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**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:** 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:** Systematic review following the 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 prior to 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 wellbeing, 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.

**Keywords:** Pain management, Advanced Cancer, Systematic review

**Running Title:** Patient and carer related factors in pain

## 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<sup>(4,5)</sup>. 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<sup>(6)</sup>. 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<sup>(5,7)</sup>. Failure to follow prescribed pain management regimes at home is common with some studies reporting non-adherence rates as high as 70%<sup>(8)</sup>. This can result in inadequate pain control, unnecessary suffering for the patient, and increased health care costs<sup>(9-11)</sup>.

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 due to attitudinal barriers including fears relating to addiction and side effects<sup>(12)</sup>. 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 as well as cognitive abilities related to capacity, such as executive functioning, can have an impact on the pain experienced by such individuals, both directly and indirectly <sup>(14,15)</sup>.

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 under or over use 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 <sup>(16,17)</sup>.

A recent review found that approximately half of the interventions addressing pain in people with advanced cancer were ineffective <sup>(18)</sup>. 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 <sup>(19)</sup>. 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 factors <sup>(20)</sup> or were purely qualitative in nature <sup>(21)</sup>.

The aim of this review is 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 which 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 behaviours<sup>(1)</sup>.

## 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)<sup>(2)</sup>. 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 6 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 added to the search strategy. This draft search strategy was reviewed by two researchers who were familiar with the area of palliative care and a subject librarian, who ensured the databases were used correctly. At this stage several terms were removed as they were deemed repetitive while others were added. Medical Subject Headings were utilized in CINAHL and Medline databases. Differences in the specific search strategies reflect the different terminology used in the various databases.

### *Study selection and data collection*

Due to the large number of articles retrieved in the search the eligibility criteria were initially applied, independently by two assessors (JS,IG), to the articles' titles and abstracts. The next stage of selection involved reviewing the full text articles. Articles reviewed at this stage included those which both assessors agreed should be included due to meeting the eligibility criteria or in situations where there was inadequate information in the title and abstracts to warrant a decision. In instances where the assessors disagreed, a third assessor (MD) decided if the article should go forward for full text review. At this stage the full text of articles were reviewed,

independently by the same two assessors with the third assessor deciding any disagreements. Finally, a quality assessment was applied to those articles which remained after full text assessment, using an adapted version of the Quality Assessment Tool for Quantitative Studies developed by the Effective Public Health Practice Project <sup>(3)</sup>. This tool was developed for use with systematic reviews of effectiveness in the area of public health and provides a score indicating if a study is of strong, moderate or weak quality. This adapted tool covers quality criteria of selection bias, validity and reliability of data collection tools, withdrawals and dropouts, sample size and if a priori power calculations had been made.

## Results

### *Data extraction and analysis*

A total of 720 articles were identified and 556 of these articles were excluded due to duplication and failure to meet the eligibility criteria. The remaining 164 articles had their full text scrutinized. A further 154 articles were excluded at this stage. Thus a total of 10 studies were included in the synthesis (see Figure 1). The characteristics of these studies are outlined in Table 2.

### *Study characteristics and quality assessment*

Of the studies retained, three were considered to be strong in quality,<sup>(6,33,51)</sup> a further four were of moderate quality,<sup>(22,25,36,42)</sup> while three studies were considered weak.<sup>(28,38,47)</sup> Seven of the ten studies used measures which had previously been assessed as both reliable and valid. Of the other three studies, two did not use a psychometrically validated measure and one had moderate ratings due to not reporting reliability. No study was found to be strong with regards to selection bias.



Six studies were classed as moderate in this area with the remaining four studies being classed as weak. Only two studies used random selection of the sample whereas all other studies sampled from the desired population in a systematic manner. High completion rates of greater than 80% were reported in only one study, another reported rates between 60 to 79 %, one further study reported below 60% participation whereas for five studies participation rates were not reported or could not be calculated. Sample size varied considerably across the studies. Five studies had samples in excess of 100 participants; a further four had between 50-99 participants included in their final analysis, whereas only one study had a sample size less than 50. Only one study provided a sample size calculation based on power considerations.

