

**Prognostic communication in cancer : a critical
interpretive synthesis of the literature.**

JOHNSON, Matthew, TOD, Angela, BRUMMELL, Stephen
<<http://orcid.org/0000-0002-1696-6518>> and COLLINS, Karen
<<http://orcid.org/0000-0002-4317-142X>>

Available from Sheffield Hallam University Research Archive (SHURA) at:

<http://shura.shu.ac.uk/9601/>

This document is the author deposited version. You are advised to consult the publisher's version if you wish to cite from it.

Published version

JOHNSON, Matthew, TOD, Angela, BRUMMELL, Stephen and COLLINS, Karen (2015). Prognostic communication in cancer : a critical interpretive synthesis of the literature. *European Journal of Oncology Nursing*, 19 (5), 554-567.

Copyright and re-use policy

See <http://shura.shu.ac.uk/information.html>

PROGNOSTIC COMMUNICATION IN CANCER: A CRITICAL INTERPRETIVE
SYNTHESIS OF THE LITERATURE

Matthew Johnson¹, Angela Tod², Karen Collins³, and Stephen Brummell⁴

¹Macmillan Lead Cancer Nurse, Royal Brompton and Harefield NHS Foundation Trust,
London, UK

²Florence Nightingale Foundation Chair of Clinical Nursing Practice Research, University of
Manchester, UK

³Professor of Health Services Research, Centre for Health and Social Care Research,
Sheffield Hallam University, UK

⁴Senior Lecturer, Centre for Health and Social Care Research, Sheffield Hallam University,
UK

Corresponding author:

Matthew Johnson, Royal Brompton and Harefield NHS Foundation Trust, Sydney Street,
London, UK SW3 6NP e: m.johnson@rbht.nhs.uk t: 020 7352 8121 x4710

Abstract:

For patients with cancer, providing appropriate information about their 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 following curative treatment for cancer. 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. Twenty papers were identified as appropriate and included. They were diverse in their 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 and a thematic framework was developed. This review identified that 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.

Key words

Communication, cancer, prognosis, recurrence risk, review

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 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 relatively wide, particularly as qualitative literature is difficult to search from electronic databases (Pope et al., 2007), and filters for qualitative research were not employed. An updated search was re-run in January 2015 to include the period of July to December 2014 in order to keep the search current.

Selection of studies

Search results were downloaded into Refworks ©, an electronic reference management system. Database search results were initially searched by title and abstracts. Papers judged potentially suitable were then downloaded in full and assessed against the inclusion / exclusion criteria to confirm their eligibility for the review. An extensive iterative process of reading and re-reading potential studies was undertaken with much of this work running concurrently with the process of quality appraisal and data extraction.

Quality appraisal

There is controversy regarding whether qualitative literature should be assessed and evaluated for its quality (Aveyard, 2010; Dixon-Woods et al., 2007; Pope et al., 2007). Some qualitative researchers argue that it is not possible to assess quality of qualitative research in any systematic manner, while others favour structured checklists or more subjective criteria, such as authenticity and credibility (Dixon-Woods et al., 2007; Tong et al., 2007, Toye et al., 2013). The Critical Appraisal Skills Programme (CASP) tool was used for qualitative observational and interview studies to assess study strengths and weaknesses and to build a deeper understanding of the research (CASP, 2013). The tool covers rigour of the overall research, selection of subjects, data collection and analysis. Questionnaire studies required modification of the CASP tool, which were influenced by a more in depth tool developed by Boynton and Greenhalgh (2004).

Risk of bias

Systematic reviews generally adopt a team approach to ensuring objectivity in selection of studies and creating a final list of included papers (Aveyard, 2010). This review used a

systematic methodological approach. Due to the resources available the selection of papers was undertaken by one researcher (MJ), which arguably introduced an element of bias and subjectivity. **Setting clear objectives, research questions, inclusion and exclusion criteria, transparency in synthesis of the studies and advice from experienced researchers, mitigated some of these risks.**

Data extraction and management

Data were extracted from all studies by using a comprehensive data extraction form (Glenton et al., 2013). Codes were assigned to significant elements of data within the results and conclusions of the original papers and were emergent, rather than being established *a priori*.

Data synthesis methods

Data were synthesised using the principles of CIS (Dixon-Woods et al., 2006a). Preliminary themes relevant to the research questions were identified. An iterative process of cross-referencing between papers, assigning codes to the different themes and then refining these until a good fit had been achieved was employed (Aveyard, 2010; Pope et al., 2007). An integrative grid using Microsoft © Excel was constructed to explore the fit between themes of the papers to identify emerging similarities and contradictions between them (Dixon-Woods et al., 2006b). These codes were subsequently entered into a second integrative grid to refine the codes and develop synthetic constructs (Flemming, 2010). Ultimately a thematic framework was developed from the codes and synthetic constructs.

Results:

Figure 1 shows a flowchart describing the process of searching and identifying the final included papers from the initial database searches. Eighty-five papers were considered potentially relevant to the review and were downloaded in full and read. Of these, 65 did not meet the inclusion / exclusion criteria and 20 papers were finally selected for the review.

The updated search conducted in January 2015 indicated five additional studies that were

potentially relevant, but only one that met the inclusion exclusion criteria (Wagner et al., 2014). Although pertinent to the search, the paper revealed no new themes and was not included in the main review.

Description of studies

The papers included 15 separate studies. Three studies included analysis of data that was collected as part of a larger research project (Liu et al., 2014; Robinson et al., 2008; Rodriguez et al., 2008). One study was based on the secondary analysis of data collected from two separate studies by the same group and then analysed together (Thorne et al., 2007). Studies were conducted within the UK, USA, Australia, The Netherlands and Canada. Eight of the papers reported on quantitative studies and were survey based (Franssen et al., 2009; Lagarde et al., 2008; Hagerty et al., 2004; Hagerty et al., 2005b), quantitative analysis of consultations between patients and doctors (Alexander et al., 2012; Jansen et al., 2008), or both (Liu et al., 2014; Robinson et al., 2008). Eleven studies utilised qualitative methodologies, including interviews (Curtis et al., 2008; Goldman et al., 2009; Lobb et al., 2011; Mitchison et al., 2012; Step and Ray, 2011), interview and focus group (Thorne et al., 2006, and 2007), analysis of medical consultations (Leydon, 2008; Rodriguez et al., 2008), or a mixture of methods (Mendick et al., 2011 and 2013). One study used mixed methodology (Kelly et al., 2013). Patients were primarily recruited from clinical settings, with nine papers recruiting patients from oncology clinics. Three papers recruited patients from a breast unit and five from tertiary oncology or surgical centres. The remaining three papers took patients from diverse settings and were largely community focused. Details of the patient populations, studies and findings are included in table 1.

Quality

Some notable approaches in design stood out, such as the use of bilingual interpreters (Mitchison et al., 2012) and reading excerpts of transcribed consultations to interviewees to help them recall moments during the consultation (Goldman et al., 2009). Two papers used a theoretical model; Kelly et al. (2012) using the Self-Regulation Model (Leventhal et al.,

1999) and Step and Ray (2011) used Problematic Integration (Babrow, 2001). Leydon (2008) used conversation analysis to explore communication between patients and their oncologist.

Across all the papers there was little consideration of the ethical aspects of research, beyond ethics approval. None of the published accounts of the studies included any consideration of the impact of the research on the participants, despite the sensitive nature of the area. Almost all of the studies provided a good summary of the context of the research in terms of location and physical context of the participants. The papers by Thorne et al. (2006 and 2007) were unusual in the fact that this was not undertaken within the secondary care context, but details of the exact context were limited.

Descriptions of participant sampling were variable throughout the papers. Some gave detailed accounts of the process and accounted for non-responders (Franssen et al., 2009; Lagarde et al., 2008). Other studies provided only vague and incomplete accounts of the process (Thorne et al., 2006 and 2007). Two papers were small research studies within the context of larger projects, looking at the effects of using question prompt sheets in both cases (Curtis et al., 2008; Jansen et al., 2008). Brief discussion was included of the potential confounding effects of the original studies, but both papers were limited in their exploration of these potential effects.

Methods of data collection were generally clearly presented. Liu et al. (2014) used doctors' self-report on usual behaviour in disclosing prognosis, which led to questioning the validity of this as a measure of when doctors would discuss prognosis. Kelly et al. (2013) asked patients to estimate their own life expectancy. Twenty per cent of survey responders failed to answer this question and low response rates could reflect the discomfort of participants being asked something that was highly emotive and possibly too difficult to face in the context of a questionnaire.

A number of the qualitative papers presented large sections of original data helping to emphasise the conceptual clarity and interpretive rigour of the papers (Goldman et al., 2009; Lobb et al., 2011; Mendick et al., 2011 and 2013). Presentation of the quantitative data varied in quality, with some papers not presenting all data, or limited presentation of statistical analysis (Franssen et al., 2009; Kelly et al., 2013).

Themes:

Ten core themes were identified within the papers. These were aggregated into three broad groups of themes: diagnostic and prognostic factors, patient factors and clinician factors. These groups were used in the process of organising ideas across all aspects of communicating prognosis and in synthesising the evidence. Table 2 gives an overview of the identified themes.

