

Review Article

A Systematic Review of the Patient- and Carer-Related Factors Affecting the Experience of Pain for Advanced Cancer Patients Cared for at Home



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Abstract

Context. Effective pain management is a priority in the palliative care of advanced cancer patients. A body of research is emerging examining the factors that influence the management and experience of pain for such individuals. Identifying such factors should allow for the development of targeted interventions to improve pain management in the home while ultimately reducing unnecessary suffering for the patient.

Objectives. The objective of this study was to identify relevant patient- and carer-related factors which have an effect on the pain experienced by advanced cancer patients cared for at home.

Method. This is a systematic review following the Preferred Reporting Items for Systematic Reviews and Meta Analyses (PRISMA) statement guidelines. Studies were retrieved from the CINAHL, MEDLINE, and Web of Science and assessed independently by two reviewers with discrepancies assessed by a third before quality assessment and data extraction. A narrative synthesis was produced.

Results. Our search strategy produced 720 hits, of which 10 studies were retained for the final analysis. The factors identified included carer knowledge of cancer pain management, carer burden, carer and patient distress, pain rating disparity, patient well-being, patient depression, patient affective experience, patient body image, and satisfaction with palliative/medical care. All factors identified are supported by only some evidence with many having only been explored in single studies.

Conclusions. There is a lack of quantitative research in the area of factors influencing the experience of pain for advanced cancer patients cared for at home. Such findings would be useful in developing theories of change that would underpin interventions aimed at improving pain outcomes for this population. *J Pain Symptom Manage* 2018;55:496–507. © 2017 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.

Key Words

Pain management, advanced cancer, systematic review

Introduction

Providing palliative care in the home can be challenging, especially when it comes to achieving sufficient control over pain, with only one-third of patients believing this to be achievable.^{1,2} In fact, some reports note that as many as 28% of patients

die in significant pain, despite the means for a pain free death being available.³ A high level of skill and knowledge is needed to confidently provide adequate pain management, the onus of which often lies with unpaid carers who feel ill-equipped for this task.^{2,4} Failure to follow prescribed pain management

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regimes at home is common with some studies reporting nonadherence rates as high as 70%.⁵ This can result in inadequate pain control, unnecessary suffering for the patient, and increased health care costs.^{6–8}

In recent years, efforts have been made to discover salient patient- and carer-related factors influencing the pain experienced by advanced cancer patients. One review noted that a large proportion of patients were reluctant to report pain or take pain medication because of attitudinal barriers including fears relating to addiction and side effects.⁹ Two major limitations of such reviews are apparent: they often fail to examine the effects such barriers actually have on the pain experienced by the patient or they restrict the populations examined to inpatients.

Other psychological variables apart from attitudinal barriers have also been shown to be related to the patient's experience of pain. A patient's mood and cognitive abilities related to capacity, such as executive functioning, can have an impact on the pain experienced by such individuals, both directly and indirectly.^{10,11}

In the home setting, as the health of the person with advanced cancer deteriorates, they become more reliant on others to assess the level of pain they are experiencing and, thus, the level of analgesia required. For pain management to be effective, a carer's estimations of the pain experienced by the patient must be congruent with the patient's own subjective experience to avoid underuse or overuse of analgesics. Studies have found that incongruence between such estimates and actual reported pain are more likely in cases where both the patient and carer report poor quality of life and higher reported levels of carer burden.^{12,13}

A recent review found that approximately half of the interventions addressing pain in people with advanced cancer were ineffective.¹⁴ The majority of such interventions lacked a strong evidence base and only focused on improving knowledge of pain management without attempting to address other salient factors.

Guidance from the UK Medical Research Council states that evidence-based models are necessary prerequisites to the development of tailored interventions, to highlight the factors that should become the focus of any complex intervention.¹⁵ Before such models can be designed and tested, a clearer picture of the factors related to the experience of pain for the advanced cancer patient cared for at home is needed. Previous reviews in this area have been conducted; however, they have not addressed carer-related factors¹⁶ or were purely qualitative in nature.¹⁷ The aim of this review was to identify the patient and carer factors that are related to pain experienced among people with

advanced cancer cared for at home. For the purpose of the review, patient and carer factors were defined as any factor that relates to a patient's or carer's psychological or physical capacity to engage in pain control. This also included any cognitive processes related to directing one's behavior or any affective responses. This definition was derived from a recent model of health-related behaviors.¹⁸

Methods

The review is reported in line with a modified version of the Preferred Reporting Items for Systematic Reviews and Meta-analyses statement guidelines (PRISMA).¹⁹ The style is modified as this review was not aimed at assessing interventions directly.

Eligibility Criteria

Studies were deemed eligible for the review if they met the following criteria:

- Quantitative research articles published in a peer-reviewed journal in the English language.
- Study samples had to include individuals with advanced cancer (in receipt of the majority of their care in the home setting) and/or their unpaid carer(s). Advanced cancer was defined broadly as a person with a diagnosis of cancer and at least one of the following: Karnofsky Performance Status of 50 or less, Eastern Co-operative Oncology Group score of 3 or more, life expectancy of six months or less, cancer unlikely to be cured, in receipt of palliative care.
- Include an estimate of pain experienced. Within the relevant literature, there is no gold standard method for assessing pain for this population, so this was defined as any self-report or validated measure of pain, pain level experienced, or satisfaction ratings of pain control.
- Assess the relationship between pain experienced and one or more patient and/or carer factors.

Information Sources

Articles were sourced from the following databases: Medline, CINAHL, and Web of Science. The search was inclusive of all articles from the earliest available date until March 2016.

Search Strategy

The exact search strategies used in the three databases are given in [Table 1](#). To devise this strategy, relevant search terms were adopted from the key terms quoted in studies identified during a scoping exercise. These terms were then entered into the three databases. Any other related terms identified were then

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