

**How do haematology patients make sense of clinical
information? A qualitative study.**

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July 2015

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Submitted in partial fulfillment of the Doctorate in Clinical Psychology, University
of Liverpool

Acknowledgements

My thanks go to my participants who have let me into their world openly, honestly, and selflessly; each wishing to use their experience to help those who will unfortunately, but inevitably, follow in their footsteps. Thanks to Dr. Kalakonda and the team for making me so welcome and giving me a trusting insight into the demanding, yet excellent, work they do.

To Peter and Bridget, thank you for taking your experienced professor expertise, and coupling it with enough patience and mentoring to sink a ship (or float a trainee)! It has been a privilege to work with you both; I have learnt such a lot.

To the wonderful Athertons, each an inspiration to me in many ways, I couldn't have done this without you. Thank you.

I could write five hundred words, and I could talk five hundred more...but you know who you are, and just how much I am thanking you for.

For Dr. Emma Howie, who showed such interest in, and support for, this project before cancer became all too relevant for her life. On her journey Emma did not have enough time to do many things she wanted to. Somewhere towards the bottom of that list may have included hearing these findings. Nevertheless, she would have shown interest to the last, as she did in supporting my development. Her clinical supervision was precious, valued and will not be forgotten.

Table of Contents

Contents	Page numbers
Introductory Chapter: Thesis overview	5
Chapter One: Review	7
Abstract	8
Introduction	9
Methods	10
Results	13
Discussion	20
References	25
Chapter Two: Empirical Paper	41
Abstract	42
Introduction	43
Methods	44
Results	48
Discussion	60
References	65
List of Figures	
Chapter One: Figure 1	12
List of Tables	
Chapter One: Table 1	32
Chapter Two: Table 1	69
Chapter Two: Table 2	73
Chapter Two: Table 3	73

Appendices

75 - 112

Word count: 22,966

Introductory Chapter: Thesis Overview

Over the last few decades there has been a shift in healthcare policy from a paternalistic system in which patients were regarded as recipients of medical services, to the current position in which patients are expected and encouraged to be actively involved in health care decisions. Within the context of cancer care this can leave the patient trying to negotiate a variety of complex medical information. Even where patients have not been involved in treatment decisions, they are expected to give informed consent to their treatment; therefore having some awareness of clinical information is crucial (Gaston & Mitchell, 2005). In addition to ethical considerations, allowing patients to be involved in treatment decisions has been demonstrated to have many beneficial outcomes for their physical and mental health (Rutten, Arora, Bakos, Aziz & Rowland, 2005).

Haematological cancers are a complex group of disease which can be unpredictable and difficult to manage (National Institute of Health and Care Excellence, 2003). In this context it is very important to understand how patients need and use information. This thesis explores this question in two ways: reviewing and synthesising current research into haematology patients' information needs and conducting a qualitative study exploring how patients make sense of complex clinical information in routine consultations. The thesis therefore asks questions of the existing evidence base and allows haematology patients themselves to contribute from their experience.

The thesis is prepared as manuscripts for the *European Journal of Cancer Care* as this journal is geared for multidisciplinary professionals working in cancer care across Europe and is distributed internationally. The journal supports a psychosocial perspective within cancer care and seeks studies which involve contributions from service-users. Instructions for authors are included as an appendix.

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What are the information needs of people with haematological cancers?

A synthesis of quantitative and qualitative research.

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Word count: 4,581

(excluding figures, tables and references)

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Abstract:

This study aimed to systematically review qualitative and quantitative evidence on haematological oncology patients' information needs, with the intention of informing how these needs are addressed in clinical practice. PsychINFO, Medline and Cinhal Plus electronic databases were searched for relevant empirical papers published between 2003 and 2015. The 21 included studies were assessed for quality using validated qualitative and quantitative tools. Following this the analysis and synthesis of findings drew on a meta-ethnographic approach. Most quantitative studies used a survey design and varied widely in their estimates of patients' preferences for information and preferred role in decision-making. Qualitative studies' interview data appeared to illuminate this disparity by indicating that having a sense of a caring relationship with the physician allows patients to achieve acceptance and contentment with information. Thus, patients who had a sense of a caring relationship found it easier to have less information and to let their physician make clinical decisions than patients who did not. There are practical applications for these findings: if physicians are able to build a trusting relationship with patients, patients should be more able to feel their information needs are met and to experience subsequent positive coping and quality of life outcomes.

Keywords:

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

Introduction:

Rationale

Although research into patients' information needs is increasing, a lack of clarity about the information needs of haematological oncology patients remains. Rutten et al. (2005) reported a range of benefits for cancer patients of being provided information: reduced anxiety and depression; increased patient satisfaction with treatment choices; increased coping throughout the cancer journey; and improved communication with family members. There is also a long-standing view in cancer care that patients need information so they can make treatment decisions (Elwyn et al., 2010). A wealth of medical information has become freely accessible since the development of the Internet (Hardey, 1999), but little is known about what information cancer patients value and how they use it (O'Leary et al., 2007).

Haematological cancers account for 7% of oncology cases in the UK. The National Institute for Clinical Excellence (NICE) describes haematological oncology as unique in the way that the component diseases often vary in severity and presentation (NICE, 2003). Reflecting the variety of conditions, treatment possibilities in the field are diverse. These treatments are generally demanding and unpleasant and require patients' commitment and adherence in the face of these demands (Kaplan et al., 1996). Therefore clinical practice in haematological malignancy involves making difficult diagnostic and treatment decisions. Understanding patients' information needs and preferred role in decision-making is particularly important in this setting. This paper will systematically review the available literature regarding patients' preferences for information and decision-making. The aim will be to increase understanding of haematological oncology patients' information needs, with the intention of informing how these needs are addressed in clinical practice.

After scoping the available literature it was apparent that, while a mix of qualitative and quantitative evidence was available, most papers had adopted a quantitative approach. However, this approach is inevitably limited because patients can only indicate their views about needs that the researchers had thought to ask about. By contrast, inductive, qualitative studies are, in principle, able to identify needs that go beyond the researchers' existing preconceptions. Therefore a review methodology was needed that could accommodate both quantitative and qualitative evidence. A meta-ethnographic methodology can do this. It does so by considering, synthesising and summarising the methodological approach and findings of papers and the authors' theoretical orientation. Meta-ethnography therefore enables an understanding, not just of the findings but of the influences upon findings. This review methodology has been used previously to review and synthesise findings from papers in clinical health psychology research (Paterson et al., 2001).

Methods:

Eligibility criteria

Primary empirical papers exploring the information needs or decision making of haematological cancer patients were included. Papers were limited to those with a human adult sample and, for quality control, only peer-reviewed published papers were included. Following the identification of a comprehensive review of relevant primary literature from 1970-2003 published by Rutten et al. (2005), the search was limited to papers published from 2003 to 2015.

Papers were excluded if they were reviewing existing literature, if they were commentary pieces, or if they were not published in English. Papers using only non-patient samples, such as carers or physicians, were also excluded.

Search resources

After several scoping searches, databases that encompassed several disciplines were chosen to ensure the search was exhaustive: Psychology (PsycInfo); Medicine and Healthcare (Medline); and Nursing (Cinahl). The initial searches were conducted in Spring 2013; the search was updated in April 2015. References from previous systematic reviews were also reviewed (Husson et al., 2011; Rood et al., 2014; Rutten et al., 2005; Swash et al., 2014). Searches were combined and duplicates removed before paper selection. Reference lists of all articles included in the review were searched for any additional relevant articles that had not been identified within the original search.

Search

Using the electronic databases, the search was structured to include all available fields including title, abstract, keywords and medical subject headings (MeSH terms). The search identified papers that included one or more of the 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 “decision making”). Limits were placed on the search to ensure that papers were written in English, referred to a human adult sample and were published between 2003 and 2015.

Selection

Using initially titles and, where necessary, abstracts, the papers returned by the search were screened for eligibility based on the above criteria. Subsequently, full texts of potentially relevant papers were read, and an assessment of their eligibility was made. Papers relating to other medical conditions, other clinical issues, or comprising wholly paediatric samples were

excluded. Eligibility decisions were made by one author and reviewed by two others; equivocal or ambiguous cases were discussed until a consensus was reached.

Figure 1 illustrates the process of selection using the Preferred Reporting Items for Systematic reviews and Meta Analysis ([PRISMA] Moher et al., 2009) flow chart in Figure 1.