Diagnostic and prognostic factors:

The nature of prognostic information: Studies with breast, haematological and with heterogeneous cancer populations identified a wide range of different prognostic information, ranging from whether or not the illness was likely to kill the patient to detailed assessments of likely length of life, or statistical assessments of the risk of cancer recurrence (Alexander et al., 2012; Goldman et al., 2009; Mendick et al., 2011 and 2013; Mitchison et al., 2012; Thorne et al., 2006). A distinction was made between a qualitative (eg whether treatment is curative, or verbal assessment, such as “good chance”) and a quantitative prognosis (eg numerical risk of mortality or life expectancy) (Alexander et al. 2012, Curtis et al. 2008, Goldman et al. 2009, Hagerty et al. 2004). Evidence from second opinion haemato-oncology patients indicated that oncologists commonly use both qualitative and quantitative estimates of survival in the same consultation (Alexander et al. 2012).

Presentation of prognostic information: Prognostic information can be presented in a wide range of different formats, from verbal to written, and words to graphical form. Generally patients preferred written prognostic information in words and numbers rather than diagrams and charts (Hagerty et al., 2004; Lagarde et al., 2008). A study in patients with various diagnoses in the metastatic setting indicated that prognosis could be framed in positive (chance of cure) or negative (chance of death) terms (Rodriguez et al., 2008). Oncologists tended to use positive terms to discuss prognosis with treatment, and negative terms to discuss prognosis without treatment. This study also indicated that doctors frame discussion about treatment or prognosis by altering how personalised the information is. Personal framing relates information to the current patient or "patients like you", while an impersonal frame relates information to a type of cancer or group of patients with cancer. The authors argue that such framing serves to distance or include the listener relative to the content and its implications. Robinson et al. (2008) found that doctors tend to use more optimistic statements about a patient's cancer than pessimistic ones in their study of heterogeneous incurable cancer patients. They argued that pessimistic statements might directly inform patients' perceptions of prognosis and balance out other factors that lead to overly optimistic estimates of prognosis by patients.

In a study of haemato-oncology second opinion consultations, medical staff frequently "hedged" the estimates given to the patient by suggesting statistics may not apply to the patient due to individual or circumstantial differences, which might allow a more positive interpretation of the statistics (Alexander et al., 2012). Post-surgical breast cancer patients were given prognostic information that covered a range of detailed, explicit and implicit information and was described as a "spectrum" of prognostic information (Mendick et al., 2013). Much of the implicit information about prognosis was in the form of judgements about the significance of the information given and doctors appeared to apply this asymmetrically, so that good news was evaluated, but bad news tended to be given without judgement. Evidence from a study of interactions between various types of cancer patients and

oncologists identified a process of “proximate pairing” of information employed by doctors, whereby relatively bad news was closely paired with relatively good news (Leydon, 2008). The good news formed the last part of the speech and this technique appeared to be used to soften the impact of the bad news and foster a sense of hope. This finding was consistently observed across settings and between oncologists. This appeared to be employed unconsciously to convey optimism in the context of diagnostic and treatment uncertainty. Leydon (2008) argued that although this was used to help maintain patient hope, it might result in patients unrealistically disregarding uncertain or bad news and having unrealistic treatment expectations.

Disease factors: Type of diagnosis and a patient’s position on the cancer trajectory alters the way in which prognostic information is given, the certainty to which a prognosis can be given, what the patient and family want to hear, and whether it is seen to be relevant (Curtis et al., 2008; Step and Ray 2011). In particular Step and Ray (2011) studied early stage solid tumour patients who had relapsed (largely breast cancer) to explore patients’ perceptions of prognostic communication at diagnosis and again at recurrence and found that there was a shift from hope for cure to a focus on chronic disease management. Thorne et al. (2007) highlighted periods in a patient’s disease trajectory where there was significant change, where hope was particularly delicate and vulnerable. Hagerty et al. (2004) found that about half of the patients in the metastatic setting wanted to have a discussion about survival at the time of diagnosis of metastatic cancer and patients might wish to delay these discussions or undertaken them over a number of clinic visits.

Prognoses rely on population statistics and providing a prognosis for an individual patient is not possible with certainty. For some patients prognosis may be completely unknown (Alexander et al., 2012; Thorne et al., 2007). The degree of uncertainty that patients experience about their illness also varies across the disease trajectory, with particular points associated with high levels of uncertainty, such as prior to diagnosis, end of treatment,

relapse and the transition into the terminal phase (Step and Ray, 2011). Uncertainty can be seen as anxiety provoking and many patients seek information about prognosis to help manage this (Thorne et al., 2007). However, the authors argue that giving patients information on the odds of cure or dying can underline the uncertain nature of cancer and can be seen as theoretically hopeful, because of the potential chance of a positive outcome.

Patient factors:

Patient desire for prognostic information: Studies repeatedly indicate that the majority of patients with a wide range of cancer diagnoses report they want to receive information regarding their illness and prognosis (Franssen et al., 2009; Hagerty et al., 2004; Jansen et al., 2008; Lagarde et al., 2008; Mendick et al., 2011; Mitchison et al., 2012). Studies with postoperative oesophageal cancer patients and heterogeneous metastatic cancer patients (Franssen et al., 2009; Lagarde et al., 2008; Hagerty et al., 2004) used an information preferences scale with approximately 65% of patients reporting that they wanted all available prognostic information. However, in a qualitative study of mixed cancer and COPD patients, despite all patients and family members starting interviews stating they wanted “all” prognostic information, a substantial minority went on to express concerns about being given explicit details of their prognosis (Curtis et al., 2008).

Patients in studies focusing on haemato-oncology, post-surgical oesophageal and metastatic cancers also wanted a “realistic approach” (Goldman et al., 2009; Hagerty et al., 2005b; Lagarde et al., 2008). In the metastatic setting, patients with longer prognoses were more likely to want the doctor to take a realistic approach (Hagerty et al., 2005b). Other patients, including some of those in the above studies, as well as high grade glioma, talked about wanting an “optimistic approach” (Goldman et al., 2009; Lagarde et al., 2008; Lobb et al., 2011; Mitchison et al., 2012). Both realistic and optimistic approaches imply a degree of processing of information prior to it being given to the patient in a usable format, but with a

different slant of the information in either case. Many patients reported that they only wanted information that was relevant to them (Curtis et al., 2008; Goldman et al., 2009; Lagarde et al., 2008). The use of numerical information appeared to hold particularly strong significance for patients, often with the power to stay with the patient for a long time (Hagerty et al., 2004; Franssen et al., 2009; Step and Ray, 2011; Thorne et al., 2006). Perceived unexplained differences between numerical estimates from various sources, or at different time points, provoked a lot of anxiety in patients (Thorne et al., 2006).

Several papers explored the predictors of patient desire for prognostic information. Patients in the metastatic setting indicated that depressed patients might be more likely to want to know full prognostic information, but patients with general anxiety were less likely to want this (Hagerty et al., 2004). Oesophageal cancer patients following surgery were more likely to want full prognostic information where they had greater fear of recurrence (Franssen et al., 2009). This study also suggested that patients with higher levels of education wanted more detail about their prognosis, but that age did not seem to predict such preferences.

Patients' need to maintain a sense of hope: Maintaining a sense of hope appeared to be central to patients' wellbeing and many patients described striving to keep this hope (Thorne et al., 2007). Not all patients wanted to have all prognostic information and some in both the curative and palliative treatment setting actively avoided hearing bad news if possible (Curtis et al., 2008; Hagerty et al., 2004; Lagarde et al., 2008; Mitchison et al., 2012). In the study by Thorne et al. (2006), patients described discounting unfavourable odds altogether. Complex or apparently irrational ways to re-frame bad news in a positive light were described by patients (Thorne et al., 2006 and 2007). Other methods of maintaining a sense of hope included a belief that the individual patient can "beat the odds" by virtue of personal attributes (Thorne et al., 2006). Some patients described discounting statistical information altogether as not being relevant (Thorne et al., 2007). Evidence from the palliative treatment setting suggested some patients take a sceptical view of any prognostic information given by

doctors (Hagerty et al., 2004; Lobb et al., 2011, Mitchison et al., 2012). Many patients cite examples of people they are aware of who have defied doctors' prognoses (Thorne et al., 2006).

Patients' need to balance hope with prognostic information: Breast cancer patients described not wanting to be overwhelmed with complex medical information (Mendick et al., 2011 and 2013). Patients with various cancers who had relapsed described trying to control the information exchange (Step and Ray, 2011). An information seeking paradox was described whereby patients sought to maintain a sense of hope and to reduce uncertainty by seeking further clinical information, only to find this increased their uncertainty, reduced hopefulness or overwhelmed them and this was echoed in other studies (Thorne et al., 2006 and 2007). Patients appear to use a range of approaches to help them balance hope with difficult prognostic information (Curtis et al., 2008). Mendick et al. (2011) highlighted the concept of "positive thinking" amongst breast cancer patients and Jansen et al. (2008) suggested an element of denial in patients' recall of prognostic information given as being one mechanism in this process.