### *Review findings*

The results extracted from the included studies are reported in Table 3.

### Carer factors

Only one of the included studies <sup>(38)</sup> examined the relationship between carer distress and the patient's own pain rating. A medium sized positive correlation was found ( $r = 0.48$ ). Related to carer distress, this study also examined the relationship between pain and carer burden. A stronger positive correlation was found ( $r = 0.59$ ). This same study was the only one included in the review that assessed the relationship between patient pain experienced and disparity between this and their carer's estimation of pain experienced. Disparity scores were calculated as the difference between the patient's pain rating and the carer's estimation item from the Family Pain Questionnaire (FPQ) <sup>(24)</sup> A small negative correlation ( $r = - 0.15$ ) was found.

## Patient factors

Yennurajalingam and colleagues <sup>(51)</sup> examined the impact of a number of covariates as predictors of pain scores on the Edmonton Symptom Assessment Scale (ESAS) <sup>(43)</sup>. This analysis found that “feelings of wellbeing” were weakly related to pain experienced ( $r = -0.05$ ). In line with these results, a contrasting concept, ‘psychological distress’, was assessed by Redinbaugh et al. <sup>(38)</sup>. A large positive correlation was reported ( $r = 0.53$ ) between distress and pain ratings. Psychological aspects of quality of life and their relationship to pain was also reported by Mendes et al <sup>(36)</sup>. Participants were separated into four groups based on the level of pain experienced (no pain, mild, moderate, intense). Only the means for each group’s scores on the various domains were reported. As seen in Table 3, the no pain group reported the highest psychological quality of life followed by the moderate pain group, mild pain group and finally the intense pain group. A fourth study by Grassi et al <sup>(25)</sup> focused on psychological wellbeing and distress however this study was concerned specifically with patients’ mood using the Hospital Anxiety and Depression Scale (HADS) <sup>(27)</sup> as a measure of depression. From the reported results it was possible to calculate the effect size between pain scores and the difference between those considered depressed and those not. A small positive effect was found ( $r = 0.15$ ). Sela et al. <sup>(6)</sup> examined the relationship between pain and aspects of psychological wellbeing. Specifically they examined if there was a relationship between a number of specific emotions and pain intensity. This study also analyzed results according to gender and found males to have a strong positive correlation between pain intensity and frustration ( $r = 0.73$ ) with weak positive correlations being reported for anger ( $r = 0.34$ ) and exhaustion ( $r = 0.32$ ). For females the strongest correlation was found between pain intensity and exhaustion ( $r$

= 0.58). Moderate positive correlations with pain intensity were found for helplessness ( $r = 0.43$ ), frustration ( $r = 0.39$ ), hopelessness ( $r = 0.37$ ) and anger ( $r = 0.30$ ).

Rhondali et al <sup>(42)</sup> also looked at patient body image and its impact on pain experienced, based on scores from the ESAS <sup>(48)</sup>. A small positive correlation was found between these pain scores and body image dissatisfaction scores as measured by the Body Image Scale (BIS) <sup>(44)</sup> ( $r = 0.25$ ).

Other patient factors identified include activities of daily living, which showed a moderate relationship with pain ( $r=0.46$ ) in a single study, <sup>(38)</sup> and existential quality of life, which showed a large relationship with pain ( $r=0.70$ ) in the same study.

#### Perception of care

One study by Yamagishi et al <sup>(47)</sup> examined the relationship between worst pain experienced in the last 24 hours, quality of palliative care received and satisfaction with medical care received. Both factors showed small negative correlations with pain intensity (quality  $r = -0.27$ , satisfaction  $r = -0.26$ ).