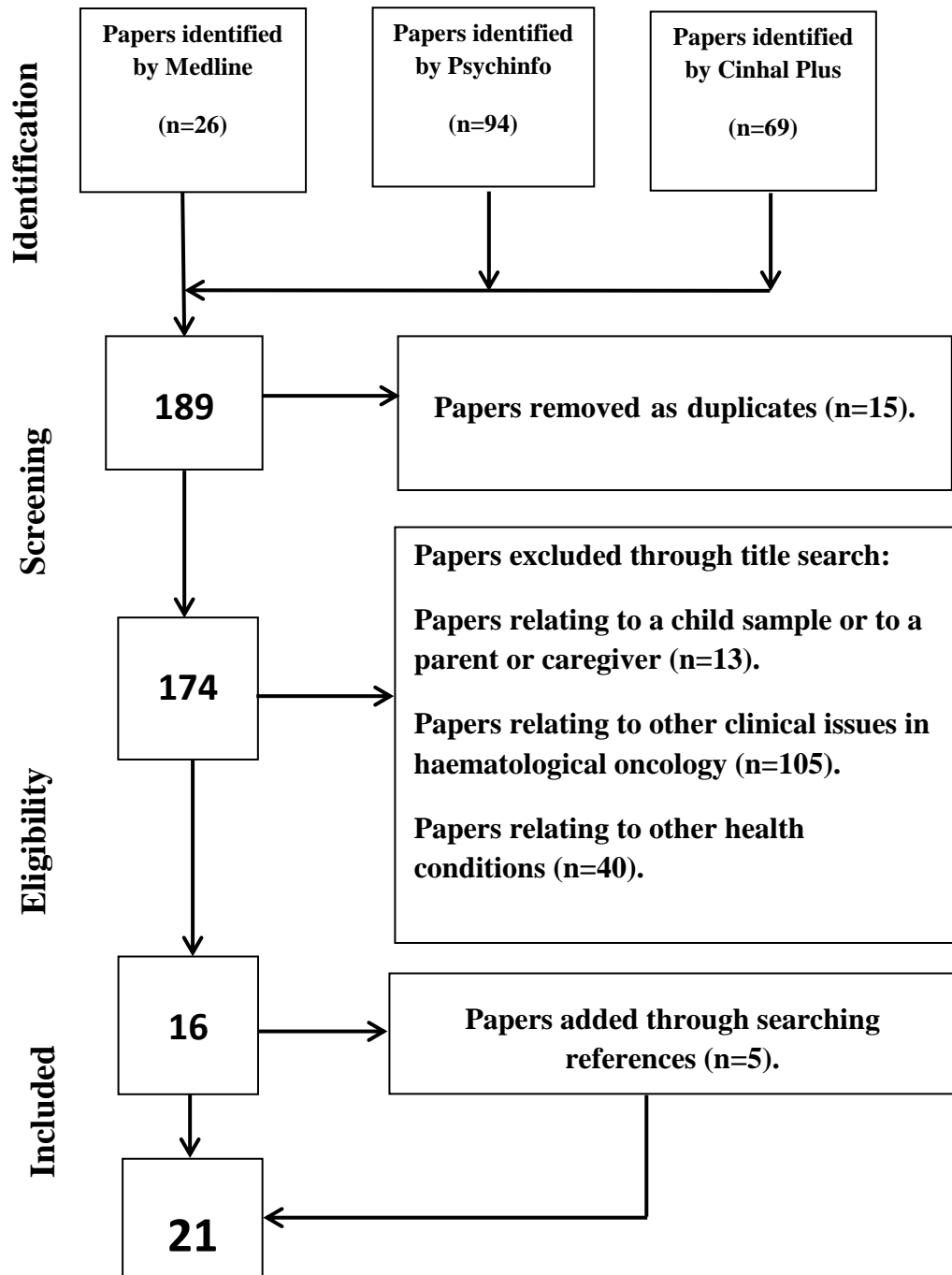


Figure 1. PRISMA flow chart of selection of papers.

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 Papers' (National Collaborating Centre for Methods and Tools, 2008). Both tools are recommended by the Cochrane Collaboration Group (Higgins and Green, 2011). Papers were not excluded on the grounds of quality; the ratings were used to inform 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-ethnographic approach informed the synthesis of papers, wherein analysis of the theoretical stance, methodology and findings were interpreted into a single synthesis. Data were extracted by one author and checked by one member of the research team. Data extracted for each paper included methodological details and results (design, sample, aims, analysis and results), and any indication of the authors' professional or conceptual background. This informed three parallel strands of analysis examining: research methodology; the authors' conceptual background; and the findings. Interpretive analysis of the three strands formed the meta-synthesis (Paterson et al., 2001).

Results:

Summary of included papers: A full summary of papers is provided in Table 1. Twenty one papers were included in the review. Papers were predominantly from North America (n=9 papers: Alexander et al., 2012; Arora et al., 2009; Chawla and Arora, 2013; Friedman et al., 2010; Gansler et al., 2010; Hammond et al., 2008; Keegan et al., 2012; Poe et al., 2012;

Yogaparan, 2009) and Europe (n=9 papers: Ernst et al., 2011 a and b, 2013; Evans et al., 2012; Friis et al., 2003; Gravis et al., 2011; Husson et al., 2013; Oorelemans, 2012; Randall and Wearn, 2005). The remaining papers were from Australia (n=2 papers: Carey et al., 2012; Lobb et al., 2009) and Jordan (n=1 paper: Al Quadire, 2014). Ernst et al. (2011a, 2011b and 2013) used the same sample for a qualitative paper and two quantitative papers. Of the quantitative papers, one paper reported on the sample of haematology patients only. The other quantitative paper compared patients from the original sample with a sample of patients who had a different cancer (Ernst et al., 2011a, 2011b and 2013). The papers from Arora et al. (2009) and Chawla and Arora (2013) used the same sample of patients. Husson et al. (2013) and Oorelemans et al. (2012) both reported on one sample of patients. The remaining papers reported on separate samples. Collectively the papers included in the review reported on 6418 participants and 62 practitioners.

Reflecting the eligibility criteria for the review, all papers included patients or survivors as participants. However, three included additional categories of participants: health practitioners, caregiving relatives and non-caregiving relatives. Similarly, whilst all papers included adult patients, one also included adolescent patients.

Quantitative sample sizes ranged from 31 to 3080 and qualitative sample size ranged from 11 to 54. All the qualitative papers (n=5 papers: Ernst et al., 2013; Evans et al., 2012; Friis et al., 2003; Gansler et al., 2010; Randall and Wearn, 2005) included only haematological cancer patient samples. The quantitative papers included some papers with only a haematological cancer patient sample (n=10 papers: Alexander et al., 2012; Carey et al., 2012; Ernst et al., 2011b; Friedman et al., 2010; Hammond et al., 2008; Keegan et al., 2012; Lobb et al., 2009; Oorelemans et al., 2012; Poe et al., 2012; Yogaparan et al., 2009), as well as papers encompassing haematological and other cancer samples (n=6 papers: Al Quadire,

2014; Arora et al., 2009; Chawla and Arora, 2013; Ernst et al., 2011a; Gravis et al., 2011; Husson et al., 2013).

Results of quality assessment

As illustrated in Table 1, most quantitative papers were rated as ‘moderate’ on the assessment tool (n=11 papers: Al Quadire, 2014; Arora et al., 2009; Carey et al., 2012; Chawla and Arora, 2013; Ernst et al., 2011 a & b; Gravis et al., 2011; Husson et al., 2013; Poe et al., 2012; Oorelemans et al., 2012; Yogaparan et al., 2009) with the remainder rated as ‘weak’ (n=5 papers: Alexander et al., 2012; Friedman et al., 2010; Hammond et al., 2008; Keegan et al., 2012; Lobb et al., 2009). Most qualitative papers scored nine or ten out of ten on the quality checklist (n=4 papers: Ernst et al., 2013; Evans et al., 2012; Friis et al., 2003; Randall and Wearn, 2005) with the remaining paper scoring eight (Gansler, 2010).

Due to the lack of variation in the results of the quality assessment procedure, it was not possible to conduct a more fine-grained critique of the papers, and consequently only general statements regarding the comparative quality of papers could be made.

Review of methods

Most papers had a quantitative design (n=16 papers: Al Quadire, 2014; Alexander et al., 2012; Arora et al., 2009; Carey et al., 2012; Chawla and Arora, 2013; Ernst et al., 2011 a & b; Friedman et al., 2010; Gravis et al., 2011; Hammond et al., 2008; Husson et al., 2013; Keegan et al., 2012; Lobb et al., 2009; Poe et al., 2012; Oorelemans et al., 2012; Yogaparan et al., 2009). These included a randomised control trial (Gravis et al., 2011), an observational study (Alexander et al., 2012) and 14 surveys (Al Quadire, 2014; Arora et al., 2009; Carey et al., 2012; Chawla and Arora, 2013; Ernst et al., 2011 a & b; Friedman et al., 2010; Hammond et al., 2008; Husson et al., 2013; Keegan et al., 2012; Lobb et al., 2009; Poe et al.,

2012; Oorelemans et al., 2012; Yogaparan et al., 2009). The trial examined the impact of giving patients full access to their medical records on patients' subsequent anxiety, quality of life, and satisfaction (Gravis et al., 2011). The observational study recorded and coded consultations to examine the exchange of information between physicians and patients. Commonly the survey papers simply quantified patients' information needs or preferred role in decision-making (Al Quadire, 2014; Carey et al., 2012; Hammond et al., 2008; Keegan et al., 2012; Yogaparan et al., 2009), although some examined associations between patients' information or decision-making preferences and other patient-reported outcomes (Arora et al., 2009; Chawla and Arora, 2013; Ernst et al., 2011 a & b; Friedman et al., 2010; Husson et al., 2013; Poe et al., 2012; Lobb et al., 2009; Oorelemans et al., 2012). These other outcomes included: quality of life (n=2 papers: Arora et al., 2009; Chawla and Arora, 2013); anxiety and depression (n = 3 papers: Ernst et al., 2011 a; Husson et al., 2013; Poe et al., 2012); self-efficacy (n=2 papers: Arora et al., 2009; Chawla and Arora, 2013); and illness perceptions (n=1 paper: Husson et al., 2013). Levels of concordance between the information needs that patients reported and physicians' estimates of these needs were also investigated (Friedman et al., 2010). One paper incorporated surveys at two time points: the beginning of treatment, and three months later (Ernst et al., 2011 b).

The remaining papers took a qualitative approach (n=5 studies: Ernst et al., 2013; Evans et al., 2012; Friis et al., 2003; Gansler et al., 2010; Randall and Wearn, 2005). All of these papers reported on semi-structured interviews. Four interviewed participants at a single time point, whilst the remaining study interviewed participants twice (Friis et al., 2003). One study had a mixed methodology, adding a card sorting task in addition to the interview (Gansler et al., 2010). All qualitative papers reported using an inductive approach to analysis. The reported analysis techniques included domain analysis, constant comparison, grounded theory and thematic content analysis. Papers examined patients' information needs (n=2 studies: Friis et al., 2003; Gansler et al., 2010) and preferred role in decision

making (n=1 study: Ernst et al., 2013) and their experiences of particular aspects of the care process: watchful waiting (n=1 study: Evans et al., 2012) and receiving bad news (n=1 study: Randall and Wearn, 2005).

Review of conceptual background

Authors were from a range of backgrounds including medical psychology, behavioural science, medicine, public health policy, epidemiology and social anthropology. Thirteen papers explicitly stated the conceptual background of the study. These included Epstein and Street's (2007) model of patient centred communication in cancer care (n=2 studies: Arora et al., 2009 ; Chawla and Arora, 2013), Charles et al.'s (1999) 'shared decision-making' model of patient-physician communication (n=5 studies: Ernst et al., 2011 a & b, 2013; Gansler et al., 2010; Poe et al., 2012) and researchers specialising in 'survivorship' addressing long term care for survivors of cancer (n=3 studies: Carey et al., 2012; Friedman et al., 2010; Oorelemans et al., 2012). Authors who did not explicitly state the paper's conceptual background took a more practical orientation. In such cases the theoretical position was often suggested implicitly through the research questions chosen. Most frequently the phrasing of research questions suggested 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.

Review of findings

Quantitative

In general the studies considered patients' preferences for information in parallel with patients' decision-making preferences. One paper specifically reported that patients wanted more information about fertility and sexual functioning (Hammond et al., 2009). Another

reported that, when offered options of information relating to various aspects of cancer care, patients opted to know ‘everything about their disease and medical tests’ (Al Quadire, 2014). Indeed, patients given access to their full medical records were more satisfied without being more anxious (Gravis et al., 2011). Nevertheless, in most studies patients reported being satisfied with the amount of information they received and with their physician’s decision-making style (Yogaparan et al., 2009; Oorelemans et al., 2012; Ernst et al., 2011b). The observational study of consultations noted that physicians frequently omitted to ask patients about their preferences for information and decision-making; nor did physicians check that patients understood the information provided (Alexander et al., 2012).