Individual patient factors: Patients vary greatly in their attitude and requirements for prognostic information as well as educational levels and ability to understand and process medical information (Curtis et al., 2008; Kelly et al., 2013). A study of mixed cancer patients of all ages recalled less than half of the information given to them (Jansen et al., 2008). Factors such as giving information immediately after major surgery, or where patients had a diagnosis that impaired their recall, also had an impact (Lobb et al., 2011). Breast cancer patients appeared to recall treatment related information more readily than prognostic information (Mendick et al., 2013). There are complex cultural differences in the attitude to prognostic information that lie outside the scope of this review; however, in the study of heterogeneous metastatic cancer patients it appeared that much of this difference related to

family attitudes. Patients actually faced with the disease may be less culturally driven and more individual in their outlook (Mitchison et al., 2012).

Clinician factors:

Clinician-patient relationship: Studies highlighted the importance of a long-term doctor patient relationship, but where this was not possible, such as in second opinion consultations, it was important to establish a relationship quickly, show respect and not be dismissive of patients' needs (Curtis et al., 2008; Goldman et al., 2009; Mendick et al., 2011). Patients acknowledged the limitations of these relationships and emphasised the importance of having access to other skilled professionals who knew their case and could help them makes sense of it (Thorne et al., 2006 and 2007).

Clinician-patient relationships vary in the willingness to discuss prognostic information and this differs between disciplines and individuals (Kelly et al., 2013; Liu et al., 2014; Mendick et al., 2013). Evidence from physicians caring for patients with advanced cancer suggested that patients had a more realistic understanding of their prognosis when their doctor was more willing to discuss prognosis early in their care. Doctors with experience of caring for dying patients tended to be more ready to discuss prognosis early (Liu et al., 2014). Evidence from breast cancer surgeons in a UK centre indicated they have a desire to specifically give hope-preserving information to patients and they were open with the interviewers regarding their selectivity in biomedical information they gave during post-surgical clinics (Mendick et al., 2013). Other breast teams appear to give much more explicit information, with a US group reporting that the majority of patients had discussed risk of recurrence with their medical oncology or surgical team (Kelly et al., 2013).

Communication skills: Professional communication skills and the relationship between patient and professional appeared to be highly important in the maintenance of hope, and

this was seen in both curative and palliative treatment patients (Curtis et al., 2008; Hagerty et al., 2005b; Lobb et al., 2011; Mendick et al., 2011; Thorne et al., 2007). Poor communication skills by professionals when delivering bad news to patients with high grade glioma seemed to reduce hopefulness further (Lobb et al., 2011). Helping patients make sense of this complex information was viewed as particularly helpful (Thorne et al., 2006). Where there was a mismatch between the patient's perceived needs and the manner and content of the prognostic information given, it was likely to be perceived as unhelpful communication (Thorne et al., 2007).

Mendick et al. (2011) argued that guidelines suggesting patients should be given all available information might not be appropriate or feasible. The reviewed papers largely endorsed guidelines that suggest checking with patients the amount and whether they wanted prognostic information (Alexander et al., 2012; Franssen et al., 2009; Goldman et al., 2009; Hagerty et al., 2004; Mitchison et al., 2012), although Curtis et al. (2008) argued that simply asking without exploring individual and emotional aspects may not adequately address true needs. No specific professional behaviours or approaches were identified that might help to ensure prognostic information was right for patients (Curtis et al., 2008).

Shared understanding: Evidence from relapsed patients suggested that patients may struggle to fully understand jargon, which can create an illusion of shared meaning between patients and professionals. The meaning of commonly used terms may also change with time and clinical condition, compounding problems (Step and Ray, 2011). Patients and doctors rarely appear to agree over prognosis or chance of cure estimates. Breast cancer patients being treated curatively both over and under estimated their risk of recurrence (Kelly et al., 2013). Patients with advanced lung or colorectal cancer tended to over-estimate length of survival (Liu et al., 2014). When doctors used at least one pessimistic statement about the future patients with advanced cancer were more likely to be accurate in their

estimation of prognosis (Robinson et al., 2008). Expressions of optimism or uncertainty by the doctor did not affect the accuracy of prognostic estimate in patients.

Synthesis of outcomes

Synthesis of the review included both the themes identified in the current review and the themes identified in the paper by Hagerty et al. (2005a). This allowed the themes and synthetic constructs identified in the papers to be organised into a thematic framework and to develop synthetic arguments, attempting to present coherent model of prognostic disclosure in cancer care. Figure 2 provides a visual overview of the synthesis in a thematic framework.

Uncertainty is a key factor of cancer and its trajectory, with key points of high uncertainty, such as at diagnosis, or relapse. Information about the disease and treatment, and attempts to provide prognostic information are often given with the aim of reducing and managing the inherent uncertainty. Hope and uncertainty are closely linked, but not in a linear fashion. Periods of high uncertainty can be threatening to hope, but also can provide opportunities to think about hoped for positive outcomes.

Professional aspects of prognostic discussion are underpinned by knowledge and experience related to the patient's case, as well as personal and discipline specific attitudes to prognostic disclosure. The ability to communicate prognosis skilfully and sensitively is very important and within this is the knowledge and confidence to deliver the right pieces of information to match the patient's agenda. It appears that full disclosure may be neither feasible, nor desirable, due to the vast array of information available and the likelihood of overwhelming patients. Professionals use a range of techniques to convey prognostic meaning, without necessarily giving explicit information. Many patients do want and receive detailed information, and although this is not clear from the literature, it may be that this is

more common with patients with good prognoses and also where detailed prognostic information is available. Doctors in the studies talked about maintaining a sense of hope in their patients and openly used these ways of communicating prognosis or treatment outcome to aim to do this.

Patients vary in their desire for prognostic information, their ability to understand, retain and recall information, and in ways of managing the information. Although most patients wanted to be given all information good and bad about their condition, a more complex process, possibly underscored by a desire not to be deceived, balanced with a need to maintain hope and linked to a need to manage the uncertainty of their situation appears to operate.

Patients used a range of different methods to manage threat to hope.

There appears to be some parallels and convergence in the ways patients and professional staff attempt to maintain hope in the face of uncertainty. Tacit agreement to share the same agenda for the maintenance of hope may underpin some elements of patient perception of good communication skills during prognostic discussion. Both patients and professionals wanted to discuss prognostic information over a number of iterations on different occasions and providing and hearing this was described as a process. Moving the conversation on and matching the patient's agenda, whilst maintaining a sense of possibly shifting hope, does seem to reflect clinical practice, particularly in situations of advanced cancer.

Discussion:

Despite finding a wide range of studies exploring different patient groups, none of the studies specifically looked at recurrence risk after lung cancer surgery and none looked at lung cancer exclusively. Several of the heterogeneous cancer populations included lung cancer patients, but lung cancer was frequently in the minority. Only one study of stage IV

lung and colorectal cancer patients had more than half of the participants with lung cancer (Liu et al. 2014).

The current review is largely consistent with, and builds on the findings of, the Hagerty et al. (2005a) review. The literature was broad in terms of both focus and methodological approach and reflected the complexity of the topic. Both reviews have identified papers that measure patients' desire for prognostic information, which on the face of it is almost universally high. The current review has identified a greater number of interview or focus group studies that have underscored nuances present, which a response on a questionnaire may fail to highlight. There is consistency between the reviews in terms of patients wanting medical staff to check whether they want prognostic information and the level of detail of that disclosure. There is recognition in both reviews that some patients may not wish to explore prognosis in order to preserve hope. In terms of the behaviours patients find helpful in professionals, there was remarkable agreement and little further development of knowledge has occurred.

Other areas of the findings showed divergence between the reviews. This included research aimed at determining predictors for patients' prognostic information preferences, particularly relating to demographic or psychological characteristics, such as anxiety, fear of recurrence, education and age. Attempting to determine patient preferences for information using individual profiles may be a scientific blind alley, destined to produce multiple contradictory and weak findings.

Studies across the two reviews highlighted attitudes of different professional groups regarding prognosis or risk of recurrence disclosure, particularly breast surgeons and physicians in the current review and oncologists and physicians in the original review.

Wagner et al. (2014) in their paper published after the completion of this review also indicate that gastrointestinal cancer surgeons may be reluctant to discuss a poor prognosis with

patients with the aim of sustaining hope. It appears that inter professional attitudes and boundaries would provide a fertile area for further research, particularly if this could incorporate the role of the specialist nurse in supporting and facilitating these discussions. There was limited exploration of how attitudes to prognostic information changed over time as clinical situations altered, with the exception of the study by Step and Ray (2011). Understanding how patients manage the information they are given and how this is processed over time should also be explored.

The current review and synthesis, does build on the interplay of hope and uncertainty and explore the concept of uncertainty management as opposed to uncertainty reduction, as proposed by Thorne et al. (2007). At its base there is recognition of the complex human interaction of individual patients and health professionals, often using parallel techniques to manage information towards a common goal of supporting hope.

