[54] A study in the outpatient setting showed that more than half of cancer patients reported that pain noticeably interferes with their life activities. Therefore, it is important to prepare patients upfront to self-manage their pain at home, independent of the current setting.[55]

Telephone

One way of regularly recording pain intensity and any side-effects of the medication for outpatients are to collect this information in regular telephone calls.

In addition to regular calls, a hotline where patients or their caregivers can reach members of the clinical care team is an easy way to allow patients to connect in case of need. This provides a simple and quick way for patients and their healthcare providers to discuss symptoms or treatment issues that arise. A study by Remy *et al.* tested a patient/caregiver hotline that allowed outpatients to reach nurses. The reason for calling was pain in more than half (59.6%) of the calls and side-effects in about a quarter (23.4%). In this study, nurses mainly provided educational services, such as non-pharmacological approaches to pain management or management of side-effects by advising patients *via* telephone, but they also clarified dosage and intake instructions and provided information about possible drug–drug interactions.[25] Therefore, nurses must be able to classify patients according to the severity of impairment even when not seeing the patients by using the right questions to determine the priority of needs and the right place of treatment.

Online tools

Another way for patients to take a more active role in monitoring their symptoms in real-time is by using online tools. Such tools can help minimize the delay in treatment that would otherwise occur.[54] These online technologies are called remote symptom monitoring technology and can include telemedicine, electronic health (e-health) and mobile health (m-health).[56]

A review by Zheng *et al.*[57] showed that these apps are well accepted by patients and their use can reduce pain intensity as well as the occurrence and severity of side-effects. Oldenmenger *et al.*[58] were able to show that an integrated programme consisting of systematic pain recording, a pain protocol and pain education for patients significantly improved the identification of patients with pain and their pain management. Over a 6-month period, the percentage of patients who rated their current pain intensity as moderate-severe decreased significantly by 32%.[58] Additionally, patients were very positive about playing a more active role in their pain management.[58] A major advantage of mobile applications is the regular and timely recording of pain and symptoms of possible side-effects. These real-time data allow for quick action when needed and shorten the time between the occurrence of a problem and the response. Using instant messenger functions, patients can easily get in touch with the nursing staff at any time, ask questions or address problems. Digital tools should be compatible with the electronic patient file to avoid time-consuming copying of data between different systems or to avoid patients having to tell their story repeatedly. When introducing new digital tools, nurses may find it difficult to find time to review patient input in parallel with the use of other systems.

Unfortunately, often not enough resources are made available to integrate these tools into the actual daily work, or the tools are developed in a way that makes integration difficult or even impossible.

Discussion

In light of new developments with respect to treatment and regarding new techniques for monitoring and follow-up of patients with cancer-related pain, it is important that nurses continue to develop their knowledge and learn new techniques for pain relief and monitoring. The differences in training and level of responsibility in different European countries reinforce the inequality in access and optimal treatment of patients with cancer across Europe. These differences are already evident when looking at the minimum educational level of cancer nurses in the different countries. The level of education on cancer pain

varies not only between countries, but even within countries and has great potential to be standardized. More uniform cancer nurse recognition, education and training would strengthen equal access to optimal pain management and would benefit patients in all European countries. Since time is the most valuable and scarce commodity in patient care, it would be desirable if each country did not have to make the same experiences itself, but could avoid mistakes, for example, in the implementation of new techniques, through a mutual exchange within professional networks based on comparable education levels and autonomy of nurses.

It would also be desirable to offer and initiate regular education and training on new developments, designed in such a way that participation is possible despite the heavy workload of nursing staff throughout Europe.

Conclusion

Nurses play a key role in the management of cancer-related pain. During the entire journey of a patient through cancer-related pain management they are responsible for symptom management, which includes the screening, assessment, diagnosis, treatment and follow-up of pain, as well as advising on the type and timing of medication administration and evaluation of dosage. In addition, nurses advise on non-pharmacological interventions. The work of cancer nurses is becoming increasingly complex and requires a constant expansion of personal knowledge. Although new technologies simplify some of the work, the social component and personal contact with the patients must not suffer as a result and remains extremely important to overcome barriers and ensure adherence to appropriate treatment. The relationship of trust between nurses, patients and their caregivers help them to cope with all the problems associated with the disease. This trustful professional relationship may become an even more important aspect in the future, as more and more cancers are transformed into chronic diseases thanks to new treatments, and as the management of pain to maintain an adequate level of quality of life becomes even more important.

