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Priorities for Cancer Research From the Viewpoints of Cancer Nurses and Cancer Patients

A Mixed-Method Systematic Review

KEY WORDS

Cancer research
Mixed-method systematic review
Nurses' perceptions
Nurses' priorities
Nursing societies
Patients' perceptions
Patients' priorities
Research agenda

Background: Setting priorities in oncology is a useful way to produce a robust set of research questions that researchers can address. **Objective:** The aim of this review was to describe cancer nurses and patients' main research priorities and describe their development over time. **Methods:** A mixed-method systematic review was conducted for the period from 2000 to 2018 through a search of multiple databases. The methodological quality of the studies included was assessed using the Mixed-Methods Appraisal Tool, and the process of setting the health research priorities was assessed using Viergever's tool. Each study's top research priorities were extracted and summarized in categories. **Results:** Fifteen studies were included: 13 addressed nurses' research priorities, and 2 focused on those of patients. The majority were Delphi and quantitative studies that were conducted in the United States and United Kingdom. The quality criteria score and the quality of the process were considered sufficiently good. The most important research priorities were categorized as disease control and management, patient-related issues, and professional dimensions and issues. Management of symptoms and pain, education, information, and communication were research priorities always present in the articles during the study period. **Conclusion:** Priorities change over time and depend on several factors; however, some have remained consistent for the last 18 years. Although there is increasing emphasis on including patients in establishing research priorities that inform cancer care, this involvement is still lacking. **Implications for Practice:** Future studies should describe the primary cancer research priorities of nurses in collaboration with patients.

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The authors have no funding or conflicts of interest to disclose.

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Accepted for publication August 22, 2019.

DOI: 10.1097/NCC.0000000000000776

Cancer care is changing constantly and is increasingly complex because of advances in science, technology, and treatments.^{1,2} These advances, including such new therapies as targeted agents and immunotherapies that require a personalized approach to care, have increased the survival of patients with cancer.³ Such improvements have been made across cancer services, from better prevention and screening (eg, home tests for colorectal cancer) to new forms of surgery (eg, robotic surgical systems) and enhanced recovery and survivorship programs.¹ These changes also concern patients' health behaviors, clinicians' decisions, medical delivery systems, and symptom management⁴ and increasingly require a multidisciplinary approach to cancer care.⁵

To compound this increasing complexity, the number of patients with cancer also is increasing rapidly.⁶ In 2018, almost 18.1 million new cancer cases were estimated and 9.6 million cancer deaths occurred worldwide compared with 14.1 million new cancer cases and 8.2 million cancer deaths in 2012.^{6,7}

Cancer nurses struggle to meet the challenges of providing quality nursing care in this changing environment. To help them keep pace and develop new competencies necessary, nursing research priorities should be established.^{2,8} While prevention and treatment modalities are being developed in clinical research, nursing research should focus on the people involved directly (patients and families) to understand the new care needs or the effects of the care practiced.⁸ Efforts, therefore, should focus not only on improving cancer care quality⁹ but also on implementing best clinical practices with the goal to improve patient outcomes.¹⁰ Outlining priorities also can help focus on a particular issue rather than promoting isolated and unrelated studies of patients' needs. There also is a practical reason to do so, in that there are limited resources available for nursing research.^{2,11}

Promoting healthcare services users' involvement in making healthcare decisions has attracted increasing attention. Such involvement has expanded from the clinical practice to the research setting to bridge any gaps between the answers that patients seek and those that research provides.^{12–14} Considering the patients' point of view makes research relevant and valuable for them and their caregivers and thus changes the traditional clinician-patient relationship.¹³ This approach has led to studies that include the patients' point of view in setting research priorities. For example, Jones and colleagues¹² identified patients, caregivers, and clinicians' top 10 kidney cancer research priorities.

Although the many innovations and rapid developments in research have brought about major changes in cancer care, it is unclear whether the research priorities related to nurses and patients reflect these changes over time.

The aims of this mixed-method systematic review were to describe primary cancer research priorities based on the perspective of oncology nurses, patients with cancer, and other users of oncology services and to report their development over time.

■ Methods

A mixed-method systematic review was performed in 2017/2018 according to the Joanna Briggs Institute Reviewers' Manual¹⁵ and reported following the Preferred Reporting Items for Systematic

Reviews and Meta-Analyses guidelines.¹⁶ This type of review integrates qualitative and quantitative research (research questions, methods, techniques for collecting/analyzing data, and the findings are of both qualitative and quantitative type), as well as mixed-methods studies, in order not to neglect any important evidence.¹⁷

The study protocol was registered at PROSPERO, the international prospective register of systematic reviews (registration number: CRD42017059721).

Eligibility Criteria and Search

The review question was defined with respect to a modified version of PICO (population, interventions, comparison, outcomes^{16,18}), in which “intervention” and “comparison” were replaced by “phenomenon of interest.” An iterative interrogative process was followed to develop the search terms for the review questions using the following definitions:

1. *Population:* Patients diagnosed with cancer (oncology patient, oncology user, healthcare user, cancer patient, cancer consumer, survivor) or nurses assisting patients with cancer in an oncology ward.
2. *Phenomenon of interest:* Issue, patients' perspective, needs and needs unmet, demand, health service needs, unresolved problems, research priorities, cancer priorities, and health priorities.
3. *Outcomes:* “Nursing research priorities” or “patient research priorities.”

Studies' inclusion criteria were that they (1) investigated oncology nurses or patients' research priorities; (2) used a quantitative, qualitative, or mixed-method research design; (3) were published in English; (4) had abstracts readily available; (5) had an adult population (≥ 18 years old); and (6) were published between 2000 and 2018. Studies' exclusion criteria were if they (1) did not report or discuss explicitly nurses or patients' research priorities or needs identified as research priorities; (2) included children, adolescents, or older patients; (3) focused on the palliative care setting; (4) involved patients with hematological cancer or those undergoing bone marrow transplantation because behaviors, treatments, and outcomes are different from solid tumors¹⁹; or (5) investigated caregivers. Furthermore, studies were excluded if they reported only nurses' perceptions of patients' priorities, or the converse. Finally, in addition, systematic reviews were excluded, although their reference lists were examined.

A systematic search of the literature was conducted with the following electronic databases: MEDLINE, CINAHL, Scopus, Psychology and Behavioral Sciences Collection, the Cochrane Database of Systematic Reviews, TDNet, and PROSPERO. Initial electronic searches were run between January 15 and March 31, 2017, and updated on November 30, 2018. This electronic research was accompanied by manual research in nursing journals.

Medical Subject Headings and key terms were exploded where possible and modified as necessary for the various databases (Appendix 1). The main key terms were “cancer nursing,” “oncology patient,” “research priorities,” and “cancer priorities.” Searching citations and checking reference lists and gray literature (Gray Literature database in the Cancer Institute's website, Oncology Nursing Societies website, The Grey Literature Report) were used only to

identify additional articles for inclusion. All records identified were inserted into EndNote (X7.8), and any duplicates were deleted.