The strengths of the current review are that it was able to build on the comprehensive review by Hagerty et al. (2005a), which has allowed a more in-depth exploration of the literature over the last decade. The approach taken has emphasised a systematic approach and clarity over the literature that was selected. Quality appraisal was used in reviewing the literature, which was particularly beneficial in being able to fully understand and critique the literature. Use of a clear method of synthesis of the findings of the different studies also added to the review and allowed a more comprehensive and integrated understanding of the whole concept of prognostic disclosure in cancer care. Some of the weaknesses of the review have been limitations of a single novice researcher, with the support and supervision of experienced researchers, attempting to be as objective as possible about selection of papers to include. The area of focus of the review is large and ill defined and has also represented a challenge to keep the study from being too large and unwieldy, but at the same time not excluding areas that are relevant to the aims of the review.

Conclusions

This review has demonstrated a dearth of information specifically focusing on the needs and preferences for prognostic information of post-surgical lung cancer patients. Studies of patients with other cancer diagnoses being treated curatively, the majority with breast cancer, and heterogeneous patients with advanced cancer, suggest that there is huge variation in prognostic disclosure, which depends on both clinician factors, as well as patient factors. When prognostic information is given it can vary greatly in terms of explicitness and clinicians employ a range of linguistic and communication styles to communicate this while attempting to maintain patient hope. However, communication skills of the person giving the information seem to particularly affect patient satisfaction with care. Patients generally report they want prognostic information, but individual patients vary greatly in their preference for prognostic information and patients appear to want clinicians to ask about the amount and detail of the information before giving it. It appears patients want prognostic information to help them manage uncertainty and to support hope for the future, but many patients appear to struggle to fully understand complex prognostic information and they value help making sense of their situation.

Implications for practice:

The review highlighted the importance of good general communication skills and the ability to break bad news in the best possible way. Studies largely endorsed techniques, such as asking patients about the amount and level of detail they want when discussing prognosis or recurrence risk.

Implications for further research:

Lung cancer patients are distinct from some other groups of cancer patients by virtue of age, comorbidities, socio-economic group, smoking history and may have distinct attitudes to information on recurrence risk and specific exploration of this group's attitudes and needs for information should be explored. To date, it appears that no studies have explored risk of

recurrence disclosure longitudinally and with a range of professional groups, who may bring different attitudes to the discussion of recurrence risk. Research should be aimed to produce a more comprehensive view of the disclosure process, as it is likely that no one professional group is likely to provide the complete picture for the patient and into development of strategies or interventions that can help patients to manage the uncertainty inherent in their situation.

Acknowledgements

Matthew Johnson is supported by a PhD Studentship funded by the Centre for Health and Wellbeing Research, Sheffield Hallam University and the National Lung Cancer Forum for Nurses.

References

Alexander, S.C., Sullivan, A.M., Back, A.L., Tulskey, J.A., Goldman, R.E., Block, S.D., et al., 2012. Information giving and receiving in hematological malignancy consultations. *Psycho-oncology* 21, 3, 297-306.

Aveyard, H., 2010. *Doing a literature review in health and social care: a practical guide*, Second ed. Open University Press, Maidenhead.

Booth, A., Fry-Smith, A., 2003. e-text on Health Technology Assessment (HTA) information resources. Chapter 2: Developing the research question. National Library of Medicine. Available from: <http://www.nlm.nih.gov/archive/20060905/nichsr/ehta/chapter2.html> (accessed 21.08.14).

Boynton, P., Greenhalgh, T., 2004. Selecting, designing and developing your questionnaire. *British Medical Journal [Online]* 328, 7451 1312-1315. Available from: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC420179/pdf/bmj32801312.pdf> (accessed 20.08.14).

CASP, 2013. Critical Appraisal Skills Programme Qualitative Checklist: 10 questions to help you make sense of qualitative research. Available from: http://media.wix.com/uqd/dded87_951541699e9edc71ce66c9bac4734c69.pdf (accessed 10.06.14).

Cassileth, B.R., Zupkis, R.V., Sutton-Smith, K., March, V., 1980, Information and participation preferences among cancer patients. *Annals of Internal Medicine* 92 832-836.

Cox, A., Jenkins, V., Catt, S., Langridge, C., Fallowfield, L., 2006. Information needs and experiences: An audit of UK cancer patients. *European Journal of Oncology Nursing* 10 263-272.

Curtis, J.R., Engelberg, R., Young, J.P., Vig, L.K., Reinke, L.F., Wenrich, M.D., et al., 2008. An approach to understanding the interaction of hope and desire for explicit prognostic information among individuals with severe chronic obstructive pulmonary disease or advanced cancer. *Journal of Palliative Medicine* 11 610-20.

Dixon-Woods, M., Bonas, S., Booth, A., Jones, D.R., Miller, T., Shaw, R.L., et al., 2006a. How can systematic reviews incorporate qualitative research? A critical perspective. *Qualitative Research* 6 27-44.

Dixon-Woods, M., Cavers, D., Agarwal, S., Annandale, E., Arthur, A., Harvey, J., et al. 2006b. Conducting a critical interpretive synthesis of the literature on access to healthcare by vulnerable groups. *BMC Medical Research Methodology* 6 35. Available from: http://download.springer.com/static/pdf/890/art%253A10.1186%252F1471-2288-6-35.pdf?auth66=1399555423_5962b3bf135335f0d33069863cea0591&ext=.pdf (accessed 06.05.14).

Dixon-Woods, M., Sutton, A., Sutton, R., Miller, T., Smith, J., Young, B., et al., 2007. Appraising qualitative research for inclusion in systematic reviews: a quantitative and qualitative comparison of three methods. *Journal of Health Services Research and Policy*, 12 42-47.

Engelhardt, G., Garvelink, M., de Haes, J.C.J.M., van der Hoeven, J.M., Smets, M.A., Pieterse, H., et al., 2014. Predicting and communicating the risk of recurrence and death in women with early-stage breast cancer: a systematic review of risk prediction models. *Journal of Clinical Oncology* 32 238-251.

Flemming, K., 2010. Synthesis of quantitative and qualitative research: an example using Critical Interpretive Synthesis. *Journal of Advanced Nursing* 66 201-217.

Franssen, S.J., Lagarde, S.M., van Werven, J.R., Smets, E.M., Tran, K.T., Plukker, J.T., et al., 2009. Psychological factors and preferences for communicating prognosis in esophageal cancer patients. *Psycho-oncology* 18 1199-207.

Friis, L.S., Elverdam, B., Schmidt, K.G., 2003. The patient's perspective: a qualitative study of acute myeloid leukaemia patients' need for information and their information-seeking behaviour. *Supportive Care in Cancer* 11 162-170.

Glenton, C., Colvin, C.J., Carlsen, B., Swartz, A., Lewin, S., Noyes, J., et al., 2013. Barriers and facilitators to the implementation of lay health worker programmes to improve access to maternal and child health: qualitative evidence synthesis (Review). *The Cochrane Database of Systematic Reviews* 10. Available from:

<http://onlinelibrary.wiley.com/doi/10.1002/14651858.CD010414.pub2/abstract> (accessed 27.07.14).

Goldman, R.E., Sullivan, A., Back, A.L., Alexander, S.C., Matsuyama, R.K., Lee, S.J., 2009. Patients' reflections on communication in the second-opinion hematology-oncology consultation. *Patient Education & Counseling* 76 44-50.

Grant, M.J., Booth, A., 2009. A typology of reviews: an analysis of 14 review types and associated methodologies. *Health Information & Libraries Journal* 26 91-108.

Hagerty, R.G., Butow, P.N., Ellis, P.A., Lobb, E.A., Pendlebury, S., Leighl, N., et al., 2004. Cancer patient preferences for communication of prognosis in the metastatic setting. *Journal of Clinical Oncology* 22 1721-30.

Hagerty, R.G., Butow, P.N., Ellis, P.M., Dimitry, S., Tattersall, M.H.N., 2005a. Communicating prognosis in cancer care: a systematic review of the literature. *Annals of Oncology* 16 1005-1053.

Hagerty, R.G., Butow, P.N., Ellis, P.M., Lobb, E.A., Pendlebury, S.C., Leighl, N., et al., 2005b. Communicating with realism and hope: incurable cancer patients' views on the disclosure of prognosis. *Journal of Clinical Oncology* 23 1278-88.

Jansen, J., Butow, P.N., van Weert, J.C., van Dulmen, S., Devine, R.J., Heeren, T.J., et al., 2008. Does age really matter? Recall of information presented to newly referred patients with cancer. *Journal of Clinical Oncology* 26 5450-7.

Jenkins, V., Fallowfield, L., Saul, J., 2001. Information needs of patients with cancer: results of a large study in UK cancer centres. *British Journal of Cancer* 84 48-51.

Kelly, M., Ajmera, M., Bhattacharjee, S., Vohra, R., Hobbs, G., Chaudhary, L., et al., 2013. Perception of cancer recurrence risk: More information is better. *Patient Education and Counseling* 90 361-366.

Lagarde, S.M., Franssen, S.J., van Werven, J.R., Smets, E.M., Tran, T.C., Tilanus, H.W., et al., 2008. Patient preferences for the disclosure of prognosis after esophagectomy for cancer with curative intent. *Annals of Surgical Oncology* 15 3289-98.

