BMJ Open Nursing support for symptoms in patients with cancer and caregiver burdens: a scoping review protocol

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ABSTRACT

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Introduction Terminally ill patients with cancer experience a variety of symptoms, and their families experience certain caregiver burdens. Most studies on this topic have focused on the symptoms experienced by patients with cancer. There is little established evidence to show how nursing support affects these symptoms and burdens. Nurses provide support by extrapolating their clinical experience, practical knowledge and insights gained from the treatment phase of patients with cancer, regardless of the existence or degree of evidence. This study presents a scoping review protocol with the aim of categorising the feasibility of nursing support from the initial to the terminal phases in the trajectory of cancer care.

Method and analysis This review will be guided by Arksey and O'Malley's five-stage scoping review framework and Levac's extension. Our research project team will focus on the pain, dyspnoea, nausea and vomiting, constipation, delirium, fatigue and skin disorders experienced by patients with cancer as well as the burdens experienced by caregivers of such patients. All available published articles from database inception to 31 January 2022 will be systematically searched using the following electrical databases: PubMed, CINAHL, CENTRAL in the Cochrane Library and Ichushi-Web of the Japan Medical Abstract Society databases. In addition, we will assess relevant studies from the reference list and manually search each key journal. The formula creation phase of the literature search involves working with a librarian to identify relevant keywords. At least two reviewers will independently screen and review articles and extract data using a data chart form. Results will be mapped according to study design and analysed for adaptation in the field of terminal cancer.

Ethics and dissemination This review does not require ethical approval as it is a secondary analysis of pre-existing, published data. The findings will be disseminated through peer-reviewed publications and conference presentations.

INTRODUCTION

Terminally ill patients with cancer experience a wide range of symptoms, including pain, dyspnoea, fatigue, anorexia, nausea, anxiety

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ Evidence of nursing support in the field of cancer has been reported mainly in the treatment phase and less in the terminal phase; however, to the best of our knowledge, no prior study has examined the applicability of evidence from the treatment phase to the terminal phase of cancer.
- ⇒ The research project team will focus on the seven symptoms experienced by patients with cancer and the burdens of caregivers, and will map nursing support reported across all phases of the trajectory of cancer care to determine whether they are adaptable in the terminal cancer phase.
- ⇒ Methods based on established scoping review methodological approaches will be applied for the process of literature search, screening, extraction and analysis.
- ⇒ With the help of a librarian, a search formula will be developed and a wide-ranging search of published articles written in English and Japanese will be conducted.
- ⇒ The quality of the articles included in the review will not be assessed, as this is outside the ambit of the scoping review methodology.

and depression, which are reported to be experienced more frequently as patients approach death.¹⁻⁴ Additionally, the need for symptom palliation is heightened during the end-of-life stage, because symptoms often worsen with progressing stages of the disease. Therefore, in clinical settings, appropriate symptom management and medical care are expected to be provided. However, treatment of the causative condition is often difficult or even impossible because of the nature of terminal cancer, and symptomatic treatment is the focus of support.

Symptomatic treatment is broadly divided into pharmacological and non-pharmacological therapies, and providing a combination of these two therapies is crucial at the symptom management stage.⁵

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In particular, clinical practice guidelines provided by the National Comprehensive Cancer Network categorise prognosis into years, months to years, weeks to months and days to weeks; these guidelines recommend pharmacological and non-pharmacological therapies for each prognosis.^{5–7} However, non-pharmacological therapies still lack well-established evidence compared with pharmacological therapies in terms of specific recommended support. Thus, accumulating evidence globally for nonpharmacological therapies in end-of-life is challenging.

The support provided by nurses is known as nursing support and is part of typical non-pharmacological therapy. Recently, nursing support has been gradually accumulating evidence of assisting with symptoms of terminally ill patients with cancer. For example, 10-15 years ago, there was no sufficient evidence related to nursing support assisting dyspnoea in terminally ill patients with cancer, and nursing support was limited to referrals or a few recommendations. In 2008, Dy et al⁸ reported no recommendations for nursing support for dyspnoea and that there were only referrals for patient education, relaxation and psychosocial support. Similarly, in 2008, Bausewein *et al*^{*p*} reported on recommendations for nonpharmacological treatment from Cochrane Library. In this study, a search strategy was developed to include patients without cancer, and most articles included were on the palliation of dyspnoea in patients with chronic obstructive pulmonary disease, with only a few articles involving cancer patients. In addition, a paper published in the Clinical Journal of Oncology Nursing in 2008 found that there were no reports with sufficient evidence on nursing support, and the nursing support introduced was categorised as 'Likely to be effective' or 'Effectiveness not established'.¹⁰ Conversely, clinical guidelines reported by European Society for Medical Oncology Open in 2020^{11} and the Journal of Clinical Oncology in 2021^{12} stated that non-pharmacological approaches, including nursing support, are the first-line treatment option in the management of dyspnoea, complementing the support provided by pharmacological interventions. For example, fan therapy for dyspnoea has been introduced as a safe, inexpensive and effective method of support, owing to evidence accumulated in recent years,^{13–22} and many systematic reviews and meta-analyses have explored this topic.²³⁻²⁸ However, few nursing supports have been introduced in clinical guidelines.

