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# The Unmet Supportive Care Needs of Patients Living with Metastatic Breast Cancer: A Literature Review

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## Background

Metastatic Breast Cancer (MBC), also commonly referred to as advanced or stage 4 breast cancer, is a mostly incurable disease of significant prevalence. The term MBC refers to breast cancer which has spread to other sites in the body, most commonly the lymph nodes, brain, bone and liver. (1)

Due to advancements in medical treatments and technology, patients with MBC are living for far longer than was previously possible. 'Living with and beyond cancer' may also be referred to as survivorship.

The Department of Health have identified survivorship as a matter of priority in their 2017 National Cancer Strategy Report, although, as of now, survivorship has mainly been interpreted as referring to post curative disease. (2) However, in reality it encompasses far more than that, beginning from time of diagnosis until the end of life. 'Survivors' include not only the patient themselves, but family, friends and carers.

We hypothesise, having spoken to patient representatives, that there are many unmet needs specific to patients with MBC requiring urgent address. This review is intended to explore these unmet needs, as support services for women with MBC have not progressed as rapidly as this patient subset has grown and therapies have improved.

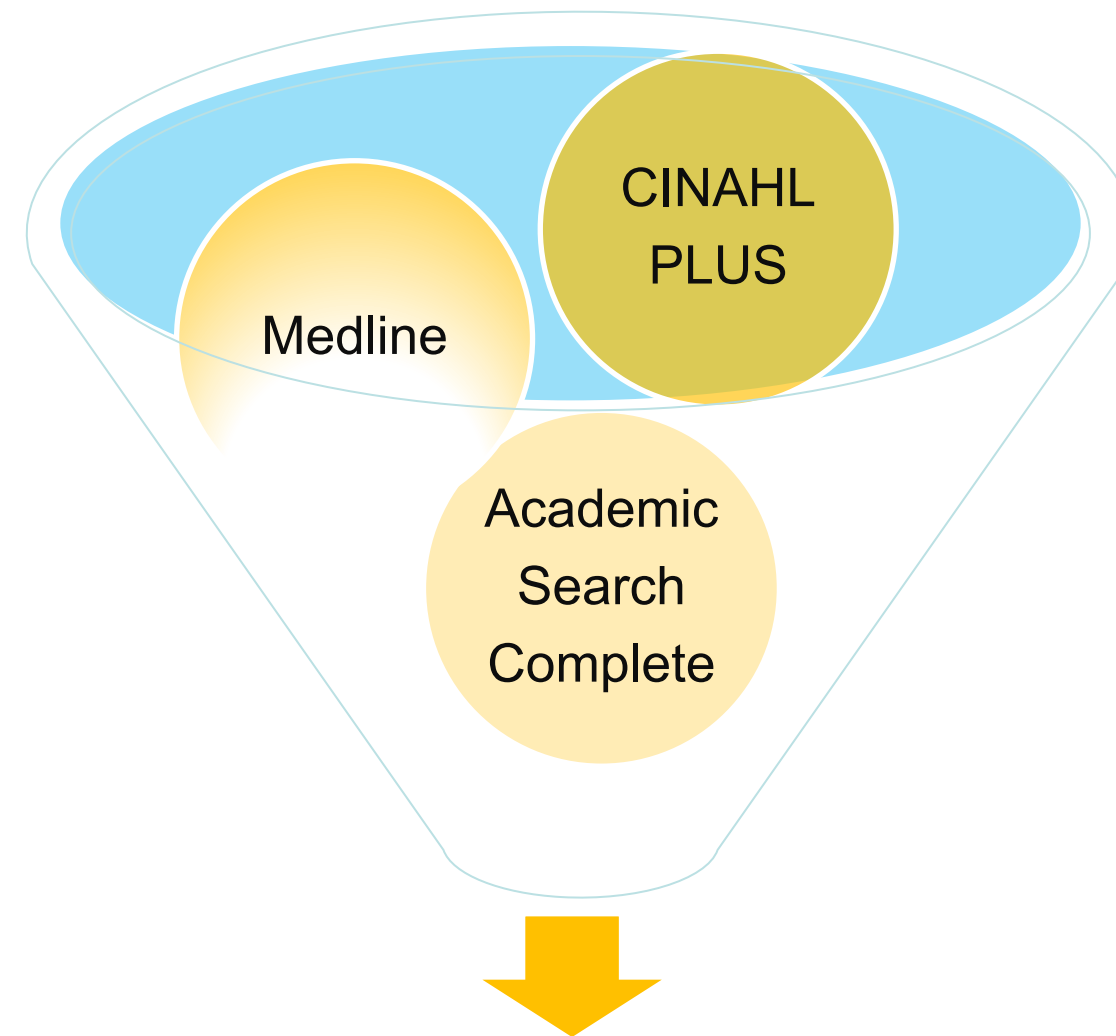
## Aims and Objectives

1. Primarily, to investigate and describe the existing evidence regarding concerns, issues and unmet needs of patients with metastatic breast cancer
2. Secondly, to explore existing evidence-based programmes and interventions both nationally and internationally dedicated to meeting these needs.