Declarations

Ethics approval and consent to participate

Not applicable.

Consent for publication

Not applicable.

Author contributions

Johan de Munter: Conceptualization; Writing – review & editing.

Nikolina Dodlek: Conceptualization; Writing – review & editing.

Ani Khmaladze: Conceptualization; Writing – review & editing.

Sara Torcato Parreira: Conceptualization; Writing – review & editing.

Helena Ullgren: Conceptualization; Writing – review & editing.

Rik de Man: Conceptualization; Writing – review & editing.

Floris A. de Jong: Conceptualization; Writing – review & editing.

Wendy H. Oldenmenger: Conceptualization; Writing – review & editing.

Acknowledgements

None.

Funding

The authors disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: Medical writing support was provided by Ashfield MedComms GmbH, Mannheim, Germany, and was financially supported by Mundipharma Research Limited.

Competing interests

JdM is a steering committee member and lecturer for the Mundipharma Pain Academy and an advisory board lead for Viatris. RdM is an employer of Mundipharma Pharmaceuticals B.V. At initiation of this work, FAdJ was employed by Mundipharma. WHO is a steering committee member and lecturer for the Mundipharma Pain Academy. ND, AK, STP and HU declare no conflicts of interest. The funders (Mundipharma Research Limited) had no role in the design of the study; in the collection, analyses or interpretation of data; in the writing of the manuscript or in the decision to publish the results.

Availability of data and materials

Not applicable.

ORCID iDs

Helena Ullgren https://orcid.org/0000-0001-5747-853X

Wendy H. Oldenmenger https://orcid.org/0000-0001-6855-6505

Supplemental material

Supplemental material for this article is available online.

References

1. Sung H, Ferlay J, Siegel RL, *et al*. Global cancer statistics 2020: GLOBOCAN estimates of incidence and mortality worldwide for 36 cancers in 185 countries. *CA Cancer J Clin* 2021; 71: 209–249.
2. Breivik H, Cherny N, Collett B, *et al*. Cancer-related pain: a pan-European survey of prevalence, treatment, and patient attitudes. *Ann Oncol* 2009; 20: 1420–1433.
3. van den Beuken-van Everdingen MH, Hochstenbach LM, Joosten EA, *et al*. Update on prevalence of pain in patients with cancer: systematic review and meta-analysis. *J Pain Symptom Manage* 2016; 51: 1070–1090.e9.
4. Raja SN, Carr DB, Cohen M, *et al*. The revised International Association for the Study of Pain definition of pain: concepts, challenges, and compromises. *Pain* 2020; 161: 1976–1982.
5. Jensen MP, Chang HY, Lai YH, *et al*. Pain in long-term breast cancer survivors: frequency, severity, and impact. *Pain Med* 2010; 11: 1099–1106.
6. Geue K, Schmidt R, Sender A, *et al*. [Pain experiences and life satisfaction of young adult cancer patients]. *Schmerz* 2017; 31: 23–30.
7. Bennett MI, Kaasa S, Barke A, *et al*. The IASP classification of chronic pain for ICD-11: chronic cancer-related pain. *Pain* 2019; 160: 38–44.
8. Muller-Schwefe G, Ahlbeck K, Aldington D, *et al*. Pain in the cancer patient: different pain characteristics CHANGE pharmacological treatment requirements. *Curr Med Res Opin* 2014; 30: 1895–1908.
9. Fallon M, Giusti R, Aielli F, *et al*. Management of cancer pain in adult patients: ESMO Clinical Practice Guidelines. *Ann Oncol* 2018; 29(Suppl. 4): iv166–iv191.
10. Portenoy RK and Ahmed E. Cancer pain syndromes. *Hematol Oncol Clin North Am* 2018; 32: 371–386.
11. Khatooni M. Cancer pain: an evolutionary concept analysis. *Prof Case Manag* 2021; 26: 275–285.
12. Raijmakers NJH, Zijlstra M, van Roij J, *et al*. Health-related quality of life among cancer patients in their last year of life: results from the PROFILES registry. *Support Care Cancer* 2018; 26: 3397–3404.
13. Sibeoni J, Picard C, Orri M, *et al*. Patients' quality of life during active cancer treatment: a qualitative study. *BMC Cancer* 2018; 18: 951.
14. Bennett MI, Eisenberg E, Ahmedzai SH, *et al*. Standards for the management of cancer-related pain across Europe: a position paper from the EFIC Task Force on Cancer Pain. *Eur J Pain* 2019; 23: 660–668.
15. Davies AN, Elsner F, Filbet MJ, *et al*. Breakthrough cancer pain (BTcP) management: a review of international and national guidelines. *BMJ Support Palliat Care* 2018; 8: 241–249.
16. Fielding F, Sanford TM and Davis MP. Achieving effective control in cancer pain: a review of current guidelines. *Int J Palliat Nurs* 2013; 19: 584–591.
17. WHO. *WHO guidelines for the pharmacological and radiotherapeutic management of cancer pain in adults and adolescents*. Geneva: WHO Guidelines Approved by the Guidelines Review Committee, 2018.
18. McCorkle R, Ercolano E, Lazenby M, *et al*. Self-management: enabling and empowering patients living with cancer as a chronic illness. *CA Cancer J Clin* 2011; 61(1): 50–62.
19. Cox-Martin E, Anderson-Mellies A, Borges V, *et al*. Chronic pain, health-related quality of life, and employment in working-age cancer survivors. *J Cancer Surviv* 2020; 14: 179–187.
20. Ripamonti C and Fulfaro F. Malignant bone pain: pathophysiology and treatments. *Curr Rev Pain* 2000; 4: 187–196.
21. Young AM, Charalambous A, Owen RI, *et al*. Essential oncology nursing care along the cancer continuum. *Lancet Oncol* 2020; 21: e555–e563.
22. Vallerand AH, Musto S and Polomano RC. Nursing's role in cancer pain management. *Curr Pain Headache Rep* 2011; 15: 250–262.
23. Gallup. Honesty and ethics of professions ranking 2021, https://news.gallup.com/poll/388649/military-brass-judges-among-professions-new-image-lows.aspx (2021, accessed 02 April 2023).
24. Sharp L, Rannus K, Olofsson A, *et al*. Patient safety culture among European cancer nurses:

