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**HEALTH INFORMATION NEEDS, SOURCES, AND ENGAGEMENT BEHAVIOURS
OF WOMEN WITH METASTATIC BREAST CANCER ACROSS THE CARE
CONTINUUM: PROTOCOL FOR A SCOPING REVIEW**

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ABSTRACT

Introduction

The health information needs, sources, and engagement behaviours of women with metastatic breast cancer (mBC) depend on personal characteristics such as education level, prior knowledge, clinical complications, comorbidities, and where they are in the cancer journey. A preliminary literature review suggests that there is little research on this topic, but that there may be lessons from a slightly broader literature.

Although many of the findings concerning information needs, sources, and engagement may be transferable from women to men, we consider that men with mBC have special needs worthy of a separate review. This protocol and scoping review will focus only on women.

Methodology and analysis

A scoping review will be performed using the guidelines of Arksey and O'Malley to systematically search scientific and grey literature for articles that discuss the health information needs, sources, engagement styles and associated personal and medical attributes of women living with mBC at different stages of the disease course. A variety of databases (including Cumulative Index to Nursing and Allied Health Literature [CINAHL], PubMed, Excerpta Medica Database [EMBASE], Academic Search Premier, Cochrane Database of Systematic Reviews, PsycINFO, Health Source: Nursing/Academic Edition, and PQDT Open), oncology, patient advocacy, and governmental websites will be searched from inception to present day.

Ethics and dissemination

This review will identify what is known and what is not known about the health information needs, acquisition, and influences of women with mBC across the care continuum. Findings will help to identify research needs and inform evidence-based interventions to address the health information needs of female mBC patients with different demographics and characteristics and across the mBC journey. Being a secondary analysis, this research will not require ethics

approval. Results will be disseminated through patient support organizations and websites and publications targeting health care professionals, advocates, and patients.

STRENGTHS AND LIMITATIONS OF THIS STUDY

- Although several studies and surveys have examined the information needs and sources of women with mBC, they have not investigated these longitudinally.
- Systematic summarisation of the evidence will identify information available from a wide array of relevant sources (scientific and grey literature) and publication types.
- The synthesis of data will provide a clear and adequate view of current knowledge on female mBC patients’ information needs, sources, and engagement behaviours and influences as these evolve across their cancer journey.
- The review will help to identify research needs and guide evidence-based interventions to meet the health information needs of women with mBC.

INTRODUCTION AND BACKGROUND

Metastatic (stage IV or stage 4) breast cancer (mBC) otherwise called advanced or secondary breast cancer is disease that has spread to distant sites of the body such as the liver, lungs, bone, brain, and/or other tissues or organs.(1) It is an incurable but treatable disease with a high risk of a shortened life span and continuous cancer-related treatment to prolong progression-free survival.

In the United States of America (USA), the median survival of women with mBC remains 2-3 years after diagnosis,(2) but overall survival may extend to several years. For some women, mBC may be a chronic relapsing-remitting disease that responds for some time to various cytotoxic and endocrine therapies.(3)

In the USA about 6% of new breast cancer cases are de novo metastatic,(4) while 20-30% of all breast cancer cases will become metastatic.(5) Breast cancer primarily occurs in women, but men will account for 2600 of the 249,260 new breast cancer cases and 440 of the 40,890 deaths from breast cancer that it is estimated will occur in the US in 2016.(6)

An estimated 150,000-250,000 women of all ages and ethnic groups in the USA are living with mBC.(2) The annual mortality rate of breast cancer has fallen from 31.4 in 1975 to 20.7 in 2013 per 100,000 women in the USA, but the total number of deaths per year remains at about 40,000.(4) About 90% of these deaths are due to metastasis.(7)

Information needs of women with mBC

Two large surveys of women with mBC (618 in the USA,(2) and 1,342 in 13 countries (8)) found that their most urgent informational needs were for accurate, in-depth information about their disease, established and emerging treatments, and methods of coping with side effects and symptoms.(9) Both surveys highlighted the inadequacy of information resources targeted to these women.(9)

Subsequently, a 2013-2014 USA-based mBC landscape analysis found that mBC websites and print materials lacked adequate information on the latest treatments; monitoring of treatments for side effects and impact on quality of life; palliation; advanced directives and end-of-life care; and experimental drugs.(10)

A March 2016, international 2005-2015 mBC Decade Report cited patient-identified shortcomings of inadequate communication about prognosis, treatment risks vs benefits, future treatment options, and clinical trials, and a need for holistic, individualized communication.(11)

Most recently, in May 2016, two mBC patient surveys — Count Us, Know Us, Join Us (Count Us [N=1273]) and Here & Now (H&N [N=304]) — reported that mBC patients find information about their disease inadequate and difficult to locate.(12)

Overall, there appears to be an enduring and significant unmet need for appropriate education tailored to the informational needs of the diverse mBC sub-groups.(13, 14)

Patient education or information is important to enhance patient outcomes by empowering patients and caregivers; optimizing treatment outcomes; limiting treatment-related adverse events; and reducing office visits and hospitalizations.(15) It has been defined as: "...the process

by which the patient comes to comprehend his or her physical condition and self-care by the use of various media and experiences”.(16)

Important considerations in providing patient information

Patient information engagement may be affected by psychological characteristics such as being an “information seeker” or not, preferences for different information formats or learning styles, sociodemographic characteristics such as age, ethnicity, and educational level, clinical factors such as the presence of comorbidities, and where a patient is on the cancer journey.(17-23)

Information seeking

Information-seeking behaviours of women with breast cancer have been observed to be highly individualistic.(24) Some women seek information to cope with cancer (“monitors”) while others avoid information to escape the negative feelings associated with information (“blunters”).(25) Some patients prefer to receive information via a proxy or surrogate (eg, a family member or caregiver).(21, 26)

Information formats and learning styles

Women with mBC have also expressed varying information source preferences and assessments. In the aforementioned Living Beyond Breast Cancer survey,(2) printed patient materials, government websites, and professional medical publications were cited as the most frequently accessed sources, but scientific conferences and telephone education sessions were most valued by the majority of respondents. In practice, effective communication of information may require several different formats that are aligned with the individual patient’s preferred learning styles to optimize their grasp of information.(27)

Age

Older women with cancer may prefer more passive roles and express less need for information.(23, 28-30) Priority research issues and informational needs for younger women (<40 years of age) with mBC may relate to body image concerns, fear of recurrence, recommended treatments, and palliative care for metastasis.(31) Women under age 45 with mBC are particularly interested in current treatment options, clinical trials, and management of anxiety

and depression.(32) Many younger women may experience treatment-related sexual dysfunction that may not completely resolve(33) so information on sexuality may be of special interest.(34)

Education and health literacy

Health literacy, which is linked to literacy,(35) and has been defined as “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions”,(36) is associated with the information needs of women with breast cancer.(37) Inadequate health literacy poses barriers to cancer patients’ understanding of their disease and treatment options.(38) Higher educational level has been found to be associated with a more active information-seeking style.(19, 23, 39, 40)

Ethnicity

Ethnicity, race, and cultural background also influence cancer patients’ information-seeking behaviours.(11, 41, 42) Recent research suggesting that coping with breast cancer among African American women is not an individual experience raises the need for family and community-based educational strategies rather than purely individually-directed approaches.(11, 43) This research suggested that African American and Latina women tend to use more religious and spiritual coping strategies than Caucasian women. This can have implications for the most effective educational or behavioural interventions.(41, 43)

Position on the care continuum

The information needs, including the type of information sought, of women with mBC varies with the stage of the patient pathway (ie, mBC diagnosis, treatment, including long-term survivorship, and the posttreatment, end-of-life phase).(10, 23) An important aspect of mBC patient care is provision of specific information that is tailored to the specific stage of the patient along the mBC continuum.(20, 44)

At initial mBC diagnosis

Most women with mBC actively seek information at initial diagnosis of mBC.(14) Preliminary research suggests that preparatory information about all aspects of their illness is desirable at the time of mBC diagnosis.(45) Many patients at this stage also want prognostic information.(46)

According to Seah et al,(47) the most important information need for patients in the first year after mBC diagnosis was information as to whether the cancer had spread elsewhere in the body, how to deal with side effects, and whether treatment-related side effects could be prevented.

During treatment

Many treatment options may be used in treating mBC, depending on disease status and patient preference. Patients receiving chemotherapy need support and information to help them to self-monitor side effects and seek supportive care when needed. In the case of novel targeted treatments, patients need information on the potential clinical benefits and side effects of therapies.(48)

Patients who are living with mBC over extended periods may have specific information needs based on their treatment goals. The treatment goals in long-term survivors of mBC (≥ 5 years) are prolongation of survival, palliation of symptoms and optimization of quality of life.(49, 50) The informational needs of these women relate to their diagnosis, prognosis, and treatment options, including understanding and management of treatment-related toxicities and effects such as psychosocial complications (eg, anxiety and depression and social complications).(11, 51, 52)

Posttreatment: end-of-life and palliative care phase

At the point where the goal of treatment shifts from active treatment to palliation of symptoms and end-of-life preparations, care involves effective management of pain and other distressing symptoms and provision of psychosocial and spiritual care congruent with the needs, values, beliefs, and cultural sensitivities of the patient and family (53). Patient-focused communication at this time relates to eliciting input about symptoms, communication about prognosis, providing emotional support, and facilitating the patient's transition to hospice care.(54) Specific information needs that should be addressed include late-disease risks, complications of advanced disease, specific palliative care therapies and potential side effects, pain management, and skin care.(55)

While several surveys examined the information needs and sources of women with mBC, a preliminary literature review did not identify research examining these longitudinally. This

represents a significant gap in available data to help in determining the right information interventions for individual patients at their specific stage of the mBC continuum.

Theoretical frameworks

Effective patient education or information dissemination may be derived from educational theories, using evidence-based approaches. These theories provide a framework for identifying the approaches to patient education or information that are most appropriate to each patient. Ultimately, a combination of theories may be needed to try and achieve the best outcomes for the individual patient.

Teaching styles and educational techniques differ between two broad theoretical perspectives, ie, behaviourist vs cognitive approaches.(56) Behavioural approaches utilize direct or “teacher”-centred instruction, while cognitive approaches employ collaborative goal-setting and decision making between the patient and health care professional; adult learning principles; and a multimodality approach.

Passive individuals may learn better from behaviourist techniques, while curious, very active, self-directed individuals may learn better from cognitive methods.(57) Well educated, communicative, and thoughtful individuals may learn better using cognitive approaches, while those with impaired cognitive processes or difficulty handling concepts or examining and communicating their thoughts and feelings may do better with behaviourist approaches.(57)

Methods and analysis

Based on preliminary literature searches of PubMed and CINAHL, it appears that there are very few articles on patient education and information interventions in women with mBC in the published literature. Nine articles were identified that discuss educational or behavioural interventions in women with metastatic breast cancer (5 from the literature search and 4 that were not from the search).(45, 51, 58-64) In addition to the previously mentioned surveys, six articles (4 from the literature search and 2 that are not from the search)(46, 47, 65-68) provide information on the educational and psychosocial needs of women with mBC. There are articles

that address the informational needs of patients with multiple types of cancer, but these do not necessarily examine mBC on its own.

