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Prognostic awareness in advanced cancer: An integrative literature review

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SM designed the focus of the literature review, was the lead in the review process and in writing the manuscript. HK was a major contributor in the literature review process, in writing the manuscript and providing critical input. Both authors revised and approved the final manuscript.

Abstract

Individuals with advanced cancer who have accurate prognostic awareness are reported to make more informed decisions about their plan of care. Despite this, it is reported that individuals do not always have accurate prognostic awareness with the rationale for this discordance unclear. The primary aim of the integrative literature review was to identify if there is concordance between actual prognosis and accurate prognostic awareness in individuals with advanced cancer. The secondary aim was to identify the rationale for any discordance between actual prognosis and prognostic awareness in individuals with advanced cancer.

An integrative literature review using a systematic approach. Literature searches were undertaken in March 2018 in four databases; Cinahl, Medline, PsycINFO, and Cochrane Library. Searches were limited to 2008-2018 and those written in the English language. Database searches were supplemented with papers from reference lists of included papers and grey literature. Two reviewers independently completed the literature search and independently reviewed the papers.

14 eligible research papers were identified. The majority of individuals with advanced cancer in the included studies did not have accurate prognostic awareness. When identified, the rationale for discordance relates to the individual not being communicated accurate prognostic information, not being able to recall prognostic conversations or prognosis being discussed in vague terms.

As individuals with advanced cancer with accurate prognostic awareness make more informed decisions at a crucial time in their life trajectory, it is imperative that health care professionals are equipped to effectively deliver accurate prognostic information, ensuring understanding is assessed.

Introduction

Patient empowerment is a relatively new concept in health care,¹ that has challenged the traditional paternalistic philosophy of care. Empowerment refers to the process that facilitates an individual to gain the knowledge, skills and attitude needed to make choices about their care.¹ It is considered a factor in improving health outcomes and better adherence to treatment regimes.² The process of empowerment involves offering individualised information, actively encouraging the patient to participate in health related decisions and paying attention to the individuals' priorities and concerns.³ To effectively translate empowerment into practice, a person-centred approach is required.⁴ In oncology, individuals who are better informed to make decisions may choose less aggressive treatments prefer symptom-directed care and contribute to more optimal end-of-life planning.⁵⁻⁷ Prognostic awareness relates to an awareness of a terminal prognosis or shortened life expectancy in patients with advanced cancer.⁸ Prognostic awareness can be related to a range of areas such as awareness of metastatic disease or awareness of life expectancy.⁸ However, it is reported individuals with advanced cancer do not always have accurate prognostic awareness.⁹ In a previous systematic review, it was reported that that less than half of individuals with advanced cancer had accurate prognostic awareness,¹⁰ however, the rationale for the lack of prognostic awareness was not explored. Therefore, the primary aim of this integrative literature review was to identify if there is concordance between actual prognosis and accurate prognostic awareness in individuals with advanced cancer. The secondary aim was to identify the rationale for any discordance between actual prognosis and accurate prognostic awareness in individuals with advanced cancer.

Methods

The integrative literature review was conducted using a systematic approach. An integrative approach was selected as the best fit to address the aims of this literature review as it is the broadest type of research review allowing for the inclusion of experimental and non-experimental research.¹¹ The five-stage framework for an integrative literature review was followed which includes problem identification, a literature search, data evaluation, data analysis and presentation.¹¹ The data analysis stage of this framework provided a structure for the least well developed component of completing integrative literature reviews.¹¹ This involved an iterative process of constant comparison of relevant extracted data to facilitate the identification of patterns, themes and also deviances,¹¹ with the classification system used being the identification of themes.

Data sources and identification of primary sources

Four databases were selected; Cinahl; Medline, PsycINFO and Cochrane Library. The selection of key terms were initially developed from the key search terms used in a previous systematic review related to the aims of this literature review⁸ and these were adapted and developed following an initial review of the literature to align to the focus of this literature review. This involved the following components which were linked together with the AND and OR Boolean operators; (1) cancer, neoplasms; (2) awareness, health, knowledge, attitudes, practice; (3) prognosis, life expectancy (Appendix 1). The search strategy was limited to 2008 to 2018 and papers written in English language. To supplement the search, reference lists of included papers and grey literature were also searched.

Inclusion and exclusion criteria

Studies were included if they met the following inclusion criteria; studies published between 2008 and 2018 to source recent published research and papers written in the English language. The database searches were updated in June 2020 with no new relevant studies identified.