an exploratory, cross-sectional survey comparing data from Estonia, Germany, Netherlands, and United Kingdom. *J Adv Nurs* 2019; 75: 3535–3543.

25. Remy C, Borniard J and Perez J. Analysis of unscheduled telephone calls received by a specialized cancer pain nurse. *Pain Manag Nurs* 2020; 21: 255–258.
26. Crellin DJ, Harrison D, Santamaria N, *et al*. The psychometric properties of the FLACC scale used to assess procedural pain. *J Pain* 2018; 19: 862–872.
27. Masman AD, van Dijk M, van Rosmalen J, *et al*. The Rotterdam Elderly Pain Observation Scale (REPOS) is reliable and valid for non-communicative end-of-life patients. *BMC Palliat Care* 2018; 17: 34.
28. Mehta A and Chan LS. Understanding of the concept of 'total pain': a prerequisite for pain control. *J Hosp Palliat Nurs* 2008; 10: 26–32.
29. Duenas M, Ojeda B, Salazar A, *et al*. A review of chronic pain impact on patients, their social environment and the health care system. *J Pain Res* 2016; 9: 457–67.
30. Hjermstad MJ, Fayers PM, Haugen DF, *et al*. Studies comparing Numerical Rating Scales, Verbal Rating Scales, and Visual Analogue Scales for assessment of pain intensity in adults: a systematic literature review. *J Pain Symptom Manage* 2011; 41: 1073–1093.
31. Chapman S. Cancer pain part 2: assessment and management. *Nurs Stand* 2012; 26: 44–49.
32. Bennett MI, Bagnall AM and Jose Closs S. How effective are patient-based educational interventions in the management of cancer pain? Systematic review and meta-analysis. *Pain* 2009; 143: 192–199.
33. Martinez KA, Aslakson RA, Wilson RF, *et al*. A systematic review of health care interventions for pain in patients with advanced cancer. *Am J Hosp Palliat Care* 2014; 31: 79–86.
34. Udlis KA. Self-management in chronic illness: concept and dimensional analysis. *J Nurs Healthcare Chronic Illness* 2011; 3: 130–139.
35. Oldenmenger WH, Sillevis Smitt PAE, de Raaf PJ, *et al*. Adherence to analgesics in oncology outpatients: focus on taking analgesics on time. *Pain Pract* 2017; 17: 616–624.
36. van Dongen SI, de Nooijer K, Cramm JM, *et al*. Self-management of patients with advanced cancer: a systematic review of experiences and attitudes. *Palliat Med* 2020; 34: 160–178.
37. Rosa WE, Riegel B, Ulrich CM, *et al*. The association between analgesic treatment beliefs and electronically monitored adherence for cancer pain. *Oncol Nurs Forum* 2021; 48: 45–58.
38. Charalambous A, Wells M, Campbell P, *et al*. A scoping review of trials of interventions led or delivered by cancer nurses. *Int J Nurs Stud* 2018; 86: 36–43.
39. Te Boveldt N, Vernooij-Dassen M, Burger N, *et al*. Pain and its interference with daily activities in medical oncology outpatients. *Pain Physician* 2013; 16: 379–389.
40. Holland JC, Andersen B, Breitbart WS, *et al*. Distress management. *J Natl Compr Canc Netw* 2013; 11: 190–209.
