

# **Understanding the information needs of people with haematological cancers. A meta-ethnography of quantitative and qualitative research.**

**K. ATHERTON, BSc, MSc, DCLINPSYC, HONORARY RESEARCH ASSOCIATE,** *Department of Psychological Sciences, Institute of Psychology, Health and Society, Whelan Building, The Quadrangle, Brownlow Hill, Liverpool, L69 3GB* , **B. YOUNG, BA, PHD, C.PSYCHOL, PROFESSOR OF PSYCHOLOGY** , *Department of Psychological Sciences, Institute of Psychology, Health and Society, Whelan Building, The Quadrangle, Brownlow Hill, Liverpool, L69 3GB* and **P. SALMON, BA, MSc, DPHIL, PROFESSOR OF CLINICAL PSYCHOLOGY**, *Institute of Psychology, Health and Society, Department of Psychological Sciences, Whelan Building, The Quadrangle, Brownlow Hill, Liverpool, L69 3GB.*

## **Correspondence to:**

Dr. Kirsten Atherton, The Acorn Centre, Vale of Leven District General Hospital, Alexandria, G83 0UA. Telephone: 01389 817324. [kirsten.atherton@ggc.scot.nhs.uk](mailto:kirsten.atherton@ggc.scot.nhs.uk)

## Acknowledgements

We are grateful to Shirley Yearwood-Jackman, Liverpool University Librarian, for help with designing the literature search.

# **Understanding the information needs of people with haematological cancers. A meta-ethnography of quantitative and qualitative research**

## **Abstract:**

Clinical practice in haematological oncology often involves difficult diagnostic and treatment decisions. In this context understanding patients' information needs and the functions that information serves for them is particularly important. We systematically reviewed qualitative and quantitative evidence on haematological oncology patients' information needs to inform how these needs can best be addressed in clinical practice. PsycINFO, Medline and CINAHL Plus electronic databases were searched for relevant empirical papers published from January 2003 to July 2016. Synthesis of the findings drew on meta-ethnography and meta-study. Most quantitative studies used a survey design and indicated that patients are largely content with the information they receive from physicians, however much or little they actually receive, although a minority of patients are not content with information. Qualitative studies suggest that a sense of being in a caring relationship with a physician allows patients to feel content with the information they have been given, whereas patients who lack such a relationship want more information. The qualitative evidence can help explain the lack of association between the amount of information received and contentment with it in the quantitative research. Trusting relationships are integral to helping patients feel that their information needs have been met.

**Keywords:**

Haematological oncology, information needs, review, meta-ethnography.

## **INTRODUCTION**

Patients with cancer want information about their disease and treatment, and being informed can bring a range of benefits, helping them to understand what is happening and to feel confident about their care (Salander, 1996; McWilliam et al, 2000; Jefford and Tattersall, 2002; Thomsen et al, 2007).

There is also a long-standing view that patients need information so they can make treatment decisions (Elwyn et al, 2010). Giving information is therefore an important clinical responsibility (Epstein and Street, 2007), and academic literature and health policy often criticise cancer clinicians for inadequately informing their patients (National Institute of Clinical Excellence, 2004; Downie and Randall, 2005; Owen and Jeffrey, 2008; Fallowfield, 2009). However, clinicians' task is complex because patients and their families also want clinicians to help them keep hopeful, even where this means constraining information (Salander, 1996; Kutner, 1999; Innes, 2009; Mendick et al, 2011; Salmon et al 2012). Clinicians are often advised to deal with this complexity by giving patients the information they want, but this is unrealistic because patients cannot know in advance what information exists (Downie and Randall, 2005). Practical and realistic guidance for clinicians is more likely to arise from better understanding the purposes for which patients seek information (Mendick et al, 2011).

The present study focuses on information needs in haematological oncology patients. Haematological cancers are the fifth most common type of cancer in the UK, accounting for 7% of all oncology cases (National Institute for Clinical Excellence, 2003). Treatment entails particularly intense psychological challenges for patients (Rodin et al, 2013). Some haematological cancers have the ability to transform into more serious conditions, adding to the uncertainty patients face. Reflecting the wide variety in severity and presentation of these conditions, treatment possibilities are diverse, and range from 'watchful waiting', entailing regular assessment without active treatment, to high dose chemotherapy treatments, or even surgery or stem cell transplantation (National Institute for Clinical Excellence, 2003). Some of these treatments, in particular chemotherapy and transplantation, can be very unpleasant, and require patients' commitment and adherence in the face of these demands

(Savage, 2013). The course of disease and treatment is often unpredictable, because treatments sometimes have to be initiated or changed urgently in response to a changing clinical picture (Eichhorst et al, 2015). Clinical practice therefore requires practitioners to convey complex results of clinical assessments, particularly changes in blood markers, or imaging of affected organs (Eichenauer et al, 2014), as the basis for difficult diagnostic and treatment decisions. In this context, understanding patients' information needs is particularly important.

More than a decade ago, Rutten et al. (2005) reviewed information needs across a range of cancer patients, finding that patients mostly wanted information about treatment. Husson et al. (2011) reviewed the relationship between information provision and quality of life across cancer survivors, reporting that those who feel better informed had better quality of life and mood. Since then, two reviews have focused specifically on haematological cancer. Rood et al. (2014) reviewed literature on the 'perceived need' for information, reporting that patients mostly looked to doctors for information and were generally satisfied with the information they were given. Swash et al. (2014) reviewed literature on unmet psychosocial needs, reporting that the most commonly described needs concerned managing fear of recurrence, although patients also indicated need for information on disease and treatment. It is hard to find practical lessons for practitioners in the findings of these reviews because none addressed the functions of the information that patients needed. Without knowing what information-giving achieves for patients, it is hard for clinician to gauge what information to give (Mendick et al, 2011). We therefore systematically reviewed the available literature on information needs of patients and survivors with haematological cancers, seeking evidence, not just about what information patients wanted, but what they wanted it for. The ultimate aim is to inform how practitioners can address information needs in clinical practice.

