

# **‘Haematological cancers, they’re a funny bunch’: A qualitative study of Non-Hodgkin lymphoma patient experiences of unmet supportive care needs.**

## Abstract

Despite high levels of psychological distress, there is a scarcity of research on unmet supportive care needs in haematological cancer patients. This qualitative study used an in-depth interpretative phenomenological approach to investigate the needs reported by six Non-Hodgkin lymphoma patients and explored how these needs consequently shaped the patient experience. Emergent themes included: concerns for family, information needs and the need for psychological support. Participants reported feeling different to other cancer patients. Lack of understanding of their diagnosis by friends and family, and access to relevant support services, are notable unmet needs that differ from previous findings.

## Introduction

Being diagnosed with a life threatening illness such as cancer can induce significant levels of emotional and psychological distress for both patients and their loved ones (Holland and Alici, 2010; Pitceathly and Maguire, 2003). Haematological cancers are a unique and highly diverse groups of diseases that are known to impact upon a person's wellbeing (Molassiotis et al, 2011; Manitta et al, 2011; Montgomery et al., 2003), with key differences between these diseases and solid cancerous tumours. Yet, there is a lack of published research relating to the specific unmet supportive care needs that are most pertinent for this patient group (Swash, Hulbert-Williams and Bramwell, 2014).

Haematological cancers display several key differences to solid tumours such as breast, lung or colorectal cancer. There are **pathological** differences that can affect treatment type, but, perhaps more importantly for patients, which translate into differences in the organisation of services; there is a clear degree of separation from those services aimed at solid tumours (NICE, 2003). There are also **access** differences: people with haematological cancers are more likely to be treated in local district general hospitals rather than specialist cancer units, they are less likely to receive specialist palliative care, and they are more likely to die in hospital (Howell et al, 2011). The reasons behind this are complex and not well defined. **Treatment** for haematological cancers can either be notably intensive, impacting upon social, vocational and functional roles (Sherman et al, 2005) or, conversely, patients may not be treated at all and instead monitored via a 'watch and wait' regime, creating a mismatch with the common understanding of what will happen when you receive a cancer diagnosis (Evans, Ziebland and Pettitt, 2012). In either case, receiving a diagnosis of this kind can have a significant impact upon a person's psychological wellbeing and the way in which they continue their everyday lives.

As haematological cancers differ from solid tumours in such basic ways, it is difficult to predict the extent to which the most common and disabling psychosocial concerns to affect this patient group may align with those identified by patients with other cancer diagnoses. Psychosocial needs are theoretically well defined and this framework has been repeatedly applied within cancer populations (Sanson-Fisher et al, 2000; Morrison et al, 2012; Armes et al, 2009). Commonly identified unmet needs in general cancer groups include: information needs, needs relating to healthcare professionals, and practical needs (Harrison et al, 2009). What is less well understood is whether the needs of haematology patients coincide with those of other cancer patients, and to what degree the differences in presentation and care result in different unmet psychosocial needs, and indeed whether the impact of these needs can provide an explanation for different profiles of psychological wellbeing.

There is a paucity of research that explores the experiences of people diagnosed with lymphoma (Elphee, 2008; Caldwell, 2014). A thorough understanding of patient experiences and unmet needs is vital if we are to adequately and effectively implement psychological or supportive care interventions for different patient groups. The lack of knowledge of specific needs in haematological cancer are thus a considerable barrier to high quality care. This study aims to investigate: (i) the experiences of psychosocial needs in haematological cancer patients, (ii) why specific needs were felt to be important, and (iii) the impact that unmet needs had on the overall patient experience.

## **Methodology**

### **Procedure**

Three small focus groups were conducted with patients with Non-Hodgkin's lymphoma, the most common type of haematological cancer diagnosed in the UK (Cancer Research UK, 2014). The focus groups were designed to explore the type of needs that patient's had throughout their experiences of diagnosis, treatment and survivorship.