41. Mori M, Elsayem A, Reddy SK, *et al*. Unrelieved pain and suffering in patients with advanced cancer. *Am J Hosp Palliat Care* 2012; 29: 236–240.
42. Kwon JH. Overcoming barriers in cancer pain management. *J Clin Oncol* 2014; 32: 1727–1733.
43. Campbell V. The challenges of cancer pain assessment and management. *Ulster Med J* 2011; 80: 104–116.
44. BMA. *Improving analgesic use to support pain management at the end of life*. London: BMA, 2017.
45. Oldenmenger WH, Sillevis Smitt PA, van Dooren S, *et al*. A systematic review on barriers hindering adequate cancer pain management and interventions to reduce them: a critical appraisal. *Eur J Cancer* 2009; 45: 1370–1380.
46. Can G, Mushani T, Rajhi BHA, *et al*. The global burden of cancer pain. *Semin Oncol Nurs* 2019; 35: 315–321.
47. Roberto A, Greco MT, Uggeri S, *et al*. Living systematic review to assess the analgesic undertreatment in cancer patients. *Pain Pract* 2022; 22: 487–496.
48. Ward SE, Goldberg N, Miller-McCauley V, *et al*. Patient-related barriers to management of cancer pain. *Pain* 1993; 52: 319–324.
49. Haverfield MC, Giannitrapani K, Timko C, *et al*. Patient-centered pain management communication from the patient perspective. *J Gen Intern Med* 2018; 33: 1374–1380.
50. Oldenmenger WH, Geerling JI, Mostovaya I, *et al*. A systematic review of the effectiveness of patient-based educational interventions to improve cancer-related pain. *Cancer Treat Rev* 2018; 63: 96–103.

51. Fahey KF, Rao SM, Douglas MK, *et al*. Nurse coaching to explore and modify patient attitudinal barriers interfering with effective cancer pain management. *Oncol Nurs Forum* 2008; 35: 233–240.

52. Cascella M, Thompson NS, Muzio MR, *et al*. The underestimated role of psychological and rehabilitation approaches for management of cancer pain. A brief commentary. *Recenti Prog Med* 2016;107: 418–421.

53. Park YJ and Lee MK. Effects of nurse-led nonpharmacological pain interventions for patients with cancer: a systematic review and meta-analysis. *J Nurs Scholarsh* 2022; 54: 422–433.

54. Oldenmenger WH, Baan MAG and van der Rijt CCD. Development and feasibility of a web application to monitor patients' cancer-related pain. *Support Care Cancer* 2018; 26: 635–642.

55. Rodriguez C, Ji M, Wang HL, *et al*. Cancer pain and quality of life. *J Hosp Palliat Nurs* 2019; 21: 116–123.

56. Oldenmenger W, van den Hurk CJG and Howell D. Utilizing technology to manage symptoms. In: Charalambous A (ed.) *Developing and utilizing digital technology in healthcare for assessment and monitoring*. Cham: Springer International Publishing, 2020, pp. 55–72.

57. Zheng C, Chen X, Weng L, *et al*. Benefits of mobile apps for cancer pain management: systematic review. *JMIR Mhealth Uhealth* 2020; 8: e17055.

58. Oldenmenger WH, Witkamp FE, Bromberg JEC, *et al*. To be in pain (or not): a computer enables outpatients to inform their physician. *Ann Oncol* 2016; 27: 1776–1781.