Several papers reported on associations between patients’ information needs and other patient-reported outcomes and characteristics. Patients who reported that their information needs had been met also reported better health-related quality of life and less anxiety and depression (Husson et al., 2013). Patients who were at the younger and older end of the age spectrum, unmarried, male, employed, and from a non-white ethnic backgrounds were more likely to report unmet information needs (Oorelemans et al., 2012; Lobb et al., 2009; Keegan et al., 2012).

When compared to patients with solid cancers, haematology patients preferred a more passive role in decision-making (Ernst et al., 2011a). However, within papers with only haematological oncology patient samples, there was disagreement over patients’ preferred role in decision-making. Studies varied widely in their estimates of the proportion of patients reporting a preference for a passive role, with the lowest reported proportion being 22% (Chawla and Arora, 2013) and highest 63% (Ernst et al., 2011b). Correspondingly, a collaborative role was preferred by a similarly variable range of patients (26-61%: Carey et al., 2012; Chawla and Arora, 2013). Some papers reported a mismatch between patients’

preferred role in decision-making and their reports of their physician's decision-making style (Arora et al., 2008). One study reported that patients were less satisfied with the process of decision-making experienced as an inpatient than as an outpatient (Ernst et al., 2011b).

Qualitative

Some papers described how having information and being involved in decision-making helped patients manage the uncertainty and loss of control evoked by their diagnosis (Ernst et al., 2013; Evans et al., 2012). However, papers also explained that at times patients preferred to avoid information about the disease, and focus on information relating to day to day treatment in order to preserve hope (Ernst et al., 2013; Friis et al., 2003).

Papers reported that patients described how their relationships with physicians affected their information and decision making needs. Papers suggested that patients valued a physician who was empathetic, honest and open. Papers suggested that patients reported these factors improved the patient-physician relationship. Papers reported that patients who had a good relationship with their physician found it easier to have less information and to let the physician have more control over clinical decisions by comparison with those who did not have a good relationship with the physician (Ernst et al., 2013; Randall and Wearn, 2005).

Two papers reported specific areas of unmet need: information on adjustment back to a normal life and management of side effects, and information on clinical trials and recent treatment advances (Evans et al., 2012; Gansler et al., 2010).

Patients' information needs differed from those of their relatives. At times, relatives sought more information from physicians than patients wanted (Gansler et al., 2010). One paper reported that patients sometimes felt that they ought to say they wanted more information, when they did not (Friis et al., 2003). Papers reported that patients appreciated the 'gesture' of being invited to be involved in decision-making, but they felt that physicians were best placed to make decisions about the treatment – and information – that patients needed (Ernst et al., 2013; Randall and Wearn, 2005).

Meta synthesis and discussion

This review included all the relevant papers found in the search without methodological restrictions. This allowed papers with contrasting methodologies to be included. Most papers used quantitative methods, with a minority using qualitative methods, and these sets produced different findings.

The quantitative papers reported that, although physicians rarely asked patients what their information preferences were, or checked whether patients understood the information that had been given, patients generally reported being satisfied with the amount and content of information they received. Papers reported that patients generally accepted all information they were offered, but did not independently request more. One paper also reported that patients given access to their full medical records were more satisfied without being more anxious. Indeed, patients who reported that they had their information needs met had a better health-related quality of life and less anxiety and depression than those who were left with unmet information needs.

Many of the quantitative studies also surveyed patients about their preferred role in decision-making. The findings varied strikingly in the estimates of patients' preferred role. The lack of consistent findings suggests that, in the absence of obvious methodological or sampling reasons, the question might not resonate with patients. Indeed, recent evidence and critiques have shown that responsibility for clinical decision-making is not a zero sum, and that feeling that the doctor has been in control is not incompatible with patients feeling fully involved (Mendick et al., 2010).

The observational study was useful to add a practical context to the research field. The findings highlighted that even if research is able to understand patients' preferences for information, it will also be important to consider if physicians are implementing guidance and checking patients' understanding of information. There are clearly limitations to the quantitative questionnaire survey method. The quality appraisal tool (National Collaborating Centre for Methods and Tools, 2008) ranked surveys as inherently weak within the methodological range of quantitative research. Therefore, with fourteen of the sixteen quantitative papers having used a survey design, the quantitative papers were scored as 'medium' or 'weak' for methodological quality. Surveys quantify information without addressing the potential ambiguity of meaning in questionnaires, or cultural norms of information seeking and decision-making. That is, the surveys are trying to capture whether patients want to either be involved in decision-making or give physicians control, when in practice patients may not experience these as mutually exclusive categories.

The one randomised controlled trial investigated the impact on patient anxiety and satisfaction of systematically providing patients with full access to their medical records. Patients who were offered the access to their full records chose to accept this. Following access, patients' satisfaction with information increased without increasing their anxiety. It

is however, hard to deduce what was helpful for patients about being given access to their records. It is unclear if the findings were due to patients having access to more detailed information, or whether perhaps being given full access was meaningful for the patient relationally. The critical appraisal tool rated this paper as 'moderate' due to its relatively robust design.

Compared to survey methods, the qualitative studies' inductive approach better allowed patients to express their own views about information. While there are differing views of the legitimacy of using a quality assessment checklist on qualitative research (Barbour, 2001), the qualitative papers were assessed by the CASP (2013) checklist. All papers scored between eight and ten out of ten, suggesting they were methodologically robust.

The qualitative papers indicated that many patients preferred to limit the information they received, and that this helped patients to manage their emotional distress and to preserve hope. The possibility that patients desire information to be constrained in order to allow them to hope is consistent with findings within other cancer populations (Sinding et al., 2010; Leydon et al., 2000; Mendick, et al. , 2013; Salander et al., 1996).

The qualitative papers also emphasised the influence of the patient-physician relationship on patient information preferences, suggesting that where patients felt they had a good relationship, they needed less information. The qualitative studies examined decision-making less than the quantitative studies did. However, one study reported that patients who perceived a positive relationship with their physician also felt their physician was best placed to make clinical decisions. These findings begin to resolve the paradox presented by the quantitative findings; patients find receiving information and using shared decision-making

valuable. However, rather than it being the information exchange that patients describe to be valuable, it is the human interaction with the physician. Research from other fields of cancer care has also emphasised the central importance of patients' perception of a good relationship with the physician to their experience of cancer care (Wright et al., 2004; Leydon et al., 2000; Salander and Hendriksson, 2005).

In summary, the quantitative papers suggested that patients are largely content with the information they receive from physicians. The qualitative papers help to understand this by suggesting that a sense of a caring relationship with the physician allows patients to achieve this acceptance and contentment with information. These findings are supported by research in other cancer groups which found that patients' faith in their physician precludes their need to seek further information (Leydon et al., 2000).

Further research could more frequently draw on qualitative approaches to explore the patient-physician relationship and increase understanding of what it is about receiving information that is meaningful to patients. It would be worthwhile to use such findings to help physicians enhance their relationships with patients and to use information appropriately for the function it is serving. For example, current research suggests that in some cases, people do not want information that could be threatening (Salmon et al., 2012). However, patients must be given some information to conform to informed consent practices. Further research could explore how physicians could best present information to allow both needs to be met.

The findings have implications for clinical practice by suggesting that patients' perceptions of a positive relationship with their physician mediate how content patients feel with the

information they have available. Whilst clinicians in cancer care are usually experienced at building relationships and aware of the importance of doing so, they may not have previously been aware how information has a role in, and is influenced by, relationships. Knowing that patients report being more likely to feel their information needs are met when they perceive a good clinical relationship could validate clinicians taking the time to build positive caring relationships with patients.

Traditionally systematic reviews select and critically appraise papers based on similar research designs. This review shows the value of using multiple methodologies to address a complex research question. Rather than allowing research to be constrained by adherence to one method, taking a pluralist approach has allowed the limitations of one method to be offset by the strengths of another (Madill and Gough 2008). This was illustrated by Ernst et al. (2011a, 2011b, 2013) in this review. Their research initially reported quantities of pre-defined categories of patient experience they had considered to be valid and important. Ernst et al. reported having recognised the benefit of adopting a qualitative approach to explore what patients thought and said, and how what was said was influenced by the social world. Following such recognition Ernst et al. contributed qualitative research to the field (Ernst et al., 2013).

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 methodological domain.

Conclusion

This review suggests that a sense of a caring relationship with the physician allows patients to achieve acceptance and contentment with information. These findings are supported by research in other cancer groups. There are practical applications for these findings: namely that if physicians are able to build a trusting relationship with patients, patients should be more able to feel their information needs are met.

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Table 1. Summary of included papers.

Condition	Author	Design	Sample	Aims	Analysis	Conceptual background	Author's orientation	Quality rating (CASP or EPHPP)	Results
Quantitative									
Haematological and gastro-intestinal cancer.	Al Quadire, 2014. (Jordan).	A descriptive cross-sectional survey exploring patients' information needs.	N=182 adult cancer patients.	To investigate the information needs of cancer patients.	Multiple-linear regression	Information needs are important. There is no published research on the needs of Jordanian patients.	Nursing and health sciences.	EPHPP: Moderate.	86% of patients prefer to have information about their disease. Patients reaching palliative care require less information than those at an earlier stage of treatment.
Haematological cancers.	Alexander et al., 2012. (USA).	Observational study, recording and coding patient-physician consultations	N=236 consultations. 236 patients with 40 physicians.	To explore the exchange of information, and the role of patient and provider characteristics in consultations.	Consultation recordings were coded using a communication evaluation tool. Multilevel models were created.	Not stated.	Communication in healthcare researcher, haematology physicians, and a professor of psychiatry.	EPHPP: Weak.	Physicians did not usually ask patients their preference for information; their preferred role in decision making; and their understanding of presented information. 81% of patients were told prognostic estimates for mortality or cure. These patients were more frequently non-white; lower socio-economic status; and those who asked more questions.
Leukaemia, bladder and colorectal cancer.	Arora et al., 2009. (USA).	Survey exploring patients' decision-making style; self-efficacy; personal control; health-	N=395 adults diagnosed 2-5 years previously who had made	To evaluate pathways linking physicians' decision-making style	Path analysis, mediation analysis and moderation analysis.	Epstein and Street's (2007) model of patient centred communication in	Research scientist, a social scientist and physicians.	EPHPP: Moderate.	54% patients reported that their physician used a sub-optimal decision-making style.