Quantitative research in this area can provide potentially generalisable information, but has the important limitation that patients can only indicate their views about needs that the researchers had specifically asked about. By contrast, inductive, qualitative studies can, in principle, identify needs that go beyond the researchers' existing preconceptions, although the generalisability of findings

cannot be assumed. Therefore a review methodology was needed that could accommodate both quantitative and qualitative evidence. We drew on ‘meta-study’ (Paterson et al, 2001) and meta-ethnography (Noblit and Hare 1988). These approaches recognise that research findings are shaped by researchers’ methods and theoretical orientation. For example, a researcher who asks patients ‘how much’ information they have received on a specific topic assumes that the main parameter of information is quantity and that patients can meaningfully estimate this. Meta-study and meta-ethnography can encompass studies with divergent methods within a single review, thereby compensating for the respective limitations of quantitative and qualitative methods. They entail reviewing findings in the context of the methodological approach that produced them and of the authors’ theoretical orientation (Noblit and Hare, 1988; Peterson et al, 2001; Campbell et al, 2011); they go beyond a synthesis of findings to reflect on the research practices of the field and any failures to progress (Zhao, 1991; Britten et al, 2002; Frost et al, 2016).

## **METHODS**

### **Eligibility criteria**

Primary empirical papers exploring the information needs and preferences of haematological cancer patients were included. Papers were limited to those with a human adult sample and included only peer-reviewed published papers in English. Following identification of a review of relevant primary literature from 1970-2003 by Rutten et al. (2005), the search was limited to papers published from January 2003 to June 2016. Papers studying only children or non-patient samples, such as carers or physicians, were excluded.

### **Search resources and terms**

Databases that encompassed several disciplines were chosen to ensure an exhaustive search: psychology (PsycInfo); medicine and healthcare (Medline); and nursing (Cinahl). Searches were conducted in April 2013 and updated in July 2016. We used scoping searches, in collaboration with a librarian, to identify terms that would be sufficiently sensitive and specific to identify literature

relevant to our research question. Information needs and preferences are so closely linked to decision-making in the literature that we included ‘decision-making’ as a search term. Bibliographies from recent systematic reviews in related areas were also searched (Husson et al, 2011; Rood et al, 2014; Swash et al, 2014). Results of searches were combined and duplicates removed before screening. We also hand searched reference lists of all included papers and searched on-line for additional papers by identified authors.

Using the electronic databases, the search included all available fields including title, abstract, keywords and medical subject headings (MeSH terms). The search strategy included one or more key terms from each of two sets: (“haematological oncology” OR “hematological oncology” OR “blood cancer” OR “leukemia” OR “leukaemia” OR “lymphoma”) and (“information needs” OR “information preference\*” OR “decision making”). Limiters ensured that papers were written in English, referred to a human adult sample and were published between January 2003 and June 2016.

## **Selection**

Using initially titles and, where necessary, abstracts, papers returned by the search were screened for potentially eligible papers reporting empirical data on the information needs of patients and survivors with a diagnosis of haematological cancer. Subsequently, full text of potentially relevant papers was read, and an assessment of eligibility was made. Papers reporting on issues unrelated to information needs or on non-malignant haematological conditions were excluded, as were papers with samples wholly comprising non-haematological or paediatric patients, health practitioners or caregivers. Papers reporting on samples across a range of cancer types were excluded if more than half the sample had a non-haematological cancer, unless authors reported separate analyses of haematological patients. Eligibility decisions were made by one author and reviewed by two others; equivocal or ambiguous cases were discussed until consensus was reached. Figure 1 shows the Preferred Reporting Items for Systematic reviews and Meta-Analysis ([PRISMA] Moher et al, 2009) flow chart for selection of papers.

### **Formal quality assessment**

Qualitative papers were assessed using the Critical Appraisal Skills Programme (CASP) ‘Qualitative Research Checklist’ (CASP, 2013). Quantitative papers were assessed using the ‘Quality Assessment Tool for Quantitative Studies’ (National Collaborating Centre for Methods and Tools, 2008). Both tools are recommended by the Cochrane Collaboration (Higgins and Green, 2011). Papers were not excluded on the grounds of quality; rather, ratings informed a “signal to noise” approach (Edwards, 2000). This allowed methodological weaknesses to be considered alongside the relevance of findings in the overall synthesis.

### **Analysis procedure**

A meta-study approach (Paterson et al, 2001) provided the overall framework, whereby three parallel analyses of the conceptual background, methodology and findings were integrated into a single synthesis. In reviewing findings, we drew on meta-ethnography, whereby we took an interpretive approach, comparing findings and interpretations between studies and creating new interpretations in the process (Noblit and Hare, 1988). Data were extracted by KA and checked by another author. Data extracted for each paper included details of the study design, sample, aims, analysis and results, and any indication of the authors’ professional or conceptual background. We analysed quantitative papers and qualitative papers separately, then combined these analyses for the meta-synthesis (Paterson et al, 2001).