All three focus groups were conducted within a hospital setting in the North West of England, although away from the ward environment for privacy and comfort. Focus groups were audio recorded and subsequently transcribed verbatim. The transcripts were analysed using Interpretative Phenomenological Analysis (IPA: Smith, 2004; Smith and Osbourn, 2004; Palmer et al, 2010). The lead researcher completed initial analysis of all transcripts, with all transcripts independently verified by a second researcher. Once a first draft of the results narrative was complete, the second researcher again reviewed the transcripts to provide a second level of validation to ensure that the analysis framework proposed fitted with the raw data accurately. In this way, the validation of themes became part of the analysis process as it added a further layer to the exploration and interpretation of the data.

All focus groups were conducted by the lead researcher, with the assistance of a co-facilitator to help with practicalities. The average length of time for the focus groups was 90 minutes.

Ethical approval for the study was obtained from NREC and the University of Chester Department of Psychology Ethics Committee, and local research governance was obtained at the participating NHS trust.

## **Sample**

Participants with a diagnosis of a haematological cancer were recruited via Consultant Haematologists in outpatient clinics in a hospital in the North West of England. Information packs were provided to participants by their Consultant Haematologist during routine clinic appointments, with an option to speak with the researcher if desired. Participants were required to be at least 18 months post-diagnosis and to have completed their treatment regimes. Any haematological cancer diagnosis was initially deemed acceptable for the study; however, all consenting participants had a diagnosis of Non-Hodgkin's Lymphoma; this is not surprising given the higher diagnostic rate of this particular cancer type in the adult population. All participants were over the age of 18, and were either married or had a long-term partner. 83% of the sample were male. All participants had been actively treated with chemotherapy for their lymphoma, with one participant having first been monitored on 'watch and wait'.

Six participants were recruited in total. Three focus groups were conducted, each containing two participants. Though small, these group sizes were beneficial in order fully explore each participant's experience, allowing for each individual narrative to emerge within a shared context, while still allowing for a direct comparison between experiences within the group.

## **Interview Schedule**

The groups were designed to prompt discussion both with the interviewer, and between participants, about the type of needs experienced throughout each patient's cancer experience, and to gain a level of understanding of why some needs were highlighted as important while others deemed not relevant.

The focus groups were facilitated to discuss the following key topics in the following schedule:

1. The majority of the session was spent discussing their met and unmet needs without prompting.

2. To spend some time looking at the item pool drawn up from existing needs assessment tools (physical, psychological, identity, social, practical, healthcare professionals, sexual, information, communication, cognitive function, financial, spiritual, employment) and to discuss the relevance of items.
3. The comparative importance of both the needs that they themselves identified and the needs identified from the current assessment tools.
4. Participants were then asked to highlight their key needs.

Analysis of the data was open and not structured around existing needs, rather the research aimed to determine the extent to which themes generated did correspond with existing needs; and a level of reflexivity was used both throughout the focus groups themselves and during the analysis process whereby the researcher was aware of the potential for bias and continued to question whether an existing knowledge of unmet needs in cancer was influencing the current situation.

## Results

Analysis of the data resulted in six super-ordinate themes as presented in Table 1. Participants were assigned pseudonyms, which will be referred to throughout the results section in order to preserve anonymity.

*Table 1: Super-and sub-ordinate themes.*

<b>Super-Ordinate Themes</b>	<b>Sub-Ordinate Themes</b>
The Everyday Impact of Cancer	Practical Physical
Psychological Needs	Adjustment Throughout the Cancer Experience The Importance of Environment Perceptions of Self Specific Areas of Psychological Need
The Need to Feel Supported Throughout the Cancer Experience	Social Support Feeling Supported by Medical Professionals Availability and Acceptability of Psychological Support Being Supported as a Haematology Patient
Barriers to Accessing Support	Feeling Unable to Ask for Help Physical vs. Psychological Psychosocial Concerns Not Discussed
Making Sense of the Cancer Experience	Personal Changes Understanding My Experiences Control
Need for Information	Delivery of Information Having Personalised Information Available

### ***The Everyday Impact of Cancer***

Being diagnosed with cancer was felt to impact upon daily routines and on participants' ability to continue in their daily lives as they had done prior to their diagnosis. This was felt to happen in two distinct ways: by affecting what people can and need to do practically; and how physically able participants felt themselves to be.