		related quality of life; control preferences.	a medical decision within the last year.	with patients' health related quality of life.		cancer care.			
Haematological cancer.	Carey et al., 2012. (Australia).	A cross-sectional survey exploring patients preferred role in decision-making.	N=268 adults diagnosed up to 3 years previously.	To examine perceived and preferred roles of patients in treatment decision-making.	ANOVAs and multiple logistic regressions.	“Patient involvement in decision-making is underpinned by strong bioethical and medico-legal imperative”. Survivorship.	Health behaviour – researcher – details only available for one author.	EPHPP: Moderate.	46% preferred a passive role in decision-making; 30% preferred collaborative decision-making; 26% preferred an active role in decision-making. 56% matched their preferred and perceived roles.
Leukaemia, bladder and colorectal cancer.	Chawla and Arora, 2013. (USA).	Survey exploring patient role preferences; trust in physician; patient self-efficacy; health-related quality of life; and health appraisal.	N=623 adults diagnosed 2-5 years previously.	To assess patients' decision-making preferences during follow-up care. To explore how decision-making, trust in the physician, and self-efficacy, effect health outcomes.	Multinomial logistic and linear regressions.	Epstein & Street's (2007) patient centred communication in cancer care.	Public health: a cancer prevention researcher and a research scientist.	EPHPP: Moderate.	61% patients preferred shared decision-making; 16% preferred to control their decisions; 22% preferred physician control over decision-making.
Solid or haematological cancer	Ernst et al., 2011a (Germany).	Survey exploring patients' anxiety, depression, and preferred roles in decision-making.	N=710.	To present empirical evidence of patient's preferred participation in medical decision-	Multivariate regression.	Shared decision making (Charles et al. 1999): theoretical model of patient-physician communication.	Researchers from the department of medical psychology and medical sociology and	EPHPP: Moderate.	Haematology patients (25%) desire less active participation and prefer a more dominant role of the physician in decision-making compared to patients with solid cancers (53%).

				making.			physicians.		
Haematological cancer.	Ernst et al., 2011b (Germany).	Survey exploring patients' preferred role in decision-making and confidence in decisions at commencement of treatment and 3 months later.	N=117.	To explore how patients perceive their involvement in decision-making. To explore patient's appraisals of the decision-making process.	A correlational analysis, nothing further stated.	Shared decision making (Charles et al. 1997): theoretical model of patient-physician communication.	Researchers from the department of medical psychology and medical sociology and physicians.	EPHPP: Moderate	63% preferred a passive decision-making style. Most reported a positive evaluation of the decision-making process. Patients' evaluations were more negative either if patients were treated as inpatients, or if they experienced no control over the decision.
Non-Hodgkin's lymphoma.	Friedman et al., 2010. (USA).	Survey exploring patients' and physicians' information needs.	N=67 patients, 22 physicians.	To identify the most important information needs of patients and treating physicians. To assess how closely the needs of patients link to their physicians.	T-tests.	In support of cancer survivorship care plans.	Physician and researchers from cancer biostatistics unit and the comprehensive cancer centre.	EPHPP: Weak.	The most highly rated information needs were medical issues. Concordance was high between patient and physician responses for medical issues but less so for psychosocial issues.
Lymphoma, breast or colon cancer.	Gravis et al., 2011. (France).	Randomised controlled trial comparing those who requested full access to their medical record with those who were provided systematic full	N=248 adults with newly diagnosed cancer.	To assess the impact of providing systematic full access to medical records on anxiety, quality of life and satisfaction.	ANOVA and logistical regression.	Non-disclosure considered outdated, physicians have an ethical and legal duty to disclose relevant information to patients.	Research physicians.	EPHPP: Moderate.	Allowing patients full access to their medical records increased their satisfaction without increasing their anxiety.

				access. Included measures of anxiety, quality of life and satisfaction.					
Non-Hodgkin's lymphoma.	Hammond et al., 2008. (USA).	Population based survey exploring patients' information needs on 16 cancer-related issues.	N=250 adult survivors 2-5 years post diagnosis.	To explore the prevalence of information needs related to fertility and sexual function, and to assess the demographic comorbidity, and treatment correlates of fertility and sexual function-related information.	Chi-square test and multivariate analysis.	Not stated.	Public health policy and planning researchers, and behavioural and social science researchers.	EPHPP: Weak.	13% survivors described wanting more information about fertility and 28% requested more information regarding sexual functioning.
Lymphoma, multiple myeloma, endometrial or colorectal cancer.	Husson et al., 2013. (Netherlands).	Population based cross-sectional survey exploring cancer patients' illness perceptions and information provision.	N=3080.	To provide insight into the relationship between information provision and illness perceptions among cancer survivors.	ANOVAs and multivariate linear regression.	Not stated.	Researchers in medical psychology and a comprehensive cancer centre.	EPHPP: Moderate.	Patients with fulfilled information needs and patients who experience fewer information barriers have a better health-related quality of life and less anxiety and depression.
Acute lymphocytic	Keegan et al., 2012. (USA).	Survey exploring unmet needs of	N=523 15-39 year olds with	To describe the unmet	Multivariate logistical	Adolescents and young adults are a	Research scientist from	EPHPP: Weak.	Adolescents and young adults had a range of unmet

leukaemia, Hodgkin's lymphoma, non-Hodgkin's lymphoma, germ cell cancer & sarcoma.		adolescent and young adult cancer survivors.	a mean time since diagnosis of 11 months.	information needs of adolescents and young adult cancer survivors. To identify socio-demographic and health related factors associated with unmet information and service needs.	regression analyses.	population under-represented in research.	the Cancer Prevention institute, physicians, and an epidemiologist and social worker.		information needs relating to their cancer returning and cancer treatments (25-62%). Older participants, men, participants of non-white ethnicity, and participants who report less than excellent general health or fair/poor quality of care were more likely to report unmet information needs.
Lymphoma, multiple myeloma, leukaemia, Hodgkin's lymphoma.	Lobb et al., 2009. (Australia).	Survey exploring cancer survivors' unmet needs.	N=66 adults up to 12 months post-treatment.	To determine patient's information, emotional and support needs at the completion of treatment.	Comparisons, correlation and descriptive analysis.	Need to learn more about the needs of patients completing treatment as well as longer term need.	Behavioural science researchers, medical psychology researcher and physicians.	EPHPP: Weak.	Predictors of unmet needs included younger patients, unmarried patients and patients in employment. 59% reported they would have found it helpful to talk with a health care professional about their experience of diagnosis and treatment at the completion of treatment.
Lymphoma and multiple myeloma.	Oorelemans et al., 2012. (Netherlands).	Population based-survey exploring patients' satisfaction with information provision.	N=1135.	To evaluate the current perceived level of, and satisfaction with, information received by patients and to identify	ANOVA and multivariate regression	Survivorship	Researchers from a nationwide initiative of haematologists, radiation oncologists, epidemiologists, and	EPHPP: Moderate.	66% of patients were satisfied with the amount of information received. At least 25% wanted more information. The factors associated with higher perceived levels of information provision were young age; having had

				associations with socio-demographic and clinical characteristics.			internists formed a working group who develop protocols for standardising long term care and establishing survivorship clinics.	chemotherapy; more recent diagnosis; using internet for information; and having no comorbidities.
Follicular lymphoma.	Poe et al., 2012. (USA).	Survey exploring patients' preferred role in decision-making; decision resources; the importance of significant others; decisional conflict; decisional regret; decision scale; impact of events; anxiety; and depression.	N=32 adults diagnosed in last 10 years.	To explore the treatment decision model and distress in a sample of individuals previously diagnosed with follicular lymphoma.	Not stated but reported scored questionnaire outcomes.	Shared treatment decision model may be made more difficult by patients' distress and may also increase distress.	Psychologist, EPHPP: physician and assistant professor of medicine and psychologist. Moderate.	59% of participants chose collaborative decision making. Most participants reported little decisional conflict or regret and wanted to be actively involved in decision-making.
Acute myeloid leukaemia.	Yogaparan et al., 2009. (Canada).	Survey exploring patients preferred roles in decision-making.	N=31.	To identify the information patients need to inform their treatment-decision. To examine patients'	Descriptive statistics only stated. Otherwise reporting patterns of questionnaire outcomes.	Not stated.	Physicians and research scientists. EPHPP: Moderate.	Most patients had enough information about the diagnosis and treatment options, and thought their physicians spent the right amount of time with them (73%). Most patients preferred a passive (51%) or

preferred and actual decision – making roles and perceptions of prognosis.

collaborative decision-making role (32%).

Qualitative

Haematological cancer.	Ernst et al., 2013. (Germany).	Semi-structured interviews.	N=11 adults 12-18 months post diagnosis.	To discuss the course of decision-making processes and patient participation in decision-making.	Content analysis.	Shared decision making (Charles et al. 1997): theoretical model of patient-physician communication.	Researchers from the department of medical psychology and medical sociology, physicians, and an assistant professor of counselling psychology and biomedical statistician.	CASP: 9/10.	Patients were often overwhelmed by complexity of the illness and therapy and did not want any responsibility in medical decision-making.
Chronic lymphocytic leukaemia.	Evans et al., 2012. (UK).	Semi-structured interviews	N=12 adults who had experienced management by watchful waiting.	To explore accounts of watchful waiting and implications for clinical management.	Constant comparison.	There is something unique about chronic lymphocytic leukaemia within haematology. Watchful waiting can be as psychologically problematic as active treatment.	Health experiences researchers and professor of haematology.	CASP: 9/10.	Patients recalled receiving little information about the condition and wanted to know more about how it would affect them in the future.