## **RESULTS**

### **Summary of included papers**

Table 1 summarises the 20 papers included in the review. Papers were predominantly from North America (n=10 papers: Nissim et al, 2013, 2014; Hammond et al, 2008; Arora et al, 2009; Yogaparan et al, 2009; Friedman et al, 2010; Gansler et al, 2010; Alexander et al, 2012; Keegan et al, 2012; Poe

et al, 2012) and Europe (n=9 papers: Friis et al, 2003; Randall and Wearn, 2005; Gravis et al, 2011; Evans et al, 2012; Oerlemans et al, 2012; Ernst et al, 2013; Husson et al, 2013; Rood et al, 2015a & b). The remaining paper was from Australia (Lobb et al, 2009). Thirteen papers were quantitative; six were qualitative; one (Gansler et al, 2010) reported mixed methods. Qualitative papers all reported on separate samples. Amongst the quantitative papers, two reports by Rood et al. (2015a & b) appeared to use the same sample although the authors did not state this. Reflecting the review's eligibility criteria, all papers included patients or survivors as participants. However, three included additional categories of participants: health practitioners, caregiving relatives and non-caregiving relatives. While all qualitative papers included only haematological cancer patients, four of the 13 papers with quantitative data included participants with other cancers. Similarly, whilst all qualitative papers studied exclusively adult samples, one quantitative paper included adolescent patients (Keegan et al, 2012).

Quantitative sample sizes ranged from 31 to 3080 and qualitative samples ranged from 11 to 54. Collectively the quantitative studies included 6575 participants (counting the sample reported by Rood et al. [2015a & b] only once) and the qualitative studies included 191 participants.

### **Summary of formal quality assessment**

As illustrated in Table 1, most quantitative papers were rated as only 'moderate' on the quality assessment tool (n=8 papers: Arora et al, 2009; Yogaparan et al, 2009; Gravis et al, 2011; Oerlemans et al, 2012; Poe et al, 2012; Husson et al, 2013; Rood et al, 2015a & b) with the remainder rated as 'weak' (n= 6 papers: Hammond et al, 2008; Lobb et al, 2009; Friedman et al, 2010; Gansler et al, 2010; Alexander et al, 2012; Keegan et al, 2012). These low scores reflected the use primarily of cross-sectional survey designs rather than randomised controlled trials. By contrast, most qualitative papers scored nine or ten out of ten on the quality checklist (n=6 papers: Friis et al, 2003; Nissim et al, 2013, 2014; Randal and Wearn, 2005; Evans et al, 2012; Ernst et al, 2013) with the remaining paper scoring eight (Gansler et al, 2010).

## Review of methods

The main methodological contrast was the use of quantitative vs qualitative methods. Amongst the quantitative studies, one randomised controlled trial examined the effect of giving patients full access to their medical records on their anxiety, quality of life and satisfaction (Gravis et al, 2011) and one observational study coded consultation dialogue to examine exchange of information between physicians and patients (Alexander et al, 2012). The remaining 12 papers with quantitative data reported cross-sectional surveys. Some of these examined patients' need for information, including asking patients to endorse areas of need then, in some studies, rate whether or not that need had been met (Lobb et al, 2009; Yogaparan et al, 2009; Gansler et al, 2010; Friedman et al, 2010; Keegan et al, 2012; Rood et al, 2015a). Others measured patients' ratings of amount of information received about specific topics, including disease, treatment and services (Hammond et al, 2008; Yogaparan et al, 2009; Oerlemans et al, 2012; Husson et al, 2013), sources of information (Yogaparan et al, 2009; Oerlemans et al, 2012) and satisfaction with information (Oerlemans et al, 2012; Husson et al, 2013; Rood et al, 2015a). A few papers linked information variables to putative outcomes such as anxiety and depression (Poe et al, 2012) and illness perceptions (Husson et al, 2013). Two papers reported on variables relevant to information-giving in the context of studies on decision-making (Arora et al, 2009; Poe et al, 2012).

Analysis of the one RCT was guided by the hypothesis that access to medical records would reduce anxiety (Gravis et al, 2011). One structural equation modelling analysis was guided by theory about mediating variables (Arora et al, 2009). One survey paper stated 12 hypotheses linking general information-seeking style to several outcomes (Rood et al, 2015b). In general, however, statistical analyses were descriptive or *post hoc*, unguided by hypotheses. Nevertheless, inferential statistics were widely used, with findings reaching  $p < .05$  reported as significant, even where these were isolated findings from multiple analyses. In interpreting the results of the RCT the authors claimed that the intervention did not increase anxiety, but their analysis tested for reduction in anxiety and did

not use a non-inferiority design that could substantiate such a claim (Gravis et al, 2011). The authors also stated that satisfaction with information improved, while acknowledging that the result did not reach significance (Gravis et al, 2011). Across the quantitative papers there was no attention to error rate. Neither was there any attention to common method variance; for instance, Oerlemans et al. (2012) reported that patients who were more satisfied with the information they received reported having received more information, but the authors did not consider whether these variables were distinct in patients' thinking.

The seven qualitative studies all used semi-structured interviews. Five studies interviewed participants once; two studies interviewed them around diagnosis, then at different stages of treatment (Friis et al, 2003; Nissim et al, 2013). Three studies focused on patients' information needs (Friis et al, 2003; Nissim et al, 2013; Gansler et al, 2010) and others addressed information needs in the context of decision making (Ernst et al, 2013), distress (Nissim et al, 2013) or experiences of specific aspects of the care process including watchful waiting (Evans et al, 2012), receiving bad news (Randall and Wearn, 2005) and the transition from inpatient to ambulatory care (Nissim et al, 2014). All these papers claimed an inductive approach to analysis, reporting analysis techniques including domain analysis, constant comparison, grounded theory and thematic content analysis.

### **Review of conceptual background**

Authors were from a range of clinical research backgrounds including medicine, medical psychology, epidemiology and health policy. One qualitative paper cited social anthropology as a background (Friis et al, 2003).

Amongst the quantitative papers, seven explicitly stated the conceptual background of the study. These included Epstein and Street's (2007) model of patient-centred communication in cancer care (Arora et al, 2009), Charles et al.'s (1999) 'shared decision-making' model (Gansler et al, 2010; Poe et al, 2012; Ernst et al, 2013) and 'survivorship', in which researchers were concerned with the long-term care needs of cancer survivors (Friedman et al, 2010; Oerlemans et al, 2012). Gansler et al.