There are a few randomized controlled trials comparing educational or behavioural interventions for women with mBC. One study examined the effect of supportive-expressive psychotherapy on the survival time of women with mBC;(64) another looked at the effectiveness of a brief, tailored, nurse-delivered psychoeducational intervention on their quality of life or perceived needs (59); and a third investigated the efficacy of cognitive therapy on reducing depression.(61)

The apparent paucity of primary research into information needs and sources across the cancer journey of women with mBC will make it difficult to undertake a systematic review of this subject. In addition, the preliminary literature search failed to discover any existing scoping reviews on the subject of the proposed review.

A scoping review will be conducted of the scientific, clinical, and broader literature for articles in English addressing mBC patient information needs, sources, utilization and related factors across the mBC disease course. By scoping review or study is meant: "...a form of knowledge synthesis that addresses an exploratory research question aimed at mapping key concepts, types of evidence, and gaps in research related to a defined area or field by systematically searching, selecting, and synthesizing existing knowledge". (69)

In their foundational article on scoping review methodology, Arksey and O'Malley(70) identified the possible aims of scoping reviews as: to examine the extent, range and nature of research activity, determine the value of undertaking a full systematic review, summarize and disseminate research findings, or identify gaps in the existing literature. Initially, at least the first two aims will be addressed via this scoping review; potentially all four may be fulfilled.

Arksey and O'Malley(70) also proposed a six-stage methodological framework: (i) identifying the research question; (ii) searching for relevant studies; (iii) selecting studies; (iv) charting the data; (v) collating, summarizing, and reporting the results; and (vi) consulting with stakeholders to inform or validate study findings (optional).

The research question for the proposed review is: What knowledge exists in the literature about the information needs, sources, engagement behaviours and associated sociodemographic and situational factors (such as disease- or treatment-related factors) of women with mBC at different time points of the cancer care continuum?

In the interest of ensuring comprehensiveness of the research, information is defined broadly as comprising both cancer-related and non-cancer-related information, viz, psychological, medical, and social information.

Literature review search strategy

The scoping review will consider the international English language literature (both peer-reviewed and “grey”) that discusses patient information needs, sources, and acquisition, including associated variables of women aged ≥ 18 with advanced or metastatic stage IV (4) breast cancer. Primary research studies, systematic reviews, meta-analyses, clinical guidelines, and other publication types will be included. No study designs will be excluded.

The review will exclude articles that are:

1. Inclusive of patients ≤ 18 years old
2. Studies that focus mainly on men or do not differentiate between the needs of male and female mBC patients
3. Solely reports of economic research (i.e., cost-effectiveness or cost-utility studies)
4. Related to prevention and screening for breast cancer
5. About genetics unless they discuss information needed by or provided to women with mBC
6. Devoted to the information needs and behaviours of women with early stage or primary breast cancer
7. Focused exclusively on the information needs and engagement of patients’ partners or family members

- 8. Inclusive of other types of cancer in addition to mBC, but which do not discuss the information needs, sources, and behaviours of women with mBC separately from those of patients with other types of cancer.
- 9. Focused on the informational or educational needs of health care professionals, unless they also address the information needs of women with mBC
- 10. Concerned with cancer risk, mortality, and epidemiology

As described in the *Joanna Briggs Institute Reviewers' Manual 2015*, a three-step search strategy will be utilized in this research:(71)

- 1. An initial limited search of PubMed and CINAHL followed by analysis of the text words contained in the title and abstract of the retrieved articles.
- 2. A second search using all identified keywords and index terms across all proposed databases.
- 3. A search of the reference list of all identified reports and articles for additional studies.

The proposed databases to be searched (from inception to present day) include CINAHL, PubMed, EMBASE, Academic Search Premier, Cochrane Database of Systematic Reviews, PsycINFO, Health Source: Nursing/Academic Edition, Epistemonikos, the Joanna Briggs Institute Database of Systematic Reviews and Implementation Reports (JBISRIR), the Evidence for Policy and Practice Information and Co-ordinating Centre (EPPI-Centre) and Education Resources Information Center (ERIC).

Patient advocacy websites and publications and cancer websites will be investigated for unpublished studies. The search for unpublished studies will also include the following websites: PQDT Open (<http://pqdtopen.proquest.com/search.html>, which provides open access to dissertations and theses), Google Scholar, World Health Organization (WHO), www.who.int, Clinical Trials.gov, Institute of Medicine (IOM), www.iom.edu, the National Cancer Institute (NCI) www.cancer.gov, National Institutes of Health (NIH), www.nih.gov, Agency for Healthcare Research and Quality (AHRQ), www.ahrq.gov, New York Academy of Medicine, <http://www.nyam.org/>, and the Virginia Henderson Global Nursing e-Repository of the Honor Society of Nursing, Sigma Theta Tau International, www.nursinglibrary.org, a repository dedicated to sharing nursing publications.

The search for grey literature will also include searches of Open-Grey (www.opengrey.edu), an open access database of European grey literature and the *Grey Literature Report* (www.greylit.org), a publication of the New York Academy of Medicine.

Relevant oncology websites will also be searched, including the American Society of Clinical Oncology (ASCO), www.asco.org, Oncology Nursing Society (ONS), www.ons.org, European Society for Medical Oncology (ESMO), www.esmo.org, and the American Cancer Society (ACS), www.acs.org websites.

The initial search will consist of each of the following terms linked by **OR**: Information-seeking, information needs, information acquisition, information resources, information sources, information support, information dissemination methods, health information, patient education, health education, patient education methods, therapeutic patient education, patient knowledge, treatment education, patient concerns, patient satisfaction, patient communication, patient information, patient experience, clinical communication, physician-patient communication, patient-provider communication, communication challenges, and patient-centred communication **AND** each of the following terms linked by **OR**: advanced breast cancer, metastatic breast cancer, secondary breast cancer, stage IV breast cancer, and stage 4 breast cancer.

To assess the completeness of the above search, hand searching of reference lists and bibliographies of included studies and two or three appropriate journals for the preceding six months to a year will be conducted. Proposed journals are the *Journal of Cancer Education*, *Patient Education and Counseling*, and *Support Care Cancer*. Endnote will be used to manage the references retrieved.

Study selection

Studies will be selected using a three-step process: (i) titles of articles will be scanned to determine eligibility based on the inclusion and exclusion criteria; (ii) article titles and abstracts will be reviewed using the eligibility criteria; (iii) full-text versions of all potentially relevant articles will be retrieved for inclusion consideration.

Data abstraction

The systematic review typology chart developed by Rutten et al(23) and modified by van Mossel et al(44) will be adapted to create a table (Table 1) to record authors and dates of included articles and types of information needs and sources mentioned using the broad categories they proposed. Relevant subcategories of information specific to breast cancer and/or mBC will be formulated using the search results; these will be used to generate two tables recording the types of information needs and sources mentioned in reviewed articles.

Table 1. Charting of included studies

Author and date	Types of information needs mentioned								Types of information sources mentioned						
	Other	Treatment-related information	Rehabilitation	Coping information	Interpersonal/social information	Prognosis information	Cancer-specific information	Body image/sexuality information	Medical system information	Health care professionals	Interpersonal	Printed materials	Media	Organizational/scientific resources	Women with metastatic breast cancer

The methodological quality of included studies will not be assessed since the aim of a scoping study is to conduct a comprehensive search enabling the identification of gaps in the evidence base and indication of subject areas for future reviews.(44, 72)

Results

Characteristics of the literature included in the review will be summarized in a table (Table 2), and the stages of the cancer care continuum in the reviewed articles will also be presented in a table (Table 3). A descriptive summary of the articles included in the review, describing the aims or purposes of included articles, concepts or approaches used in each, and the results that relate to the review question, will be presented.

Table 2. General characteristics of included articles

Characteristic	n	%
<i>Type of article</i>		
Research study		
Commentary/narrative		
Clinical practice guideline		
Literature review		
Description of a program		
Other		
<i>Data collection method</i>		
Multiple collection methods		
Original questionnaire/survey		
Existing questionnaire/survey		
Interview		
Focus groups		
Chart review/medical records		
Other		
Unknown		
<i>Research study design</i>		
Quantitative		

Qualitative		
Mixed methods		
Clinical trial		
Concurrent		
Prospective/longitudinal		
Other (mixed designs)		
Unknown		
<i>Learning theory</i>		
Discussed		
Not discussed		
<i>Geographical location of the work</i>		
United States		
United Kingdom		
Other European countries		
Australia		
Canada		
Other		
<i>Publication date</i>		

Table 3. Stages of the cancer care continuum mentioned in the reviewed articles

Stage in cancer care continuum	n	%
At diagnosis		
Treatment		
Posttreatment (including survivorship)		
End-of-life		

Any potential implications for evidence-based patient education practice and knowledge gaps meriting primary research and/or systematic reviews will be presented.(71)

Ethics and dissemination

This scoping review aims to synthesize current knowledge on female mBC patients' information needs, sources, and engagement behaviours and influences as these evolve across their cancer journey.

All data in this review will be gathered through searches of literature and other online databases, and no personal health information will be collected; thus, ethics committee approval will not be required.

Research findings will be published and presented to patients and their families and caregivers through patient support and advocacy websites and organizations.

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Contributors

All authors (CAT, MPM, and RBJ) made substantive intellectual contributions to the development of this protocol. CAT conducted the preliminary research, which was critically reviewed and with contributions from MPM and RBJ. All authors (CAT, MPM, and RBJ) were involved in developing the review question and the review design. RBJ provided substantial guidance to CAT in the elaboration of the review design. CAT initiated the first draft of the manuscript, which was then followed by several iterations with substantial input, appraisal, and revisions from MPM and RBJ. All authors (CAT, MPM, and RBJ) approve the final version of the manuscript.

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Competing interests

None

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Health Information Needs, Sources, and Engagement Behaviours of Women With Metastatic Breast Cancer Across the Care Continuum: Protocol for a Scoping Review

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**HEALTH INFORMATION NEEDS, SOURCES, AND ENGAGEMENT BEHAVIOURS
OF WOMEN WITH METASTATIC BREAST CANCER ACROSS THE CARE
CONTINUUM: PROTOCOL FOR A SCOPING REVIEW**

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ABSTRACT

Introduction

The health information needs, information source preferences, and engagement behaviours of women with metastatic breast cancer (mBC) depend on personal characteristics such as education level, prior knowledge, clinical complications, comorbidities, and where they are in the cancer journey. A thorough understanding of the information behaviours of women living with mBC is essential to the provision of optimal care. A preliminary literature review suggests that there is little research on this topic, but that there may be lessons from a slightly broader literature.

This review will identify what is known and what is not known about the health information needs, acquisition, and influences of women with mBC across the care continuum. Findings will help to identify research needs and inform evidence-based interventions to address the health information needs of female mBC patients with different demographics and characteristics and across the mBC journey.

Methods and analysis

A scoping review will be performed using the guidelines of Arksey and O'Malley as updated by subsequent authors to systematically search scientific and grey literature for articles in English that discuss the health information needs, sources, engagement styles and associated personal and medical attributes of women ≥ 18 years living with mBC at different stages of the disease course. A variety of databases (including Cumulative Index to Nursing and Allied Health Literature [CINAHL], PubMed, Excerpta Medica Database [EMBASE], Academic Search Premier, Cochrane Database of Systematic Reviews, PsycINFO, Health Source: Nursing/Academic Edition, and PQDT Open), oncology, patient advocacy, and governmental websites will be searched from inception to present day. Research and non-research literature will be included; no study designs will be excluded.