#### Knowledge of pain management

Three studies examined the effects (on patient experience of pain) of interventions designed to improve knowledge of pain management. These studies do not directly provide information about the association between knowledge and pain. Although it is relevant to note that interventions aimed at improving knowledge about pain have an effect on patient perception of pain (which indicates a potential association), no conclusions can be drawn about associations when the intervention does not have the intended effect.

Lovell et al <sup>(33)</sup> demonstrated a large effect for their interventions on average pain intensity and a moderate effect for worst pain experienced. Aubin et al <sup>(22)</sup> also found a large effect on average pain intensity for their intervention and for maximum pain experienced. Another intervention study <sup>(28)</sup> aimed at improving knowledge of pain management using a partner guided training protocol. The intervention arm showed marginally greater improvements compared to the control arm for 'weeks usual pain intensity'. However when pain experienced was measured based on 'weeks worst pain' the control arm was superior.

## **Discussion**

This review was conducted to assess what patient and career related factors have been shown to be related to pain experienced by advanced cancer patients cared for at home. Only a small number of factors were identified with studies showing inconsistent results.

### *Patient Knowledge*

There is a lack of research available focusing on the relationship between knowledge of pain management and pain outcomes for advanced cancer patients. This begs the question why efforts have been made to develop interventions when the relationship in question remains unclear. If a lack of knowledge leads to poorer pain related outcomes then one would expect to find much greater efficacy for knowledge based interventions than previous reviews have <sup>(55-57)</sup> . Although some authors have pointed to a lack of heterogeneity amongst educational interventions as the source of such inconsistent findings <sup>(55)</sup>, one must consider that there is a lack of a strong theoretical basis for these interventions due to the lack of a thorough examination of the critical factors. Our review mirrors this inconsistency. In the one

study which looked at knowledge directly <sup>(38)</sup> a small effect was found between carer knowledge of pain management and pain experienced. On the other hand, one of the other intervention studies <sup>(22)</sup> included here found a large positive effect for improvements in pain experienced, measured in a number of ways for participants whose knowledge improved following the intervention whereas the control group actually showed a decrease in knowledge and no improvement in pain experienced. Conclusions drawn from this study must be done so with caution due to the use of non-equivalent comparison groups which differed significantly at pre intervention and potential for selection bias. Furthermore the interventions used appear to differ greatly. Therefore, no concrete conclusions can be drawn regarding the impact, or indeed the associations that carer knowledge of pain management has on pain outcomes in this population.

### *Patient well-being*

A number of patient related factors were identified including psychological distress, which was noted in one study <sup>(38)</sup> to have a medium size positive correlation with pain experienced. This finding was further supported by another study, <sup>(25)</sup> which reported a small positive correlation between scores on the HADS <sup>(27)</sup> depression subscale and pain intensity. Whilst these constructs cannot be considered identical, they are related. The former study is, however, hampered by its small sample size. Another study <sup>(6)</sup> examined the relationship between psychological distress and pain and found a range of relationships from weak to strong. Again one must be cautious in comparing the findings to those previously mentioned as this study relies on very simplistic measures of the various emotions (Visual Analogue Scales for each emotion).

Another psychological construct, body image, was found to have a small correlation with pain intensity <sup>(42)</sup> and showed a strong association with depression. Again this relationship was only supported by findings from a single study which, although it claims to be prospective in design, this is only partially true as patients were required to retrospectively recall their satisfaction with their body image prior to entering palliative care.

In summary these findings indicate that there is no strong evidence about the relationship between psychological distress and severity of pain experienced by people with advanced cancer, partly due to the lack of consistency of assessing psychological distress. Other research suggests mood and wellbeing may mediate other processes which in turn impact pain. As Li et al <sup>(15)</sup> noted, the advanced cancer patient's mood may impact on aspects of their cognitive functioning such as executive functioning abilities and subsequently their quality of life. This review was unable to conclusively indicate the true impact of mood or psychological wellbeing on pain, and it may be the case that a causal or reciprocal relationship exists between such distress and pain.