Acute myeloid leukaemia.	Friis et al., 2003. (Denmark).	Ethnographic interviews at two time points: soon after diagnosis and 2-5 months later.	N=21 patients, resulting in 40 interviews.	To obtain knowledge of patients' perception of information; motives for seeking or avoiding information; and how norms of society may influence attitudes to information.	Domain analysis	Anthropology/ethnography. Context: Danish healthcare system information policy is to provide thorough information about all aspects of illness and treatment while taking the individual needs of each patient into account.	Social anthropologist. CASP: 10/10.	Most patients did not recall information from the time of diagnosis, except the diagnosis itself and the feelings it aroused in them. All patients had basic knowledge of their condition but many did not want further medical information. Patients described feeling they ought to seek information but not doing so, explaining that by avoiding information they were able to maintain hope.
Haematological cancer.	Gansler et al., 2010 (USA).	Mixed methods, Interview and card sort ranking survey.	N=54 adults, either cancer survivors/patients, caregivers or non-caregiver relatives.	To guide development of materials to fill high priority unmet information needs of haematological cancer patients, survivors, caregivers and non-caregiving relatives.	Thematic or grounded theory analysis.	Information informs patient shared decision-making which leads to better health outcomes.	Supported by CASP: Division of Cancer Prevention and Control. 8/10	Information priorities vary by position (patient/caregiver/non-caregiver) and over time.
Leukaemia or lymphoma.	Randall and Wearn, 2005. (UK).	Semi-structured interviews.	N=15	To explore patients' experiences of the process and	Thematic content analysis.	A patient's satisfaction with care, hope, and psychological	A research physician and researcher. CASP: 10/10.	Patients described the importance of not feeling rushed during a bad news consultation. Patients valued

content of
receiving bad
news.

adjustment are all
influenced by the
way bad news is
given.

from a
clinical skills
resource
centre.

the doctor's ability to adapt
to their emotional needs;
information leaflets; having a
companion with them; and
genuinely personalising the
approach.

How do haematology patients make sense of clinical information? A qualitative study.

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Word count: 7,274

(excluding figures, tables and references)

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Abstract:

Haematological cancers are often unpredictable, leaving clinical decisions to be made throughout the trajectory of the illness. In this context, the way patients make sense of complex clinical information becomes particularly important. The study aimed to understand the ways in which patients make sense of clinical results, and to identify the psychological and other influences on this process. Semi-structured interviews were conducted with 20 patients who had been diagnosed with haematological cancer and had received results from clinical investigations or relating to treatment response. A constant comparative approach was taken for analysis. Patients described the need for information to be carefully managed, and the alarming nature of information that they did not experience as having been managed for them. Where patients had difficulty trusting their clinician they found it more difficult to accept and be content with the information the clinician provided. These findings can be illuminated using attachment theory. There are also clinical implications for how clinicians could give patients confidence in their ability to manage the uncertainty associated with haematological cancer. By facilitating an attachment process patients could be helped to feel that they are able to trust and build hope from the information they receive.

Keywords

Information needs; haematological oncology; attachment; clinical relationship; qualitative.

Introduction:

Haematological cancers account for 7% of oncology cases in the UK. The National Institute for Clinical Excellence (NICE) describes this group of cancers as unique in the way that the component diseases vary in severity and presentation (NICE, 2003). Some haematological cancers have the ability to transform into more serious conditions which means that the course of treatment can be unpredictable. Treatments in this setting are generally demanding and unpleasant and require patients' commitment and adherence in the face of these demands (Kaplan et al., 1996). NICE (2003) report that even for the most prevalent form of haematological cancer 'there is considerable uncertainty about optimum management.' (NICE, 2003, P.16). This lack of a programmed sequence of care and uncertain treatment course leaves important clinical decisions to be made throughout the trajectory of the illness. In these instances, the way patients make sense of complex clinical information becomes particularly important. If patients are unable to make sense of information, and therefore treatment decisions, it can affect their acceptance of decisions, their ability to hope, and consequently their quality of life (Fallowfield et al., 1990; Husson et al., 2013; Mager and Andrykowski, 2002; Ong et al., 2000; Rutten et al., 2005; Shilling et al., 2003).

How patients make sense of information depends on patient factors as well as how clinicians provide the information (Salmon et al., 2011). Research has highlighted significant disparities between the information provided in a consultation and the message a patient takes from the consultation (Rodin et al., 2009). Patients can make sense of information in ways that diverge from what the clinician intended for varied reasons (Salander, 2000). Patients may have incomplete or insufficient background knowledge to understand biomedical information (Elwyn et al., 2010). In addition, patients' ways of understanding information can be 'motivated'; that is, patients can use information in ways that allow them to manage or avoid the distress associated with potentially threatening information (Friis et

al., 2003; Salander et al., 1996). Understanding the ways in which haematological oncology patients' make sense of results, and identifying the psychological and other reasons for this, could inform clinical practice in haematology and other clinical settings and, in addition, inform communication education.

Much of the existing research on patients' information needs in haematological oncology has taken a quantitative approach, finding that patients generally report being satisfied with the information they receive (Yogaparan et al., 2009; Oerlemans et al., 2012; Ernst et al., 2011). However, these studies tell us little about how patients make sense of the information. The few qualitative studies suggest that patients prefer to avoid information about the severity and prognosis of their disease and focus on information regarding day to day implications of treatment (Ernst et al., 2013; Friis et al., 2003). These were the first studies in the field that allowed information to be considered as more than a simple quantity that patients either want more or less of, and to explore the ways in which different types of information have different functions for patients. Exploration through further qualitative research could help to increase scope of understanding of what is important for patients.

The present study therefore aimed to: explore how patients in a haematological oncology setting make sense of complex results; to explore influences upon the way patients make sense of results, including patients' psychological strategies to manage distress; and to discuss the implications of the findings for how to manage patients' information needs when providing complex results in haematology clinics.

Participants and methods

Sample

Purposive sampling was used to include patients who were aged 18 and over, diagnosed with a haematological cancer and who were receiving curative treatment. Recruitment aimed to reflect the range of patients accessing the clinic; therefore sampling sought to access patients with a diversity of haematological cancers. Participants were selected who attended the clinic to receive results from investigations to inform diagnosis, or to provide information about response to treatment or to inform decisions about treatment options. Patients were excluded if the medical or research team judged that patients were too distressed or unwell to be able to give informed consent. Maximum variation sampling was used to select patients across the range of prognoses, gender and age seen in the clinic. The aim of this method was to include patients whose experiences might be considered 'typical' as well as those with more unusual experiences (Coyne, 1997). Sociodemographic characteristics including patients' highest education level and occupation were recorded and variability was also sought on these characteristics. Recruitment was conducted in parallel with analysis until saturation of analysis was reached (Marshall, 1996).

Data collection

The study received NHS ethical approval (13/NW/0865). Participants were recruited from weekly treatment and follow up clinics. Each participant had attended the clinic to receive clinical information about response to treatment and/or treatment options. During the participants' medical consultation clinicians presented the idea of the research. The consultation was henceforth termed the index consultation. Patients who were interested in taking part saw the researcher (KA), who discussed the content of the participant information sheet. KA arranged to contact the patient the following day to answer any further questions and request participation. She reassured patients that the research team was independent of the clinical team and that decisions about participation would not influence patients' clinical care or their relationship with the clinical team. If the patient agreed to participate, a time

was arranged to meet, gain written consent and conduct the interview. Interviews were arranged at time convenient for the participant and at the location of their choice (the clinic, their home or at the affiliated university).

The interviews were semi-structured and conversational in style, using open questions and reflection to facilitate participants' contribution, with closed questions where necessary to probe specific points. The interviews explored participants' accounts of receiving and understanding the results they were given in their index consultation. Using the interview guide (Appendix 11), the interviewer prompted patients specifically about: what information they received and what they felt it meant; how they used it to inform their treatment or other decisions; and what significance it had in their lives including in relationships with family, friends or others. The interview guide was revised and developed in line with ongoing analysis in order to test and explore findings. That is, some questions were refined in order to explore gaps in participants' reports, and new questions were added to explore emerging aspects of the analysis (Appendix 11). A procedure for dealing with participants' distress was in place, but not required. Participants were offered a summary of the study's findings following study completion: eight participants requested this. Field notes and reflections were kept to inform analysis, and interviews were recorded using digital audio recorders. The researcher transcribed the first four interviews to become immersed in the data. The remaining sixteen interviews were transcribed by an independent transcriber. The transcriber recorded the content of the speech, major hesitations and sub-vocalisations. The researcher checked transcriptions for accuracy. Transcript extracts have been included within the results section to illustrate categories of analysis. Where necessary within transcript extracts, ellipses were added where words have been omitted, and explanatory text has been included in square brackets.

Analysis:

The analysis drew upon a pluralist qualitative approach. Qualitative methodologists studying clinical care have warned of the practical dangers and epistemological limitations of constraining analysis by strict adherence to a single method, or ‘brand’ (Barbour, 2001; Chamberlain, 2000; Salmon, 2003; Seale, 1999). Taking a pluralist approach allows the flexibility pragmatically to apply inductive methods and epistemological positions appropriate for the data and research questions. Rather than being constrained by rigid adherence to one method, pluralism allows the limitations of one method to be offset by the strengths of another (Madill and Gough, 2008). In this study elements were drawn from several qualitative approaches: drawing approaches from grounded theory ensured all findings were derived from and “grounded in” the data (Glaser and Strauss, 1967; Strauss and Corbin, 1994); drawing perspectives from ethnography allowed participants’ culture and ‘taken for granted’ assumptions to be considered (Hammersley and Atkinson, 2007); drawing understandings from discourse analysis allowed attention to be paid to the language the participants used (Phillips and Hardy, 2002).

This pluralist approach to data analysis has been adopted previously by researchers within the fields of clinical communication and cancer care (Salmon et al., 2012; Wright et al., 2004). Procedurally, analysis was informed by the constant comparative approach and grounded theory principles to explore what was present and what was noticeably absent (Glaser and Strauss, 1967). The transcripts were each read and re-read by each member of the research team (BY, PS, KA) and discussed collectively. To guide these discussions, the researcher recorded a narrative summary of the salient points of each patient’s experience. In addition, she documented the evolving analysis after each discussion. These documents

informed the subsequent discussion and were in turn developed in light of the new data (See Appendix 12). Throughout the analysis patients' accounts were understood from a social constructionist position thus acknowledging the social and environmental context the patients were in when interviewed. Data was considered descriptively at first, regarding it as a report of patients' experiences and views; the language patients used was understood to reflect the patients' representation of their internal world. As analysis proceeded, it took a more interpretive approach, considering the meaning of the text in the context of the interview as a whole and in the context of the developing analysis. Interpretation such as this was aided by the researcher's field notes and an understanding of the patient's present medical condition as described by the patient. Through this approach, analytic categories were built and developed based on patterns in the data within and between cases (Patton, 2002). Analytic categories were built into a coherent overall structure using the structure bullet documents (as shown in Appendix 12). Where sub-sections were felt to be less prevalent within, and therefore less evidenced by, the interviews, they were felt to be less able to support a category of their own. In these cases revisions to the structure bullets were made to ensure a better fit was found within the overall structure. Final categories were reported using the final structure document dated 16.04.15 in Appendix 12.