Data Collection Process

Two reviewers selected the studies independently according to their titles, keywords, and abstracts and then read the full texts of the articles selected. Discrepancies in the selection process were resolved in a consensus meeting with a third researcher. Interrater agreement on the inclusion of studies was calculated using the weighted κ statistic with $\kappa < 0$ indicating poor agreement, $\kappa = 0-0.20$ indicating slight agreement, $\kappa = 0.21-0.40$ indicating fair agreement, $\kappa = 0.41-0.60$ indicating moderate agreement, $\kappa = 0.61-0.80$ indicating substantial agreement, and $\kappa = 0.81-1.00$ indicating nearly perfect agreement.²⁰

The details of each study included were noted according to the Institute of Medicine's²¹ (2011) criteria: goal and study design, research priority identified, methodology, sample and setting, and findings and conclusions. At the end of each phase of the review process, the number of studies excluded and the reasons for their exclusion were recorded.

Appraisal

Two different evaluation approaches were used in this review.

The methodological quality of studies included was assessed using the Mixed-Methods Appraisal Tool (MMAT).²² This tool was chosen because it can evaluate the primary studies' methodology—quantitative, qualitative, and mixed-method/combined. The MMAT's validity and reliability have been documented previously.²³⁻²⁵ The tool poses 2 questions for screening purposes and 4 questions about methodological quality that differ for qualitative and quantitative study designs. There are 3 possible answers to each question (“yes,” “no,” or “can't tell”). For the 4 questions about methodological quality, every “yes” (star) is converted to a percentage that is summed for a total score that ranges from 1 (25%) to 4 (100%) stars.²²

The process of setting the health research priority was evaluated using the principles of good practice proposed by Viergever and colleagues.²⁶ Their checklist encompasses 9 common themes to prioritize the research process grouped into 3 categories: (1) preparatory work (context [7 items], use of a comprehensive approach [1 item], inclusiveness [5 items], information gathering [1 item], and planning for implementation [1 item]), (2) deciding on priorities (criteria [1 item] and methods for deciding on priorities [1 item]), and (3) after priorities have been set (evaluation [1 item] and transparency [1 item]). There are 2 possible answers to each item (“yes” or “no”). A total of 20 aspects of the process of setting health research priorities were assessed.

Two reviewers assessed the methods and process quality of the studies included independently, and discrepancies were resolved through discussion between these 2 and other reviewers.

Synthesis of Study Findings

First, the 2 researchers collected information about the following variables: research priorities (outcomes), description, and references. Then, content analysis was performed to identify the most

frequent outcomes, as Vaismoradi et al²⁷ described. This method was chosen because it is suitable for summarizing assorted data. The outcomes were classified into categories, which were developed by regrouping similar characteristics and differences to establish the narrative summary of the research priority.

Specifically, the units of analysis were the top research priorities extracted, condensed, organized, and combined into categories. The 2 researchers (L.C., an oncology nurse, and V.B., a clinical nurse), who were familiar with the data in their entirety, made the initial codification, but the categories were refined in discussions and finally confirmed by the entire research group. In addition, the 2 researchers checked that all of the information relevant to the research questions was included and fit in the final categories.

Results

After an initial screening of 1596 records, 66 potentially eligible articles were retained and their full text was retrieved. Of these, 48 were excluded (Figure 1), whereas 15 studies that met our eligibility criteria were included.^{1-4,8,28-37} Interrater agreement to include the studies was 0.70 (SE = 0.87, $P < .001$), indicating strong agreement between the reviewers.

Study Characteristics

Among the 15 studies identified for this review (Table 1), 12 addressed nurses' research priorities,^{2-4,8,28,29,31-37} 2 focused on patients' research priorities,^{30,33} and 1 addressed nursing research priorities from both nurses' and patients' perspectives.¹ For this last study, we considered only the data on the nurses' point of view, because the patients reported only what they believed nurses' research priorities were, without expressing their own priorities.

Nearly all articles were descriptive or Delphi studies that used a quantitative or qualitative approach: 9 were descriptive, 5 were Delphi (multistaged survey), and 1 was an exploratory qualitative study. In details, 5 had been conducted in the United States,^{3,4,8,29,35} 3 had been conducted in the United Kingdom,^{1,30,33} 2 had been conducted in Australia,^{28,37} 1 had been conducted across Europe,² and 1 each had been conducted in Ireland,³⁵ Northern Ireland,³² Norway,³⁶ and South Korea.³¹ The sample size varied widely among the studies, from 45²⁸ to 895³ nurses and from 18¹ to 780³³ patients, for a total of 5400 participants (3649 nurses and 903 patients). The studies included data collected using forms adapted from previous surveys (11 studies^{1,3,4,8,28,31,33-37}), used a new questionnaire (3 studies^{2,29,32}), or used a focus group technique (1 study³⁰). Most of those concerning nurses' priorities (10 of 15 studies) involved professional associations, including the US-based Oncology Nursing Society, the European Oncology Nursing Society, the Korean Oncology Nursing Society, the Norwegian Society of Nurses, and the United Kingdom Oncology Nursing Society.

With respect to the nurse participants' qualifications and experience in oncology, there were large differences among the 13 studies that included nurses. Of the study participants, 1% to 23% held a doctoral degree, the highest nursing qualification, whereas cancer nursing experience ranged from 1 to more than

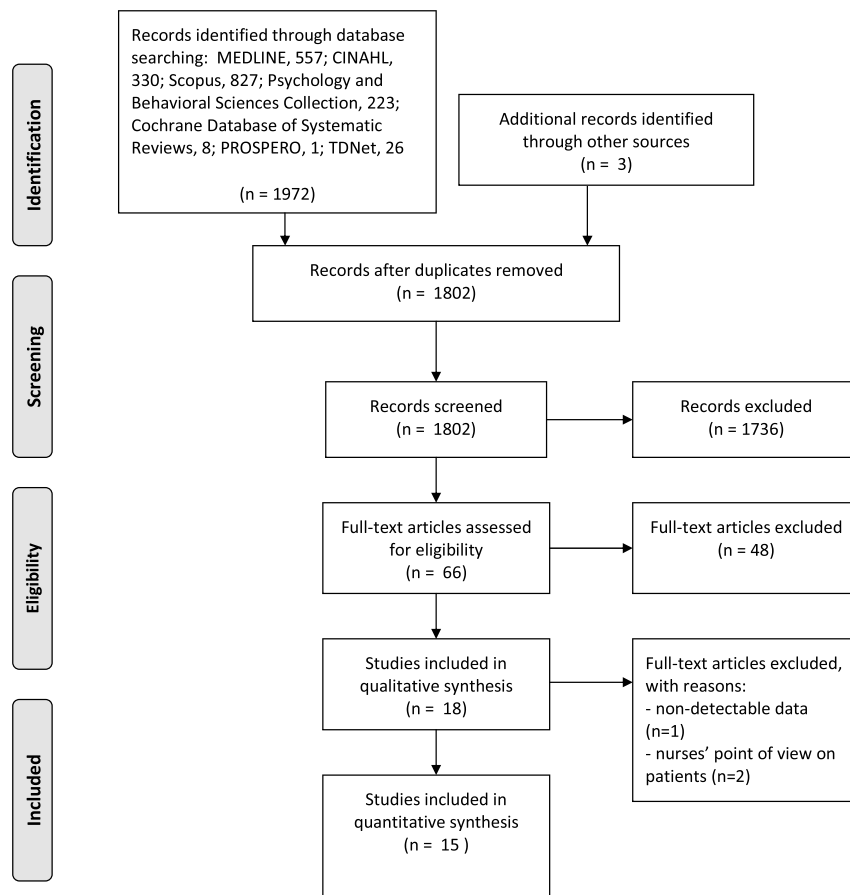


Figure 1 ■ Preferred Reporting Items for Systematic Reviews and Meta-Analyses flow diagram for selecting articles to include in the mixed-method systematic review.