## Methods



CASP Qualitative Studies  
Checklist used as critical  
appraisal tool. (3)



172 Records Screened  
92 assessed for eligibility  
10 chosen for inclusion

INCLUSION	EXCLUSION
Full text online or available to access via University College Cork Library	Unavailable to access full text online or through University College Cork Library
Published between 2005 and 2021	Published before 2005
Qualitative Research	Quantitative research
Text available in English	Text not available in English
Specific to metastatic/advanced breast cancer	Not specific to metastatic breast cancer
Survivorship refers to MBC as a chronic, incurable illness	Survivorship refers to post curative treatment of breast cancer
Refers to symptom management and quality of life, as well as psychosocial, cognitive, informational, spiritual, financial and relationship needs of MBC patients	Refers to treatment related needs of MBC patients or research needs in terms of gaps in the MBC research field

## Conclusion

This review aims to highlight the most prevalent unmet needs of women with MBC. These include but are not limited to, the informational, palliative, psychological, financial and practical needs of these women. It is evident that the development of services to support women with MBC, has not kept up with the rapid advancements in life prolonging treatment that have taken place over the course of the last century. This review outlines many evidence-based suggestions for the development of supports and services, to be put in place to meet the unmet needs of this forgotten cohort, which may significantly improve patients' quality of life. An integrative approach, including links to local primary care workers such as GPs, or the assignment of SCNs to act as a local point of contact and support for patients is advised, as well as the involvement of multiple disciplines, namely physiotherapists, psychologists, psychiatrists, palliative care specialists and social workers to collaborate with the hospital team to create holistic patient care. Greater accessibility to information, especially regarding treatment options, clinical trials and practical/financial services is also advised. Considering these findings, our team of researchers, led by Professor Roisin Connolly and Professor Josephine Hegarty, are currently conducting a country wide, qualitative needs assessment. We are gathering data regarding unmet needs from both patients with MBC themselves, and health care workers with an interest in this field. We hope that this research will inform the development of further supports for these patients and enable change.

## Key Needs Identified

### Informational

Almost all studies identified an unmet informational need in patients with MBC, with the preferred method of acquiring information at present being online.

**Tailored Treatment Plan** – This review finds that an excess of information is often unloaded onto patients during initial hospital visits, at a time when the patient may not be in the position to process this information. The research suggests that concise, written, short term treatment plans tailored to individual patients would be helpful, as well as more time to discuss this information with their doctor. (4,5)

**Designated Point of Contact** – This review suggests a need for more regular contact with health care professionals, both in hospital and in the community to address relevant queries. A designated clinical nurse specialist, or other point of contact was suggested, as well as a more involved GP that patients could check in within the community. (4,5)

**Clinical Trials** – Several studies identified a need for more information regarding clinical trials. 34% of women who express interest in trial participation actually go on to enter one, suggesting a lack of information and/or ease of access (6)

**Public Information** - Patients expressed the need for more public awareness around MBC, which may lead to decreased stigma around the illness and knock-on benefits regarding social, employment/financial needs. (4,6,7)

### Symptom Management

The adverse symptoms affecting patients with metastatic breast cancer can either be disease or treatment related.

**Pain** – The severity, and associated concerns of living with chronic pain differ greatly depending on clinical factors, including patients age, site of metastasis and comorbidities. (8) Different palliative approaches must be tailored to different cohorts of these patients, as well as assessed and updated throughout the disease course. This review calls for a need for earlier palliative care intervention as well as psychological treatments to help people cope with the mental challenges associated with chronic pain (7,9)

**Fatigue** - After pain, fatigue is described as the most pressing concern for patients with MBC (7, 9, 10) Fatigue (both disease and treatment related) interferes with even the simplest of daily tasks and is a significant player in the loss of women with MBCs ability to go to work, maintain relationships and avoid social withdrawal. It is vital to monitor this side effect, inform the patient and take its consequences into consideration when deciding treatment options.

**'Chemo Brain'** - 'chemo brain', or cognitive impairment due to the neurotoxic effects of chemotherapy is a noteworthy side effect of cancer therapy. (7) This is an area in need of further research, however there is evidence to suggest that the effects can be distressing for some patients with MBC and may require post treatment counselling and support.

### Wellbeing

For the purpose of this review, wellbeing encompassed non-disease related physical and psychological health.

**Mental Health** – Metastatic breast cancer is a lifechanging diagnosis, associated with high levels of psychological stress. The MBBCD report (n=515) found that one in 3 participants with MBC experienced clinical levels of depression. (8) Specific patient cohorts also experience different kinds of psychosocial distress, for example younger patients experience more distress from social isolation, while older women are more troubled by physical pain. Once again, a need has been identified not only to help coping with a specific symptom, but to do so using a tailored approach specific to individual characteristics and needs.

**Career and Finances** - The MBBCD report mentioned above listed the top three categories experiencing the most collateral damage from their illness as those with limited financial resources, women with children under 18 and women under 50. Loss of employment and financial independence was described as a major cause of distress and a large contributor to the idea of their illness resulting in a 'loss of role function' and a subsequent loss of identity outside of their illness, in both society, and the home. (9) This review strongly supports the need for more employer awareness of these issues, resources for financial aid and increased public awareness to help decrease stigma associated with long term illness,

**Diet/Exercise**- Evidence suggests that dietary, physical activity and mindfulness classes/services may improve patients' psychological wellbeing and even improve both mental and physical symptoms, as well as alleviate fatigue (11,12,13)

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