Differences of interpretation that arose during discussions of the data alerted the team to potential competing explanations in the analysis. In addition to this interrogation of the analysis, the research team used deviant cases to test the analysis. This approach facilitated consensus validity (Stiles, 1999). As analysis developed concurrently with recruitment, adaptations were made to the interview guide allowing testing of the analysis through exploration of emerging findings (Marshall, 1996; Seale, 1999; Stiles, 1993, 1999; Yardley, 2000). Theoretical validity was also considered by looking beyond the analysis to the existing literature to compare and contrast findings (Kincheloe and McLaren, 2000).

Results:

Sample characteristics

Saturation of analysis was achieved with twenty participants. As illustrated in Table 1 (located on page 70 of this thesis), the sample comprised 11 men and nine women whose ages ranged from 26 to 85 years. Participants had diverse educational and occupational backgrounds: ten reported having school as their highest academic level, the remainder attended higher education. Time since participants' diagnosis ranged from one week to 156 months, and their current treatment status included pre-treatment, to mid-treatment, and post-treatment.

Overview of analysis

The findings reported under the categories of 'The challenge of a fluid and uncertain condition', 'The importance of managing information' and 'Clues as unmanaged information' were derived through analysis of individual transcripts and the data set as a whole as described in the analysis section. The analysis allowed development of categories from the data which have been formed into an overall coherent structure to represent those findings best supported by quotations from participants (see Appendix 12).

A striking feature of the interviews was the pervasive sense of uncertainty that patients described trying to manage. Uncertainty was present throughout the course of patients' care as a feature of the illness. Patients also perceived uncertainty in the management of the clinic and in the trajectory of the treatment pathway. In this context, patients described the need for information to be carefully managed, and the often alarming nature of information that they did not experience as having been managed for them.

The challenge of a fluid and uncertain condition

Patients described the uncertainty created by the changeable nature of their condition. They described it being difficult to have a predictable trajectory for treatment and recovery as treatment options depend on specifics of the condition that often unfolded over time or as treatment continued. Some patients described being unsettled by their clinician changing their planned treatment unexpectedly. Some were aware that their condition had the potential to transform into a more serious one at any time.

Undetectable, unpredictable and unusual: the uncertainty of the condition

Patients tried to make sense of how the condition could have been present in their body before diagnosis yet unidentified: *“they were taking blood for 12 months from me, wouldn’t [lymphoma] have shown up?”* (P3). P13 spoke of the worry that she had previously voiced to the medical team: *“the lymphoma in my body before I gave the bloods for hysterectomy didn’t show up, tell me what you’re looking for in these bloods?”*, adding that her worry had not been addressed: *“and no-one gives me an answer....That’s what is bamboozling me”* (P13). Patients spoke also of uncertainty about the future resulting from awareness of cancer’s ability to relapse: *“that’s the cruel thing with this sort of illness...it can always come back”*(P1); *“so it’s just dependent on how long it takes to grow again...the uncertainty.”*(P19). P1 described the threat of relapse as *“a ticking time bomb”* (P1). Additionally, some patients were aware that haematological cancers also have the ability to transform into more dangerous ones. P8 thought he had recovered from his condition but it then transformed: *“I thought I’d beat it and as time went on the disease actually changed...it changed and went more aggressive.”*(P8). P16 understood that his condition had become more serious and thus more threatening: *“it just turned out it was worse than what it was and a more rarer kind, a higher grade”* (P16).

Some patients reported that clinicians had explained that their condition was unusual: *“nobody can put their finger on it...They have used this phrase of a rogue cell but they don’t know what the rogue cell is.”*(P10); a patient who was diagnosed in his forties commented *“they’re a bit intrigued...I think they wanted to know why this is not affecting me like it would do somebody in their sixties and seventies.”* (P4). Patients recounted finding the clinician’s uncertainty confusing and surprising: *“he said and it’s very rare for somebody of forty years of age to have CLL...I was kind of in shock.”*(P4). P10 revealed being unsettled by how many investigations the medical team were completing to no avail: *“I just hope they will find the cause...they take blood counts, samples and I’ve had scans and from here to there and they haven’t come up with an answer...They know there’s something wrong. I know there’s something wrong.”*(P10).

The importance of managing information

Biomedical information in consultations: patients needed clinicians to ‘manage’ it, not ‘give’ it.

Talk of prognosis was prominent in patients’ interviews: *“when someone says you’ve got cancer you automatically say, you connect it with death”* (P8); *“I sweat at nights thinking I’m dying”* (P7); *“you want to know terminal diagnosis I suppose...Face the inevitable. The uncertainty is the worst of it.”* (P12). However, patients reported very little discussion with clinicians about prognosis. P17 had experienced cancer several times and reported that prognosis had never been discussed: *“perhaps they don’t till it, you do get to a prognosis that is terminal...perhaps it’s best to just carry on like that really because...no-one wants to have it sort of possibly spelled out that no we can’t do anything more for you now.”*(P17). Similarly, patients described receiving little biomedical information in consultations and provided only sparse details in their interviews. Information that patients recounted having received mainly related to implications that biomedical results had for short-term treatment

plans. While patients indicated that clinicians had given them little in the way of biomedical information, their accounts suggested they were generally content with the volume of biomedical detail they had received. Indeed many said that, at times, they had received too much. Their accounts indicated several clues to their reasons for valuing constrained information of this kind.

The challenges of information

Consistently patients explained that when being introduced to treatment there was “*just too much information*” to take in. P3 recalled “*we went through each of the drugs ...saying what it did what each of these drugs was doing but then a list of half a dozen side effects so five times six so maybe thirty things*” and described finding it “*pretty overwhelming*” (P3). P15 described it being “*an awful lot*” of information that clinicians “*throw at you*” (P15).

Whilst patients did want to know the important messages from the results, such as “*how much cancer and stuff I’ve got left.*”(P11), commonly patients described not being able to understand the biomedical information. P9 reported explaining to the clinician: “*well am only a layman for heaven’s sake. I don’t know these things you’re talking about.*” (P9); “*it’s all numbers, I don’t understand the numbers.*”(P10). Other patients doubted whether they “*would understand the specifics*” so did not seek further information. P15 described knowing he did not have a detailed understanding of his condition “*I know it’s Hodgkin’s Lymphoma the cellular type, but I don’t really know what subtype*” but not seeking more information because “*it wouldn’t be any use to me anyway.*”(P15), as P7 also described, “*you don’t get, not a lot of information. Couldn’t really, if you’re not medical, you don’t really understand these things.*”(P7).

Many patients reported that emotions impaired their ability to take in information, that when they received “*really serious information*” it was “*easy to freeze, mentally freeze*” (P3), and

often they were “*just numb really*” (P2). P1 explained that she could not “*think so quickly* [when receiving results] *because of the tension*” (P1). A few patients described an asymmetry in the information that they wanted: ‘all’ of the information as long as it’s ‘good’. P7 explained “*your brain doesn’t want to accept a lot of things...You know you only want to know good news. I want to know how I’m going on if it’s good but if I’m not doing very well, better not knowing.*” (P7). P19 also acknowledged that, at times, avoidance of information entirely can be a preference: “*I know if I asked her she’d tell me, so I can only conclude really that I don’t really wanna know*” (P19). Commonly patients explained that information about the possible side effects of treatment increased their worry. P7 explained “*when you have ten or thirty of them...you start to imagine all the side effects*” and that it was “*a worry*”, P19 described it as “*a nightmare ...I thought I’m gonna be vomiting, I’m gonna be, I’m not gonna be able to eat again or I’m gonna have a heart-attack, me head’s going to explode*” though he actually had “*no reaction to it at all*” (P19).

Patients valued information about a tangible ‘marker’ of their condition

Though patients encountered challenges with information, many described valuing clinicians’ use of biomedical markers to manage information giving and explain their condition. Patients could then use these markers to self-monitor their disease. P18 recalled his clinician explaining: “*she said sometimes your thingy levels go up and down, your white blood cells or something, and she said it could keep happening*”. P18 was reassured by having an understanding of the markers in his condition: “*coz of the type of leukaemia it is, which they explained to me on a graph from 0 to 200, mine’s 19 so I’ve got a lot to go ‘til they’re to 200 you know you just have to think I like that.*”(P18). This visual representation helped P18 as it helped him to see his condition was currently some distance from the point at which intervention would be required: “*I know where I am on the graph and I know where I’m going and I don’t want to go there as long as I stay down there.*”(P18).

Some patients found having visual evidence of their condition that clinicians had shown, such as pictures of scans, gave them “*peace of mind*” in a way that blood results did not (P11). P16 described the use of a visual comparison of “*the size of the lymphoma to see if it’s shrunk or even if it’s gone*” (P16). P17 was “disappointed” that she had not been show this evidence to make the comparison: “*I was hoping to see a screen with no hot spots*”. One patient diverged from this picture: P19 explained that having a visual representation of his condition would make it more tangible, which he found more frightening than receiving the information verbally: “*it’s black and white that’s in front of you, that’s where it is, that’s where it is, that’s how big [the condition mass] is...I think it’d scare me, I don’t think I’d like that*” (P19).

As well as representing her condition, P7 described finding being shown a chart on the clinician’s computer screen useful as “*something to look at*” whilst trying to manage her emotions “*because obviously you’re a bit emotional and if you can look at something...as I opposed to looking at somebody if its bad news...that kind of helps*” (P7).

Clinicians’ preparation was pivotal for patients

Patients’ perception of the doctors’ preparation for the consultation seemed pivotal to their experience of the consultation. Preparation implied the clinician cared. When patients perceived that the clinician had managed the information they gave, patients seemed more able to trust the clinician’s care. In contrast, patients who perceived that their clinician had not prepared were alarmed that they had not. It was noticeable that most patients did describe the doctor preparing information. Some patients elaborated explicitly on the value that the doctor doing so held for them, and indicated that they regarded preparing information as a part of clinicians’ role. Preparation for the consultation took many forms,

including any indicator that suggested that the clinician had thought about the consultation before it took place. Sometimes patients noticed, described and praised these types of preparation; other forms of preparation were more noticeable in their absence.

Table 2 (located on page 73 of this thesis) illustrates the ways that many patients spoke of clinicians preparing for consultations, using the account of one patient: P1. Methods of preparation included consideration of the level of information a patient would be able to manage, the selection of information specifically tailored for individual patients and gathering information for patients to take away (Table 2, P1). Patients also noticed that preparation occasionally included wider members of the team: "*there's about four doctors...they sat down and they discussed it*" and added "*obviously you appreciate it*" (P9).