Leventhal, H., Kelly, K.M., Leventhal, E., 1999. Population risk, actual risk, perceived risk and cancer control: a discussion. *Journal of the National Cancer Institute Monographs* 25 81-85.

Leydon, G.M., 2008. 'Yours is potentially serious but most of these are cured': optimistic communication in UK outpatient oncology consultations. *Psycho-oncology* 17 1081-8.

Liu, P., Landrum, M.B., Weeks, C., Huskamp, A., Kahn, L., He, Y., et al., 2014. Physicians' Propensity To Discuss Prognosis Is Associated with Patients' Awareness of Prognosis for Metastatic Cancers. *Journal of Palliative Medicine* 17 673-683.

Lobb, E.A., Halkett, G.K, Nowak, A.K., 2011. Patient and caregiver perceptions of communication of prognosis in high grade glioma. *Journal of Neuro-Oncology* 104 315-22.

Mays, N., Pope, C., Popay, J., 2005. Systematically reviewing qualitative and quantitative evidence to inform management and policy-making in the health field. *Journal of Health Services Research and Policy* 10 SUPPL. 1 6-20.

Mendick, N., Young, B., Holcombe, C., Salmon, P., 2011. Telling "everything" but not "too much": the surgeon's dilemma in consultations about breast cancer. *World Journal of Surgery* 35 2187-95.

Mendick, N., Young, B., Holcombe, C., Salmon, P., 2013. The 'information spectrum': A qualitative study of how breast cancer surgeons give information and of how their patients experience it. *Psycho-oncology* 22 2364-2371.

Mitchison, D., Butow, P., Sze, M., Aldridge, L., Hui, R., Vardy, J., et al., 2012. Prognostic communication preferences of migrant patients and their relatives. *Psycho-oncology* 21 496-504.

Noblit, G.W., Hare, R.D., 1988. *Meta-ethnography: synthesizing qualitative studies*. SAGE, Newbury Park, California.

O'Brien, M.A., Whelan, T.J., Villasis-Keever, M., Gafni, A., Charles, C., Roberts, R., et al., 2009. Are cancer-related decision aids effective? A systematic review and meta-analysis. *Journal of Clinical Oncology* 27 974-85.

Pope, C., Mays, N., Popay, J., 2007. *Synthesizing qualitative and quantitative health evidence. A guide to methods*. Open University Press, Maidenhead.

Quirt, C.F., Mackillop, W.J., Ginsburg, A.D., Sheldon, L., Brundage, M., Dixon, P., et al., 1997. Do doctors know when their patients don't?: A survey of doctor–patient communication in lung cancer. *Lung Cancer* 18 1-20.

Rabin, B.A., Gaglio, B., Sanders, T., Nekhlyudov, L., Dearing, J.W., Bull, S., et al., 2013. Predicting cancer prognosis using interactive online tools: A systematic review and implications for cancer care providers. *Cancer Epidemiology Biomarkers and Prevention* 22 1645-1656.

Robinson, T.M., Alexander, S.C., Hays, M., Jeffreys, A.S., Olsen, M.K., Rodriguez, K.L., et al., 2008. Patient-oncologist communication in advanced cancer: predictors of patient perception of prognosis. *Supportive Care in Cancer* 16 1049-57.

Rodriguez, K.L., Gambino, F.J., Butow, P.N., Hagerty, R.G., Arnold, R.M., 2008. 'It's going to shorten your life': framing of oncologist-patient communication about prognosis. *Psycho-oncology* 17 219-25.

Sell, L., Devlin, B., Bourke, S.J., Munro, N.C., Corris, P.A., Gibson, G.J., 1993. Communicating the diagnosis of lung cancer. *Respiratory Medicine* 87 61-63.

Simard, S., Thewes, B., Humphris, G., Dixon, M., Hayden, C., Mireskandari, S., et al., 2013. Fear of cancer recurrence in adult cancer survivors: A systematic review of quantitative studies. *Journal of Cancer Survivorship* 7 300-322.

Step, M.M., Ray, E.B., 2011. Patient perceptions of oncologist-patient communication about prognosis: changes from initial diagnosis to cancer recurrence. *Health Communication* 26, 48-58.

The, A.M., Hak, T., Koëter, G., van der Wal, G., 2000. Collusion in doctor-patient communication about imminent death: an ethnographic study. *British Medical Journal* 321, 7273, 1376-81.

Thorne, S., Hislop, T.G., Kuo, M., Armstrong, E.A., 2006. Hope and probability: patient perspectives of the meaning of numerical information in cancer communication. *Qualitative Health Research* 16 318-36.

Thorne, S., Oglov, V., Armstrong, E.A., Hislop, T.G., 2007. Prognosticating futures and the human experience of hope. *Palliative & Supportive Care* 5 227-39.

Tong, A., Flemming, K., McInnes, E., Oliver, S., Craig, J., 2012. Enhancing transparency in reporting the synthesis of qualitative research: ENTREQ. *BMC Medical Research Methodology* 12 181. Available from: <http://www.biomedcentral.com/1471-2288/12/181> (accessed 10.12.14).

Tong, A., Sainsbury, P., Craig, J., 2007. Consolidation criteria for reporting qualitative research (COREQ); a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care* 19 349-357.

Toye, F., Seers, K., Allcock, N., Briggs, M., Carr, E., Andrews, J., et al., 2013. 'Trying to pin down jelly' - Exploring intuitive processes in quality assessment for meta-ethnography. *BMC Medical Research Methodology* 13 1. Available from: <http://www.biomedcentral.com/1471-2288/13/121> (accessed 04.04.14).

Wagner, J.Y., Wuensch, A., Friess, H., Berberat, P.O., 2014. Surgeon-patient communication in oncology. *European Journal of Cancer Care* 23 585-594.

Weeks, J.C., Cook, E.F., O'Day, S., 1994. Relationship between cancer patients' predictions of prognosis and their treatment preferences. *Journal of the American Medical Association* 279 1709-1714.

| INCLUSION: | EXCLUSION: |
|---|---|
| <ul style="list-style-type: none"> • 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 | <ul style="list-style-type: none"> • Non-English language articles • Predominantly patients at “end of life”. • Predominantly non-cancer, or patients with borderline malignant conditions, (myelodysplastic syndrome, carcinoma <i>in situ</i>, 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 |