(2010) described a practical context to their study: a programme to produce information materials to ‘empower’ patients’ healthcare choices’ and ‘facilitate coping’. Where authors did not explicitly state the paper’s conceptual background we interpreted this from the research questions that they chose. Most frequently the framing of questions suggested that researchers took a positive view of the value of information for patients. For example, papers investigated the effects of giving patients ‘more information’, and exploring patients’ ‘unmet’ information needs.

Two qualitative papers also approached the subject from the perspective of shared decision making (Ernst et al, 2013; Gansler et al, 2010, see above). The others described wanting to illuminate patients’ perspective, in response to lacunae or contradictions in the literature (Friis et al, 2003; Randall and Wearn, 2005; Evans et al, 2012; Nissim et al, 2013, 2014).

## **Review of findings**

### *Quantitative studies*

Patients generally rated information as important, particularly information about clinical management (Lobb et al, 2009; Friedman et al, 2010; Gansler et al, 2010 ; Rood et al, 2015a). One study reported that 81.6% of patients wanted ‘all the available information’ (Rood et al, 2015a). However, where studies asked about a broader range of priorities, information proved not the most important. For instance, needing information that was ‘up to date’ and given ‘in a way I can understand’ were endorsed as needs by most patients in Lobb et al.’s (2009) study, but even more wanted to feel that they had the ‘best care’ and that ‘all my doctors talk to each other to coordinate my care’ and to have help to manage fears of recurrence. When patients were asked specifically about unmet information needs, these generally emerged with even lower priority. In Lobb et al.’s (2009) study, information needs did not appear in the top ten needs endorsed as unmet; that is, unmet information needs were less of a priority for patients than having help with fear of cancer recurrence, having a case manager, and hospital parking being more accessible (Lobb et al, 2009). Nevertheless, some studies did point to unmet information needs. Keegan et al. (2012) reported that 85% of young adult survivors had one or

more unmet 'information needs', most commonly around managing concerns about recurrence and around treatments. Hammond et al. (2008) found that a minority of patients wanted more information about fertility and sexual function. Patients who were younger (under 55 years), unmarried, male, employed, with more education, members of a patient association, with comorbidity and poorer quality of life, with general information-seeking or information-avoiding coping styles, and from a non-white ethnic backgrounds were reported as being more likely to report information needs of different kinds (Lobb et al, 2009; Keegan et al, 2012; Oerlemans et al, 2012; Rood et al, 2015 a & b).

Unsurprisingly, although patients reported obtaining information about their illness from family members, other patients, written materials and the Internet, clinical staff were the most important sources (Yogaparan et al, 2009; Poe et al, 2012; Rood et al, 2015a). Most haematological patients were satisfied with the information they had received, even more so than patients with non-haematological cancers (Oerlemans et al, 2012). Those with best quality of life were most satisfied (Rood et al, 2015a). In one study, most patients felt they had enough information about diagnosis and treatment, and had enough time talking with the doctor, despite half reporting that they did not know their prognosis (Yogaparan et al, 2009). The observational study of consultations found that, while physicians gave extensive information about treatment and prognosis, when meeting a patient for the first time physicians rarely asked patients about their information needs or checked whether patients had understood the information provided (Alexander et al, 2012). As part of a complex statistical model linking physicians' decision-making style with survivors' mental health, Arora et al. (2009) found an association between trusting the physician and feeling less uncertain about the illness.

In the RCT, 98% of patients offered full access to their medical records accepted this, but the prediction that anxiety would be reduced was not confirmed (Gravis et al, 2011). In multivariate analyses that included patients with solid tumours, patients who reported having received more information scored higher on measures of control over, and understanding of, their illness (Husson et al, 2013). However, those who reported having received more information about non-clinical care services had more negative attitudes to the illness, which the authors attributed to confounding by

seriousness of their disease (Husson et al, 2013).

### *Qualitative studies*

Despite many patients feeling that they ‘ought’ to seek medical information (Friis et al, 2003), patients generally preferred to avoid information about the disease, and focus on information about day-to-day treatment to preserve hope, particularly during treatment of acute conditions (Friis et al, 2003; Ernst et al, 2013; Nissim et al, 2013, 2014; Randall and Wearn, 2005). This was not ‘denial’, in that patients did think about prognosis, despite not wanting information about it (Friis et al, 2003; Nissim et al, 2013, 2014). The need for hope might explain why patients wanted information about trials and recent advances in treatment (Gansler et al, 2010). Interviewed around diagnosis, patients anticipated that they would want and request more information about their disease later but, when re-interviewed after 2-5 months, they had not done so (Friis et al, 2003). Many patients reported receiving more information than they wanted, and recalled little of the information they had been given, particularly at diagnosis when they felt too shocked to take it in (Friis et al, 2003; Nissim et al, 2013, 2014). Having information that maintained hope was important in receiving bad news specifically (Randall and Wearn, 2005; Evans et al, 2012), and feeling informed about plans for the future was important where patients knew that treatment options were limited (Friis et al, 2003). Similarly, patients progressing from inpatient to ambulatory care wanted to know details of the treatment plan (Nissim et al, 2014), and patients on ‘watchful waiting’ regimens wanted information about how the illness might develop (Evans et al, 2012). Patients contrasted their information needs with those of their relatives, who they thought sought more information from physicians than patients themselves wanted (Friis et al, 2003; Gansler et al, 2010).

Three papers reported specific areas of unmet need: information on adjustment to ambulatory care or life after treatment; management of side effects; and information on clinical trials and recent treatment advances (Gansler et al, 2010; Evans et al, 2012; Nissim et al, 2014). No paper identified a need for

information to inform decision-making, even the one that focused on decision-making (Ernst et al, 2013).