The six-stage Arksey and O’Malley scoping review methodological framework involves: (i) identifying the research question; (ii) searching for relevant studies; (iii) selecting studies; (iv) charting the data; (v) collating, summarizing, and reporting the results; and (vi) consulting with stakeholders to inform or validate study findings (optional).

Data will be extracted and analysed using a thematic chart and descriptive content analysis.

Ethics and dissemination

Being a secondary analysis, this research will not require ethics approval. Results will be disseminated through patient support organizations and websites and publications targeting health care professionals, advocates, and patients.

STRENGTHS AND LIMITATIONS OF THIS STUDY

- Systematic summarization of the evidence will identify information available from a wide array of relevant sources (scientific and grey literature) and publication types.
- The study will be a comprehensive review of published papers identified via major biomedical databases, not limited by time but covering a period from their inception to present day.
- No study designs or publication types will be excluded. As such, the review will integrate a wide and diverse body of literature and allow the combination of qualitative and quantitative knowledge synthesis approaches and research and non-research sources.
- The research will not be representative of the entire mBC population as men with mBC and paediatric patients with mBC will be excluded from the scope of the review.
- The research will not specifically address the information needs and influences of mBC subpopulations, characterized by factors including age, race, site of metastases, hormone status, timing of advanced disease diagnosis (ie, initial versus recurrent), and stage of metastasis, which may be unique to each group.
- As a scoping review, the quality of included studies will not be evaluated.
- Included studies will be limited to those published in English due to resource constraints represented by an inability to have articles in other languages translated for inclusion. As

such, the results of the review will not encompass the full international literature landscape on this topic.

INTRODUCTION AND BACKGROUND

Metastatic (stage IV or stage 4) breast cancer (mBC), otherwise called advanced or secondary breast cancer, is a disease that has spread to distant sites of the body such as the liver, lungs, bone, brain, and/or other tissues or organs.(1) It is an incurable but treatable disease with a high risk of a shortened life span and continuous cancer-related treatment to prolong progression-free survival. Breast cancer occurs primarily in women though men can also be affected by the disease; the review will focus on women.

Women with metastatic disease have unique characteristics, needs, including information needs, and experiences that differ from those with early stage disease. Information and other resources provided to the broader breast cancer community may not be appropriate to them.

Information needs of women with mBC

Several large patient surveys—the 2006 US-based Silent Voices Survey,(2) and international BRIDGE Survey (2009),(3) Count Us, Know Us, Join Us, and Here & Now (both 2016)(4)—have attested to the inadequacy and inaccessibility of mBC-specific patient information currently. Additionally, a 2013-2014 USA-based mBC landscape analysis(5) and a March 2016, international 2005-2015 mBC Decade Report(6) have reported the same conclusion. Gaps identified included disease state information, prognosis, information on treatments, symptom and side effect management, and palliation. Overall, there appears to be an enduring and significant unmet need for appropriate education tailored to the informational needs of diverse mBC sub-groups.(7, 8)

Patient education or information is important to enhance patient outcomes by empowering patients and caregivers; optimizing treatment outcomes; limiting treatment-related adverse events; and reducing office visits and hospitalizations.(9) It has been defined as: “...the process by which the patient comes to comprehend his or her physical condition and self-care by the use of various media and experiences”.(10)

Important considerations in providing patient information

Patient information-seeking and engagement may be affected by multiple factors. Patient information engagement may be affected by psychological characteristics such as being an “information-seeker” or not, preferences for different information formats or learning styles, sociodemographic characteristics such as age, ethnicity, and educational level, clinical factors such as the presence of comorbidities, and where a patient is on the cancer journey.(11-17)

Information-seeking behaviours

Information-seeking behaviours of women with breast cancer are highly individualistic (18), with some women seeking information to cope with cancer (“monitors”) while others avoid information to escape the negative feelings associated with information (“blunters”).(19) Some patients also prefer to receive information via a proxy or surrogate (eg, a family member or caregiver).(15, 20)

Information formats and learning styles

Women with mBC have also expressed varying information source preferences and assessments. Living Beyond Breast Cancer survey respondents cited printed patient materials, government websites, and professional medical publications as the most frequently accessed sources, but scientific conferences and telephone education sessions were most valued by the majority.(2) Cancer patients’ reactions to content, format, sources, and preferences for the timing and delivery mechanisms of information will impact their information behaviours.(21) For example, readability, comprehensibility, and cultural relevance may influence patient engagement with health information.(21, 22)

Age

Generational differences affect information needs, sources, engagement behaviours, and preferences. Older women with cancer may prefer more passive roles and express less need for information.(6, 17, 23, 24) Many younger women with breast cancer may experience treatment-related sexual dysfunction that may not completely resolve (25) so information on sexuality may be of special interest.(26)

Education and health literacy

Inadequate health literacy, (“the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions”),(27) poses barriers to cancer patients’ understanding of their disease and treatment options.(28) Moreover, higher educational level has been found to be associated with a more active information-seeking style.(13, 17, 29, 30)

Ethnicity

Ethnicity, race, and cultural background also influence cancer patients’ information-seeking behaviours.(6, 31, 32) Thus, the use of family- and community-based (vs purely individually-directed), religious and spiritual coping strategies by African American and Latina women with breast cancer may influence the way they access health information. (6, 31, 33)

Position on the care continuum

The information needs, including the type of information sought, of women with mBC varies with the stage of the patient pathway (ie, mBC diagnosis, treatment, including long-term survivorship, and the posttreatment, end-of-life phase).(5, 17) An important aspect of mBC patient care is provision of specific information that is tailored to the specific stage of the patient along the mBC continuum.(14, 34)

Around the time of diagnosis, patients want information about the disease, side-effect management, prevention of treatment-related side effects, and prognosis (35-37); at the time of treatment, treatment information (ie, monitoring treatment-related side effects and the risk-benefit profile of novel treatments) may be most relevant.(38) Long-term survivors’ informational needs relate to their diagnosis, prognosis, and treatment options, including understanding and managing treatment-related toxicities and effects such as psychosocial complications (eg, anxiety and depression and social complications).(6, 39, 40) In the end-of-life and palliative treatment phase, specific information needs include late-disease risks, complications of advanced disease, specific palliative care therapies and potential side effects, pain management, and skin care.(41)

Study objectives

The aim of this study is to explore the question: What information exists in the literature about the information needs, sources, engagement behaviours and associated sociodemographic and situational factors (such as disease- or treatment-related factors) of women ≥ 18 years with metastatic breast cancer at different time points of the cancer care continuum?

Study rationale: preliminary literature search summary

In this first phase of the research, initial literature searches were conducted on PubMed and CINAHL for the preliminary literature review. The period searched was 1950 (approximate start of oral chemotherapy) to present. This initial search was framed around a proposed exploration of the most effective teaching strategies and methods of delivery for patient education in women with metastatic breast cancer, including underserved subpopulations such as African American and Latina women. The role of digital media—computer/internet-based patient education methodologies—in optimizing the education of women with MBC was also considered.

Topics searched were: internet and patient education and metastatic or advanced breast cancer; patient education/patient education methods and advanced/metastatic breast cancer; patient education and advanced breast cancer and African American/black/Latina/minority women. The searches returned a total of 340 results.

The preliminary literature searches indicated that there are very few articles on patient education and information interventions in women with mBC in the published literature. Nine articles discuss educational or behavioural interventions in women with metastatic breast cancer (5 from the literature search and 4 that were not from the search).(35, 39, 42-48) Six further articles (4 from the literature search and 2 that were not from the search) (36, 37, 49-52) provide information on the educational and psychosocial needs of women with mBC. There are articles that address the informational needs of patients with multiple types of cancer, but these do not necessarily examine mBC on its own.

There are a few randomized controlled trials comparing educational or behavioural interventions for women with mBC. One study examined the effect of supportive-expressive psychotherapy on the survival time of women with mBC; (48) another looked at the effectiveness of a brief, tailored, nurse-delivered psychoeducational intervention on their quality of life or perceived needs (43); and a third investigated the efficacy of cognitive therapy on reducing depression.(45) The preliminary literature search also failed to discover any existing scoping reviews on the subject of the proposed review.

These search results support the need to explore the information needs, preferences, and sources of women with metastatic breast cancer across the continuum of care in the published literature. The rationale for the proposed research is that provision of quality care to women with mBC requires information provision appropriate to different time points in the care continuum.(34) This scoping review aims to synthesize current knowledge on female mBC patients' information needs, sources, and engagement behaviours and influences as these evolve across their cancer journey.

The apparent paucity of relevant primary research calls into question the feasibility of undertaking a systematic review of this subject. This suggests the utility of an exploratory scoping review in assessing the feasibility of performing a systematic review of the topic.

Methods and analysis

A scoping review will be conducted of the scientific, clinical, and broader literature for articles in English addressing female mBC patient information needs, sources, utilization and related factors across the mBC disease course. Because of a lack of resources for translation, articles published in languages other than English will be excluded.

While recognizing the existence of several varying definitions of this methodology, for purposes of this review, by scoping review or study is meant: "...a form of knowledge synthesis that addresses an exploratory research question aimed at mapping key concepts, types of evidence, and gaps in research related to a defined area or field by systematically [and iteratively] (*insertion by O'Brien et al (53)*) searching, selecting, and synthesizing existing knowledge". (54)

In their foundational article on scoping review methodology, Arksey and O’Malley (55) identified possible aims of scoping reviews as: to examine the extent, range and nature of research activity, determine the value of undertaking a full systematic review, summarize and disseminate research findings, or identify gaps in the existing literature. Initially, at least the first two aims will be addressed via this scoping review; potentially all four may be fulfilled.

Arksey and O’Malley(55) also proposed a six-stage methodological framework: (i) identifying the research question; (ii) searching for relevant studies; (iii) selecting studies; (iv) charting the data; (v) collating, summarizing, and reporting the results; and (vi) consulting with stakeholders to inform or validate study findings (optional).

Both Levac et al (56) and Daudt et al (57) have made significant updates to the Arksey and O’Malley scoping review framework. This study protocol is informed by and incorporates enhancements and refinements made by these two groups.

The primary objective is to provide a critical review of the state of the research apparent from the literature about the information needs and behaviours of women with mBC as they evolve across the disease course, including identifying gaps insofar as possible.

To ensure comprehensiveness of the research, information is defined broadly as comprising both cancer-related and non–cancer-related information, viz, psychological, medical, and social information.

Literature review search strategy

The scoping review will consider the international English language literature (both peer-reviewed and “grey”) that discusses patient information needs, sources, and acquisition, including associated variables of women aged ≥ 18 with advanced or metastatic stage IV (4) breast cancer. Primary research studies, systematic reviews, meta-analyses, clinical guidelines, meeting abstracts and dissertations, interviews, text and opinion literature, and other publication types will be included. In order to capture a diverse body of evidence, encompassing

quantitative, qualitative, and mixed methods approaches, and in keeping with the scoping review methodology focus on summarizing breadth of evidence, no study designs will be excluded.