Box 1: Inclusion exclusion criteria

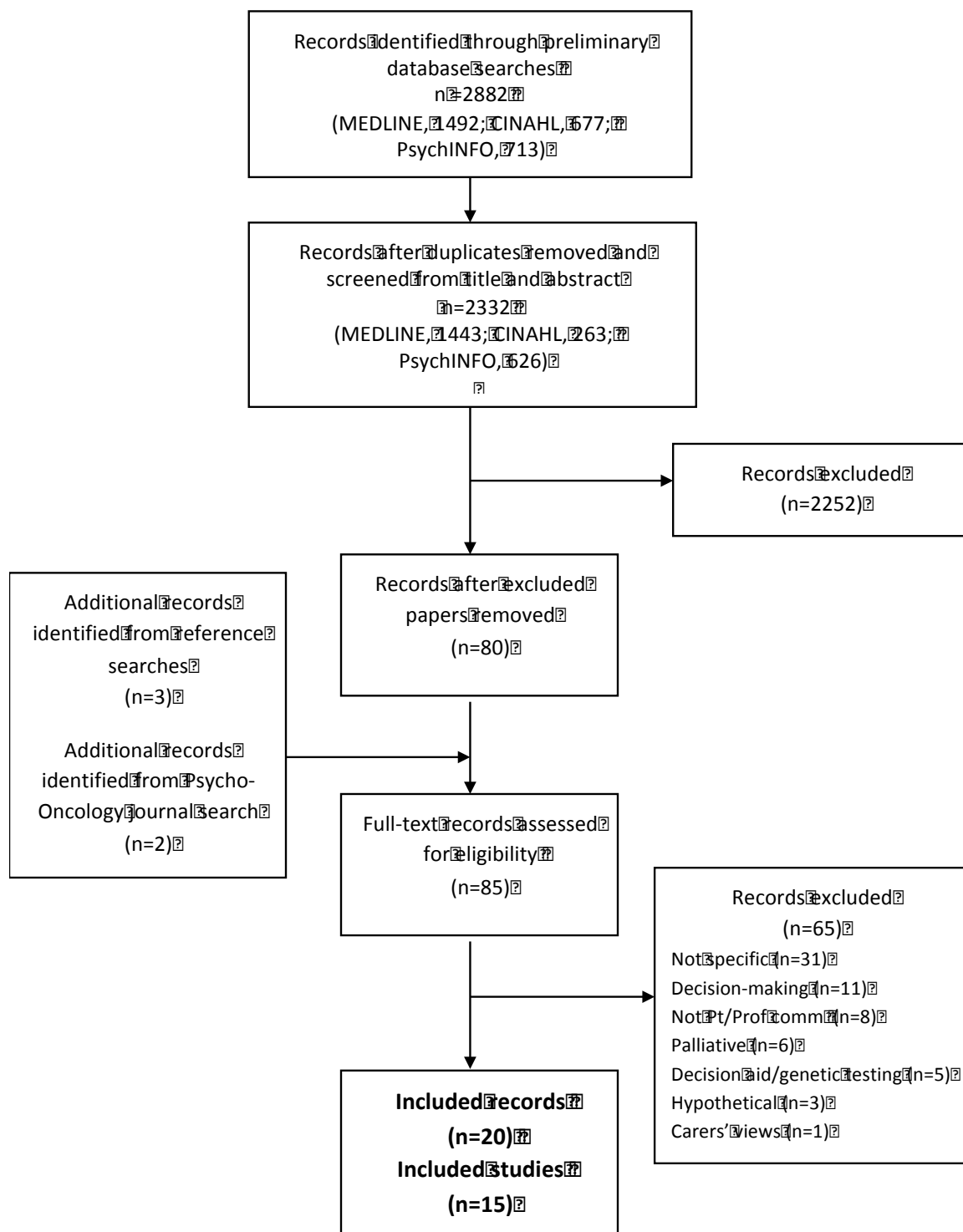
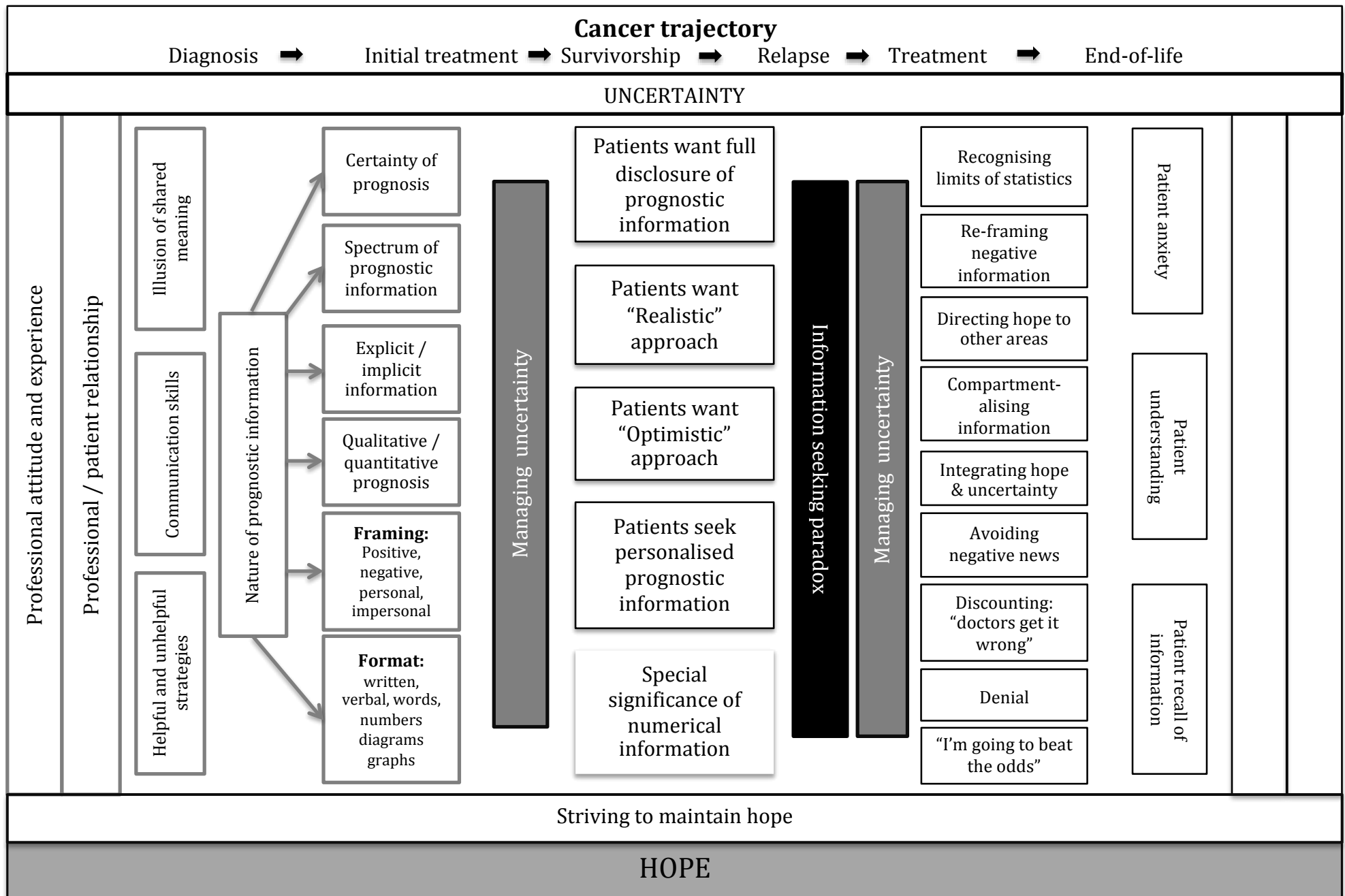


Figure 2: Conceptual model for prognosis disclosure from evidence synthesis



| Authors (year) Country | Study aims | Design and methods | Sample population | Measures and analysis | Results |
|------------------------------------|---|--|---|--|--|
| Curative treatment patients | | | | | |
| Mendick et al. (2011) UK | Examine how surgeons manage information-giving to patients with breast cancer, and how their approach converges with what breast cancer patients want. | Qualitative Grounded Theory approach using audio recording of consultation and semi-structured interviews. | n=20. Purposeful sampling post-operative breast cancer patients and 9 surgeons within surgical breast cancer clinic (2 declined). Age 39 - 86 years (mean 60) with a range of prognostic characteristics. | Patient and surgeon interviews analysed individually and in "pairs" using a constant comparative approach within a Grounded Theory framework | Surgeons talked about needing to give patients "honest" information and not to "hide" or "withhold", but there was a potential for giving "too much" information. Patients described the need to be told "everything", but also warned of the possibility of "too much" information. Surgeons wanted patients to leave the consultation with a sense of "hope". Patients emphasised the need for "positive thinking" |
| Mendick et al. (2013) UK | Delineate the types of information that surgeons provide to breast cancer patients and understand the functions of this information in the tension between "hope" and "information" | As for Mendick et al. (2011) | As for Mendick et al. (2011) | Constant comparative approach within a Grounded Theory framework to analyse data within and across cases. | Surgeons gave factually explicit biomedical information at every consultation, but were less explicit in expressing judgements about implications. Surgeons gave no statistical estimates of prognosis, but presented comparisons. Evaluative comments tended to always be positive. Information given on a spectrum of explicitness. Patients did not report wanting more information than they received. Giving explicit factual information on medical findings plays a small part in the information a patient receives from their surgeon, with significant information being received in less explicit ways. |
| Kelly et al. (2013) USA | Explore: 1) perceptions of medical communication regarding recurrence risk, 2) patient perception of recurrence risk, 3) accuracy of recurrence risk estimates in patients | Mixed methods cross-sectional study. Patients completed quantitative questionnaires, plus open-ended questions regarding thoughts and feelings about recurrence. | n=113. (RR 80%) Women with breast cancer in university oncology clinic. Within 1 year, or between 2 - 5 years of diagnosis. Mean age 58.6 (SD = 10.6) years. | Profile of Mood States (POMS), modified breast cancer recurrence specific POMS, Cancer Worry Scale (CWS), 8 item perceived lifetime risk of recurrence. Individual risk of breast cancer recurrence calculated. Comparison made between calculation and patient estimate. Modified Grounded Theory used for open question responses. | Most patients expressed wish to know their recurrence risk. Almost 40% of participants felt that their health team had not discussed their risk of recurrence with them. Women were largely inaccurate in their estimate of recurrence risk, both over and under estimating the risk. Adjuvant! Online calculated risk did not correlate with the patient estimates. Patients living in rural areas, more worried, or 2 - 5 years out from diagnosis, were more likely to over estimate their risk. Affective data on recurrence came from the open questions. Women expressed more positive affective outlook (25.3%) against negative affect (5.1%). |