Although patients valued access to written information (Randall and Wearn, 2005) and talking with other patients (Gansler et al, 2010; Evans et al, 2012), the most important information source was the physician (Randall and Wearn, 2005; Nissim et al, 2014). Patients who were on ‘watchful waiting’ regimens could therefore feel confused and abandoned between specialist consultations (Evans et al, 2012) and patients receiving ambulatory care could feel ‘lost’ without regular contact with their clinical team (Nissim et al, 2014). Papers that explored the patient–physician relationship showed that patients’ information needs were intimately connected with their sense of relationship with clinicians. Patients felt overwhelmed by the complexity of the illness and shock of diagnosis and valued being able to trust physicians to take responsibility, including for what patients needed to know (Ernst et al, 2013; Nissim et al, 2013; Randall and Wearn, 2005). Patients therefore valued feeling that information that they did not need to know was withheld at times to protect them (Nissim et al, 2013). Reflecting the importance of clinical relationships, patients valued continuity, seeing the same physician regularly (Randall and Wearn, 2005). The sense of a strong relational bond allowed patients not to question or worry about their care (Nissim et al, 2013). Nevertheless, patients wanted physicians to be open and honest in answering their questions, and not to withhold information that they asked for (Randall and Wearn, 2005).

## **META SYNTHESIS AND DISCUSSION**

We reviewed papers without methodological restrictions, allowing studies with contrasting methodologies to be included. Quantitative and qualitative papers produced different findings reflecting, in part, their different methods and conceptual starting points.

### **The influence of authors’ methods and starting points on findings**

In general, quantitative findings did not address the function of information for the patient and were reported in ways that reflected authors’ assumptions that information-provision underpinned quality

care. Nevertheless, findings did not show that being given information was as important to patients as authors assumed. Despite physicians rarely asking patients what their information preferences were, or checking whether patients understood the information they had been given, and although patients said that they wanted ‘all available information’ about their illness (Rood et al, 2015a), patients generally reported being satisfied with the information they received. Similarly, patients could feel they had enough information, even while saying that they did not know their prognosis (Yogaparan et al, 2009), warning us that being content with information is not simply a function of being ‘fully informed’. Whereas patients generally rated information needs as very important, one study provided, in effect, a scale of importance by asking patients about other aspects of care. Having additional information proved less important than convenient hospital parking. Other care needs that were higher priorities than information provided clues that a sense of being cared for mattered more to patients than being given information; patients wanted to know that care was as good as possible and that doctors talked to each other to coordinate care, and to have a case manager to organise their care (Lobb et al, 2009). The qualitative evidence discussed below also suggests that the relational context of care is key to understanding patients’ attitudes to being given information.

The inductive approach of qualitative papers yielded more insights into functions of information and into why patients wanted it – or did not want it. These papers found no evidence that patients wanted information in order to make decisions. Instead, patients generally wanted to limit the information they received in order to preserve hope, a finding consistent with research in other cancer populations in which patients have described a need, not for greater quantities of information, but for having information carefully managed by clinicians so that it supports hope (Salander et al, 1996; Leydon et al, 2000; Sinding et al, 2010; Salmon et al, 2012; Mendick et al, 2013). The qualitative papers also emphasised the importance of the patient-physician relationship. Where patients felt they could trust their physician, they did not seek more information and felt content with the information that their physicians had given them; indeed, they relied on physicians to select what information needed to be given. The central importance of the clinical relationship is also consistent with qualitative research in other cancer populations, in which patients and their families describe gaining comfort from being

able to trust their physicians to tell them what they need to know (Salander et al, 1996; Salander, 2002; Mendick et al, 2011; Salmon et al, 2012). This process might explain the finding in the present review that patients who trusted the physician felt less uncertain about the illness (Arora et al, 2009).

There are clearly limitations to the questionnaire survey method used in most of the quantitative studies. The quality appraisal tool (National Collaborating Centre for Methods and Tools, 2008) ranked cross-sectional surveys as inherently weak within the methodological range of quantitative research. Therefore, with 12 of the 14 quantitative papers having used a questionnaire survey design, it was inevitable that most would score 'medium' or 'weak' for methodological quality.

Questionnaires quantify information without addressing potential ambiguities in meaning of the questions from patients' perspective. For instance, when patients tick the statement that they want 'all available information' about their illness (Rood et al, 2015a), they are probably endorsing a cultural norm around being informed, or indicating that they do not want important information kept from them (Mendick et al, 2011). Unfortunately, the logical implausibility of the statement, given that much more information is available about haematological cancers and their treatments than could ever be conveyed to patients in practice, did not prompt the authors to question what patients might have meant when they ticked the item.

Similarly, a probable source of unreliability in the quantitative findings is that survey questions may not resonate consistently with patients. For instance, when surveys ask whether patients are 'satisfied' with information on a topic, or 'want more' information, patients may not view these concepts as distinct from what they hope the information would show. This could explain why patients with poorer quality of life, whose illness is probably affecting them badly, report being less satisfied with information they had received (Rood et al, 2015a). Similarly, although quantitative papers routinely ask patients 'how much' information they have received or want (Oerlemans et al, 2012; Husson et al, 2013; Yogaparan et al, 2009) or whether they have 'enough' information (Keegan et al, 2012), none addressed how quantity of information could be measured except through patients' subjective experience. Nevertheless, they freely drew objective inferences about information needs

from patients' subjective feelings. Moreover, authors commonly attributed causal primacy to information variables, even in the context of inherently ambiguous cross-sectional correlational findings. For example, Husson et al. (2013) reported that information satisfaction 'predicted' positive views of illness but the opposite view is just as plausible theoretically and statistically.