Although patients described benefitting from the consequences of clinicians' preparation, in most cases the indication the clinician had tried to prepare for the consultation seemed to be what patients appreciated. That is, clinicians' preparation helped patients to feel that they mattered to the team. As P8 explained, his clinicians made him feel as though he was "*top of the agenda*" by telling him "*they have a meeting about me every week*" (P8). P11 described an exception to this. P11 was distressed by being told of the team's preparation as her clinician reported a difference of opinion concerning the patient's treatment: "*half of them thought I should stay on the treatment I was having... but some of them felt that because of the size of it I should go onto the stronger treatment*". The patient described finding this "*a big shock*" (P11).

As Table 3 (located on page 73 of this thesis) indicates, the importance of the perception of the clinician's preparation for consultation seemed most salient when patients perceived its

absence. Where patients felt that the clinician had not prepared, they worried about the quality of care. They became more cautious and reported asking more questions out of concern that clinicians might not be fully informed: “*she had obviously not looked at my notes and it was very, very unsatisfactory...she might get the wrong end of the stick about something...She wasn't in full knowledge of my case and I don't know, it was just unsatisfactory really*” (P17). P13 spoke of having to describe her medical history to a clinician who seemed unaware she had been recalled to the clinic: “*she should have read up before I came in the room to say actually why I was coming back in...And that's how mistakes happen.*”(Table 3, P13). Patients also felt alarmed if they did not feel that the clinician was managing information for them. P3 described finding this lack of preparation worrying: “*I'm seeing this person who hasn't even read my file...was quite worrying I don't think she did it very well*” (P3).

Lack of trust demands more information

A few patients described an unconditional trust in their clinician. Such trust could be robust enough to withstand the challenge of treatment with an unpredictable course and with poor and uncertain outcomes. P8 explained that he had a condition which had become aggressive and had required several different types of treatment. He described being unsure what intervention, if any, would now be left available to him. Nevertheless, his trust in the team to do all that was possible seemed to help him manage this uncertainty: “*they never give it up do they, try anything...I've had a lot of treatment.*”(P8). However, it seemed difficult for most patients to build such a trusting relationship with an individual clinician in this setting. The clinician patients saw varied from consultation to consultation as most patients were cared for by the team rather than one particular clinician. Additionally, patients were not given a named figurehead for their care. P3 explicitly reported that knowing one doctor was overseeing his care would have helped him: “*that's one of the worst things about the whole*

sort of the whole process, you get passed on from one person to another to another and nobody knows you, you're just a file" (P3). A few patients described incomplete or damaged trust in clinicians. These patients trusted clinicians but with vigilance rather than absolutely: "not that I just trust like stupidly" (P16). P16 described explicitly how changes to his investigation plans, and disruptions to his care had made him more cautious: "things have happened... Obviously overworked and understaffed there're budget cuts and all that but things lately have started taking their time to get done and that, you know what I mean... I'm not doubting their professionalism, their skills, it's just the way it's ran in general, do you know what I mean. Communication between them seems a bit lax to be honest." "You know they are just people aren't they you forget stuff and make mistakes."(P16). Similarly, being told that changes were being made to care due to differing opinions within the team on the best treatment plan made patients concerned: "we were given different kind of stories about the treatment... that was a bit worrying" (P3). A few patients tried to cope with these changes by finding ways to understand why they had occurred. P3 explained that he spoke to his wife and they were "trying to rationalise [the change in treatment plans], yeah trying to explaining to ourselves as to why things are happening the way they're happening". More commonly patients coped with their doubts or uncertainty by seeking information from other sources in order to check and scrutinise what they have received. P1 described unequivocally how being initially misdiagnosed by her GP made her question her trust in clinicians: "when I first got ill I just put my trust, because I did feel so ill, I just put my trust in somebody else completely, and now I think look where, look where it got me, nowhere..." (P1). P1 spoke of her experiences making her more proactive in seeking information: "I don't think I've had enough information about it yet...I looked, it was only last night I looked on the Macmillan website and NHS website about radiotherapy but there's different types and when I googled 'radiotherapy for Lymphoma'" (P1). However, this strategy of being more proactive did not seem to help patients as it left them with unmanaged information to interpret (see below) and open to "start reading things that I can scare myself with" (P1).

Friends and family: a managed information exchange

Some patients described how family and friends gathered information from external sources and filtered it before reporting it to the patient: “*she knows all about this so she lets me have little dribs and drabs.*”(P12). Patients had various understandings of, and explanations for, this behaviour. In general patients believed their family did this “*because they are trying to protect*” the patient (P16). Unusually, P15 explained that his parents had deliberately given him threatening information because they were concerned he was not taking his condition seriously: “*he’s trying to make me more nervous...He’ll say do you understand the situation and how you can really be so calm.*”(P15).

Patients described, in turn, selecting the information they felt was appropriate for their friends and family, sometimes by creating take-home messages for such individuals: “*the treatment I’m having at the moment is working and things are diminishing, going away, going into remission, that sort of thing and they always say ‘oh that’s great, that’s great to hear’.*”(P17). Most patients described this as a way to reduce the family’s worry: “*I’m being selective with what I tell to certain people... I don’t want them to be hurt or worry too much*” (P19). P6 described managing information for friends including hiding frightening content and creating a positive message: “*I’ll just say ‘Oh its clearing up’, but thing is, you’re going to say that anyhow even if it wasn’t, you’re gonna put a, oh they reckon its doing well on...People just do, I mean when you’ve got cancer like, the word frightens people*” (P6). P15 even described giving his family incorrect information to try and protect them: “*I just told them like it was in two areas and actually it was in three or four so I didn’t tell them how advanced it was ...I just didn’t want to worry them.*”(P15).

Clues as unmanaged information

Information that was unmanaged by the clinician or care team or relatives left clues for patients to draw their own conclusions about aspects of their care. Often these conclusions felt threatening to patients.

Clues from the clinician

Whilst some clues led patients to make comforting interpretations, many clues were experienced as alarming. Though several patients explained that clinicians' demeanour indicated their genuineness and depth of care: "*his you know bedside manner, it's fantastic. Just his mannerisms I suppose and the way he's so tactful he's you know he really just oozes care*" (P20); "*he was lovely, he really was nice...It was helpful because it showed me how compassionate he is and how concerned he was*" (P2), patients also described using the clinician's demeanour as a lens through which they interpreted results: "*it did seem like it could be really really serious, because he looked a bit he looked a bit serious*" (P3); "*he was nervous telling me when he diagnosed it... he looked a bit worried*" (P6). P3 described being uncertain about the nature of the results he was receiving because the clinician's "*manner to me was guarded*" (P3).

Clues from outside the consultation

Unmanaged information often arose from outside the clinician's consultation, particularly from the Internet, and was often interpreted negatively: "*I went and had a look on the internet which was a mistake... don't go on the internet, it will frighten the life out of you.*"(P9); "*looking on the internet is the worst thing ever if you don't know what you're looking for*" (P19). P19 spoke of being given, perhaps accidentally, the technical report from his scan which he felt was threatening because it enclosed information regarding how advanced his condition was. P19 explained that he found it difficult that such information

was not managed for him: “*without giving me that they should have explained where [the disease] was*” because being left independently to interpret the report led to him “*making me own stories up*” (P19).

Patients also interpreted procedures of the healthcare system as clues. Some described how hospital letters contained information which may or may not have been important, but caused them to interpret something of importance about their medical situation: “*it was only when I got the letter for the rapid access clinic at [LOCATION] hospital that I thought ‘oh gosh’*” (P1). One lady described received a letter recalling her to clinic three months early and interpreting it as foreboding: “*my initial reaction is they’ve found something, what’s happening?*” (P13). A few patients described making negative judgements about aspects of their care based on which clinician they had been designated to see. Having described that he would have benefitted from having a senior clinician to be a figurehead for his care, P3 spoke of the questioning the team’s care after being assigned a less senior clinician to deliver his treatment outcome results: “*I just felt it would’ve been good to see the main person for such an important set of results, felt important to us anyway perhaps it wasn’t so important for them*” (P3).

Discussion:

To the author’s knowledge, this is the first study to identify the importance haematology patients placed on having information ‘managed for’ them rather than simply ‘given to’ them. In particular, indications that information had been prepared and managed demonstrated clinicians’ care and helped the patient to trust them. By contrast, patients often experienced unmanaged information as threatening and even alarming. The context for this finding was the intense uncertainty that patients described experiencing, reflecting the

variable and unpredictable course of their particular illness and treatment and also the working of the unit.

Patients did not describe wanting access to unlimited information; rather they wanted information to be constrained and managed for them. This is consistent with other findings in cancer care (Mendick et al., 2013). Some patients in the current study described an asymmetry in the information they wanted; that is, they wanted 'all' the information as long as it was 'good'. These findings reinforce research that described patients wanting doctors to constrain and manage information for them in a way that allows them to maintain hope (Sinding et al., 2010; Leydon et al., 2000; Salander et al., 1996). Some patients reported that they were given too much information. Recent research has suggested the importance of clinicians carefully selecting information to allow patients to be informed, rather than overwhelmed, by what they are given (Mendick et al., 2013). Patients receiving curative treatment need information that allows them to hope for their recovery or survival, and they need to trust their clinician to manage their overall care. Having hope for their health and trust in their clinician enabled patients to focus on day to day requirements which felt more manageable (Wright et al., 2004; Leydon et al., 2000; Salander and Hendriksson, 2005; Tan et al., 2005).

Existing research suggests that patients who experience poor interactions with the clinical team and system of care are left feeling anxious and insecure (Lilliehorn et al., 2010). Findings from the current study suggest that, if patients have difficulty trusting their clinician they find it more difficult to accept the information the clinician provides and to find it helpful. Indeed, patients who had difficulty trusting often reported seeking further information. This information was usually from sources external to the clinician and medical team. Frequently this consisted of looking for information on the Internet which,

paradoxically, patients generally reported to increase alarm as the information felt overwhelming. Sinding et al., (2010) also reported patients' descriptions of feeling overwhelmed and distressed by searching for information on the Internet.