21 years. Only 3 of the studies involving nurses failed to report these data about their participants.^{30,33,37}

■ Methodological Quality

When the 15 studies were evaluated for methodological quality with MMAT (Appendix 2), nearly all received a “yes” score on both of the 2 screening questions, with the exception of Moorcraft et al’s³³ study, which received only one. With respect to methodological quality, the scores varied from 25% (1 of 4 quality criteria met) to 100% (all criteria met). For the 14 studies with a quantitative descriptive or Delphi design, only one met all 4 methodological criteria,³³ 12 met 3 of the 4 criteria,^{1–4,8,28,29,31,32,35–37} and one met 1 of the 4 criteria.³³ The single qualitative study³⁰ had a score of 75%. As a whole, the studies’ methodological quality was considered sufficiently good.

Low scores were attributable to a response rate less than 60% (10 studies), unreported response rate (2 studies), lack of information about researchers’ influence in qualitative research (1 study), or concerns about the measurements’ appropriateness or the sample’s representativeness in quantitative research (1 study).

The process of setting the health research priorities was evaluated using Viergever et al’s²⁶ checklist and Appendix 3. The degree to which the evaluation was complete varied from two to all items

assessed. In the context theme, the environment and the research priorities’ focus were detailed in all studies (100%). In 14 studies (93.4%), the process of setting priorities was reported in detail, and the participants involved in the studies always were described (100%). The information and sources were reported in 12 studies (80%). Plans to translate and implement the research priorities were referenced in 7 (46.7%) and 9 (60%) studies, respectively. All studies reported the way in which priorities were determined; however, only 6 (40%) reported when, and the way in which, the priorities established were evaluated. Finally, all studies described the approach used well.

■ Research Priorities

All 15 studies summarized the top research topics (mean, 10; range, 5–20). Nurses’ 5 top research priorities are shown in Table 2. Nine studies set research priorities for nurses’ knowledge of symptom and pain control, including in the palliative setting.^{1–4,8,28,31,35,37} The symptoms of greatest concern in these studies were nausea and vomiting^{3,37}; constipation, mucositis, and nutrition³⁷; and fatigue, neuropathy, psychological distress, cognitive impairment, and depression.³ With respect to education, information, and communication, the studies highlighted communication between nurses and both physicians and patients,³⁶ patients’ educational needs,^{2,37}

Table 1 • Characteristics of 15 Studies Included in the Mixed-Method Systematic Review

Reference	Viewpoint	Aims	Study Design	Participants' Characteristics ^a	Country, Society
Rustøen & Schjøllberg, ³⁶ 2000	Nurses	Determine research priorities among nurses in cancer care	Survey using a questionnaire of Bakker and Fitch ⁴² (1998)	197 nurses (43% RR); age (y): <29, 4.1%; 30–39, 32.0%; 40–49, 41.7%; ≥50, 22.3%	Norwegian Society of Nurses
Barrett et al, ²⁸ 2001	Nurses	Identify nurses' research priorities for adult cancer nursing	Delphi study: first questionnaire (WCCNR, 1998) ⁴⁹ followed by a second ad hoc questionnaire	Round 1: 45 nurses (56% RR); mean age, 39 y Round 2: 30 nurses (70% RR); mean age, 39 y	Australia
Browne et al, ² 2002	Nurses	Examine the research priorities of European cancer nurses	Delphi study using an ad hoc questionnaire in 2000	Phase 1: 219 nurses (98% RR); age (y): 21–30, 15%; 31–40, 41%; 41–50, 36%; 51–60, 8% Phase 2: 7 nurses Phase 3: 117 nurses (55% RR)	European Oncology Nursing Society
Ropka et al, ³⁵ 2002	Nurses	Determine research priorities for oncology nursing	Survey using a questionnaire modified from studies by Bakker and Fitch ⁴² (1998) and Lindquist et al (1993) ⁵⁰ conducted in 2000	788 nurses (39% RR); 96% female; age (y): 20–29, 14%; 30–39, 22%; 40–49, 41%; 50–59, 19%; ≥60, 4%	United States, Oncology Nursing Society
Yates et al, ³⁷ 2002	Nurses	Establish priorities for cancer nursing research in Queensland	Descriptive survey using a questionnaire modified from Wright et al (1997) ⁵¹	319 respondents (54.3% RR); 97.8% female; age (y): 20–29, 10.1%; 30–39, 26.4%; 40–49, 34.6%; 50–59, 26.7%; ≥60, 2.2%	Australia, Oncology Nurses Group of Queensland
McIlpatrick & Keeney, ³² 2003	Nurses	Identify cancer nursing research priorities	Delphi study with ad hoc questionnaire	Round 1: 60 delegates (54% RR) Round 2: 47 (78% RR) Age (y): 20–30, 21.3%; 31–40, 40.4%; 41–50, 21.4%; 51–60, 8.5% Round 3: 43 (91% RR)	Northern Ireland, European Oncology Nursing Society
Lee et al, ³¹ 2003	Nurses	Identify oncology nursing research priorities	Descriptive survey using a questionnaire modified from Ropka et al ³⁵ (2002)	59 nurses (26.9% RR); age (y): ≤29, 30.5%; 30–39, 37.3%; 40–49, 22%; ≥50, 10.2%	Korea, Korean Oncology Nursing Society
Cohen et al, ²⁹ 2004	Nurses	Identify oncology nurses' priorities for topics and issues	Delphi study using an ad hoc questionnaire with open-ended questions	Round 1: 642 nurses (54% RR); 91% female; mean age, 40.7 y Round 2: 567 nurses (48% RR); 87% female; mean age, 40.9 y	United States, Nursing Research Council
Berger et al, ⁴ 2005	Nurses	Determine research priorities of the Oncology Nursing Society membership	Descriptive, cross-sectional study using an online questionnaire modified from Ropka et al ³⁵ (2002)	431 society members (15% RR); 97% female; age (y): <30, 2%; 30–49, 16%; 40–49, 37%; 50–59, 38%; 60–69, 6%; >70, 1%	United States, Oncology Nursing Society
Corner et al, ³⁰ 2007	Patients	1. Establish research priorities from the patients' viewpoint 2. Reach consensus over priorities for cancer research	Exploratory, qualitative study with focus groups	105 participants with a median of 6 (range, 3–11) participants in each focus group: 68,6% female; age (y): 30–39, 3.8%; 40–49, 9.5%; 50–59, 23.8%; 60–69, 26.7%; ≥70, 21.9%	United Kingdom
Doorenbos et al, ⁸ 2008	Nurses	Determine the priorities of oncology nursing research	Descriptive, cross-sectional, online Delphi survey conducted in 2008	713 nurses (12% RR); age (y): 20–29, 2%; 30–39, 7.2%; 40–49, 18.2%; 50–59, 25%; 60–69, 41%; >69, 1%	United States, Oncology Nursing Society
LoBiondo-Wood et al, ³ 2014	Nurses	Identify priorities for research- and evidence-based practice initiatives	Survey using a questionnaire with open-ended questions, modified from Doorenbos et al ⁸ (2008) conducted in 2013	895 nurses (11% RR); 95% female; age (y): 20–29, 5%; 30–39, 12%; 40–49, 21%; 50–59, 42%; 60–69, 18%; >69, 2%	United States, Oncology Nursing Society