As described in the *Joanna Briggs Institute Reviewers' Manual 2015*, a three-step search strategy will be used in this research:(58)

1. An initial limited search of PubMed and CINAHL followed by analysis of the text words contained in the title and abstract of the retrieved articles.
2. A second search using all identified keywords and index terms across all proposed databases.
3. A search of the reference list of all identified reports and articles for additional studies.

The proposed databases to be searched (from inception to present day) include CINAHL, PubMed, EMBASE, Academic Search Premier, Cochrane Database of Systematic Reviews, PsycINFO, Health Source: Nursing/Academic Edition, Epistemonikos, the Joanna Briggs Institute Database of Systematic Reviews and Implementation Reports (JBISIRIR), the Evidence for Policy and Practice Information and Co-ordinating Centre (EPPI-Centre) and Education Resources Information Center (ERIC).

Patient advocacy websites and publications and cancer websites will be investigated for unpublished studies. The search for unpublished studies will also include the following websites: PQDT Open (<http://pqdtopen.proquest.com/search.html>, which provides open access to dissertations and theses), Google Scholar, World Health Organization (WHO), www.who.int, Clinical Trials.gov, Institute of Medicine (IOM), www.iom.edu, the National Cancer Institute (NCI) www.cancer.gov, National Institutes of Health (NIH), www.nih.gov, Agency for Healthcare Research and Quality (AHRQ), www.ahrq.gov, New York Academy of Medicine, <http://www.nyam.org/>, and the Virginia Henderson Global Nursing e-Repository of the Honor Society of Nursing, Sigma Theta Tau International, www.nursinglibrary.org, a repository dedicated to sharing nursing publications.

The search for grey literature will include searches of Open-Grey (www.opengrey.edu), an open access database of European grey literature and the *Grey Literature Report* (www.greylit.org), a publication of the New York Academy of Medicine.

Relevant oncology websites will be searched, including the American Society of Clinical Oncology (ASCO), www.asco.org, Oncology Nursing Society (ONS), www.ons.org, European Society for Medical Oncology (ESMO), www.esmo.org, and the American Cancer Society (ACS), www.acs.org websites.

The initial search will consist of each of the following terms linked by **OR**: Information-seeking, information needs, information acquisition, information resources, information sources, information source preferences, information support, information dissemination methods, health information, patient education, health education, patient education methods, therapeutic patient education, patient knowledge, treatment education, patient concerns, patient satisfaction, patient communication, patient information, patient experience, clinical communication, physician-patient communication, patient-provider communication, communication challenges, and patient-cent(e)red communication **AND** each of the following terms linked by **OR**: advanced breast cancer, metastatic breast cancer, secondary breast cancer, stage IV breast cancer, and stage 4 breast cancer. A flexible and iterative approach will be employed enabling redefining and/or fine tuning of this initial search strategy based on the results obtained. (53)

To assess the completeness of the above search, hand searching of reference lists and bibliographies of included studies and two or three appropriate journals for the preceding six months to a year will be conducted. Proposed journals are the *Journal of Cancer Education*, *Patient Education and Counseling*, and *Support Care Cancer*. Endnote will be used to manage the references retrieved.

Study selection

The review will exclude articles that:

- 4. Include patients ≤ 18 years old. As with other paediatric cancer patients, paediatric patients with mBC are likely to have unique information and support needs that cannot be adequately addressed within the framework of this review, but will require a separate specific review.
- 5. Focus mainly on men or do not differentiate between the needs of male and female mBC patients. Although many of the findings concerning information needs, sources, and engagement may be transferable from women to men, we consider that men with mBC

have special needs worthy of a separate review. This protocol and scoping review will focus only on women with mBC.

6. Solely report economic research (ie, cost-effectiveness or cost-utility studies)
7. Relate to prevention and screening for breast cancer
8. Describe genetics unless they discuss information needed by or provided to women with mBC
9. Focus on the information needs and behaviours of women with early stage or primary breast cancer
10. Focus exclusively on the information needs and engagement of patients' partners or family members. However, articles containing information relative to the influence of patient/caregiver interactions on the patient information engagement behaviours of women mBC will be included.
11. Include other types of cancer in addition to mBC, but which do not discuss the information needs, sources, and behaviours of women with mBC separately from those of patients with other types of cancer.
12. Focus on the informational or educational needs of health care professionals, unless they also address the information needs of women with mBC
13. Concern cancer risk, mortality, and epidemiology

Articles for inclusion will be selected using a three-step process: (i) titles of articles will be scanned to determine eligibility based on the inclusion and exclusion criteria; (ii) article titles and abstracts will be reviewed using the eligibility criteria; (iii) full-text versions of all potentially relevant articles will be retrieved for inclusion consideration.

As recommended in the Levac et al methodological update, this stage of the review will be approached as an iterative process comprising searching the literature, refining the search strategy, and reviewing articles for study inclusion.⁽⁵⁶⁾

Given the patient-centred focus of the proposed research, it is likely that qualitative evidence will be an important element of the output of this study. It has been expressed as both a strength and a limitation of scoping reviews that at best they encompass a wide array of literature and research study designs though the diverse and potentially complex character of the data obtained may

make analysis and synthesis very demanding. (53) Despite the contrasting methodologies of quantitative and qualitative research, the proposed review will iteratively address these issues as the literature review evolves, data is generated, and a clearer understanding of the scope and character of the mBC information behaviour literature develops. Qualitative data will be addressed using qualitative methodology: an interpretive approach to understanding mBC patients’ perceptions, values, beliefs and experiences relative to information needs, seeking, quality, and knowledge assimilation, may be an applicable approach to an analysis and synthesis of qualitative literature results. (59, 60)

Data abstraction

This step in the review process relates to “charting the results” in review terminology. Given the iterative nature of scoping reviews the exact path and methodology of data abstraction may change depending on the data obtained. The proposals outlined here are preliminary and subject to modification as the review evolves.

The systematic review typology chart developed by Rutten et al(17) and modified by van Mossel et al (34) will be adapted to create a preliminary table (Table 1) to record authors and dates of included articles and types of information needs and sources mentioned using the broad categories they proposed. Relevant subcategories of information specific to breast cancer and/or mBC will be formulated using the search results; these will be used to generate two tables recording the types of information needs and sources mentioned in reviewed articles.

The methodological quality of individual included studies will not be assessed since the aim of a scoping study is to conduct a comprehensive search enabling the identification of gaps in the evidence base and indication of subject areas for future reviews. (34, 61) While Daudt and colleagues strongly recommend incorporation of this component into the scoping review exercise, there does not appear to be currently sufficient guidance contained within the scoping review literature to assist in conducting this process. This consideration is especially pertinent as the evaluative task involves assimilation of evidence drawn from a diverse body of qualitative, quantitative, research and non-research and other literature that is not necessarily amenable to the usual methods of quality assessment. (62)

Author and date	Types of information needs mentioned								Types of information sources mentioned						
	Other	Treatment-related information	Rehabilitation	Coping information	Interpersonal/social information	Prognosis information	Cancer-specific information	Body image/sexuality information	Medical system information	Health care professionals	Interpersonal	Printed materials	Media	Organizational/scientific resources	Women with metastatic breast cancer

Table 1. Charting of included studies

As recommended by Levac et al (56), charting will be an iterative step; data will be continually extracted and the charting form updated accordingly. Additionally, the charting form will be piloted using the first 5-10 studies and reviewed jointly by the authors to assess whether it meets the needs of the research question and the purpose of this review, with refinements made before embarking on the full scale charting exercise. (56, 57)

Also, as observed by O'Brien et al (53), since the process of charting, collating and summarizing of included publications will be iterative, knowledge synthesis may involve a descriptive component (presenting frequencies of literature characteristics) as well as an analytical aspect, ie, synthesis of qualitative and quantitative data with thematic or content analysis for relevant variables.

Results

Data abstraction and synthesis will use both tabular and textual (descriptive) approaches, which will provide adequate flexibility to accommodate both quantitative and qualitative literature.

This stage of the scoping review exercise falls under the collating, summarizing, and reporting the results stage of the Arksey and O’Malley framework. (55) As suggested by Levac et al, this stage may be segmented into 3 discrete steps: analyzing the data (including descriptive numerical summary analysis and qualitative thematic analysis); reporting the results linked to the research question; and interpreting the implications of the results for research, policy, and practice. (56)

Characteristics of the literature included in the review will be summarized in a table (Table 2), and the stages of the cancer care continuum in the reviewed articles will also be tabulated (Table 3). A descriptive (narrative) summary of the articles included in the review, describing the aims or purposes of included articles, concepts or approaches used in each, and the results that relate to the review question, will be presented. As suggested by Levac et al (56), a thematic analysis akin to a qualitative data analysis approach may be attempted intended to organize the data into overarching themes. The findings might be presented using tables and descriptions aligned with identified themes. (57)

Table 2. General characteristics of included articles

Characteristic	n	%
<i>Type of article</i>		
Research study		
Commentary/narrative		
Clinical practice guideline		
Literature review		
Description of a program		
Other		
<i>Data collection method</i>		
Multiple collection methods		
Original questionnaire/survey		
Existing questionnaire/survey		

Interview		
Focus groups		
Chart review/medical records		
Other		
Unknown		
Research study design		
Quantitative		
Qualitative		
Mixed methods		
Clinical trial		
Concurrent		
Prospective/longitudinal		
Other (mixed designs)		
Unknown		
Learning theory		
Discussed		
Not discussed		
Geographical location of the work		
United States		
United Kingdom		
Other European countries		
Australia		
Canada		
Other		
Publication date		

Table 3. Stages of the cancer care continuum mentioned in the reviewed articles

Stage in cancer care continuum	n	%
At diagnosis		
Treatment (including long-term survivorship)		
Posttreatment/ End-of-life		

Any potential implications for evidence-based patient education practice and knowledge gaps meriting primary research and/or systematic reviews will be presented.(58)

Ethics and dissemination

All data in this review will be gathered through searches of literature and other online databases, and no personal health information will be collected; thus, ethics committee approval will not be required for the scoping review portion.

Research findings will be published and presented to patients and their families and caregivers through patient support and advocacy websites and organizations.

The second part of the study will involve primary research and entails interaction with mBC patients to solicit their contributions on their cancer-related information needs and information engagement across the disease course. Ethics approval for this phase of the study will be sought from the Education Research Ethics Sub-Committee of the Faculty of Arts FREC of Plymouth University.

The methodology will be two-pronged: (i) Monitoring of online sources, including social networking sites, discussion boards, and on-line support groups for relevant postings, including tweets and chats. These inputs will be synthesized using qualitative thematic analysis/discourse or conversation analysis. In-person engagement with mBC patient support groups around the same questions will provide additional data on the research topics and context to the scoping review findings. (ii) A survey of mBC patients (using an on-line method as well as hard copy

questionnaires) will be conducted to test the findings from the online monitoring exercise. This corresponds to the sixth stage of the Arksey and O'Malley framework: stakeholder consultation.

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Contributors

All authors (CAT, MPM, and RBJ) made substantive intellectual contributions to the development of this protocol. CAT conducted the preliminary research, which was critically reviewed and with contributions from MPM and RBJ. All authors (CAT, MPM, and RBJ) were involved in developing the review question and the review design. RBJ provided substantial guidance to CAT in the elaboration of the review design. CAT initiated the first draft of the manuscript, which was then followed by several iterations with substantial input, appraisal, and revisions from MPM and RBJ. All authors (CAT, MPM, and RBJ) approved the final submission version of the manuscript. The revised version of this manuscript, which was prepared by CAT, was also reviewed, edited, revised, and approved by MPM and RBJ.