Data extraction and quality appraisal

Relevant data were extracted from each paper using a standardised data extraction form (SM) and this was independently reviewed (HK). Relevant data extracted included the country, setting, study objective, study design, population, sample size, description of intervention, outcome measures, results and relevance. In addition, extracted data focused data related to the primary and secondary aim of the integrative literature review. The methodological rigor of each paper was assessed using the relevant Critical Appraisal Skills Programme (CASP) tool.¹² The outcome of the critical appraisal process is provided in the Supplementary file.

Results

Outcome of literature search

Study selection

The literature search was conducted in four databases in March 2018 with a total of 2647 papers identified. Four further papers were identified from reference lists of included papers and two papers identified from the grey literature resulting in 2653 records. Following the removal of duplicates, the titles and abstracts were reviewed for 2613 records and 2588 papers were identified as not being related to the aims of the literature review. 25 full text papers were reviewed and a further eleven papers were excluded at this stage for reasons including the primary aim of the research was not directly related to the aims of the literature review. The two authors independently reviewed title and abstracts and full text papers on the

papers which related to the aims of the literature review. A total of 14 papers met the inclusion criteria and were included in the literature review (Figure 1¹³). 14 papers were examined and analysed using the framework published by Whitemore and Knafl¹¹ with two themes emerging related to the primary aim of the literature review. Theme one relates to individuals who did have accurate prognostic awareness related to their advanced cancer diagnosis and theme two relates to individuals who had inaccurate prognostic awareness related to their advanced cancer diagnosis.

Study Characteristics

A range of countries were represented in the included papers; United States of America (USA) (n=9), Taiwan (n=1), South Korea (n=1), Cuba (n=1), Turkey (n=1) and Belgium (n=1). Cancer diagnosis included a range of cancers (n=7), gastrointestinal cancer (n=1), lung cancer (n=1), breast cancer (n=1), malignant glioma (n=1), thoracic cancer (n=1), lung cancer and gastrointestinal cancer (n=1) and lung and colorectal cancer (n=1). 12 papers used a quantitative research design, one a mixed methods design and one paper used a secondary analysis of clinical data.

Methodological rigor

Of the 14 studies included in the review, three were rated as having strong methodological rigour,¹⁴⁻¹⁶ nine as having moderate methodological rigour,^{9,15-24} and two as having weak methodological rigor.²⁵⁻²⁶ This information is provided in the Supplementary file.

Primary aim of literature review

Theme one: Individuals with advanced cancer who had accurate prognostic awareness

This theme includes research studies in which the majority of individuals with advanced cancer, that is, 50% or more, was reported to have accurate prognostic awareness. Three of the 14 studies reported the majority of individuals had accurate prognostic awareness or recognised their condition was terminal.^{14, 20, 23} Accurate prognostic awareness was reported in 71% of individuals in one study in South Korea²³ in a study in USA, 60.8% of those who had been informed of their prognosis were more likely to acknowledge they were terminally ill, indicating a more accurate prognostic awareness, and in the context of Taiwan, 59.5% of patients were prognostically aware.¹⁴ It was not clearly reported whether patients had been involved in a discussion with the oncologist regarding their prognosis. Methods used to assess prognostic awareness involved interviews with individuals with advanced cancer to determine

their understanding of their prognosis,¹⁴ terminal status²³ or life expectancy.²⁰ This was then compared with the estimation of prognosis at the time of interview¹⁴ or survival time and date of death.^{20, 23}

Theme two: Individuals with advanced cancer who had inaccurate prognostic awareness

11 of the 14 papers reported the majority of individuals with advanced cancer had inaccurate prognostic awareness, that is, less than 50% reported in each study.^{9, 15, 16-19, 21, 22, 24-26} Methods used to assess inaccurate prognostic awareness involved interviews with individuals with advanced cancer,^{9, 16, 19, 25} completed questionnaires^{15, 17, 18, 22, 24, 26} and secondary analysis of questionnaires.²¹ There were variations with regards how these findings were reported. A number of papers reported the percentage of individuals who had accurate prognostic awareness ranging from 5-45%, highlighting that the greater percentage of individuals with advanced cancer in these studies had inaccurate prognostic awareness. In one study, it was reported 5% of patients had an *accurate illness understanding which means 95% did not have accurate illness understanding*.¹⁶ In another study 8.8% of individuals with advanced cancer were reported to have made statements that were indicative of a knowledge of a poor prognosis in the context of Cuba.²⁴ In another study, 16.5% had accurate prognostic awareness,²² rising to 40% of patients in another study¹² and 45% of patients having accurate prognostic awareness in a further study.¹⁸ Further studies reported the percentage of patients who had inaccurate understanding of the intent of treatment being curative, or their condition not being terminal, providing insights into their inaccurate prognostic awareness. In one study, 54% of patients perceived their cancer was likely to be cured²⁶ with a similar outcome in another study with 58.2% of patients reported to have an inaccurate perception of treatment intent as curative.¹⁹ 38.2% of patients reported being seriously, but not terminally ill in one study²¹ and 49.4% reported their current status as terminally ill¹⁷, all highlighting the greater majority of individuals with advanced cancer in these studies had an inaccurate prognostic awareness.