(continues)

Table 1 • Characteristics of 15 Studies Included in the Mixed-Method Systematic Review, Continued

Reference	Viewpoint Aims	Study Design	Participants' Characteristics ^a	Country, Society
Moorcraft et al, ³³ 2016	Patients Investigate patients' views on areas that should be priorities for cancer research	Survey with online or printed questionnaire	780 respondents: 55% female; age (y): <45, n = 119 (15%); 46–60, n = 234 (30%); 61–75, n = 326 (42%); >75, n = 85 (11%)	United Kingdom
Murphy & Cowman, ³⁴ 2006	Nurses Identify research priorities of cancer nurses	Descriptive study using a self-reporting instrument modified from McIlpatrick and Keeney ³² (2003)	79 nurses (66.4% RR); 78% female; age: 30–39 y, 39 (43%)	Ireland
Cox et al, ¹ 2017	Patients and nurses Establish priorities for UK oncology nursing research	Delphi study using an online questionnaire modified from Berger et al ⁴ (2005) and Ropka et al ³⁵ (2002)	Round 1: 68 nurses (97% RR); age (y): 26–34, n = 2; 35–44, n = 17; 45–54, n = 24; ≥55, n = 7; missing, n = 18 Round 1: 18 patients; age (y): 26–34, n = 1; 35–44, n = 0; 45–54, n = 3; 55–64, n = 5; 65–84, n = 8; ≥85, n = 1 Round 2: 62 responders (91% RR) Round 3: 60 responders (88% RR)	United Kingdom Oncology Nursing Society

Abbreviation: RR, response rate. WCCNR, Western Consortium for Cancer Nursing Research.

^a Gender and RR are listed for all studies in which they were specified in the report.

communication issues for patients throughout the cancer journey,^{32,34} and the way to involve the patients in care decisions.²⁸ Several studies highlighted patients' and families' quality of life (QoL^{4,30,35}) and medical care's effect on it.^{2,8} Quality of life is a multidimensional concept that emphasizes personal feelings and judgments, including their physical, psychological, social, interpersonal, and financial aspects.^{2,31,36} Issues about the professional dimension included interdisciplinary working and networking stress, burnout, and coping²; improving retention and reducing turnover²⁹; and health system issues.³⁷

The 2 studies on patients' perspectives (Table 3) prioritized cancer detection and prevention, including the development of techniques to identify particular cancers easily and effectively and identify cancer's risk factors and causes. These studies have furthermore prioritized the need of a better scientific understanding.^{30,33} They also revealed that patients want research on whether, and the way in which, environmental factors (eg, air pollution, electricity pylons, mobile phones, TVs, computers, microwave ovens, and aerosols), genetics, diet, anxiety and stress cause cancer.^{30,33}

■ Research Categories

From the analysis, nurses and patients' research priorities (only top 5 considered) were grouped into 3 categories (Table 4): (1) “disease control and management” (cancer prevention, early detection, management of treatments and symptoms, therapy adherence, complementary and alternative therapies, late effects, participation in making decisions to end of life, palliative care, and QoL/effect on life), (2) “patient-related issues” (psychological/psychosocial experiences, relational aspects, communication, and education), and (3) “professional dimension and issues” (satisfaction, staffing, turnover, stress, burnout, coping, cancer nursing research, health system issues, access to and continuity of care, department organization, cost-effectiveness).

■ Discussion

This mixed-method systematic review identified both cancer nurses' and patients' priorities for research through a comprehensive assessment of the literature from 2000 to 2018. Contributions about research priorities came from the United States, Australia, and various European countries. Nine of the 15 studies included used a descriptive methodology, in which the study design used most commonly was a cross-sectional survey, followed by the Delphi technique. According to Keeney et al,³⁸ the most appropriate method to investigate research priorities in this type of research is a multistaged survey, the goal of which is to achieve consensus on an issue, and 6 of the 15 studies included in this review used such a survey.

In assessing the quality of the studies selected, several methodological limitations were identified that suggested the need for greater attention in planning future studies with more rigorous methodologies. For example, 10 of these studies had response rates less than 60%, and 2 did not report the response rate. Furthermore, in 1 report, it was unclear whether the study

Table 2 • Nurses' Top 5 Research Priorities

Reference	First Priority	Second Priority	Third Priority	Fourth Priority	Fifth Priority
Rustøen & Schjølberg, ³⁶ 2000	Quality of life	Psychosocial support/counseling	Patient participation in decision making	Communication patient-nurse	Nurse burnout and self-care
Barrett et al, ²⁸ 2001	Management of terminal care	Professional issues	Symptom management	Education and information	Communication
Browne et al, ² 2002	Communication and information	Cancer nursing research	Psychological experience; care experiences of disease	Cancer nursing and symptom intervention	Stress, burnout, and coping
Cohen et al, ²⁹ 2004	Acute and chronic pain	Infection rates and control	Job satisfaction	Nurse-patient ratios and staffing	Improving retention of nurses and reducing turnover
Ropka et al, ³⁵ 2002	Pain	Quality of life	Early detection of cancer	Prevention/risk reduction	Neutropenia/immunosuppression
Yates et al, ³⁷ 2002	Psychosocial support	Pain management	Symptom management	Health system issues	Patient/community education
McIlfratrick & Keeney, ³² 2003	The identification of communication issues for patients throughout the cancer journey	Exploring the levels of stress and burnout for cancer nurses	Continuity of care between hospital, community, and hospice settings	The experience of a single parent diagnosed with cancer	The informational needs of patients after treatment
Lee et al, ³¹ 2003	Prevention of cancer/cancer risk reduction	Pain	Quality of life	Hospice/end-of-life care	Standards of care
Berger et al, ⁴ 2005	Quality of life	Participation in decision making about treatment	Patient/family education	Participation in decision making about treatment	Pain
Murphy & Cowman, ³⁴ 2006	Communication and information giving	Nursing issues	Family issues	Cancer service issues	Palliative care issues
Doorenbos et al, ⁸ 2008	Quality of life	Pain	Late effects of treatment	Access to care	Palliative care
LoBiondo-Wood et al, ³ 2014	Develop and evaluate intervention: adherence	Persistent and late effects: neurocognitive	Cancer screening and early detection (to minorities)	Symptom management: self-management symptom control	Screening early detection: underserved or underinsured
Cox et al, ¹ 2017	Patients' early presentation with cancer symptoms	Early diagnosis of cancer	Availability of psychological support services across the cancer trajectory, particularly recurrence	Management of anxiety and uncertainty after cancer treatment	Ways to evidence the cost-effectiveness of clinical nurse specialists