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Competing interests

None

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For peer review only

PRISMA-P Checklist

Item 1a: Identification. Identify the report as a protocol of a systematic review

Health Information Needs, Sources, and Engagement Behaviours of Women With Metastatic Breast Cancer Across the Care continuum: Protocol for a Scoping Review (page 1 of manuscript)

Item 1b: Update. If the protocol is for an update of a previous systematic review, identify as such

N/A

Item 2. If registered, provide the name of the registry (such as PROSPERO) and registration number

N/A

Item 3a: Contact information. Provide name, institutional affiliation, and email address of all protocol authors; provide physical mailing address of corresponding author

Corresponding author: Carol A. Tucker, 799 East 40th Street, Brooklyn, NY, 11210, USA, 347-409-3662, carol.tucker@plymouth.ac.uk

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(pages 1 and 18)

Item 3b: Contributions. Describe contributions of protocol authors and identify the guarantor of the review

RBJ is the guarantor. All authors (CAT, MPM, and RBJ) made substantive intellectual contributions to the development of this protocol. CAT conducted the preliminary research, which was critically reviewed and with contributions from MPM and RBJ. All authors (CAT, MPM, and RBJ) were involved in developing the review question and the review design. RBJ provided substantial guidance to CAT in the elaboration of the review design. CAT initiated the first draft of the manuscript, which was then followed by several iterations with substantial input, appraisal, and revisions from MPM and RBJ. All authors (CAT, MPM, and RBJ) approved the final submission version of the manuscript. The revised version of this manuscript, which was

prepared by CAT, was also reviewed, edited, revised, and approved by MPM and RBJ.
(page 18)

Item 4. If the report represents an amendment of a previously completed or published protocol, identify as such and indicate what changes were made; otherwise state plan for documenting important protocol amendments

N/A

Item 5a: Sources. Indicate sources of financial or other support for the review

This research received no financial or other support from any funding agency in the public, commercial or not-for-profit sectors.
(page 19)

Item 5b: Sponsor. Provide name of the review funder and/or sponsor

N/A

Item 6. Describe the rationale for the review in the context of what is already known

The health information needs, information source preferences, and engagement behaviours of women with metastatic breast cancer (mBC) depend on personal characteristics such as education level, prior knowledge, clinical complications, comorbidities, and where they are in the cancer journey. A thorough understanding of the information behaviours of women living with mBC is essential to the provision of optimal care. A preliminary literature review suggests that there is little research on this topic, but that there may be lessons from a slightly broader literature.

The rationale for the planned review is that provision of quality care to women with mBC requires information provision appropriate to different time points in the care continuum.

This review will identify what is known and what is not known about the health information needs, acquisition, and influences of women with mBC across the care continuum. Findings will help to identify research needs and inform evidence-based interventions to address the health information needs of female mBC patients with different demographics and characteristics and across the mBC journey.

(pages 2 and 8)

Item 7. Provide an explicit statement of the question(s) the review will address with reference to participants, interventions, comparators, and outcomes (PICO)

Participants: Women aged 18+ with metastatic breast cancer

Interventions: Not applicable – we are looking at their information needs, information sources, and engagement behaviours.

Comparators: Sociodemographic and situational factors, stages on the cancer care continuum.

Outcomes: All relevant measures of psychological and possibly physical well-being.

(pages 2 and 7)

Item 8. Specify the study characteristics (such as PICO, study design, setting, timeframe) and report characteristics (such as years considered, language, publication status) to be used as criteria for eligibility for the review

The scoping review will consider the international English language literature (both peer-reviewed and “grey”) that discusses patient information needs, sources, and acquisition, including associated variables of women aged ≥ 18 with advanced or metastatic stage IV (4) breast cancer. Primary research studies, systematic reviews, meta-analyses, clinical guidelines, meeting abstracts and dissertations, interviews, text and opinion literature, and other publication types will be included. In order to capture a diverse body of evidence, encompassing quantitative, qualitative, and mixed methods approaches, and in keeping with the scoping review methodology focus on summarising breadth of evidence, no study designs will be excluded.

The review will exclude articles that are:

1. Inclusive of patients ≤ 18 years old
2. Studies that focus mainly on men or do not differentiate between the needs of male and female mBC patients;
3. Devoted to the information needs and behaviours of women with early stage or primary breast cancer;
4. Focused exclusively on the information needs and engagement of patients’ partners or family members. However, articles containing information relative to the influence of patient/caregiver interactions on the patient information engagement behaviours of women with mBC will be included.

5. Focused on the informational or educational needs of health care professionals, unless they also address the information needs of women with mBC

(pages 9-10 and 11-12)

Item 9. Describe all intended information sources (such as electronic databases, contact with study authors, trial registers or other grey literature sources) with planned dates of coverage

A scoping review will be performed to systematically search scientific and grey literature for articles that discuss the health information needs, sources, engagement styles and associated personal and medical attributes of women living with mBC at different stages of the disease course. A variety of databases (including Cumulative Index to Nursing and Allied Health Literature [CINAHL], PubMed, Excerpta Medica Database [EMBASE], Academic Search Premier, Cochrane Database of Systematic Reviews, PsycINFO, Health Source: Nursing/Academic Edition, and PQDT Open), oncology, patient advocacy, and governmental websites will be searched from inception to present day.

The search for grey literature will include searches of Open-Grey (www.opengrey.edu), an open access database of European grey literature and the *Grey Literature Report* (www.greylit.org), a publication of the New York Academy of Medicine.

(pages 2 and 10)

Item 10. Present draft of search strategy to be used for at least one electronic database, including planned limits, such that it could be repeated

The initial search will consist of each of the following terms linked by **OR**: Information-seeking, information needs, information acquisition, information resources, information sources, information support, information dissemination methods, health information, patient education, health education, patient education methods, therapeutic patient education, patient knowledge, treatment education, patient concerns, patient satisfaction, patient communication, patient information, patient experience, clinical communication, physician-patient communication, patient-provider communication, communication challenges, and patient-centred communication **AND** each of the following terms linked by **OR**: advanced breast cancer, metastatic breast cancer, secondary breast cancer, stage IV breast cancer, and stage 4 breast cancer.

A flexible and iterative approach will be employed enabling redefining and/or fine tuning of this initial search strategy based on the results obtained.
(page 11)

Item 11a: Data management. Describe the mechanism(s) that will be used to manage records and data throughout the review

Upon completion of searches, the references will be documented and references will be exported into database-specific folders in Endnote, a reference management software that will be used to manage the references retrieved.
(page 11)

Item 11b: Selection process. State the process that will be used for selecting studies (such as two independent reviewers) through each phase of the review (screening, eligibility, and inclusion in meta-analysis)

Article selection will be an iterative process comprising searching the literature, refining the search strategy, and reviewing articles for study inclusion.

Articles for inclusion will be selected using a three-step process: (i) titles of articles will be scanned to determine eligibility based on the inclusion and exclusion criteria; (ii) article titles and abstracts will be reviewed using the eligibility criteria; (iii) full-text versions of all potentially relevant articles will be retrieved for inclusion consideration.
(page 12)

Item 11c: Data collection process. Describe planned method of extracting data from reports (such as piloting forms, done independently, in duplicate), any processes for obtaining and confirming data from investigators

A series of tables will be created to collect relevant data from the articles selected. It will be piloted using the first 5-10 studies and reviewed jointly by the authors to assess whether it meets the needs of the research question, with refinements made before embarking on the full scale charting exercise.

(pages 13-17)

Item 12: List and define all variables for which data will be sought (such as PICO items, funding sources) and any pre-planned data assumptions and simplifications.

A preliminary table will be created to record authors and dates of included articles and types of information needs and sources mentioned using broad categories. Relevant subcategories of information specific to breast cancer and/or metastatic breast cancer will be formulated using the search results; these will be used to generate two tables recording the types of information needs and sources mentioned in reviewed articles.

Characteristics of the literature included in the review will be summarized in a table, and the stages of the cancer care continuum in the reviewed articles will also be tabulated. A descriptive (narrative) summary of the articles included in the review, describing the aims or purposes of included articles, concepts or approaches used in each, and the results that relate to the review question, will be presented.

(pages 13 and 15)

Item 13. List and define all outcomes for which data will be sought, including prioritization of main and additional outcomes, with rationale

N/A

Item 14. Describe anticipated methods for assessing risk of bias of individual studies, including whether this will be done at the outcome or study level or both; state how this information will be used in data analysis.

N/A. The methodological quality of individual included studies will not be assessed since the aim of a scoping study is to conduct a comprehensive search enabling the identification of gaps in the evidence base and indication of subject areas for future reviews.

Item 15a. Describe criteria under which study data will be quantitatively synthesised.

N/A

Item 15b. If data are appropriate for synthesis, describe planned summary measures, methods of handling data, and methods of combining data from studies, including any planned exploration of consistency (such as I^2 , Kendall's τ)

N/A

15c. Describe any proposed additional analyses (e.g., sensitivity or subgroup analyses, meta-regression)

N/A

15d. If quantitative synthesis is not appropriate, describe the type of summary planned.

Data abstraction and synthesis will use both tabular and textual (descriptive) approaches, encompassing both quantitative and qualitative literature. A descriptive (narrative) summary of the articles included in the review, describing the aims or purposes of included articles, concepts or approaches used in each, and the results that relate to the review question, will be presented. A thematic analysis akin to a qualitative data analysis approach may be attempted intended to organize the data into overarching themes. The findings may be presented using tables and descriptions aligned with the identified themes.

(pages 14-15)

Item 16. Specify any planned assessment of meta-bias(es) (such as publication bias across studies, selective reporting within studies)

N/A. The methodological quality of individual included studies will not be assessed since the aim of a scoping study is to conduct a comprehensive search enabling the identification of gaps in the evidence base and indication of subject areas for future reviews.

17. Describe how the strength of the body of evidence will be assessed (such as GRADE).

N/A. No evaluative standards for scoping studies have yet been developed.

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HEALTH INFORMATION NEEDS, SOURCE PREFERENCES, AND ENGAGEMENT BEHAVIOURS OF WOMEN WITH METASTATIC BREAST CANCER ACROSS THE CARE CONTINUUM: PROTOCOL FOR A SCOPING REVIEW

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ABSTRACT

Introduction

The health information needs, information source preferences, and engagement behaviours of women with metastatic breast cancer (mBC) depend on personal characteristics such as education level, prior knowledge, clinical complications, comorbidities, and where they are in the cancer journey. A thorough understanding of the information behaviours of women living with mBC is essential to the provision of optimal care. A preliminary literature review suggests that there is little research on this topic, but that there may be lessons from a slightly broader literature.

This review will identify what is known and what is not known about the health information needs, acquisition, and influences of women with mBC across the care continuum. Findings will help to identify research needs and specific areas where in-depth systematic reviews may be feasible, as well as inform evidence-based interventions to address the health information needs of female mBC patients with different demographics and characteristics and across the mBC journey.