Another approach to reporting information on levels of inaccurate prognostic awareness related to the percentage of patients who accurately estimated their life expectancy. 11.79% of patients who were within three months of their survival accurately estimated their life expectancy and 39.30% who were within 12 months of survival accurately estimated their survival.⁹ In another study, 68% of patients rated their 2 year survival prognosis discordantly from their oncologist, highlighting an inaccurate prognostic awareness.²⁵

Secondary aim of literature review

The secondary aim of this literature review related to identifying the rationale for any discordance between actual prognosis and accurate prognostic awareness. Rationale for individuals with advanced cancer not having accurate prognostic awareness is not reported in the majority of the studies in this literature review. When rationale is offered it relates to the individual not being able to recall prognostic conversations due to being overwhelmed at the time of these discussions, or the subject of prognosis being discussed in vague terms, with patients not recognising it as such.²⁰ Despite patients being informed of their prognosis, how a patient responds emotionally to this information may influence their prognostic awareness. An individual may be in a state of denial,¹⁷ and unable to fully comprehend their prognosis. Further rationale for discordance outlined relates to the patients misunderstanding of the intent of chemotherapy or radiotherapy treatment as curative, as patients in included studies were of the opinion, or alternatively hoping, that treatment had a curative, rather than palliative intent.^{17, 19}

Individuals not being involved in a discussion with their oncologist regarding their prognosis also provided rationale for individuals with advanced cancer not having accurate prognostic awareness.^{9, 21, 24} It was unclear in many studies whether oncologists had disclosed the prognosis to patients which could provide one rationale for the lack of accurate prognostic awareness in patients with advanced cancer. In the studies that did report if prognostic discussions had taken place, there was great variation reported with regards the percentage of patients who did not have a conversation about prognosis with the oncologist. In one study, 38% of patients reported they never had discussions related to their prognosis with their oncologists¹⁶ whilst 84% of patients stated the prognostic information they received was either excellent, very good or satisfactory in another study.¹⁵

Further rationale for discordance is provided in a study undertaken in the context of South Korea which acknowledged that prognostic information may not always be disclosed unless requested based on a fear from healthcare professionals of taking away hope from patients along with concerns about reducing their quality of life.¹⁴ Irrespective of whether patients with advanced cancer had been involved in a discussion with their oncologist regarding their prognosis and treatment decision making, it is reported that individuals with advanced cancer prefer to be informed of their prognosis.^{17, 20, 24, 26}

Discussion

The primary aim of this integrative literature review was to identify if there is concordance

between actual prognosis and accurate prognostic awareness in individuals with advanced cancer. The results build on the findings from a previous literature review with a similar focus published in 2014¹⁰, however, this review has also included an exploration on the rationale for patients lack of prognostic awareness. The results of this review demonstrate that in the majority of research papers included in this literature review, there was discordance between actual prognosis and accurate prognostic awareness in individuals with advanced cancer. In this integrative literature review, concordance between actual prognosis and accurate prognostic awareness in individuals with advanced cancer was reported to range from 5% to 71%. This is in keeping with the result of a systematic literature review which reported the range of prognostic awareness ranged from 0-75%, identifying this was linked to an absence of the awareness of the cancer diagnosis itself.⁸ Another study identified that 55% of individuals with advanced cancer had inaccurate prognostic awareness, with rationale provided as individuals were of the opinion that treatment had curative intent.²⁷

The secondary aim of the literature review was to identify the rationale for any discordance between actual prognosis and accurate prognostic awareness in individuals with advanced cancer. Rationale identified included patients not being informed of their prognosis, patients misunderstanding the intent of palliative treatment as curative and individuals feeling overwhelmed when discussions regarding prognosis have taken place. It was reported in the context of Taiwan that in order to preserve hope for individuals with advanced cancer, there was a well-intentioned lack of transparency regarding disclosing the actual prognosis¹⁴ highlighting the cultural variations with regards transparency regarding prognosis.