 **Table 3 • Patients' Top 5 Research Priorities**

Reference	First Priority	Second Priority	Third Priority	Fourth Priority	Fifth Priority
Corner et al, ³⁰ 2007	Effect on life, how to live with cancer, and related support issues	Risk factors and causes	Early detection and prevention	General information needs (on cancer, treatment, and research)	Use and effectiveness of complementary and alternative therapies
Moorcraft et al, ³³ 2016	Detection and prevention	Scientific understanding	Curative treatment	Personalized treatment	Detecting recurrence

sample represented the population studied (inclusion and exclusion criteria were not described) and the measurements were appropriate. The 14 quantitative studies largely were descriptive surveys and Delphi projects that did not use validated tools but, instead, used tools adapted from previous studies without piloting them in advance. Similar survey questionnaires were moreover used, but the items did not cover all possible research areas. Some priorities, therefore, may not have been considered, so these studies may not necessarily represent all cancer nurses' or patients' views. Nearly all of the articles included provided complete descriptions of the data collection methods (study design and instruments), yet most lacked important information, such as the study period, which makes it difficult to evaluate the evolution of priorities over time. In qualitative research, the researcher's role is influential at all stages, from the formulation of the research question to data collection and analysis, and interpretation of the findings.²² The qualitative study included here³⁰ did not provide information on their searchers' influence (eg, whether nurses and researchers knew each other), and this lack of information may represent a bias. To evaluate the process of setting health research priorities, such features as context, use of a comprehensive approach, gathering information, planning for implementation, determining priorities and methods, evaluation, and transparency also were evaluated.²⁶ The results of these evaluations showed distinct variability. Significant attention was paid to the context (resources available; focus on priorities, values, and principles considered; environment in which the priorities were investigated), and the participants' engagement was notable in all studies, suggesting the solidity of the methods and relevance of the topics selected. Only 2 studies^{31,33} considered the economic and financial aspects, which suggests that future studies need to give these factors more attention. The reduction in the availability of financial resources for nursing research or for health professionals in general is a problem felt acutely, which translates to limited approval of resource requests or failure to allocate resources for research.

Nursing research priorities have been studied in the United States and Canada for many years, where studies have been conducted since the late 1980s.^{39–42} Today, studies on nursing research priorities continue to attract considerable interest because many research areas are complex, subject to frequent changes and updates, and require sustained focus and effort. Several nursing societies have surveyed their members for the past 30 years. For example, the Oncology Nursing Society, founded in 1975, has conducted this type of survey in the United States approximately every 4 years since 1980.³ Other associations have conducted surveys in European countries^{1,2,32,36} and in Australia³⁷ and South Korea.³¹ The Asian Oncology Nursing Society is relatively young and represents 9 Asian countries' oncology

nursing societies; it includes the Korean Oncology Nursing Society, which conducted a membership survey in 2003, whereas the first Asian conference was held in Thailand in 2013.⁴³ Although these organizations are important, only members' opinions are considered in their surveys, which could limit the identification of nursing research priorities.

In several of the articles included in this review, research priorities were ranked in order of importance (eg, Cox et al,¹ Berger et al,⁴ Barrett et al,²⁸ Cohen et al²⁹). The priorities, however, were illustrated with examples only in 4 articles: 2 studies described in detail talking about symptoms,^{2,30} whereas the difference between “QoL” and “effect on life” was explained to participating patients only in 2 surveys.^{3,37}

We categorized nurses and patients' research priorities into 3 main research fields. The first, “disease control and management,” refers to medical interventions' delivery (eg, prevention and risk reduction, screening, treatment, survivorship, and end-of-life care) and is similar to the cancer care continuum Charalambous and colleagues⁴⁴ described. This field includes symptom management, disease trajectory, prevention and risk reduction, late treatment effects, early presentation of cancer symptoms and early diagnosis, and uncertainty after cancer treatment. We believe that most nurses gave high priority to this area because of interventions' great complexity and frequent clinical use to manage and prevent symptoms. Symptom management, such as acute and chronic pain, or pain management in general, was always present in the studies from 2000 to 2018 (10 of 15 studies), unlike QoL/effect on life, which has not been considered often in the past 10 years (present in 6 of 15), perhaps because it is assessed indirectly already and is no longer a priority. All of these aspects were important to both nurses and patients. Symptom burden represents a significant problem because of the very complex therapies, and many interventions still fail to be effective, as Coolbrandt and colleagues⁴⁵ demonstrated. Recent studies have focused on CHEMO-SUPPORT as nursing interventions to reduce symptoms during chemotherapy.⁴⁶ From the patients' point of view, the care concept in the 2 studies considered includes cancer's effect on life/QoL, early cancer detection and prevention, risk factors and causes, and treatment and research.^{30,33} Patients also were concerned about environmental risks, hereditary factors, and carcinogenesis. Patients in 1 study also indicated that they wanted to know more about cancer science's development.³⁰

“Patient-related issues” is another research field important to nurses and includes psychological, behavioral, relational, and communication factors, all of which are patients' information needs that often are problematic for them to obtain. In particular, education and information fields were considered as research priorities

Table 4 • Nurses' Research Priorities Categories: Interstudy Frequency Sizes of Subthemes

Research Priorities: Themes/Subthemes	Rustoen & Schjølberg, 2000	Barrett et al., 2001	Browne et al., 2002	Ropka et al., 2002	Yates et al., 2002	McIlfrick & Keeney, 2003	Lee et al., 2003	Cohen et al., 2004	Berger et al., 2005	Murphy & Cowman, 2006	Corner et al., 2007	Doorenbos et al., 2008	LoBiondo-Wood et al., 2014	Moorcraft et al., 2016	Cox et al., 2017	Interstudy Frequency, % (n/N)
Disease control and management																
Quality of life/effect on life	✓		✓	✓			✓	✓	✓		✓	✓				40% (6/15)
Patient participation in decision making	✓							✓	✓							13.3% (2/15)
Symptom management (acute and chronic pain, pain management, symptom intervention)		✓	✓	✓	✓		✓	✓	✓			✓	✓		✓	66.6% (10/15)
Treatment (curative and personalized); late effects of treatment (infection rates and control, neutropenia/ immunosuppression, neurocognitive)			✓	✓			✓					✓	✓	✓		33% (5/15)
Early detection of cancer (screening, prevention cancer/cancer risk reduction, scientific understanding)											✓		✓	✓	✓	33% (5/15)
Prevention/risk factor/reduction											✓					13.3% (2/15)
Adherence													✓			6.6 (1/15)
Patient-related issues																
Psychosocial support (counseling, management of anxiety)	✓				✓								✓		✓	20% (3/15)
Communication, education, and information (patient/family, community education, informational living, the informational needs of patients after treatment)	✓	✓	✓		✓	✓		✓	✓	✓	✓					53% (8/15)

(continues)

Table 4 • Nurses' Research Priorities Categories: Interstudy Frequency Sizes of Subthemes, Continued

Research Themes/Subthemes	Rustøen & Schjølberg, ³⁶ 2000	Barrett et al., ²⁸ 2001	Browne et al., ² 2002	Ropka et al., ³⁵ 2002	Yates et al., ³⁷ 2002	McIlpatrick & Keeney, ³² 2003	Lee et al., ³¹ 2003	Cohen et al., ²⁹ 2004	Berger et al., ⁴ 2005	Murphy & Cowman, ³⁴ 2006	Comer et al., ³⁰ 2007	Doorenbos et al., ⁸ 2008	LoBiondo-Wood et al., ³ 2014	Moorcraft et al., ³³ 2016	Cox et al., ¹ 2017	Interstudy Frequency, % (n/N)
Psychological experiences and care experiences of disease (the experience of a single parent diagnosed with cancer)	✓					✓										13.3% (2/15)
Professional dimension		✓						✓✓✓								13.3 (2/15)
Professional dimension (job satisfaction, nurse-patient ratios, and improving retention of nurses and reducing turnover)								✓✓								20% (3/15)
Professional issues (stress, burnout, and coping)	✓		✓			✓				✓✓						6.6% (1/15)
Nursing issues/family issues			✓							✓						6.6% (1/15)
Cancer nursing research			✓							✓						13.3% (2/15)
Health system issues (cancer service issues)					✓											13.3% (2/15)
Access to care and continuity of care between hospital, community, and hospice						✓						✓				13.3% (2/15)
Hospice/end-of-life care, palliative care, management of terminal care		✓					✓			✓		✓				26.6% (4/15)
Standards of care and department organization							✓									6.6% (1/15)
Cost-effectiveness																6.6% (1/15)
Complementary and alternative therapies											✓					6.6% (1/15)

✓, once present in the top 5; ✓✓, twice present in the top 5; ✓✓✓, thrice present in the top 5.