### *Systemic factors*

Only one study can be considered to examine the relationship between systemic factors and pain. <sup>(47)</sup> Less pain was seen to be related to: higher quality palliative care, and greater satisfaction with the medical care received. Due to the location of this study in a non-western society in Japan where individuals are often seen to have “stoic” attitudes towards pain <sup>(65,66)</sup> this may limit the comparisons that could be made to patients in Western countries .

### *Carer factors*

Three additional carer factors were identified by this review, two of which (burden and distress) were shown to have medium size correlations with patients' reported pain levels. Both of these factors were assessed by only one study <sup>(38)</sup> which was cross-sectional in nature and had a small sample size. This study also noted that there was a relationship between higher carer distress and greater inaccuracy in carer estimates of pain. Although this study found no relationship between the disparity scores of carer's estimation of patient pain with actual levels of pain experienced, such disparities may be important, especially towards the latter stages of cancer where patients are reliant on carers to provide accurate estimations and adapt treatment accordingly. For example it has been noted elsewhere that high disparity was related to higher levels of pain experienced <sup>(59)</sup> and poorer quality of life for both patient and carer <sup>(60,61)</sup>.

Again the lack of research in the area of carer burden, distress and inaccurate pain estimation for advanced cancer patients in the home setting must be addressed before efforts are made to develop interventions targeting such variables. Research exists which implicates such factors for those in inpatient settings but it is important to consider the effects of complex interactions which exist between the carer and the patient <sup>(62)</sup>. Additional variables (such as beliefs <sup>(63)</sup>) may exist in the home setting which could potentially complicate such interactions.

### *Summary and implications of findings*

The conclusions derived from this review must be considered in light of its limitations. The use of a third reviewer to analyze disagreements between the two

independent reviewers at the screening stages helped to reduce bias although there was a less than perfect inter-rater reliability score. The review also focused solely on the direct experience of pain reported by the patient, and so cannot make any claims about related variables such as pain interference.

The emphasis of this review was to identify the patient and carer related factors that have a potential relationship to the pain experienced by advanced cancer patients cared for at home. A small number of studies examined such relationships, with psychological distress being the most commonly studied factor included in the review.

Clearly there is a need for more research in this area before any conclusions can be drawn that might benefit the design of interventions. Specifically, we recommend that:

- An agreed measure of patient distress is used among people with advanced cancer, to enable comparison of studies focusing in this area and which would be a useful outcome measure in any future intervention study (as per the recommendations of the Core Outcome Measures in Effectiveness Trials (COMET) Initiative (<http://www.comet-initiative.org/>)).
- Further research is undertaken to determine whether there are modifiable patient and carer factors that are related to pain severity. Research with a longitudinal design would be helpful in allowing some estimation of the directionality of any relationships found.
- Future interventions aimed at improving the experience of pain for patients need to be based on a theory of change that is evidence



based, to increase the likelihood of effectiveness and reduce opportunity costs.

As noted previously there is a move within wider health care provision to shift the location of care from institutional settings to a person's own home <sup>(68)</sup> in line with patients' own preferences <sup>(4)</sup>. The current review calls into question the legitimacy of such interventions in the home setting as it cannot be assumed that the factors influencing pain outcomes are identical for both inpatient and outpatient settings. Identifying such factors for the home setting should be considered the first step in developing clinical interventions to improve pain outcomes in line with recommendations by the UK Medical Research Council <sup>(19)</sup>. As briefly alluded to previously, it is unlikely that the factors simply have a linear causal relationship and are more likely to affect pain outcomes through complex interactions with a number of variables which could not be identified through the nature of this review eg. barriers due to beliefs around opioid use <sup>(12)</sup>. Utilizing behavior change models, such as the Capability, Opportunity, Motivations and Behaviour (COM-B) model, can be a useful framework for identifying factors worthy of investigation, that can then be matched with an appropriate intervention technique <sup>(1)</sup>.

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