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Prognostic communication in cancer: A critical interpretive synthesis of the literature

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A B S T R A C T

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Purpose: For patients with cancer, providing appropriate information about prognosis or chances of recurrent disease remains a difficult area of practice. Much research has suggested that patients want to be given all available information, although the realities of attempting to do this are complex and may be perceived by some as uncaring. A review of recent literature was undertaken to explore the process of disclosure, patient experience and preferences for information regarding prognosis or risk of recurrence.

Methods: A systematic approach was taken to searching electronic databases for relevant literature from 2004 to June 2014. Primary research from a range of methodological approaches was included and critical interpretive synthesis was employed to explore themes and identify gaps in the evidence.

Results: Twenty papers were identified as appropriate. They were diverse in objectives and patient groups. Themes identified included: the nature of prognostic information, patient need for prognostic information, patient need to maintain hope, balancing hope and realism, patient factors, disease factors and clinician factors. A thematic framework was developed.

Conclusions: Patients often struggle to fully understand complex prognostic information. They value help in making sense of this information and generally want information that supports hope. Working with patients to understand and manage the uncertainty of their situation may be particularly valuable. Further research is needed to fully understand the process of prognostic information giving and what information patients want regarding recurrence risk. Research should be aimed at identifying strategies helpful to patients in managing uncertainty inherent in their situation.

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Introduction

What and how to tell patients with cancer about the likely course of their disease remains a complicated and difficult area of cancer care. Many studies have explored patients' information preferences, including information on prognosis and have indicated that most patients prefer to be given all available information good and bad (Cassileth et al., 1980; Cox et al., 2006; Jenkins et al., 2001). However, a qualitative study with acute leukaemia patients suggested a more nuanced requirement for information giving balanced with maintaining hope (Friis et al., 2003). In 2005 a wide-ranging and comprehensive review of the literature exploring

communication of prognosis in cancer care was published (Hagerty et al., 2005a). This review explored evidence from early stage cancer patients, as well as with more disseminated disease, and at end of life and included studies published up until the end of 2003. Eleven research questions were constructed including patient preferences and predictors for prognostic information, style of communication, current practice and patient understanding.

The impetus for undertaking this review came from a desire to understand the information requirements regarding prognosis in patients with lung cancer following surgery. Much of the evidence in early stage disease has been derived from the breast cancer population and only four papers within the Hagerty review specifically looked at the communication of prognosis in patients with lung cancer. None of them looked at post-surgical patients (Quirt et al., 1997; Sell et al., 1993; The et al., 2000; Weeks et al., 1994). Initial scoping of more recent literature using broad searches on MEDLINE, CINAHL and Google Scholar suggested that early stage

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lung cancer remained unexplored. A number of more recent reviews focused specifically on fear of recurrence (Simard et al., 2013) and risk in early stage cancer, or decision-making tools (Engelhardt et al., 2014; O'Brien et al., 2009; Rabin et al., 2013). Therefore, with the review conducted by Hagerty et al. (2005a) as a starting point, a review of the literature exploring prognosis disclosure in patients with all stages of cancer from 2004 to June 2014 was undertaken.

Review approach

There is a plethora of literature review typologies with considerable overlap between approaches and choosing the most appropriate approach can be difficult (Grant and Booth, 2009). Critical Integrative Synthesis (CIS) (Dixon-Woods et al., 2006a) is one such approach and was derived from meta-ethnography (Noblit and Hare, 1988). CIS allows evidence to be synthesised from very diverse approaches, translating key themes, metaphors and concepts from the original research studies into each other, identifying wider patterns and constructs across the literature, and bringing to light contradictions between studies to achieve a greater understanding of the phenomenon and to develop new theory or insight (Dixon-Woods et al., 2006a). In keeping with the principles of much qualitative research, such reviews are iterative in their methodology as evidence emerges from the data (Mays et al., 2005). In this case the review objectives and the inclusion and exclusion criteria for the incorporated papers were refined as the searches were explored and the process of reading and re-reading papers was undertaken.

The Enhancing Transparency in Reporting the Synthesis of Qualitative Research (ENTREQ) (Tong et al., 2012) was used to conduct and report this review.

Objectives

In order to develop a focused search question, “Population”, “Intervention”, “Control” and “Outcome” (PICO) principles were used (Booth and Fry-Smith, 2003). Two search strategy questions were developed.

1. What do we know about the process of disclosure of information about the risk of recurrence or prognosis in adult patients with cancer?

2. What do we know about the patient experience and patient preferences for the disclosure of information about the risk of recurrence or prognosis in adult patients with cancer?

Methods

The review was exploratory in nature and therefore a broad base of research papers from a range of methodological approaches was considered. Peer reviewed, published studies in English were included. However, “expert opinion”, or best practice guideline papers were not incorporated, nor studies in the form of unpublished work, such as unpublished theses. The review encompassed papers published from 2004 in view of the review by Hagerty et al. (2005a). Inclusion and exclusion criteria were developed which reflected the search strategy questions and are included in Box 1.

Search methods for identification of studies

CINAHL, MEDLINE and PsychINFO electronic databases were searched from January 2004 to June 2014 using Open Athens. Cochrane database was also searched for suitable studies. Reference lists of downloaded papers were checked for relevant papers not identified via the electronic searches. Scopus database was used to search for papers citing the papers initially selected for the review to identify newer research. One journal was identified as being particularly relevant (The Journal Psycho-oncology) and was hand-searched for relevant articles.

The search strategy was developed from the outline provided within in the Hagerty et al. (2005a) review. The search comprised of search terms including:

- NEOPLASMS (MeSH term), cancer, oncology
- Prognos*, recurrence risk, information
- PROFESSIONAL-PATIENT RELATIONS (MeSH term), TRUTH DISCLOSURE (MeSH term)

It was important that the search was kept wide, particularly as qualitative literature is difficult to search from electronic databases (Pope et al., 2007). It was anticipated that a broad search strategy such as this would result in a high number of irrelevant papers that would require subsequent manual screening. An updated search

Box 1

Inclusion exclusion criteria

Inclusion:

- Papers published between January 2004 and June 2014.
- Patients diagnosed with cancer as primary focus
- Early stage, locally advanced or metastatic cancer diagnosis or “all stages”
- Analysis of professional-patient communication
- Significant discussion of prognosis or recurrence risk
- Adult patients over 18 years

Exclusion:

- Non-English language articles
- Predominantly patients at “end of life”.
- Predominantly non-cancer, or patients with borderline malignant conditions, (myelodysplastic syndrome, carcinoma *in situ*, etc.)
- Studies primarily involving genetic testing to estimate recurrence risk
- Studies primarily involving the use of decision aids
- Reviews or expert opinion
- Studies exploring relatives' communication only
- Research exploring only professionals' perceptions of patient communication
- Hypothetical or simulated scenarios with patients or non-patients as the primary focus

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