^aIndividual report contribution to subthemes: percentage and number of studies containing findings/total number of findings across studies.

very often during the period this study investigated (present in 8 of 15 studies). Nursing research investigates these kinds of problems rarely, and they continue to remain a priority. According to Charalambous et al,⁴⁴ the main field nurses have investigated is “teaching, counseling, and guidance,” which includes activities to encourage and promote cancer patients' self-care and coping. Nursing research also should include investigations of forms of psychological support to promote patients' well-being.

A third research field important to nurses is the “professional dimension and issues,” which includes the nurse as a professional figure and his or her position in health services. The nurse as a professional figure includes one in cancer nursing education and research, interdisciplinary work and networking, skills and competencies, stress, burnout, coping, job satisfaction, participation in making decisions, and departmental organization. The nurses' role in health services includes the range of positions and responsibilities that cancer nurses have developed to support people who live with cancer or are at risk of cancer.⁴⁴ Research on the nurses' position in health services seems to be missing in part from the cancer research agenda.^{47,48} Considering that nurses play a crucial role in oncology care, further studies are needed urgently. These priorities were seen infrequently in the studies described here, unlike the issues related to patients' priorities. It seems that nurses' attention has focused primarily on addressing priorities that respond to the patients' needs (the disease itself or their nursing problems) with respect to the professional dimension or the context of care.

Among the studies analyzed, Cox and colleagues'¹ study is novel among the surveys of cancer priorities because they investigated nursing research priorities from both the nurses' and patients' points of view. Their Delphi survey, however, led patients to respond by thinking about nursing activities rather than their own problems or needs. For this reason, we excluded the article from the analysis in the section of this study that reports patients' point of view. Except for this example, oncology nurses generally have not collaborated with patients, although such collaborations exist in other professional groups (eg, physiotherapists and osteopaths). The main factor to be considered for future clinical studies remains patients' primary role in research; thus, cancer researchers and clinicians must consider their needs and perspectives.³³

It may be useful to develop qualitative studies and involve patients in focus or discussion groups to share the results of the literature and establish with them the main priorities. This may be conducted, for example, by asking patients what do they expect from nurses through perception studies (these studies can be very inspirational) and by planning future investigations/surveys with other health professionals (ie, doctors, psychologists).

This review has some limitations. First, only primary studies were included, and thus, any studies reported in the gray literature were not considered because they are not formally published. Second, no studies were found that were conducted in lower income countries, although cancer risk factors and mortality have been reported in these regions.⁶ Thus, the research priorities of patients and nurses from these countries are unknown. This is unfortunate, as it would be useful to understand the different perspectives of these cancer patients and the nurses who care for them, as well as other treatment and nursing issues in conditions of severe economic hardship, such as poor access to cancer or pain

drugs, or care facilities. Third, we searched with English terms and included articles written only in English from 2000 to 2018, which may have caused selection bias. Fourth, we excluded patients with hematological cancer or those undergoing bone marrow transplantation. Fifth, to ensure that we investigated nurses and patients' specific points of view, we excluded studies in which nurses reported their perceptions of patients' interests, or the converse. As a consequence, 2 studies were omitted and the results of one were considered only in part.

■ Conclusions

Many oncology nursing societies and organizations have explored the priorities in oncology nursing and have provided important suggestions to researchers.

During the years, certain priorities always have been included among the top 5 (symptom management or communication, education, and information fields), in contrast to others that have not been reported in recent years (QoL/effect on life) or those identified recently (early detection of cancer).

Despite the increasing emphasis on the need to include patients when establishing research priorities that inform cancer care, we found few studies that did so. Researchers and oncology nursing societies are the stakeholders better represented, but priority topics for future research also should include patients and their advocacy organizations. The integration of nurses and patients' priorities for research would be a starting point to develop a new research priority agenda that can be adapted locally according to each context. To do so, it would be useful not to limit oneself to simple lists of priorities but to explore further from a qualitative point of view what these priorities mean for patients and nurses. In addition, greater collaboration with other professionals is desirable in such issues as psychological support or counseling. Greater attention to nurses' role and their leadership also is necessary, given the increasing complexity of cancer care in which nurses have a clear central position. A reflection on their educational needs and on developing competence in the cancer nursing research field is also necessary. Finally, understanding the way the development of nursing research leadership and a clinical cancer nursing specialization influences patients' outcomes, as well as the cost and its relation to efficacy in cancer nursing, should become a priority.

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Appendix 1 • Electronic Databases Searched and Search Terms Used

Database	Search Strategy
Cochrane Database of Systematic Reviews	cancer nursing, oncology patient, research priorities (cancer nursing OR oncology patient) AND research priorities
CINAHL	“cancer patients” AND “issues” AND unresolved OR “cancer patients” AND “needs” AND priorities OR (MH “Health Services Needs and Demand+”) AND (MH “Needs Assessment”) AND “unmet needs” AND AFT2000 (“cancer priorities” OR “research priorities”) AND (User OR healthcare users OR oncology patient OR cancer patient OR oncology user OR cancer consumers) AND research priorities (“research priorities”[All Fields] OR “health priorities”[All Fields]) AND “cancer patients”[All Fields] OR (“patients perspective”[All Fields] OR “patients perspectives”[All Fields] OR Patient Participation/methods) AND (“Needs Assessment”[MeSH] OR “Health Services Needs and Demand”[MeSH] OR needs[ti] OR priorities[ti]) AND (“Patients”[MeSH] OR patients[ti] OR patient [ti]) AND (“Neoplasms”[MeSH] OR cancer[tiab] OR oncology[tiab]) OR (priorities[ti] AND “cancer patients”[All Fields]) OR (survivors[ti] AND cancer[ti] AND needs[ti]) AND (“2000/01/01”[PDAT]: “3000/12/31”[PDAT]) NOT (palliative[All Fields] OR (“pediatrics”[MeSH Terms] OR “pediatrics”[All Fields] OR “pediatric”[All Fields])) NOT (“pediatrics”[MeSH Terms] OR “pediatrics”[All Fields] OR “paediatric”[All Fields] OR child*)
MEDLINE	(((((“research priorities” AND (neoplasms[MeSH] OR cancer) NOT (children OR child OR paediatric OR pediatric) AND jsubsetn[ti])) OR (((“research priorities”[All Fields] OR “nursing research priorities”[All Fields] OR (“nursing methodology research”[MeSH Terms] AND priorit*[tiab] AND cancer[tiab])) AND (“cancer nursing”[All Fields] OR “Oncology Nursing”[MeSH] OR (“nursing”[MeSH Terms] OR “Oncology nurses”[tiab]) AND “neoplasms”[MeSH Major Topic]) OR (nursing[tiab] AND cancer[tiab]) OR “neoplasms/nursing”[MeSH Terms])) OR (“Oncology Nursing”[MeSH] AND “Health Priorities”[MeSH] AND “Research”[MeSH] NOT (“pediatric nursing”[MeSH Terms] OR pediatric[tiab]))) OR (((“unresolved problem” OR “unresolved problems”) OR unmet needs[MeSH] AND (nursing research[MeSH] OR research/nu[sh] OR “nursing research”[tiab] OR (research[tiab] AND nurses[tiab]) OR (research[tiab] AND “oncology nursing”)) AND (neoplasms[MeSH] OR cancer[tiab])) NOT (pediatric OR paediatric OR child* OR palliative)) AND (research[ti] OR research[MeSH]) AND (nurs*[ti] OR nurs*[MeSH])
PROSPERO	cancer nursing, oncology patient, research priorities
Psychology and Behavioral Sciences Collection	(“oncology nursing” AND (research OR priorit*)) NOT pediatric (“cancer patients” OR “cancer survivors”) AND (“unmet needs” OR unresolved OR priorit*) NOT pediatric (TITLE-ABS-KEY (*cancer patients) AND TITLE-ABS-KEY (unmet needs)) AND TITLE-ABS-KEY (patient perspective*)
Scopus	((TITLE-ABS-KEY (“oncologic nursing” AND research AND priorit*)) AND ((nurs)) AND (research priorit*) AND PUBYEAR >2000) AND NOT child* AND NOT palliative
TDNet	(oncologic nursing) AND priority* AND NOT pediatric AND NOT pediatric AND NOT palliative AND NOT child*