For physical symptoms such as fatigue, pain, constipation, nausea and vomiting and skin disorders (eg, xerosis, oedema and skin fragility) that many patients with terminal cancer experience, most studies related to non-pharmacological therapies have been conducted on patients with cancer in the treatment phase, and few have been conducted on those in the terminal phase. For example, studies have reported on energy conservation,²⁹ aerobic exercise,^{30 31} massage,³² foot baths³³ and educational intervention^{34 35} for fatigue; music therapy,³⁶ reflexology³⁷ and massage³⁸ for pain; abdominal massage³⁹ and acupressure⁴⁰ for constipation; massage,⁴¹ breathing exercises⁴² and progressive muscle relaxation⁴³ for nausea and vomiting and moisturisers^{44–47} for skin disorders. Delirium is one of the most common psychiatric symptoms and is reported to be experienced by 44% of patients with cancer on admission to a palliative care ward and 88% immediately before death. For nursing support aimed at preventing the onset and severity of delirium, many studies have been reported in the field of terminal cancer; however, evidence for such nursing support has not yet been established.^{48–50}

Furthermore, family members of patients with terminal cancer also experience varied burdens associated with the worsening of the patient's condition and have a potentially high need for support.⁵¹⁻⁵³ Approximately 80% of the families of patients with cancer who experienced delirium reported that they felt severe distress.⁵⁴ Similar to patient support, support for family members is provided primarily through nursing support. These interventions include teaching coping skills,55 psychosocial education,⁵⁶⁻⁵⁸ mindfulness⁵⁹ and telephonic support. Moreover, similar to patient support, support for caregivers who experience burdens is mainly provided by nurses.⁶⁰ However, few studies have been conducted on the burdens of caregivers of patients with terminal cancer, and evidence that effective nursing support reduces such burden is yet to be established.

Nurses provide support to patients with terminal cancer and their families, regardless of the existence or level of evidence. This support is provided by nurses extrapolating their clinical experience, putting their knowledge to good use and using insights gained from the treatment phase. Some of these support mechanisms may not have been studied for patients with terminal cancer and their families; however, this does not indicate that they are ineffective. This can be described as the gap between clinical practice and research reports or evidence. To bridge this gap, it would be advisable to first summarise research reports on nursing support for patients with cancer in all phases, including the most recent studies, and then discuss their applicability to patients with terminal cancer or their families. Conducting a comprehensive scoping review that includes a variety of research designs and nursing supports to summarise all research and existing findings would be an appropriate way to clarify the gap. Scoping reviews are used to provide an overview of the key concepts that support an area of research, and the source and type of evidence available.⁶¹ Therefore, we organised a research project team with the following goals to tackle the above gap.

Objectives

Primary objective

To comprehensively explore the nursing support provided to alleviate pain, dyspnoea, nausea and vomiting, constipation, delirium, fatigue and skin disorders experienced by patients with cancer and the caregiver burdens experienced by their families, and to map them by research designs.

Secondary objective

To examine the feasibility of the nursing support mapped for each research design to patients with terminal cancer and their families.

METHODS AND ANALYSIS Definition

In this study, nursing support will be defined as 'support that can be implemented by nurses', and the extracted data in respect of nursing support will be discussed among the researchers to decide whether it can be implemented by nurses. The nurses include advance practice nurses (APNs), but pharmacological interventions provided by APNs are outside the scope of this review.

Design

This scoping review is designed in a standard framework proposed by Arksey and O'Malley⁶¹ and expanded by the Joanna Briggs Institute.⁶² The scoping review process follows five stages: (1) identifying the research question, (2) identifying relevant studies, (3) selecting studies, (4) charting the data and (5) collating, summarising and reporting the results.⁶¹

Stage 1: identifying the research question

The first stage of the scoping review is to identify the research question. To meet the objectives of the scoping review, as outlined above, this study will focus on the pain, dyspnoea, nausea and vomiting, constipation, delirium, fatigue and skin disorders (hereinafter collectively referred to as 'the symptoms') experienced by patients with cancer as well as the burdens experienced by caregivers of such patients. We selected these symptoms based on a literature review and discussion among nursing experts for patients with cancer. This research team will analyse the following research questions:

- 1. What types of nursing support are provided to reduce the symptoms experienced by patients with cancer and the caregiver burdens experienced by their families? For example, for Nursing Support 'X' for dyspnoea, what study design was set up, what types of patients with cancer were targeted, what are the duration and frequency of the Nursing Support 'X' intervention, and how has the efficacy been reported?
- 2. What is the feasibility of these nursing supports in reducing the symptoms of patients with terminal cancer and burdens of caregivers? For example, the efficacy of Nursing Support 'X' for dyspnoea has been reported in a randomised controlled trial (RCT) in patients with cancer in the treatment phase, but can this support be applied to patients with cancer in the palliative phase?

Stage 2: identifying relevant studies

The following eligibility criteria were determined by physicians and nurses who specialise in symptom management for patients with cancer or individuals experiencing caregiver burdens. Throughout the screening and data

extraction process, eligibility criteria will be discussed within the research team and updated to ensure that all relevant literature is collected.