Psychologists have used attachment theory to explain the importance of having a clinician to trust in the face of a cancer diagnosis (Bowlby, 1998; Lilliehorn et al., 2010; Salmon and Young, 2009). Research suggests that, in the face of a medical threat such as cancer, patients regard clinicians as an attachment figure (Ciechanowski et al., 2002). The role of an attachment figure is to provide "a secure base" to look to when feeling vulnerable (Bowlby, 2005). However, the uncertainty and changeability inherent in haematology care might make it more difficult for clinicians to provide security. Moreover, patients in this study reported not having a named clinician leading their care, which meant they had consultations with various members of the clinical team. This reflects the working of the study unit, where a shared multidisciplinary approach was taken to patient care. The resulting lack of continuity could have made it more difficult for patients to identify an attachment figure. Indeed, there were surprisingly few instances of patients describing a clinician in ways resembling attachment when compared to the findings in other areas of cancer care, such as breast cancer (Wright et al., 2004; Lillehorn et al., 2010) or and head and neck cancer (Isaksson et al., 2014). Several patients even explicitly described difficulty trusting their clinician and consequently not being content with the information they received.

Many of the existing studies into haematological oncology patients' information needs have approached the topic from the perspective that information is positive for, and valued by, patients. Findings from the current study contrast with this, indicating that, information is positive and valued by patients, but only when it has been managed for them by a clinician they trust. The present study findings are, however, consistent with existing qualitative

findings which suggest that patients prefer to avoid information from their clinicians about the severity and prognosis of their disease (Ernst et al., 2013; Friis et al., 2003; Salander and Hendriksson, 2005). Within this study's interviews, talk of prognosis was prominent, perhaps indicating that patients found it lacking from their consultations, but whether patients want to wholly avoid thinking about prognosis, or just to avoid hearing information about it from their clinician, is difficult to establish. Research in other areas of cancer care suggests that patients feel the need to maintain the clinical consultation as a place of safety and therefore to keep it separate from threatening information (Salander et al., 1999). Therefore not seeking this information from clinicians may be the patients' way of protecting the relationship and allowing themselves to maintain hope (Salander et al., 2014).

A key strength of this study was its inductive design which allowed patients to introduce and explore what they felt was important. The study had some weaknesses however. Although maximum variation sampling was used, a limitation is that all recruitment took place from one clinic and findings might differ in other clinics. Clinical diversity within the sample meant that aspects of importance to patients at specific points of their care, or for specific types of patients, may not have been identified. Nevertheless, the findings do identify processes that are seen across literature from other areas of cancer care, suggesting theoretical validity of the findings. The findings indicate that some patients had experiences through the process of care which affected their ability to trust the clinician and which, in turn, made them wary of information. This suggests that there may be critical periods or events which are more important for the development of trust in the clinician, or times when information is more threatening than others. However, this suggestion is to be considered tentative until it is possible to seek confirmation through longitudinal study.

Therefore, one implication for future research is the importance of illuminating how patients' information needs change over time and in response to events that affect their relationship with the clinician or medical team. In addition, further research could explore the importance of preparation and management of information to patients in other clinical populations. Exploring this could allow increased understanding of whether patients looking for indications that clinicians have managed information for them is something they are doing to help them cope with the uncertainty specifically found in haematological oncology, or if it is a more widely occurring management strategy.

The study suggests several potential implications for changes to clinical practice, at least in the study setting. This study identified a need for patients to be able to feel that they have a trusting relationship with a clinician. Therefore, within the context of the uncertainty inherent in haematological cancer and its treatment there is a need for clinicians to foster patients' confidence in their ability to manage the condition. One way of reconciling patients' need for this 'secure base' with the inherent uncertainty of the condition may be for the clinician to undertake "orientation" work with patients at their initial contact with the clinic. If the clinician shows awareness of the potential uncertainty of the precise disease trajectory this could allow patients to expect it and not be overwhelmed when changes occur. Clinicians would also need to explain their experience of working with uncertainty and how, if there are changes to a patients' condition, there is a plan to manage these. With this in place patients might feel more of a sense of safety from their care. Clinicians offering some certainty about relational aspects of care, such as assigning a named senior clinician who would have continued oversight of the patient's care, may also help to provide patients with some security by facilitating an attachment process. This could help patients to experience their care as being managed and therefore make it easier for patients to trust and build hope with the information they receive. Undertaking this work might protect patients from feeling they need to search for information from outside of the relationship. Additionally, it is

important for clinicians to be aware that patients can see aspects of the working of the clinic as containing information about their condition, and that such unmanaged information can be alarming. Finding that patients benefit from knowing they are under ‘a caring plan’ allows the team to provide security in addition to the single clinician (Lillihorn et al., 2010). This approach may be beneficial as systemic multidisciplinary team-based management of haematology patients is now recommended practice (NICE, 2003).

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Table 1. Sample Characteristic

Participant number	Gender	Age	Highest level of education	Most recent job sector	Present working status	Diagnosis	Months since diagnosis	Clinical situation	Format of results	Results received in index consultation	Days post-index consultation when interviewed	Location of interview
1	Female	30-35	Higher education	Professional/Management	Sickness absence	Lymphoma	6	Mid-course of treatment	CT scan	Treatment response-treatment effective: continue	7	Hospital
2	Female	55-60	Higher education	Care	Sickness absence	Lymphoma	0.5	Newly diagnosed	Blood tests	More detailed diagnosis and treatment ideas	2	Patient's home
3	Male	65-70	Higher education	Professional/Management	Retired	Lymphoma	8	Post treatment	CT scan	Treatment response-treatment effective: continue	2	Patient's home
4	Male	50-55	School	Manual	Working	Chronic Lymphocytic Leukaemia	120	Recently began treatment	Blood tests	Treatment response-treatment effective: continue	14	Patient's home
5	Female	80-85	School	Manual	Retired	Chronic Lymphocytic Leukaemia	156	Mid-course of treatment	Blood tests	Treatment response-treatment effective: continue	14	Patient's home
6	Male	70-75	School	Manual	Retired	Hodgkin's Lymphoma	5	Mid-course of treatment	PET scan	Treatment response-treatment effective:	.5	Hospital

										continue		
7	Female	65-70	Higher education	Professional/Management	Retired	Chronic Lymphocytic Leukaemia	24+	Mid-course of treatment	Blood tests	Bloods approved for more treatment	28	Hospital
8	Male	50-55	School	Manual	Sickness absence	Non-Hodgkin's Lymphoma	72	Ongoing treatment until it is no longer effective	CT scan and blood tests	Treatment response: some improvement but more treatment needed.	28	Hospital
9	Male	65-70	School	Manual	Retired	A low grade of non-Hodgkin's Lymphoma	60	Managed by watchful waiting, now requiring treatment	Blood tests	Relapse indicated: treatment to begin soon	.5	Hospital
10	Male	75-80	Higher Education	Professional/Management	Retired	Chronic Lymphocytic Leukaemia	24+	Managed by watchful waiting, now requiring treatment	Blood tests	Relapse indicated: treatment to begin soon	28	Hospital
11	Female	30-35	Higher education	Professional/Management	Sickness absence	Hodgkin's Lymphoma	4	Having treatment, changed mid-course	PET scan	Change to treatment plan, stronger dose prescribed.	14	Hospital
12	Female	65-70	School	Office/Clerical	Retired	Lymphoma	0.25	Newly diagnosed but still under investigation	CT and MRI scan	Confirming diagnosis and disease location	7	Hospital
13	Female	50-55	Higher education	Care	Working	Lymphoma	84	Managed by watchful waiting	Stomach biopsy, ultrasound, blood tests	Watchful waiting no intervention required	.5	Hospital
14	Female	60-65	School	Office/clerical	Retired	Chronic Lymphocytic	22	Blood results indicating	CT scan and blood	Commencing treatment	7	Hospital

						Leukaemia		treatment needed	tests	imminently		
15	Male	25-30	Higher education	Professional/Management	Sickness absence	Hodgkin's lymphoma	1.5	Mid-course of treatment	Blood tests	Bloods approved for more treatment	.5	Hospital
16	Male	25-30	School	Manual	Sickness absence	Non-Hodkin's lymphoma ?Burkitt's transformation	0.5	Having treatment, changed due to disease transformation	PET Scan and blood tests	Initial diagnosis given, treatment to commence	7	Hospital
17	Female	60-65	Higher education	Office/clerical	Retired	Hodgkin's lymphoma	14	Mid-course of treatment	PET Scan and blood tests	Treatment response-treatment effective: continue	21	Patient's home
18	Male	60-65	School	Manual	Unemployed	Chronic Lymphocytic Leukaemia	36	Watchful waiting	Blood tests	No intervention needed	5	Hospital
19	Male	60-65	School	Office/clerical	Retired	Follicular lymphoma	2.5	Recently started treatment	Blood tests	Bloods approved for more treatment	5	Hospital
20	Male	40-45	Higher education	Professional/Management	Working	T-cell leukaemia	6	Mid-course of treatment	CT Scan and blood tests	Bloods approved for more treatment	21	Hospital

Table 2. Forms of preparation described by P1

Form of preparation	Example from data
Selecting information	<i>“I suppose you have to make judgement calls don’t you, on how you tell people, what you tell people, in the time that you’ve got”</i>
Arranging take-home material	<i>“he gave me loads of paper, booklets and different websites so I’ve got all the information to hand”</i>
Meeting with other professionals to discuss patient’s needs and adjust care accordingly	<i>“[COUNSELLOR] had already been in and said ‘[PARTICIPANT] is waiting and she’s nervous’”</i>
Knowing the results to be delivered in advance	<i>“so as soon as I got in he just blurted out ‘it’s good news’, so yeah, which was relaxed, just relaxed me straight away.”</i>
Consideration of a patient’s ability to manage or understand information	<i>“they’d discussed and wondered how much to tell me but because I’d asked, I was knowledgeable and asked questions, I knew that they’d given me the full information”.</i>

Table 3. Forms of preparation which were noticeable in their absence

Form of preparation	Example from data
Clinician knowing the news that s/he has to deliver before the consultation	<i>“she was like reading them off the screen for the first time, I don’t think, I’m not even sure knew what they were when I walked through the door!”(P3).</i>
Knowing the reason for the consultation	<i>“I said ‘ok so what was the reason for the callback?’ She said ‘oh have you been called back?’ Now that to me is not good, that to me is like oops I’m seeing a doctor who doesn’t know why I’m here...she should have read up before I came in the room to say actually why I was coming back in.” (P13).</i>
Knowing the patient’s history if it is available	<i>“to say ‘what have you had done?’ with the reports and the notes in front of you is a bit stupid really” (P13).</i>

Trying to obtain missing information in a timely manner

“He could have done more to find the results of the MRI scan. You know like he did try to chase up the pathologist but this was like a week after I had, had the biopsy done and he said ‘oh she is not there’ and he said he promised me that he would call if he got the results and that. Whether he, I felt as though he wouldn’t. Soon as I come home I thought I am not going to get any phone call. I knew.”(P2).