Abbreviations: CINAHL, Cumulative Index to Nursing and Allied Health; PROSPERO, International Prospective Register of Systematic Reviews—Centre for Review and Dissemination University of York; TDNet, TDNet’s basic discovery portal service.



Appendix 2 • Quality Evaluation of the 15 Studies Included in the Review Using MMAT, the Mixed Method Appraisal Tool by Pluye et al²² (2011)

Reference	MMAT Question	Evaluation			
		Yes	No	Can't Tell	Comment
Barrett et al, ²⁸ 2001	Screening questions	Are there clear qualitative and quantitative research questions or a clear mixed-methods question?	*		
		Do the collected data allow one to address the research question (objective)?	*		
	Quantitative descriptive	Is the sampling strategy relevant to address the quantitative research question?	*		
		Is the sample representative of the population under study?	*		
		Are measurements appropriate?	*		
Berger et al, ⁴ 2005	Screening questions	Is there an acceptable response rate (60% or above)?		*	56% response rate
		Are there clear qualitative and quantitative research questions or a clear mixed-methods question?	*		
	Quantitative descriptive	Do the collected data allow one to address the research question (objective)?	*		
		Is the sampling strategy relevant to address the quantitative research question?	*		
		Is the sample representative of the population under study?	*		
Browne et al, ² 2002	Screening questions	Are measurements appropriate?	*		
		Is there an acceptable response rate (60% or above)?		*	15% response rate
	Quantitative descriptive	Are there clear qualitative and quantitative research questions or a clear mixed-methods question?	*		
		Do the collected data allow one to address the research question (objective)?	*		
		Is the sampling strategy relevant to address the quantitative research question?	*		
Cohen et al, ²⁹ 2004	Screening questions	Is the sample representative of the population under study?	*		
		Are measurements appropriate?	*		
	Quantitative descriptive	Is there an acceptable response rate (60% or above)?		*	30%-33% response rate
		Are there clear qualitative and quantitative research questions or a clear mixed-methods question?	*		
		Do the collected data allow one to address the research question (objective)?	*		
Corner et al, ³⁰ 2007	Screening questions	Is the sampling strategy relevant to address the quantitative research question?	*		
		Are there clear qualitative and quantitative research questions, or a clear mixed methods question?	*		
	Qualitative	Do the collected data allow one to address the research question (objective)?	*		
		Are the sources of qualitative data (archives, documents, informants, observations) relevant to address the research question (objective)?	*		
		Is the process for analyzing qualitative data relevant to address the research question (objective)?	*		
		Is appropriate consideration given to how findings relate to the context, eg, the setting, in which the data were collected?	*		
		Is appropriate consideration given to how findings relate to researchers' influence, eg, through their interactions with participants?	*		There is no information about the influence of researchers.

(continues)

Appendix 2 • Quality Evaluation of the 15 Studies Included in the Review Using MMAT, the Mixed Method Appraisal Tool by Pluye et al²² (2011), Continued

Reference	MMAT Question	Evaluation			
		Yes	No	Can't Tell Comment	
Cox et al, ¹ 2017	Screening questions	Are there clear qualitative and quantitative research questions or a clear mixed-methods question?	*		
		Do the collected data allow one to address the research question (objective)?	*		
	Quantitative descriptive	Is the sampling strategy relevant to address the quantitative research question?	*		
		Is the sample representative of the population under study?		*	
		Are measurements appropriate?	*		
Doorenbos et al, ⁸ 2008	Screening questions	Are there clear qualitative and quantitative research questions or a clear mixed-methods question?	*		
		Do the collected data allow one to address the research question (objective)?	*		
	Quantitative descriptive	Is the sampling strategy relevant to address the quantitative research question?	*		
		Is the sample representative of the population under study?	*		
		Are measurements appropriate?	*		
Lee et al, ³¹ 2003	Screening questions	Is there an acceptable response rate (60% or above)?	*		12% response rate
		Are there clear qualitative and quantitative research questions or a clear mixed-methods question?	*		
	Quantitative descriptive	Do the collected data allow one to address the research question (objective)?	*		
		Is the sampling strategy relevant to address the quantitative research question?	*		
		Is the sample representative of the population under study?	*		
LoBiondo Wood et al, ³ 2014	Screening questions	Are measurements appropriate?	*		
		Is there an acceptable response rate (60% or above)?	*		33% response rate
	Quantitative descriptive	Are there clear qualitative and quantitative research questions or a clear mixed-methods question?	*		
		Do the collected data allow one to address the research question (objective)?	*		
		Is the sampling strategy relevant to address the quantitative research question?	*		
Mcilfratrick & Keeney, ³² 2003	Screening questions	Is the sample representative of the population under study?	*		
		Are measurements appropriate?	*		
	Quantitative descriptive	Is there an acceptable response rate (60% or above)?	*		11% response rate
		Are there clear qualitative and quantitative research questions or a clear mixed-methods question?	*		
		Do the collected data allow one to address the research question (objective)?	*		
Moorcraft et al, ³³ 2016	Screening questions	Is the sampling strategy relevant to address the quantitative research question?	*		
		Is the sample representative of the population under study?	*		
	Quantitative descriptive	Are measurements appropriate?	*		
		Is there an acceptable response rate (60% or above)?	*		54% response rate
		Are there clear qualitative and quantitative research questions or a clear mixed-methods question?	*		The study aim is stated only in the abstract.
Quantitative descriptive	Do the collected data allow one to address the research question (objective)?	*			
	Is the sampling strategy relevant to address the quantitative research question?	*			
	Is the sample representative of the population under study?	*		Data are not reported.	
	Are measurements appropriate?	*		Data are not reported.	
	Is there an acceptable response rate (60% or above)?	*		Data are not reported.	