Patients who are well informed about their prognosis make different decisions to patients who are less informed.²⁰ They are more likely to choose less aggressive treatments,²⁸ more likely to engage in advanced care planning²⁰ and make more informed decisions about their care, ensuring they choose their preferred course of treatment²⁹ therefore facilitating acceptance of their advanced cancer prognosis,³⁰ Individuals who do not have accurate prognostic awareness do not feel empowered to make informed decisions.³¹

It was reported in a number of studies that individuals with advanced cancer were not involved in a critical conversation with healthcare professionals regarding prognostic information. Transparent disclosure of prognosis in health care is a broad, sometimes unclear area, that often encompasses wide ranging ethical issues. This includes the human right of individuals in receiving information about their diagnosis and prognosis. The reasons for patients not being informed of their prognosis could include a lack of training or confidence in healthcare

professionals regarding breaking bad news such as a poor prognosis, highlighting the need for healthcare professionals to receive adequate training. Delivering prognostic information to individuals with advanced cancer is a daunting task. Prognostic information should be delivered using a sensitive and supportive approach, encouraging people to make informed decisions about their care and ensuring patients have accurate prognostic awareness.³² The way in which healthcare professionals present bad news is an important factor in how it is received, understood, and dealt with.³³ This requires a person-centred approach seeking to empower the patient with relevant information and supported to make their own decisions. Communicating prognostic information requires an assessment related to how much information the patient desires. The difficulties healthcare professionals face when discussing prognosis includes deciding whether to provide patients with survival time, estimated life expectancy, how to convey a sense of hope, and to communicate this all sensitively, honestly and ethically.³⁴⁻³⁵ Professionalism and effective communication skills are key in the delivery of prognosis.³⁶ It is important that healthcare professionals are prepared when discussing the prognosis with individuals such as ensuring the setting is appropriate, preparing the patient for the news they are about to receive, providing accurate information, checking the individuals level of understanding, providing support, and having a plan to move forward.³⁷ Considerations should include simplifying the prognostic information, considering the timing of the delivery of prognostic information, training healthcare professionals to communicate accurate prognostic information, discussing prognosis frequently if appropriate, and implementing teach-back methods, which could allow the healthcare professional to see improvements in the level of understanding individuals have of their prognosis. Omitting to check the patient's level of understanding after the delivery of prognostic information is one possible rationale for discordance between actual prognosis and accurate prognostic awareness. Furthermore, the timing of the delivery of prognostic information may also contribute to inaccurate prognostic awareness as patients may be advised of their prognosis on the first visit to the medical doctor when diagnostic information is also being delivered. It has been reported that patients who had recent discussions with their medical doctors about disease progression had a better understanding of their prognosis, suggesting that individuals with advanced cancer do require regular discussions to reinforce their perception of the actual prognosis.¹⁶ These results suggest that the timing of the delivery of prognostic information is essential, in addition to prognostic conversations taking place frequently. In addition to the timing of these challenging conversations, further rationale for individuals not being accurately aware of their prognosis is they appear to struggle in fully comprehending the information, even when they are keen to know their prognosis. This perceived lack of clarity could be, in part, due to the individual longing to preserve hope³⁸ highlighting the importance of ensuring

the interpretation of information communicated, is assessed, using a supportive and person-centred approach.

Strengths and limitations

The focus of this literature review was to explore whether there was concordance between actual prognosis and accurate prognostic awareness in individuals with advanced cancer and to identify the rationale for any discordance. In a number of included studies, the primary aim of the research was not related to the aims of this literature review so limited information was relevant which restricted the ability to more fully identify the rationale for any reported discordance. A further limitation related to the variation in assessment techniques in measuring prognostic awareness which led to challenges in reporting the results. This was reported in a similar systematic literature which identified that it led to an inability to make comparisons between studies.⁸ Despite this, the value of this integrative literature review was in the identification of both experimental and non-experimental research designs providing a more heterogeneous methodological approach. As 12 of the 14 studies used a quantitative methodology a meta-analysis methodology may be more appropriate in future literature reviews focusing on the aims of this literature review.

Conclusion

The findings of this literature review demonstrate the majority of individuals with advanced cancer had inaccurate prognostic awareness. Reasons for the discordance between actual prognosis and accurate prognostic awareness included individuals not being informed of their prognosis, or not accurately interpreting or retaining the information. Despite this finding, the majority of individuals reported they would like to be informed of their prognosis. The benefits of having accurate prognostic awareness relates to individuals with advanced cancer feeling empowered to make their own decisions about their healthcare with evidence confirming these decisions are different if there is accurate prognostic awareness. Healthcare professionals require further training and support to enhance the effective delivery of prognostic information to individuals with advanced cancer. There is a need for additional research to evaluate the delivery of accurate prognostic information in attempting to more accurately inform and support individuals with advanced cancer.

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