The quantitative papers were compromised by a further weakness beyond those that the formal quality assessment exposed. Inferential statistics are normally used to make generalizable inferences guided by hypotheses. Nevertheless, hypotheses were rare in the papers we reviewed, and the error rate was ignored. Therefore, there is very little that can be generalized from any single study.

Compared to survey methods, the inductive approach of the qualitative studies was designed to allow patients to express their views in their own terms. While views differ regarding the legitimacy of using quality assessment checklists in qualitative research (Barbour, 2001), all the included qualitative papers scored highly on the CASP (2013) checklist, suggesting they were methodologically robust.

### **Implications of the findings**

The quantitative papers suggested that patients are largely content with the information they receive from physicians, however much or little they actually receive. The qualitative papers help to understand this by suggesting that a sense of being in a caring relationship with a physician that they trust allows patients to achieve this acceptance and contentment with information. These findings are supported by research in other types of cancer, which showed the close link between information needs and clinical relationships, such that patients' faith in their physician often precludes their need to seek detailed information (Leydon et al, 2000; Salander and Henriksson, 2005). Whilst clinicians in cancer care are usually experienced at building relationships and aware of the importance of doing so, our findings highlight how information needs are intimately linked to the relationship. From this perspective, 'unmet information needs' could be markers of difficulties in the relationship, not necessarily indicators of a problem that will be solved by additional information (Salander and Henriksson, 2005).

There are implications for future research too. Ethical practice requires patients to receive sufficient information to achieve informed consent and ensure transparent clinical care. It is therefore important to understand both ethical and relational aspects of information-giving in order to reconcile patients' need to be given information with their right to cope by putting their trust in their clinician. Further research could draw more on qualitative approaches to explore ways in which clinicians and patients can find this balance, and to understand how the clinical relationship shapes patients' attitudes to information.

Traditionally, systematic reviews select and critically appraise papers based on similar research designs. This review shows the value of reviewing papers using different methodologies to address a complex research question. Rather than allowing research to be constrained by adherence to one method, taking a mixed method approach allowed us to include all relevant literature, unconstrained by methodological boundaries. It has strengthened the review by enabling the limitations of studies using one method to be offset by the strengths of studies that used another (Madill and Gough, 2008; Durif-Bruckert et al, 2015). However, a challenge of conducting a mixed method synthesis is that a rigorous quality assessment technique has not yet been established (Pace et al, 2012). In this review specific appraisal tools validated for each methodology were used so that each paper was judged within its own methodological domain.

## **CONCLUSION**

This review suggests that a sense of a caring relationship with the physician is pivotal to helping patients with haematological cancers feel content that their information needs have been met. These findings are consistent with research in other cancer populations. There are practical applications of our findings. Where physicians are able to build a trusting relationship with patients, patients are likely to feel more confident that their information needs have been met. It follows that, where patients feel their information needs have not been met, the solution may lie in the quality of the clinical relationship rather than in the quantity or nature of the information given.

## References

- Alexander, S., Sullivan, A., Back, A., Tulskey, J., Goldman, R., Blocks, S., Stewart, S., Wilson-Genderson, M., and Lee, S. (2012) Information giving and receiving in haematological malignancy consultations. *Psycho-Oncology*, 21, 297-306.
- Arora, N., Weaver, K., Clayman, M., Oakley-Girvan, I., and Potosky, A. (2009) Physicians' decision-making style and psychosocial outcomes among cancer survivors. *Patient Education and Counseling*, 77, 404-412.
- Barbour, R. (2001) Checklists for improving rigour in qualitative research: a case of the tail wagging the dog? *British Medical Journal*, 322, 1115-1117.
- Britten, N., Campbell, R., Pope, C., Donovan, J., Morgan, M., and Pill, R. (2002) Using meta ethnography to synthesise qualitative research: A worked example. *Journal of Health Services Research and Policy*, 7, 209-215.
- Campbell, R., Pound, P., Morgan, M., Daker-White, G., Britten, N., Pill, T., et al. (2011). Evaluating meta-ethnography: systematic analysis and synthesis of qualitative research. *Health Technology Assessment*, 15, 43.
- Charles, C., Gafni, A., and Whelan, T. (1999) Decision-making in the physician-patient encounter: Revisiting the shared treatment- decision making model. *Social Science and Medicine*, 49, 651-661.
- Critical Appraisal Skills Programme. (2013) Critical Skills Appraisal Program: Qualitative Research Checklist. Retrieved from [www.casp-uk.net](http://www.casp-uk.net) on 31<sup>st</sup> August 2014.
- Downie, R. and Randall, F. (2005) Truth-telling and consent. In: Doyle, D., Hanks, G., and Cherny, N. (2005) *Oxford Textbook of Palliative Medicine*. 3<sup>rd</sup> ed. Oxford: Oxford University Press, 61-65.
- Durif-Bruckert, C., Roux, P., Morelle, M., Mignotte, H., Faure, C., and Moumjid-Ferdjaoui, N. (2015) Shared decision-making in medical encounters regarding breast cancer treatment: the contribution of methodological triangulation. *European Journal of Cancer Care*, 24, 461-472.
- Edwards, A., Elwyn, G., Hood, K., and Rollnick, S. (2000) Judging the 'weight of evidence' in systematic reviews: introducing rigour into the qualitative overview stage by assessing Signal and Noise. *Journal of Evaluation in Clinical Practice*, 6, 177-84.

Eichenauer, D., Engert, A., Andre, M., Federico, Illidge, T., Hutchings, M. and Ladetto, M. (2014) Hodgkin's lymphoma: ESMO Clinical Practice Guidelines for diagnosis, treatment and follow-up. *Annals of Oncology*, 25, 1170-1175.