| | | | | | |
|---|--|--|--|--|---|
| Franssen, et al. (2009) The Netherlands | Explore how patient preferences for disclosure of prognosis relates to psychological characteristics of patients | Cross sectional postal questionnaire sent to patients between 1 and 24 months following potentially curative surgery. | n=176. (RR 86%) Post potentially curative surgery for oesophageal cancer. Average age 63 (range 30 - 80). 82% male. | As for Lagarde et al. (2008) plus involvement preferences (Information subscale of Krantz Health Opinion Survey), fear of recurrence, anxiety and depression (HADS), striving scale (Quality-Quantity Questionnaire), trust in doctors (modified Wake-Forest Physician Scale). | 66% patients wanted maximum prognostic information. This group of patients had greater fear of recurrence and wanted to be more actively involved during their consultations. Patients with worse quality of life tended to report more fear of recurrence. Preferences for prognostic information not related to anxiety, depression, physician trust, or striving scores in this study. |
| Lagarde et al. (2008) The Netherlands | Determine preference and predictors for content, style and format of prognostic information following oesophageal surgery for cancer | As for Franssen et al. (2009) | As for Franssen et al. (2009) | Modified survey developed by Hagerty et al. (2005). EORTC QoL 30 and OES18. Hypothetical scenario to determine type of graphical data preferred by patients. | 93% patients wanted to know their average prognosis. Information preferences declined when information became more specific and more short-term. 71% wanting to know chance of recurrence within 6 months. 63% wanted specialist to initiate discussion of survival. 22% wanted the doctor to ask if the patient wanted to know first. 5% wanted to lead the disclosure or did not want the information at all. 59% wanted to have an optimistic approach. Words and numbers were preferred over visual presentations |
| Mixed curative and palliative treatment patients | | | | | |
| Leydon (2008) UK | Explore how experienced oncologists and their patients organise talk about cancer and the uncertain treatment-related outcomes of radiotherapy and chemotherapy. | Qualitative analysis of transcribed audio recordings of first oncology consultations. | n=28. Patients (6 female, 22 male) with breast, head & neck, or gastrointestinal cancer at 3 cancer centres. Most referred following initial cancer surgery. Participants aged 40 to 80 years. | Jefferson's orthography used in transcription. Analysis guided by "unmotivated looking", using Roter's Interaction Analysis System (RIAS) and Conversation Analysis (CA) | Following uncertain or bad news with relatively better news was one method used to give honest information without reducing hope and future optimism. This "proximate pairing" of information was used repeatedly across consultations at all three centres. Proximate pairing can help doctors to deliver information with both honesty and hope. However, this technique may result in patients unrealistically disregarding uncertain or bad news and could result in patients having unrealistic treatment expectations. |
| Jansen et al. (2008) Australia | Examine age and age-related differences in recall of information provided during oncology consultations. | Cross sectional quantitative study. Clinic consultation audio recorded with follow-up structured phone interview within 10 days. | n=260. (RR 74%) Consecutive heterogeneous cancer patients approached during initial oncology consultation. Patient age 18 to 83 years. 53% of patients having curative treatment. | Spielberger State Anxiety Scale. Information Styles Questionnaire (needs and preferences). Recall of information measured using structured telephone interview. Analysis conducted by dividing the sample into <65 years and >= 65. | No age difference found for information needs or preferences. Patients wanted all available information about their illness. Recall of all facts 49.5% in under 65s and 48.4% in the over 65s. Worse prognosis, more information presented and longer consultations were predictive of less %age recall. Increasing age had negative correlation with recall, but effect was masked by variation in older patients' consultations and amount of information given. The more prognostic information presented, the less patients recalled. |

| | | | | | |
|-----------------------------|---|--|---|--|--|
| Robinson et al. (2008) USA | Identify communication factors that may influence concordance about chance of cure between oncologists and patients | Cross sectional quantitative questionnaire study and analysis of consultations. Part of larger study looking at educational strategies to improve oncologist communication skills. | n=187. Oncologist / patient pairs. Patients diagnosed with heterogeneous cancers where oncologist "would not be surprised if patient died or admitted to ITU in next year". No estimate of RR in this element of study. 23% of patients considered "curative". Age range 33 - 86 years, 47% male. | Patient and oncologist independently estimated chance of cure on 11-point scale of 0% to 91%-100%. Concordance graded as "good" (n=69) and "poor" (n=72). "Intermediate" concordance group excluded (n=39). Consultations coded for optimistic and pessimistic or uncertain prognostic elements. Multivariate analysis undertaken. | Where oncologists made at least one pessimistic statement about chance of cure, patients were more likely to be concordant with the oncologist about chance of cure compared to where no pessimistic statements were given (OR=2.92, 95% CI = 1.35-6.32). Patient education, age, gender and diagnosis were not independently associated with concordance. Statements of optimism, pessimism about the past or present and expressions of uncertainty did not have an effect on concordance. Oncologists only expressed pessimism in 46% of encounters and expressed optimism twice as often as pessimism. |
| Alexander et al. (2011) USA | 1) Describe and quantify the content of second-opinion haemato-oncology consultations regarding information exchange. 2) Identify patient and provider characteristics associated with discussion elements. | Cross sectional study. Audio recording of physician - patient consultations in clinic with quantitative analysis | n=236. "Second opinion" haemato-oncology patients attending tertiary care clinic. Average age 55 (range 20 - 79). | Communication evaluation tool developed for study. Conversations coded. Prognostic discussions reported as unambiguous quantitative through to qualitative only | Prognosis discussed qualitatively and quantitatively, framing in terms of mortality, chance of cure or both. Most contained at least one quantitative estimate of cure or mortality without "hedging". Physicians discussed purpose of consultation and patient's prior knowledge. Discussions of preferred decision-making role less common. Discussion of information preference was uncommon. |
| Goldman et al. (2008) USA | Elucidate patient experience of communication in second opinion consultations in haemato-oncology conditions. | Cross sectional semi-structured in-depth interviews and transcribed clinic visit. Telephone interviews at 2 - 4 wks. Sections of transcribed consultation text used to ask further questions of the subject. | n=20. Patients seeking second opinion for haemato-oncology conditions at one of three major university teaching hospitals. Subset of the patients recruited to Alexander et al 2011 | Anthropological methodology using collaborative group analysis with mersion and crystallisation | Patients want expert, honest advice delivered with empathy. Amount and style of information wanted is individual. Doctors should apply expertise to specifics of individual case. Most patients wanted to contribute to agenda, but felt unable to do so. Most patients supported bringing list of prepared questions to help ensure agenda met. Demonstrating respect and care led to positive feelings, regardless of outcome. Patients wanted information to help maintain hope. Where the prognosis was not good, patients need to recognise this, but not hear too much about it. |

Palliative treatment patients

| | | | | | |
|---|---|--|---|--|---|
| Lobb, Halkett & Nowak (2010) Australia | Elicit patient and carer perceptions of the initial communication of the diagnosis and its prognosis in high grade glioma | Retrospective cross sectional design. Semi structured interviews with patients (and carers, if designated by the patient). Interviews audio recorded and transcribed verbatim | n=19. Patients diagnosed with Grade III or IV High Grade Glioma referred to a tertiary neuro-oncology clinic within first year of diagnosis. Care givers interviewed (n=21). 11 patients approached but did not take part. Age range 31 - 74 | Data analysed using the principles of Grounded Theory and the constant comparative method. Open axial and selective coding employed. | Five overarching themes emerged: shock at hearing diagnosis; understanding and processing prognostic information when in shock; perception of hope taken away; individualizing prognostic information; clinicians' lack of communication skills. Findings highlighted the inability of people to process detailed prognostic information when in a state of initial shock and distress or at the time immediate post-operative period. Some patients did not recall all the details of their diagnosis or prognosis and chose not to seek further information. |
| Step & Ray (2011) USA | 1. What are patients' recollections of oncologists' communication about prognosis when first diagnosed? 2. What are patients' recollections of oncologists' communication about prognosis when told of cancer recurrence? | In-depth semi-structured interview study with cross sectional design. | n=30. Female cancer patients (23 breast, 4 lung, 1 colon, 1 gynae, 1 head & neck) within 3 months of diagnosis of recurrence of stage I - III cancer. RR 68%. No male patients recruited. Age range 42 - 84 years (mean 63 yrs). Average disease free time 7.3 years. | Interviews transcribed verbatim and coded using Atlas-ti software. Research coder identified all prognosis related quotes. Authors undertook iterative analysis to identify similar and contrasting themes. | Patients described oncologists communicating optimism during the initial diagnosis. This changed at diagnosis of recurrence to one of chronic disease management. Three subthemes identified at recurrence: <i>managing the new information</i> and coming to terms with the new situation; <i>ambiguous communication</i> about the prognosis, especially relating to changing meanings in shifting contexts with an illusion of shared meaning; <i>information seeking paradox</i> medical and patient attempts to manage hope v access to detailed explicit truth. Authors propose Problematic Integration as a useful model for understanding the dynamics of uncertainty in prognosis communication. |
| Curtis et al. (2008) USA | Examine interactions between patients' and family members' desire for hope to be supported, and the need to receive explicit prognostic information. Explore clinicians' need to provide prognostic information and the desire to foster hope | Longitudinal qualitative study. Open-ended interview questions with patients, physicians, nurses and family members. | Cascade recruitment of 31 physicians (RR 37%), 55 patients (RR 82%), 36 family members (RR 86%) and 25 nurses (RR 100%). 24 patients COPD, 30 metastatic cancer or inoperable lung cancer. | Open-ended interview questions. Participants responded to 4 diagrams of conceptual models for integration of hope and desire for prognostic information. Follow-up interview at 4 - 6 months. Subset at 12 months. Data analysed with grounded theory. | Patients and family members initially wanted "all" prognostic information. During interviews substantial minority expressed reservations about explicit prognostic information. Patients and families described changes in attitude to prognostic information and hope. Participants endorsed the models proposed. |
| Hagerty et al. (2004) Australia | Determine preferences of metastatic cancer patients for content and format of prognostic information and explore predictors of these preferences. | Cross sectional survey 6 weeks to 6 months after a diagnosis of metastatic cancer. Surveys completed at home or in clinic setting across 12 oncology units in New South Wales. | n=126. (RR 58%). Newly diagnosed metastatic cancer patients; 54% male, 25% breast, 18% colorectal, 15% prostate, 10% lung. Patients identified by 30 oncologists (RR 28%). Mean patient age 63 years (range 34 - 82). 92% receiving active treatment. | Krantz Health Opinion survey, HADS, prognostic information desired (15 item yes/no response with open answer). Preferred presentation of survival information (vignette and sample presentations). When and who to initiate discussion of treatment goals, symptoms and side effects, life | Strong preference for prognostic information, strongest with longer time frames (ie 5 year survival figures), reducing with shorter time frames. Words and numbers were preferred over diagrams and charts. Patients wanted to discuss prognosis at the time of diagnosis and wanted the doctor to "just tell them". 59% wanted to know how long they would live when first diagnosed. 11% never wanted to discuss palliative or end of life issues. |