Methods and analysis

A scoping review will be performed using the guidelines of Arksey and O'Malley as updated by subsequent authors to systematically search scientific and grey literature for articles in English that discuss the health information needs, source preferences, engagement styles and associated personal and medical attributes of women ≥ 18 years living with mBC at different stages of the disease course. A variety of databases (including Cumulative Index to Nursing and Allied Health Literature [CINAHL], PubMed, Excerpta Medica Database [EMBASE], Academic Search Premier, Cochrane Database of Systematic Reviews, PsycINFO, Health Source: Nursing/Academic Edition, and PQDT Open), oncology, patient advocacy, and governmental websites will be searched from inception to present day. Research and non-research literature will be included; no study designs will be excluded.

The six-stage Arksey and O’Malley scoping review methodological framework involves: (i) identifying the research question; (ii) searching for relevant studies; (iii) selecting studies; (iv) charting the data; (v) collating, summarizing, and reporting the results; and (vi) consulting with stakeholders to inform or validate study findings (optional).

Data will be extracted and analysed using a thematic chart and descriptive content analysis.

Ethics and dissemination

Being a secondary analysis, this research will not require ethics approval. Results will be disseminated through patient support organizations and websites and publications targeting health care professionals, advocates, and patients.

STRENGTHS AND LIMITATIONS OF THIS STUDY

- Systematic summarization of the evidence will identify information available from a wide array of relevant sources (scientific and grey literature) and publication types.
- The study will be a comprehensive review of published papers identified via major biomedical databases, not limited by time but covering a period from their inception to present day.
- No study designs or publication types will be excluded. As such, the review will integrate a wide and diverse body of literature and allow the combination of qualitative and quantitative knowledge synthesis approaches and research and non-research sources.
- The research will not be representative of the entire mBC population as men with mBC and paediatric patients with mBC will be excluded from the scope of the review.
- The research will not specifically address the information needs and influences of mBC subpopulations, characterized by factors including age, race, site of metastases, hormone status, timing of advanced disease diagnosis (ie, initial versus recurrent), and stage of metastasis, which may be unique to each group.
- As a scoping review, the quality of included studies will not be evaluated.
- Included studies will be limited to those published in English due to resource constraints represented by an inability to have articles in other languages translated for inclusion. As

such, the results of the review will not encompass the full international literature landscape on this topic.

INTRODUCTION AND BACKGROUND

Metastatic (stage IV or stage 4) breast cancer (mBC), otherwise called advanced or secondary breast cancer, is a disease that has spread to distant sites of the body such as the liver, lungs, bone, brain, and/or other tissues or organs.(1) It is an incurable but treatable disease with a high risk of a shortened life span and continuous cancer-related treatment to prolong progression-free survival. Breast cancer occurs primarily in women though men can also be affected by the disease; the review will focus on women.

Women with metastatic disease have unique characteristics, needs, including information needs, and experiences that differ from those with early stage disease. Information and other resources provided to the broader breast cancer community may not be appropriate to them.

Information needs of women with mBC

Several large patient surveys—the 2006 US-based Silent Voices Survey,(2) and international BRIDGE Survey (2009),(3) Count Us, Know Us, Join Us, and Here & Now (both 2016) (4)—have attested to the inadequacy and inaccessibility of mBC-specific patient information currently. Additionally, a 2013-2014 USA-based mBC landscape analysis(5) and a March 2016, international 2005-2015 mBC Decade Report(6) have reported the same conclusion. Gaps identified included disease state information, prognosis, information on treatments, symptom and side effect management, and palliation. Overall, there appears to be an enduring and significant unmet need for appropriate education tailored to the informational needs of diverse mBC sub-groups.(7, 8)

Patient education or information is important to enhance patient outcomes by empowering patients and caregivers; optimizing treatment outcomes; limiting treatment-related adverse events; and reducing office visits and hospitalizations.(9) It has been defined as: “...the process by which the patient comes to comprehend his or her physical condition and self-care by the use of various media and experiences”.(10)

Preliminary literature search summary

To further probe the educational needs of women with mBC and the approaches to addressing these needs, a preliminary review of the literature was conducted using literature searches on PubMed and CINAHL. The period searched was 1950 (approximate start of oral chemotherapy) to present. This initial search was primarily concerned with gaining some insights into the character and effectiveness of teaching strategies and methods of delivery for patient education in women with metastatic breast cancer, including underserved subpopulations such as African American and Latina women. The role of digital media—computer/internet-based patient education methodologies—in optimizing the education of women with mBC was also considered.

Topics searched were: internet and patient education and metastatic or advanced breast cancer; patient education/patient education methods and advanced/metastatic breast cancer; patient education and advanced breast cancer and African American/black/Latina/minority women. The articles selected were full articles that described educational/health behavioral interventions in women with mBC or studies of these interventions. The selection focused on papers published in the previous 10 years. The searches returned a total of 340 results. The titles and (in many cases) abstracts of all 340 articles were reviewed.

The preliminary literature searches indicated that there are very few articles on patient education and information interventions in women with mBC in the published literature. Nine articles discuss educational or behavioural interventions in women with metastatic breast cancer (5 from the literature search and 4 that were not from the search). (11-19) Six further articles (4 from the literature search and 2 that were not from the search) (20-25) provide information on the educational and psychosocial needs of women with mBC. There are articles that address the informational needs of patients with multiple types of cancer, but these do not necessarily examine mBC on its own.

There are a few randomized controlled trials comparing educational or behavioural interventions for women with mBC. One study examined the effect of supportive-expressive psychotherapy on the survival time of women with mBC; (19) another looked at the effectiveness of a brief,

tailored, nurse-delivered psychoeducational intervention on their quality of life or perceived needs (12); and a third investigated the efficacy of cognitive therapy on reducing depression.(16) The preliminary literature search also failed to discover any existing scoping reviews on the subject of the proposed review. These results suggest the need for a more comprehensive and detailed examination of the literature.

Important considerations in providing patient information

Patient information-seeking and engagement may be affected by multiple factors. Patient information engagement may be affected by psychological characteristics such as being an “information-seeker” or not, preferences for different information formats or learning styles, sociodemographic characteristics such as age, ethnicity, and educational level, clinical factors such as the presence of comorbidities, and where a patient is on the cancer journey.(26-32)

Information-seeking behaviours

Information-seeking behaviours of women with breast cancer are highly individualistic (33), with some women seeking information to cope with cancer (“monitors”) while others avoid information to escape the negative feelings associated with information (“blunters”).(34) Some patients also prefer to receive information via a proxy or surrogate (eg, a family member or caregiver).(30, 35)

Information formats and learning styles

Women with mBC have also expressed varying information source preferences and assessments. Living Beyond Breast Cancer survey respondents cited printed patient materials, government websites, and professional medical publications as the most frequently accessed sources, but scientific conferences and telephone education sessions were most valued by the majority.(2) Cancer patients’ reactions to content, format, sources, and preferences for the timing and delivery mechanisms of information will impact their information behaviours.(36) For example, readability, comprehensibility, and cultural relevance may influence patient engagement with health information.(36, 37)

Age

Generational differences affect information needs, source preferences, engagement behaviours, and preferences. Older women with cancer may prefer more passive roles and express less need for information.(6, 32, 38, 39) Many younger women with breast cancer may experience treatment-related sexual dysfunction that may not completely resolve (40) so information on sexuality may be of special interest.(41)

Education and health literacy

Inadequate health literacy, (“the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions”),(42) poses barriers to cancer patients’ understanding of their disease and treatment options.(43) Moreover, higher educational level has been found to be associated with a more active information-seeking style.(28, 32, 44, 45)

Ethnicity

Ethnicity, race, and cultural background also influence cancer patients’ information-seeking behaviours.(6, 46, 47) Thus, the use of family- and community-based (vs purely individually-directed), religious and spiritual coping strategies by African American and Latina women with breast cancer may influence the way they access health information. (6, 46, 48)

Position on the care continuum

As with other cancers,(32) the information needs, including the type of information sought, of women with mBC varies with the stage of the patient pathway (ie, mBC diagnosis, treatment, including long-term survivorship, and the posttreatment, end-of-life phase).(5) An important aspect of cancer care is provision of specific information that is tailored to the specific stage of the patient along the disease continuum.(29, 49)

Around the time of diagnosis, patients want information about the disease, side-effect management, prevention of treatment-related side effects, and prognosis (15, 21, 25); at the time of treatment, treatment information (ie, monitoring treatment-related side effects and the risk-

benefit profile of novel treatments) may be most relevant.(50) Long-term survivors' informational needs relate to their diagnosis, prognosis, and treatment options, including understanding and managing treatment-related toxicities and effects such as psychosocial complications (eg, anxiety and depression and social complications).(6, 14) In the end-of-life and palliative treatment phase, specific information needs include late-disease risks, complications of advanced disease, specific palliative care therapies and potential side effects, pain management, and skin care.(51)

Study rationale

The rationale for the proposed research is that provision of quality care to women with mBC requires information provision appropriate to different time points in the care continuum.(14, 15, 21, 25, 50, 51) This scoping review aims to synthesize current knowledge on female mBC patients' information needs, source preferences, and engagement behaviours and influences as these evolve across their cancer journey.

Study objectives

The aim of this study is to explore the question: What information exists in the literature about the information needs, source preferences, engagement behaviours and associated sociodemographic and situational factors (such as disease- or treatment-related factors) of women ≥ 18 years with metastatic breast cancer at different time points of the cancer care continuum?

Anticipated utility of the review

The feasibility of in-depth, systematic reviews will be determined by the scoping review. Findings will also help to identify research needs and inform evidence-based interventions to address the health information needs of female mBC patients with different demographics and characteristics and across the mBC journey.

Methods and analysis

A scoping review will be conducted of the scientific, clinical, and broader literature for articles in English addressing female mBC patient information needs, source preferences, utilization and

related factors across the mBC disease course. Because of a lack of resources for translation, articles published in languages other than English will be excluded.

While recognizing the existence of several varying definitions of this methodology, for purposes of this review, by scoping review or study is meant: "...a form of knowledge synthesis that addresses an exploratory research question aimed at mapping key concepts, types of evidence, and gaps in research related to a defined area or field by systematically [and iteratively] (insertion by O'Brien et al (52)) searching, selecting, and synthesizing existing knowledge". (53)

In their foundational article on scoping review methodology, Arksey and O'Malley (54) identified possible aims of scoping reviews as: to examine the extent, range and nature of research activity, determine the value of undertaking a full systematic review, summarize and disseminate research findings, or identify gaps in the existing literature. Initially, at least the first two aims will be addressed via this scoping review; potentially all four may be fulfilled.

Arksey and O'Malley(54) also proposed a six-stage methodological framework: (i) identifying the research question; (ii) searching for relevant studies; (iii) selecting studies; (iv) charting the data; (v) collating, summarizing, and reporting the results; and (vi) consulting with stakeholders to inform or validate study findings (optional).

Both Levac et al (55) and Daudt et al (56) have made significant updates to the Arksey and O'Malley scoping review framework. This study protocol is informed by and incorporates enhancements and refinements made by these two groups.

The primary objective is to provide a critical review of the state of the research apparent from the literature about the information needs and behaviours of women with mBC as they evolve across the disease course, including identifying gaps insofar as possible.

To ensure comprehensiveness of the research, information is defined broadly as comprising both cancer-related and non-cancer-related information, viz, psychological, medical, and social information.