Eichhorst, B., Robak, T., Montserrat, E., Ghia, P., Hillmen, P., Hallek, M., and Buske, C. (2015) Chronic Lymphocytic Leukemia: ESMO Clinical Practice Guidelines. *Annals of Oncology*, 26, 78-84.

Elwyn, G., Laitner, S., Coulter, A., Walker, E., Watson, P., and Thomson, R. (2010) Implementing shared decision making in the NHS. *British Medical Journal*, 14, 341.

Epstein, R. and Street, R. (2007) Patient-centred communication in cancer care: Promoting healing and reducing suffering. National Cancer Institute, US Department of Health and Human Services: Bethesda, MD.

Ernst, J., Berger, S., Weissflog, G., Schroder, C., Korner, A., Niederwiesser, D., Brahler, E., and Singer, S. (2013) Patient participation in the medical decision-making process in haemato-oncology – a qualitative study. *European Journal of Cancer Care*, 22, 684-690.

Evans, J., Ziebland, S., and Pettitt, A. (2012) Incurable, invisible and inconclusive: watchful waiting for chronic lymphocytic leukaemia and implications for doctor-patient communication. *European Journal of Cancer Care*, 21, 67-77.

Fallowfield, L. and Jenkins, V. (1999) Effective communication skills are the key to good cancer care. *European Journal of Cancer*, 35, 1592-1597.

Fallowfield, L. (2009) The challenge of interacting with patients in oncology. *European Journal of Cancer*, 45, 445-446.

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

Friedman, D., Coan, A., Smith, S., Herndon, J., and Abernethy, A. (2010) Information needs assessment of non-Hodgkin lymphoma survivors and their physicians. *American Journal of Hematology*, 85, 528-532.

Frost, J., Garside, R., Cooper, C., and Britten, N. (2016) Meta-Study as diagnostic: Toward content over form in Qualitative Synthesis. *Qualitative Health Research*, 26, 307-319.

- Gansler, T., Kepner, J., Willacy, E., Soloe, C., Rupert, D., Jarblum, M., Driscoll, D., Orr, A., Fitzgerald, T., and Esparza, A. (2010) Evolving information priorities of hematologic cancer survivors, caregivers, and other relatives. *Journal of Cancer Education*, 25, 302-311.
- Gravis, G., Protiere, C., Eisinger, F., Boher, J., Tarpin, C., Coso, D., Cappiello, M., Camerlo, J., Genre, D., &Viens, P. (2011) Full access to medical records does not modify anxiety in cancer patients. *Cancer*, 117, 4796-804.
- Hammond, C., Beckjord, E., Arora, N., Bellizzi, K., Jeffery, D., and Aziz, N. (2008) Non-Hodgkin's lymphoma survivors' fertility and sexual function related information needs. *Fertility and Sterility*, 90, 1256–1258.
- Higgins, J. and Green, S. (2011) *Cochrane Handbook for Systematic Reviews of Interventions*, Version 5.1.0, The Cochrane Collaboration.
- Husson, O., Mols, F., and van de Poll-Franse, L. (2011) The relation between information provision and health-related quality of life, anxiety and depression in cancer patients: a systematic review. *Annals of Oncology*, 22, 761-772.
- Husson, O., Thong, M., Mols, F., Oerlemans, S., Kaptein, A., and van de Poll-Franse, L. (2013) Illness perceptions in cancer survivors: what is the role of information provision? *Psycho-Oncology*, 22, 490-498.
- Innes, S. and Payne, S. (2009) Advanced cancer patients' prognostic information preferences: a review. *Palliative Medicine*, 23, 29-39.
- Jefford, M. and Tattersall, M. (2002) Informing and involving cancer patients in their own care. *Lancet Oncology*, 3, 629-637.
- Keegan, T., Lichtensztajn, D., Kato, I., Kent, E., Xiao-Cheng, W., West, M., Hamilton, A., Zebrack, B., Bellizzi, K., and Smith, A. (2012) Unmet adolescent and young adult cancer survivors information and service needs: a population-based cancer registry study. *Journal of Cancer Survivorship*, 6, 239-250.
- Kutner, J., Steiner, J. and Corbett, K. (1999) Information needs in terminal illness. *Social Science and Medicine*, 48, 1341-52.

- Leydon, G., Boulton, M., Moynihan, C., Jones, A., Mossman, J., Boudioni, M., and McPherson, K. (2000) Cancer patients' information needs and information seeking behaviour: in depth interview study. *British Medical Journal*, 320, 909–13.
- Lobb, E., Joske, D., Butow, P., Kristjanson, L., Cannell, P., Cull, G., and Augustson, B. (2009) When the safety net of treatment has been removed: Patients' unmet needs at the completion of treatment for haematological malignancies. *Patient Education and Counseling*, 77, 103-108.
- Madill, A. and Gough, B. (2008) Qualitative research and it's place in psychological science. *Psychological Methods*, 13, 254-271.
- McWilliam, C., Brown, J., and Stewart, M. (2000) Breast cancer patients' experiences of patient-doctor communication: a working relationship. *Patient Education and Counseling*, 39, 191-204.
- Mendick, N., Young, B., Holcombe, C., and Salmon, P. (2011) Telling “everything” but not “too much”: the surgeon's dilemma in consultations about breast cancer. *World Journal of Surgery*, 35, 2187-2195.
- Mendick, N., Young, B., Holcombe, C., and 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.
- Moher, D., Liberati, A., Tetzlaff, J. and Altman, D. (2009) Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. *Public Library of Science Medicine* 6, 6.
- National Collaborating Centre for Methods and Tools (2008) Quality Assessment Tool for Quantitative Studies. Hamilton, ON, McMaster University.
- National Institute for Clinical Excellence (2003) Guidance on Cancer Services- Improving Outcomes in Haematological Cancers - The Manual. Retrieved from [www.nice.org.uk](http://www.nice.org.uk) on April 10<sup>th</sup> 2015.
- National Institute of Clinical Excellence 2004 Supportive and palliative care: Improving supportive and palliative care for adults with cancer. NICE Guideline CSG4. Retrieved from [www.nice.org.uk](http://www.nice.org.uk) on April 10<sup>th</sup> 2015.
- Nissim, R., Zimmermann, C., Minden, M., Rydall, A., Yuen, D., Mischitelle, A., Gagliese, L., Schimmer, A., and Rodin, G. (2013) Abducted by the illness: A qualitative study of traumatic stress in individuals with acute leukemia. *Leukemia Research*, 37, 496-502.