Inclusion criteria

The following inclusion criteria will be applied:

▶ Patients/participants

Patients with cancer or their family members.

- 18 years and older.
- Intervention

Nursing support for pain, dyspnoea, nausea and vomiting, constipation, delirium, fatigue and skin disorders in patients with cancer or nursing support for caregiver burdens.

- Outcomes
- Quantitative data.
- Study design

RCT, non-RCT, crossover trial, single-arm precomparative/postcomparative study, cohort study (prospective/retrospective).

► Articles written in Japanese or English.

Exclusion criteria

The following exclusion criteria will be applied:

- Patients/participants
- Including at least 20% patients without cancer.
- Outcomes
- Oualitative data.
- Secondary analysis.
- Study design

Review article (systematic review/meta-analysis), response to letter, opinion (expert opinion), study protocol, conference proceedings or abstract, crosssectional study, case series study, case study, case study and literature review, books or books review and any form of qualitative research (eg, observations, interviews and focus groups).

Search strategy

All available published articles from database inception to 31 January 2022 will be systematically searched using the following electrical databases: PubMed, CINAHL, Cochrane Central Register of Controlled Trials in the Cochrane Library and Ichushi-Web of the Japan Medical Abstract Society databases. Additionally, we will assess the relevant studies from the reference list and manually search through key journals.

The formula creation phase of the literature search involves working with a librarian to identify relevant keywords. The final version of the search formula will first be used in the PubMed database (see online supplemental file 1) and then converted to suit each alternate database.

Stage 3: study selection

In this study, we will organise a research team (eight subgroups) to address the symptoms experienced by patients with cancer and burdens experienced by caregivers with respect to each research question. Each research subteam will meet to discuss preliminary inclusion and exclusion criteria during the protocol development phase. At least two researchers on each research subteam will independently review the entire article to refine the search strategy based on the abstracts obtained from the search and include them in the study, if relevant. Reviewers will meet at the beginning, middle and final stages of the abstract review process to discuss any challenges or uncertainties associated with study selection and to refine the search strategy as needed. Two reviewers will independently review the entire article if it meets the eligibility criteria or if the relevance of the article is unknown at the screening stage. When the two reviewers disagree, they must first meet to discuss the disagreement, and if it cannot be resolved, a third reviewer will be consulted to make a final decision.

Stage 4: charting the data

The research team will collaboratively develop a data chart form to extract and record data based on variables related to the research questions. Each subgroup will then be piloted with 5–10 articles to ensure complete data extraction related to the research questions and discuss the data extraction process and procedures. Following full data extraction, the data extracted by each researcher independently will be compared for discrepancies to ensure consistency between researchers.

A preliminary data extraction framework was developed to answer the predefined research questions. Along with basic bibliographic information (first author, year of publication, study location or country, etc.), information on (1) study design, setting and sample size; (2) age, gender and primary cancer sites of the target population; (3) contents, purpose and methods of nursing support, duration and frequency of implementation, provider and details of the control group; (4) outcome measurement tools, evaluation points and frequency and (5) details of the effect was included.

Stage 5: collating, summarising and reporting the results

This stage will be conducted in three phases, referring to the framework of Arksey and O'Malley and the guidelines of Levac *et al*⁶³ as follows:

1. Analysis: each study will be described, and the research design, sample size and demographic data will be summarised as quantitative analysis, and the nursing support will be classified based on its characteristics by qualitative thematic analysis.

- 2. Reporting the results of the analysis and producing outcomes that mention the research objectives and research questions.
- 3. Considering the significance of the findings in relation to the overall research objectives and discussing the implications for future research, practice and policy. In addition, it is anticipated that the scope of care that can be provided by nurses in different countries will vary. Therefore, depending on the nursing support identified, the feasibility will be discussed, including the characteristics of the reported country.

This research team, consisting of eight subgroups, will conduct a scoping review of each of the symptoms experienced by patients with cancer and the burdens of caregivers. First, each study will be described for the research question that each subgroup is responsible for, and the level of evidence by research design will be mapped with reference to the evidence pyramid. Each nursing support will be classified by qualitative thematic analysis. The mapped results will be summarised to generate a cancer-wide framework for the seven symptoms and the caregiver burdens. Next, we will discuss the applicability of the framework for patients with terminal cancer based on the generated data. Despite its high feasibility, there are few reports on nursing support for patients with terminal cancer or their families, and we will discuss its meaning and facilitating and inhibiting factors.

The results will be reported using figures and tables as appropriate. The final review will be reported using the Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews.⁶⁴

Patient and public involvement statement

Patients and the public are not involved in the design, execution and analysis of the study.

ETHICS AND DISSEMINATION

This review does not require ethical approval as it is a secondary analysis of pre-existing, published data. In order to disseminate the results of the study, we plan to submit the results to a peer-reviewed journal and to present them at local and international conferences to share the results with a wide range of population. Furthermore, the results of this study will be disseminated widely at academic conferences in Japan through exchange meetings.

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