Literature review search strategy

The scoping review will consider the international English language literature (both peer-reviewed and “grey”) that discusses patient information needs, sources, and acquisition, including associated variables of women aged ≥ 18 with advanced or metastatic stage IV (4) breast cancer. Primary research studies, systematic reviews, meta-analyses, clinical guidelines, meeting abstracts and dissertations, interviews, text and opinion literature, and other publication types will be included. In order to capture a diverse body of evidence, encompassing quantitative, qualitative, and mixed methods approaches, and in keeping with the scoping review methodology focus on summarizing breadth of evidence, no study designs will be excluded.

As described in the *Joanna Briggs Institute Reviewers' Manual 2015*, a three-step search strategy will be used in this research:(57)

1. An initial limited search of PubMed and CINAHL followed by analysis of the text words contained in the title and abstract of the retrieved articles.
2. A second search using all identified keywords and index terms across all proposed databases.
3. A search of the reference list of all identified reports and articles for additional studies.

The proposed databases to be searched (from inception to present day) include CINAHL, PubMed, EMBASE, Academic Search Premier, Cochrane Database of Systematic Reviews, PsycINFO, Health Source: Nursing/Academic Edition, Epistemonikos, the Joanna Briggs Institute Database of Systematic Reviews and Implementation Reports (JBISIRIR), the Evidence for Policy and Practice Information and Co-ordinating Centre (EPPI-Centre) and Education Resources Information Center (ERIC).

Patient advocacy websites and publications and cancer websites will be investigated for unpublished studies. The search for unpublished studies will also include the following websites: PQDT Open (<http://pqdtopen.proquest.com/search.html>, which provides open access to

dissertations and theses), Google Scholar, World Health Organization (WHO), www.who.int, Clinical Trials.gov, Institute of Medicine (IOM), www.iom.edu, the National Cancer Institute (NCI) www.cancer.gov, National Institutes of Health (NIH), www.nih.gov, Agency for Healthcare Research and Quality (AHRQ), www.ahrq.gov, New York Academy of Medicine, <http://www.nyam.org/>, and the Virginia Henderson Global Nursing e-Repository of the Honor Society of Nursing, Sigma Theta Tau International, www.nursinglibrary.org, a repository dedicated to sharing nursing publications.

The search for grey literature will include searches of Open-Grey (www.opengrey.edu), an open access database of European grey literature and the *Grey Literature Report* (www.greylit.org), a publication of the New York Academy of Medicine.

Relevant oncology websites will be searched, including the American Society of Clinical Oncology (ASCO), www.asco.org, Oncology Nursing Society (ONS), www.ons.org, European Society for Medical Oncology (ESMO), www.esmo.org, and the American Cancer Society (ACS), www.acs.org websites.

The initial search will consist of each of the following terms linked by **OR**: Information-seeking, information needs, information acquisition, information resources, information sources, information source preferences, information support, information dissemination methods, health information, patient education, health education, patient education methods, therapeutic patient education, patient knowledge, treatment education, patient concerns, patient satisfaction, patient communication, patient information, patient experience, clinical communication, physician-patient communication, patient-provider communication, communication challenges, and patient-cent(e)red communication **AND** each of the following terms linked by **OR**: advanced breast cancer, metastatic breast cancer, secondary breast cancer, stage IV breast cancer, and stage 4 breast cancer. A flexible and iterative approach will be employed enabling redefining and/or fine tuning of this initial search strategy based on the results obtained. (52)

To assess the completeness of the above search, hand searching of reference lists and bibliographies of included studies and two or three appropriate journals for the preceding six months to a year will be conducted. Proposed journals are the *Journal of Cancer Education*,

Patient Education and Counseling, and Support Care Cancer. Endnote will be used to manage the references retrieved.

Study selection

The review will exclude articles that:

4. Include patients ≤ 18 years old. As with other paediatric cancer patients, paediatric patients with mBC are likely to have unique information and support needs that cannot be adequately addressed within the framework of this review, but will require a separate specific review.
5. Focus mainly on men or do not differentiate between the needs of male and female mBC patients. Although many of the findings concerning information needs, sources, and engagement may be transferable from women to men, we consider that men with mBC have special needs worthy of a separate review. This protocol and scoping review will focus only on women with mBC.
6. Solely report economic research (ie, cost-effectiveness or cost-utility studies)
7. Relate to prevention and screening for breast cancer
8. Describe genetics unless they discuss information needed by or provided to women with mBC
9. Focus on the information needs and behaviours of women with early stage or primary breast cancer
10. Focus exclusively on the information needs and engagement of patients' partners or family members. However, articles containing information relative to the influence of patient/caregiver interactions on the patient information engagement behaviours of women with mBC will be included.
11. Include other types of cancer in addition to mBC, but which do not discuss the information needs, sources, and behaviours of women with mBC separately from those of patients with other types of cancer.
12. Focus on the informational or educational needs of health care professionals, unless they also address the information needs of women with mBC
13. Concern cancer risk, mortality, and epidemiology

Articles for inclusion will be selected using a three-step process: (i) titles of articles will be scanned to determine eligibility based on the inclusion and exclusion criteria; (ii) article titles and abstracts will be reviewed using the eligibility criteria; (iii) full-text versions of all potentially relevant articles will be retrieved for inclusion consideration.

As recommended in the Levac et al methodological update, this stage of the review will be approached as an iterative process comprising searching the literature, refining the search strategy, and reviewing articles for study inclusion.(55)

Given the patient-centred focus of the proposed research, it is likely that qualitative evidence will be an important element of the output of this study. It has been expressed as both a strength and a limitation of scoping reviews that at best they encompass a wide array of literature and research study designs though the diverse and potentially complex character of the data obtained may make analysis and synthesis very demanding. (52) Despite the contrasting methodologies of quantitative and qualitative research, the proposed review will iteratively address these issues as the literature review evolves, data is generated, and a clearer understanding of the scope and character of the mBC information behaviour literature develops. Qualitative data will be addressed using qualitative methodology: an interpretive approach to understanding mBC patients’ perceptions, values, beliefs and experiences relative to information needs, seeking, quality, and knowledge assimilation, may be an applicable approach to an analysis and synthesis of qualitative literature results. (58, 59)

Data abstraction

This step in the review process relates to “charting the results” in review terminology. Given the iterative nature of scoping reviews the exact path and methodology of data abstraction may change depending on the data obtained. The proposals outlined here are preliminary and subject to modification as the review evolves.

The systematic review typology chart developed by Rutten et al (32) and modified by van Mossel et al (49) will be adapted to create a preliminary table (Table 1) to record authors and dates of included articles and types of information needs and sources mentioned using the broad categories they proposed. Relevant subcategories of information specific to breast cancer and/or

mBC will be formulated using the search results; these will be used to generate two tables recording the types of information needs and sources mentioned in reviewed articles.

The methodological quality of individual included studies will not be assessed since the aim of a scoping study is to conduct a comprehensive search enabling the identification of gaps in the evidence base and indication of subject areas for future reviews. (49, 60) While Daudt and colleagues(56) strongly recommend incorporation of this component into the scoping review exercise, there does not appear to be currently sufficient guidance contained within the scoping review literature to assist in conducting this process. This consideration is especially pertinent as the evaluative task involves assimilation of evidence drawn from a diverse body of qualitative, quantitative, research and non-research and other literature that is not necessarily amenable to the usual methods of quality assessment. (61)

Table 1. Charting of included studies

Author and date	Types of information needs mentioned							Types of information sources mentioned						
	Other	Treatment-related information	Rehabilitation	Coping information	Interpersonal/social information	Prognosis information	Cancer-specific information	Body image/sexuality information	Medical system information	Health care professionals	Interpersonal	Printed materials	Media	Organizational/scientific resources

As recommended by Levac et al (55), charting will be an iterative step; data will be continually extracted and the charting form updated accordingly. Additionally, the charting form will be

1 piloted using the first 5-10 studies and reviewed jointly by the authors to assess whether it meets
2 the needs of the research question and the purpose of this review, with refinements made before
3 embarking on the full scale charting exercise. (55, 56)
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10 Also, as observed by O'Brien et al (52), since the process of charting, collating and summarizing
11 of included publications will be iterative, knowledge synthesis may involve a descriptive
12 component (presenting frequencies of literature characteristics) as well as an analytical aspect, ie,
13 synthesis of qualitative and quantitative data with thematic or content analysis for relevant
14 variables.
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20 **Results**

21 Data abstraction and synthesis will use both tabular and textual (descriptive) approaches, which
22 will provide adequate flexibility to accommodate both quantitative and qualitative literature.
23 This stage of the scoping review exercise falls under the collating, summarizing, and reporting
24 the results stage of the Arksey and O'Malley framework. (54) As suggested by Levac et al, this
25 stage may be segmented into 3 discrete steps: analyzing the data (including descriptive numerical
26 summary analysis and qualitative thematic analysis); reporting the results linked to the research
27 question; and interpreting the implications of the results for research, policy, and practice. (55)
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35 Characteristics of the literature included in the review will be summarized in a table (Table 2),
36 and the stages of the cancer care continuum in the reviewed articles will also be tabulated (Table
37 3). A descriptive (narrative) summary of the articles included in the review, describing the aims
38 or purposes of included articles, concepts or approaches used in each, and the results that relate
39 to the review question, will be presented. As suggested by Levac et al (55), a thematic analysis
40 akin to a qualitative data analysis approach may be attempted intended to organize the data into
41 overarching themes. The findings might be presented using tables and descriptions aligned with
42 identified themes. (56)
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Table 2. General characteristics of included articles

Characteristic	n	%
<i>Type of article</i>		
Research study		
Commentary/narrative		
Clinical practice guideline		
Literature review		
Description of a program		
Other		
<i>Data collection method</i>		
Multiple collection methods		
Original questionnaire/survey		
Existing questionnaire/survey		
Interview		
Focus groups		
Chart review/medical records		
Other		
Unknown		
<i>Research study design</i>		
Quantitative		
Qualitative		
Mixed methods		
Clinical trial		
Concurrent		
Prospective/longitudinal		

Other (mixed designs)		
Unknown		
<i>Learning theory</i>		
Discussed		
Not discussed		
<i>Geographical location of the work</i>		
United States		
United Kingdom		
Other European countries		
Australia		
Canada		
Other		
<i>Publication date</i>		

Table 3. Stages of the cancer care continuum mentioned in the reviewed articles

Stage in cancer care continuum	n	%
At diagnosis		
Treatment (including long-term survivorship)		
Posttreatment/ End-of-life		

Any potential implications for evidence-based patient education practice and knowledge gaps meriting primary research and/or systematic reviews will be presented.(57)

Stakeholder consultation

The second part of the study will involve primary research and entails interaction with mBC patients to solicit their contributions on their cancer-related information needs and information engagement across the disease course. Ethics approval for this phase of the study will be sought

from the Education Research Ethics Sub-Committee of the Faculty of Arts FREC of Plymouth University.