(continues)



Appendix 2. • Quality Evaluation of the 15 Studies Included in the Review Using MMAT, the Mixed Method Appraisal Tool by Pluye et al²² (2011), Continued

Reference	MMAT Question	Evaluation				
		Yes	No	Can't Tell	Comment	
Murphy & Cowman, ³⁴ 2006	Screening questions	Are there clear qualitative and quantitative research questions or a clear mixed-methods question?	*			
		Do the collected data allow one to address the research question (objective)?	*			
	Quantitative descriptive	Is the sampling strategy relevant to address the quantitative research question?	*			
		Is the sample representative of the population under study?	*			
		Are measurements appropriate?	*			
		Is there an acceptable response rate (60% or above)?	*			
Ropka et al, ³⁵ 2002	Screening questions	Are there clear qualitative and quantitative research questions or a clear mixed-methods question?	*			
		Do the collected data allow one to address the research question (objective)?	*			
	Quantitative descriptive	Is the sampling strategy relevant to address the quantitative research question?	*			
		Is the sample representative of the population under study?	*			
		Are measurements appropriate?	*			
		Is there an acceptable response rate (60% or above)?	*			
Rustøen & Schjølberg, ³⁶ 2000	Screening questions	Are there clear qualitative and quantitative research questions or a clear mixed-methods question?	*		Data are not reported.	
		Do the collected data allow one to address the research question (objective)?	*			
	Quantitative descriptive	Is the sampling strategy relevant to address the quantitative research question?	*			
		Is the sample representative of the population under study?	*			
		Are measurements appropriate?	*			
		Is there an acceptable response rate (60% or above)?	*			
Yates et al, ³⁷ 2002	Screening questions	Are there clear qualitative and quantitative research questions or a clear mixed-methods question?	*		43%–54% response rate	
		Do the collected data allow one to address the research question (objective)?	*			
	Quantitative descriptive	Is the sampling strategy relevant to address the quantitative research question?	*			
		Is the sample representative of the population under study?	*			
		Are measurements appropriate?	*			
		Is there an acceptable response rate (60% or above)?	*			
					54.2% response rate	

Appendix 3. • Process Evaluation of the 15 Studies Included in the Review Using the Principles of Good Practice Proposed by Viergever et al²⁶ (2010) and Adapted by Tong et al⁴⁷ (2015)

Item References	LoBiondo-															Total n (%)
	Rustøen & Schjøllberg, ³⁶ 2000	Barrett et al, ²⁸ 2001	Brownne et al, ² 2002	Ropka et al, ³⁵ 2002	Yates et al, ³⁷ 2002	McIlpatrick & Keeney, ³² 2003	Lee et al, ³¹ 2003	Cohen et al, ²⁹ 2004	Berger et al, ⁴ 2005	Corner et al, ³⁰ 2007	Doorenbos et al, ⁸ 2008	Wood et al, ³ 2014	Moorcraft et al, ³³ 2016	Murphy & Cowman, ³⁴ 2006	Cox et al, ¹ 2017	
1. Context																
The resources available for the exercise were reported.	Y	N	Y	N	N	N	N	N	N	Y	N	N	Y	N	Y	Y = 5 (33.4%)
The focus of the exercise was clearly stated (what it was about and who it was for).	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y = 15 (100%)
The underlying values or principles were clear.	Y	Y	Y	N	Y	Y	Y	Y	Y	Y	Y	Y	N	Y	Y	Y = 12 (80%)
The health environment in which the process took place was described.	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y = 15 (100%)
The research environment in which the process took place was described	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y = 15 (100%)
The political environment in which the process took place was described.	N	Y	Y	Y	Y	Y	N	N	Y	Y	N	N	Y	Y	Y	Y = 10 (66.7%)
The economic/financial environment in which the process took place was described.	N	N	N	Y	N	N	N	N	N	N	N	N	Y	N	N	Y = 2 (13.4%)
2. Use of comprehensive approach																
The process of priority setting was described in detail.	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	N	Y	Y	Y = 14 (93.4%)
3. Inclusiveness																
The participants involved in setting research priorities were described.	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y = 15 (100%)

(continues)

Appendix 3. • Process Evaluation of the 15 Studies Included in the Review Using the Principles of Good Practice Proposed by Viergever et al²⁶ (2010) and Adapted by Tong et al⁴⁷ (2015), Continued

Item References	LoBiondo-										Total n (%)					
	Rustøen & Schjølberg, 2000	Barrett et al, ²⁸ 2001	Browne et al, ² 2002	Ropka et al, ³⁵ 2002	Yates et al, ³⁷ 2002	Malfatrick & Keeney, ³² 2003	Lee et al, ³¹ 2003	Cohen et al, ²⁹ 2004	Berger et al, ⁴ 2005	Corner et al, ³⁰ 2007		Doorenbos et al, ⁸ 2008	Wood et al, ³ 2014	Moorcraft et al, ³³ 2016	Murphy & Cowman, ³⁴ 2006	Cox et al, ¹ 2017
An appropriate representation of expertise was included.	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y = 15 (100%)
An appropriate representation of sex was included.	N	N	Y	Y	N	N	Y	Y	Y	N	Y	Y	Y	Y	Y	Y = 9 (60%)
An appropriate representation of regional participation was included.	Y	Y	N	Y	Y	Y	N	N	Y	N	Y	N	Y	Y	Y	Y = 10 (66.7%)
Relevant health sectors and other constituencies were included.	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y = 15 (100%)
4. Information gathering	Y	Y	Y	Y	Y	Y	Y	N	Y	N	Y	Y	Y	Y	Y	Y = 12 (80%)
The information and sources used to inform the priority setting exercise were referenced.	Y	Y	Y	Y	Y	Y	Y	N	Y	N	Y	Y	Y	Y	Y	Y = 12 (80%)
5. Planning for implementation	Y	N	Y	Y	Y	N	Y	Y	Y	N	N	N	N	N	N	Y = 7 (46.7%)
Plans for translation of research priorities were discussed.	N	N	Y	Y	Y	N	Y	Y	Y	Y	Y	Y	Y	N	N	Y = 9 (60%)
Who will implement the research priorities and how	N	N	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y = 15 (100%)
6. Deciding on priorities	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y = 15 (100%)
Relevant criteria to focus discussion around setting priorities were stated.	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y = 15 (100%)
7. Methods for deciding on priorities	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y = 15 (100%)
Approach for deciding on priorities was described (eg, consensus or metrics based)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y = 15 (100%)

(continues)

Appendix 3. • Process Evaluation of the 15 Studies Included in the Review Using the Principles of Good Practice Proposed by Viergever et al²⁶ (2010) and Adapted by Tong et al⁴⁷ (2015), Continued

Item	Rustøen & Schjøllberg, ³⁶ 2000	Barrett et al, ²⁸ 2001	Browne et al, ² 2002	Ropka et al, ³⁵ 2002	Yates et al, ³⁷ 2002	McIntick & Keeney, ³² 2003	Lee et al, ³¹ 2003	Cohen et al, ²⁹ 2004	Berger et al, ⁴ 2005	Corner et al, ³⁰ 2007	Doorenbos et al, ⁸ 2008	Wood et al, ³ 2014	Moorcraft et al, ³³ 2016	Murphy & Cowman, ³⁴ 2006	Cox et al, ¹ 2017	Total n (%)
8. Evaluation When and how evaluation of the established priorities and the priority setting process took place were defined (eg, multiple sessions).	N	Y	Y	N	N	Y	N	Y	N	Y	N	N	N	N	Y	Y = 6 (40%)
9. Transparency Clarity about the approach used (eg, how priorities were set)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y = 15 (100%)

Abbreviations: Y, yes; N, no.