| | | | | | |
|-----------------------------------|--|--|---|--|---|
| | | | | expectancy and dying and palliative care. | |
| Hagerty et al. (2005b) Australia | Identify the context and way in which patients with incurable metastatic cancer wanted to be informed about their prognosis and to explore the features of this communication that patients would experience as more or less hopeful. | As for Hagerty et al. (2004) | As for Hagerty et al. (2004) | "Doctor style" (35 informational and supportive behaviours with 5-point Likert scale), Patient Definition of Hope (four suggested definitions of hope, plus open question of own definition). "What Patients Find Hopeful" (30 doctor behaviours that might convey or discourage hope, rated for hopefulness). | Patients wanted their doctor to be realistic, provide opportunity to ask questions and acknowledge the individual when discussing prognosis. Offering up-to-date treatments and being knowledgeable were seen as the most hope giving behaviours. Patients were split equally (feeling positive, negative or neutral) with regard to the hopefulness of expressing uncertainty and giving survival statistics. Patient definition of hope was wide ranging. Common themes related to quality of life and fulfilment of goals. Patients diagnosed for a longer time and those with longer expected survival were more likely to want a realistic approach. |
| Mitchison et al. (2011) Australia | Elicit migrant cancer patients' personal experiences of communication during consultations and their preferences for prognostic communication | Cross sectional retrospective qualitative interview study | n=73. Newly diagnosed metastatic cancer (lung 33%, breast 26%) from 4 biggest cultural groups in Australia (31 Anglo-Australians, and 20 Chinese, 11 Arabic, 11 Greek migrant patients) and 66 family members. Patients 64% female and 67% over 60 years. | Demographic data and 8-item Rissel Acculturation Scale (Cronbach α = 0.88 for Arabic population) collected. Structured interview in patient's preferred language. Thematic and comparative analysis approach used to code and elicit themes. Development of thematic tree. | Migrant patients often wanted to be informed of their prognosis. Some Anglo-Australian patients did not want their prognosis discussed, or wanted to leave discussion until they were more unwell. Some patients and families wanted the doctor to ask before disclosing this information. Others wanted the doctor to make a judgement. Migrant families sometimes wanted to withhold prognosis when the patient wanted to know. |
| Liu et al. (2014) USA | Test whether patients with metastatic cancer at diagnosis who have a physician who reports generally discussing prognosis earlier have a more accurate awareness of prognosis than those with a physician who delays a prognosis discussion. | Cross sectional quantitative study. Patient or carer interviews 3 - 6 months after diagnosis. Questionnaire sent to patient-nominated significant doctor regarding attitude to prognosis disclosure. Part of larger CanCORS study. | n=686. (RR 64% - eligible patients who had completed survey and identified a doctor). Stage IV lung or colorectal cancer. Average age 63 years. 49% women, 57% lung cancer, 88% had received chemotherapy at the time of the interview. | Open-ended question to elicit patient estimation of prognosis. Accurate prognosis deemed <2years (lung), <5 years (colorectal). Physicians asked to identify when they would discuss prognosis with patient with estimated prognosis of 4-6 months. Analysis of co-variables. | 70% of physicians would discuss prognosis at earliest opportunity. 19% of lung patients and 14% of colorectal patients were deemed to have an "accurate" estimation of prognosis. 36% of patients stated "do not know" prognosis and 11% stated, "it was in God's hands". Patients whose "most important doctor" would discuss prognosis early were more likely to have an accurate estimate of prognosis (OR 3.23, 95%CI 1.39 - 7.52) |

| | | | | | |
|---|---|--|---|---|---|
| Rodriguez et al. (2008) Australia | How oncologists, patients with incurable cancer and their kin use framing when they discuss treatment-related and disease-related prognosis during clinic visits. | Cross sectional qualitative analysis of oncology consultations. Part of larger project looking at the effect of prompt sheets in oncology consultations on patient questioning. | n=29. Incurable cancer patients (no diagnoses given). Randomly selected transcripts from larger study of 319 new cancer patients. 51% male, age range 38 - 83 years. 23 out of 29 had a relative present. | Initial consultation digitally recorded, transcribed and analysed. Constant comparative analysis (grounded theory) to develop and apply codes and analyse data. | 23 out of 29 visits contained discussion of prognosis. 166 episodes of prognostic discussion occurred; the majority were by oncologists (128). Patients made 29 prognostic utterances. 62% of prognostic talk was about the current patient or "patients like you". Oncologists talked about treatment related prognosis 72% of the time and patients 55%. 48% of utterances were framed positively and 31% negatively. During discussion of treatment outcomes, oncologists tended to address patients in personalised language and positive terms. Discussions of death or other negative outcomes tended to be framed in impersonal language. |
| Patients recruited outside treatment setting | | | | | |
| Thorne et al. (2006) Canada | Examine the impact on patients with cancer of information provided in numerical form. | In-depth qualitative interviews with additional written patient accounts and focus groups. Cross sectional design (within an overall longitudinal study) | n=200. Heterogeneous cancer patients (50% breast cancer). Purposeful sampling to achieve a range of cancer sites and disease stages as well as demographic differences. | Study used an interpretive description approach. Interviews and focus groups were transcribed and all material analysed. No details of interview schedule presented, but investigators stated that the researcher did not initiate any specific questions regarding numerical data. | Almost all patients expressed a preference for being well informed about their illness. Patients used numerical information in a variety of ways and in some cases struggled to make sense of the information. Some patients used a narrative to reframe the numerical information in a way that was seen as more positive, or used it within treatment decision-making. Many patients found they received different numerical estimates from different sources. Most patients recognised the difference between population data and individual data. Some patients discounted negative odds as a means of coping. |
| Thorne et al. (2007) Canada | How patients with cancer or chronic illness describe the balance between hope and honesty in their communication with health care professionals, particularly in the context of information exchange associated with prognostication. | Secondary analysis of two previous qualitative studies. In-depth interviews conducted with patients was the primary source of data in both studies, conducted by the same research team. | As for Thorne et a. 2006, plus 30 patients with chronic illness (diabetes, fibromyalgia and multiple sclerosis) | Interpretive description used to analyse content using detailed coding of interview content. | <u>Helpful and unhelpful communications</u> ; Various factors were cited as helpful, but timely, compassionate and appropriate were key features. Unhelpful communication often had a mismatch between patients' perceived need and the manner and content the professional disclosed. <u>Impact of prognostic communications on hope</u> ; Hope was perceived as essential. Where prognostic information supported hope this was seen as positive. Where it did not, patients required significant reframing to attempt to rebuild their fragile hope. <u>Patient recommendations for supportive prognostic communications</u> ; an overarching theme of balancing "hope" and "honesty" through individualising information, guiding interpretation and facilitating uncertainty management. |

Abbreviations: n= sample size, RR response rate, CI confidence interval, OR odds ratio, HADS hospital anxiety and depression scale, QoL quality of life

Table 1: Summary of study aims, methods and findings

| Thematic grouping | Theme | Codes |
|--|---|--|
| Diagnostic and prognostic factors | The nature of prognostic information | Scope of prognostic information Spectrum of prognostic information Qualitative and quantitative prognoses Framing of information Format of information |
| | Disease factors | Temporal / cancer trajectory Disease uncertainty |
| Patient factors | Patient desire for prognostic information | Patient need for full prognostic disclosure Patient desire for a realistic approach Patient desire for optimistic approach Patient need for personalised information Significance of numerical information for patients |
| | Patient need to maintain a sense of hope | Patients strive to maintain a sense of hope Patient avoidance of negative news Patient re-framing of negative news "Beating the odds" Statistics do not reflect individuals "Doctors get it wrong" |
| | Patient need to balance hope with prognostic information | Avoiding "too much" information Information seeking paradox Ways patients balance hope and prognostic information Effect of professional communication on hope |
| | Individual patient factors | Patients are individuals Patient anxiety Patient understanding of prognostic information Patient recall of prognostic information Denial Cultural effects |
| Clinician factors | Clinician-patient relationship Communication skills | Willingness to discuss prognostic information Desire to give hope preserving information Helpful and unhelpful communication strategies Clinician experience Communication guidelines in relation to prognostic disclosure |
| | Shared understanding | Illusion of shared meaning Prognostic concordance |

Table 2: Summary of thematic analysis of included papers