The methodology will be two-pronged: (i) Monitoring of online sources, including social networking sites, discussion boards, and on-line support groups for relevant postings, including tweets and chats. These inputs will be synthesized using qualitative thematic analysis/discourse or conversation analysis. In-person engagement with mBC patient support groups around the same questions will provide additional data on the research topics and context to the scoping review findings. (ii) A survey of mBC patients (using an on-line method as well as hard copy questionnaires) will be conducted to test the findings from the online monitoring exercise. This corresponds to the sixth stage of the Arksey and O'Malley framework: stakeholder consultation.

Ethics and dissemination

All data in this review will be gathered through searches of literature and other online databases, and no personal health information will be collected; thus, ethics committee approval will not be required for the scoping review portion.

Research findings will be published and presented to patients and their families and caregivers through patient support and advocacy websites and organizations.

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Contributors

All authors (CAT, MPM, and RBJ) made substantive intellectual contributions to the development of this protocol. CAT conducted the preliminary research, which was critically reviewed and with contributions from MPM and RBJ. All authors (CAT, MPM, and RBJ) were involved in developing the review question and the review design. RBJ provided substantial guidance to CAT in the elaboration of the review design. CAT initiated the first draft of the manuscript, which was then followed by several iterations with substantial input, appraisal, and revisions from MPM and RBJ. All authors (CAT, MPM, and RBJ) approved the final submission version of the manuscript. The revised versions of this manuscript (including the present document), which were prepared by CAT, was also reviewed, edited, revised, and approved by MPM and RBJ.

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Competing interests

None

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PRISMA-P Checklist

Item 1a: Identification. Identify the report as a protocol of a systematic review

Health Information Needs, Sources, and Engagement Behaviours of Women With Metastatic Breast Cancer Across the Care continuum: Protocol for a Scoping Review (page 1 of manuscript)

Item 1b: Update. If the protocol is for an update of a previous systematic review, identify as such

N/A

Item 2. If registered, provide the name of the registry (such as PROSPERO) and registration number

N/A

Item 3a: Contact information. Provide name, institutional affiliation, and email address of all protocol authors; provide physical mailing address of corresponding author

Corresponding author: Carol A. Tucker, 799 East 40th Street, Brooklyn, NY, 11210, USA, 347-409-3662, carol.tucker@plymouth.ac.uk

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2. M. Pilar Martin, Adelphi University College of Nursing and Public Health, Garden City, NY, USA. E-mail: mpmartin@adelphi.edu

(pages 1 and 18)

Item 3b: Contributions. Describe contributions of protocol authors and identify the guarantor of the review

RBJ is the guarantor. All authors (CAT, MPM, and RBJ) made substantive intellectual contributions to the development of this protocol. CAT conducted the preliminary research, which was critically reviewed and with contributions from MPM and RBJ. All authors (CAT, MPM, and RBJ) were involved in developing the review question and the review design. RBJ provided substantial guidance to CAT in the elaboration of the review design. CAT initiated the first draft of the manuscript, which was then followed by several iterations with substantial input, appraisal, and revisions from MPM and RBJ. All authors (CAT, MPM, and RBJ) approved the final submission version of the manuscript. The revised version of this manuscript, which was

prepared by CAT, was also reviewed, edited, revised, and approved by MPM and RBJ.
(page 18)

Item 4. If the report represents an amendment of a previously completed or published protocol, identify as such and indicate what changes were made; otherwise state plan for documenting important protocol amendments

N/A

Item 5a: Sources. Indicate sources of financial or other support for the review

This research received no financial or other support from any funding agency in the public, commercial or not-for-profit sectors.
(page 19)

Item 5b: Sponsor. Provide name of the review funder and/or sponsor

N/A

Item 6. Describe the rationale for the review in the context of what is already known

The health information needs, information source preferences, and engagement behaviours of women with metastatic breast cancer (mBC) depend on personal characteristics such as education level, prior knowledge, clinical complications, comorbidities, and where they are in the cancer journey. A thorough understanding of the information behaviours of women living with mBC is essential to the provision of optimal care. A preliminary literature review suggests that there is little research on this topic, but that there may be lessons from a slightly broader literature.

The rationale for the planned review is that provision of quality care to women with mBC requires information provision appropriate to different time points in the care continuum.

This review will identify what is known and what is not known about the health information needs, acquisition, and influences of women with mBC across the care continuum. Findings will help to identify research needs and inform evidence-based interventions to address the health information needs of female mBC patients with different demographics and characteristics and across the mBC journey.

(pages 2 and 8)

Item 7. Provide an explicit statement of the question(s) the review will address with reference to participants, interventions, comparators, and outcomes (PICO)

Participants: Women aged 18+ with metastatic breast cancer

Interventions: Not applicable – we are looking at their information needs, information sources, and engagement behaviours.

Comparators: Sociodemographic and situational factors, stages on the cancer care continuum.

Outcomes: All relevant measures of psychological and possibly physical well-being.

(pages 2 and 7)

Item 8. Specify the study characteristics (such as PICO, study design, setting, timeframe) and report characteristics (such as years considered, language, publication status) to be used as criteria for eligibility for the review

The scoping review will consider the international English language literature (both peer-reviewed and “grey”) that discusses patient information needs, sources, and acquisition, including associated variables of women aged ≥ 18 with advanced or metastatic stage IV (4) breast cancer. Primary research studies, systematic reviews, meta-analyses, clinical guidelines, meeting abstracts and dissertations, interviews, text and opinion literature, and other publication types will be included. In order to capture a diverse body of evidence, encompassing quantitative, qualitative, and mixed methods approaches, and in keeping with the scoping review methodology focus on summarising breadth of evidence, no study designs will be excluded.

The review will exclude articles that are:

1. Inclusive of patients ≤ 18 years old
2. Studies that focus mainly on men or do not differentiate between the needs of male and female mBC patients;
3. Devoted to the information needs and behaviours of women with early stage or primary breast cancer;
4. Focused exclusively on the information needs and engagement of patients’ partners or family members. However, articles containing information relative to the influence of patient/caregiver interactions on the patient information engagement behaviours of women with mBC will be included.

5. Focused on the informational or educational needs of health care professionals, unless they also address the information needs of women with mBC

(pages 9-10 and 11-12)

Item 9. Describe all intended information sources (such as electronic databases, contact with study authors, trial registers or other grey literature sources) with planned dates of coverage

A scoping review will be performed to systematically search scientific and grey literature for articles that discuss the health information needs, sources, engagement styles and associated personal and medical attributes of women living with mBC at different stages of the disease course. A variety of databases (including Cumulative Index to Nursing and Allied Health Literature [CINAHL], PubMed, Excerpta Medica Database [EMBASE], Academic Search Premier, Cochrane Database of Systematic Reviews, PsycINFO, Health Source: Nursing/Academic Edition, and PQDT Open), oncology, patient advocacy, and governmental websites will be searched from inception to present day.

The search for grey literature will include searches of Open-Grey (www.opengrey.edu), an open access database of European grey literature and the *Grey Literature Report* (www.greylit.org), a publication of the New York Academy of Medicine.

(pages 2 and 10)

Item 10. Present draft of search strategy to be used for at least one electronic database, including planned limits, such that it could be repeated

The initial search will consist of each of the following terms linked by **OR**: Information-seeking, information needs, information acquisition, information resources, information sources, information support, information dissemination methods, health information, patient education, health education, patient education methods, therapeutic patient education, patient knowledge, treatment education, patient concerns, patient satisfaction, patient communication, patient information, patient experience, clinical communication, physician-patient communication, patient-provider communication, communication challenges, and patient-centred communication **AND** each of the following terms linked by **OR**: advanced breast cancer, metastatic breast cancer, secondary breast cancer, stage IV breast cancer, and stage 4 breast cancer.

A flexible and iterative approach will be employed enabling redefining and/or fine tuning of this initial search strategy based on the results obtained.
(page 11)

Item 11a: Data management. Describe the mechanism(s) that will be used to manage records and data throughout the review

Upon completion of searches, the references will be documented and references will be exported into database-specific folders in Endnote, a reference management software that will be used to manage the references retrieved.
(page 11)

Item 11b: Selection process. State the process that will be used for selecting studies (such as two independent reviewers) through each phase of the review (screening, eligibility, and inclusion in meta-analysis)

Article selection will be an iterative process comprising searching the literature, refining the search strategy, and reviewing articles for study inclusion.

Articles for inclusion will be selected using a three-step process: (i) titles of articles will be scanned to determine eligibility based on the inclusion and exclusion criteria; (ii) article titles and abstracts will be reviewed using the eligibility criteria; (iii) full-text versions of all potentially relevant articles will be retrieved for inclusion consideration.
(page 12)

Item 11c: Data collection process. Describe planned method of extracting data from reports (such as piloting forms, done independently, in duplicate), any processes for obtaining and confirming data from investigators

A series of tables will be created to collect relevant data from the articles selected. It will be piloted using the first 5-10 studies and reviewed jointly by the authors to assess whether it meets the needs of the research question, with refinements made before embarking on the full scale charting exercise.

(pages 13-17)

Item 12: List and define all variables for which data will be sought (such as PICO items, funding sources) and any pre-planned data assumptions and simplifications.

A preliminary table will be created to record authors and dates of included articles and types of information needs and sources mentioned using broad categories. Relevant subcategories of information specific to breast cancer and/or metastatic breast cancer will be formulated using the search results; these will be used to generate two tables recording the types of information needs and sources mentioned in reviewed articles.

Characteristics of the literature included in the review will be summarized in a table, and the stages of the cancer care continuum in the reviewed articles will also be tabulated. A descriptive (narrative) summary of the articles included in the review, describing the aims or purposes of included articles, concepts or approaches used in each, and the results that relate to the review question, will be presented.

(pages 13 and 15)

Item 13. List and define all outcomes for which data will be sought, including prioritization of main and additional outcomes, with rationale

N/A

Item 14. Describe anticipated methods for assessing risk of bias of individual studies, including whether this will be done at the outcome or study level or both; state how this information will be used in data analysis.

N/A. The methodological quality of individual included studies will not be assessed since the aim of a scoping study is to conduct a comprehensive search enabling the identification of gaps in the evidence base and indication of subject areas for future reviews.

Item 15a. Describe criteria under which study data will be quantitatively synthesised.

N/A

Item 15b. If data are appropriate for synthesis, describe planned summary measures, methods of handling data, and methods of combining data from studies, including any planned exploration of consistency (such as I^2 , Kendall's τ)

N/A

15c. Describe any proposed additional analyses (e.g., sensitivity or subgroup analyses, meta-regression)

N/A

15d. If quantitative synthesis is not appropriate, describe the type of summary planned.

Data abstraction and synthesis will use both tabular and textual (descriptive) approaches, encompassing both quantitative and qualitative literature. A descriptive (narrative) summary of the articles included in the review, describing the aims or purposes of included articles, concepts or approaches used in each, and the results that relate to the review question, will be presented. A thematic analysis akin to a qualitative data analysis approach may be attempted intended to organize the data into overarching themes. The findings may be presented using tables and descriptions aligned with the identified themes.

(pages 14-15)

Item 16. Specify any planned assessment of meta-bias(es) (such as publication bias across studies, selective reporting within studies)

N/A. The methodological quality of individual included studies will not be assessed since the aim of a scoping study is to conduct a comprehensive search enabling the identification of gaps in the evidence base and indication of subject areas for future reviews.

17. Describe how the strength of the body of evidence will be assessed (such as GRADE).

N/A. No evaluative standards for scoping studies have yet been developed.