Nissim, R., Rodin, G., Schimmer, A., Minden, M., Rydall, A., Yuen, D., Mischitelle, A., Fitzgerald, P., Lo, C., Gagliese, L., and Zimmerman, C. (2014) Finding new bearings: a qualitative study on the transition from inpatient to ambulatory care of patients with acute myeloid leukemia. *Supportive Care in Cancer*, 22, 2435-2443.

Noblit, G. and Hare, R. (1988) *Meta-ethnography: synthesizing qualitative studies*. Newbury Park, California: Sage.

Oerlemans, S., Husson, O., Mols, F., Poortmans, P., Daniels, L., Creutzberg, C. and van de Poll-Franse, L. (2012) Perceived information provision and satisfaction among lymphoma and multiple myeloma survivors-results from a Dutch population-based study. *Annals of Hematology*, 91, 1587-1595.

Owen, R. and Jeffrey, D. (2008) Communication: Common challenging scenarios in cancer care. *European Journal of Cancer*, 44, 1163-1168.

Pace, R., Pluye, P., Bartlett, G., Macaulay, A., Salsberg, J., Jagosh J. and Seller, R. (2012) Testing the reliability and efficiency of the pilot Mixed Methods Appraisal Tool (MMAT) for systematic mixed studies review. *International Journal of Nursing Studies*, 49, 47–53.

Paterson, B., Thorne, S., Canam, C., and Jillings, C. (2001) *Meta-study of qualitative health research: A practical guide to meta-analysis and meta-synthesis*. Thousand Oaks, CA, Sage.

Poe., K., Hayslip, J., and Studts, J. (2012) Decision Making and Distress Among Individuals Diagnosed with Follicular Lymphoma. *Journal of Psychosocial Oncology*, 30, 426-445.

Randall, T. and Wearn, A. (2005) Receiving bad news: patients with haematological cancer reflect upon their experience. *Palliative Medicine*, 19, 594-601.

Rood, J., Eeltink, C., van Zuuren, F., Verdonck-de Leeuw, I., and Huijgens, P. (2014) Perceived need for information of patients with haematological malignancies: a literature review. *Journal of Clinical Nursing*, 24, 353-369.

Rood, J., van Zuuren, F., Stam, F., van der Ploeg, T., Eeltink, C., Verdonck-de Leeuw, I., and Huijgens, P. (2015a) Perceived need for information among patients with a haematological malignancy: associations with information satisfaction and treatment decision-making preferences. *Haematological Oncology*, 33, 85-98.

- Rood, J., van Zuuren, F., Stam, F., van der Ploeg, T., Huijgens, P., and Verdonck-de Leeuw, I. (2015b) Cognitive coping style (monitoring and blunting) and the need for information, information satisfaction and shared decision making among patients with haematological malignancies. *Psycho-Oncology*, 24, 564-571.
- Rutten, L., Arora, N., Bakos, A., Aziz, N., and Rowland, J. (2005) Information needs and sources of information among cancer patients: a systematic review of research (1980-2003). *Patient Education and Counseling*, 57, 25-261.
- Salander, P., Bergenheim, T., and Henriksson, R. (1996) The creation of protection and hope in patients with malignant brain tumours. *Social Science and Medicine*, 42, 985-996.
- Salander, P. (2002) Bad news from a patient's perspective: an analysis of written narratives of newly diagnosed cancer patients. *Social Science and Medicine*, 55, 721-32.
- Salander, P. and Hendriksson, R. (2005) Severely diseased lung cancer patients narrate the importance of being included in a helping relationship. *Lung Cancer*, 50, 155-162.
- Salmon, P., Hill, J., Ward, J., Gravenhorst, K., Eden, T., and Young, B. (2012). Faith and protection: The construction of hope by parents of children with leukemia and their oncologists. *Oncologist*, 17, 398-404.
- Savage, M. (2013) Communicating with haematology patients: a reflective account. *Nursing Standard*, 28, 37-43.
- Sinding, C., Hudak, P., Wiernikowski, J., Aronson, J., Miller, P., Gould, J., and Fitzpatrick-Lewis, D. (2010) "I'd like to be an informed person but..." Negotiating responsibility for treatment decisions in cancer care. *Social Science and Medicine*, 71, 1094-1101.
- Swash, B., Hulbert-Williams, N., and Bramwell, R. (2014) Unmet psychosocial needs in haematological cancer: a systematic review. *Supportive Care in Cancer*, 22, 1131-41.
- Thomsen, D., Pedersen, A., and Johansen, M. (2007) Breast cancer patients' narratives about positive and negative communication experiences. *Acta Oncologica*, 46, 900-908.
- Yogaparan, T., Panju, A., Minden, M., Brandwein, J., Mohamedali, H., and Alibhai, S. (2009) Information needs of adult patients 50 or older with newly diagnosed acute myeloid leukemia. *Leukemia Research*, 33, 1288-1290.

Zhao, S. (1991). Meta-theory, meta-method, meta-data analysis: What, why and how? *Sociological Perspectives*, 34, 377-390.