Practically, what had previously been viewed as simply part of everyday life, now became matters of concern that required attention.

*"I was thinking only the other day that I need to update my will" David*

However, while present, practical needs were felt to have been well supported by the healthcare teams at the hospital.

*"They do go to quite a lot of effort don't they to find out who you live with, who's there. What your property's like" Mark*

As a result of needs being met, there was little in the way of associated psychological distress or anxiety. This was also reflected in how participants perceived the presence of physical need. There was an expectation that cancer would affect physical wellbeing, as such, these needs were expected by participants and healthcare professionals who were felt to be geared up to help with this.

*"Anything around, if you needed, you know... the washing, the dressing, the sleeping stuff, yeah that was dealt with" Mark*

It was accepted that cancer treatment would have a physical impact. The physical impact of treatment was perceived to vary across the sample but generally this was a time when participants felt supported



due to frequent contact with HCPs. Once treatment ended, however, the level of support available to participants was felt to drop away without allowing participants time to acclimatise which was felt by participants to be difficult to manage. When combined with the on-going physical effects of cancer treatment, it was at this stage that the physical impact was harder to cope with as this defied the hope that life would return to normal after treatment.

*"It made me so ill. It's taken me... this is my hair now, and I lost it two years last August. And this is all I've still got so you can imagine (...) but the fact that I've never been as thin as this in my life, and so you feel a mess, a mess in clothes. And so I found it hard to, to... get going to put one foot in front of the other, I was just so exhausted. And, I have to say, still am a lot of the time."* Daphne

### **Psychological Needs**

Adjusting psychologically to the knowledge that they had cancer was felt to be far more difficult than the physical impact of disease. The initial delivery of the diagnosis was felt to be important and had a real impact on how participants perceived their situation, where conversations around diagnosis were felt to be less sensitive than would be desired.

*"Basically I sat in front of him and he said, "you've got cancer"... what you got is probably incurable, and you need to see a specialist. And then, off you go. So." David*

Diagnosis was felt to be a crucial time psychologically: one that had the potential to cause a great deal of anxiety and distress. Once this had been overcome, the end of treatment was also identified as another pivotal time in how people coped and adjusted to having cancer. This latter time point is especially pertinent due to the swift and often unexpected removal of the safety net of regularly seeing clinicians, frequently being in the cancer treatment setting, and knowing that any concerns could easily

be addressed. Being left to cope alone was difficult. Participants described giving their all to 'fighting' their illness, and then being left empty once the immediate danger had passed.

*"I just, having got the all clear and having got that letter, I just... just descended. I just couldn't face anything. And I don't know... I'd just given everything." Ray*

It was at this point that participants' sense of purpose could become lost, and uncertainty around what the future might hold sets in.

The perceptions of others were also felt to be important. There was a need to believe that they would get better and to keep positive, both from themselves and from those around them. Where this was not the case, the lack of positivity was difficult.

*"a lot of people think as soon as you've mentioned cancer, they think god, we'll be burying him soon."*  
*James*

The importance of the perceptions of others was a theme that continued throughout the focus groups. Participants felt that the way in which they were seen by others changed as a result of their cancer diagnosis and often meant that people felt labelled as a cancer patient rather than seen as an individual.

*"I think, sometimes, when people are ill, some people see the illness and not the individual (...)I think sometimes, if you've had cancer, people see you as a cancer sufferer, or a recovering cancer sufferer, rather than as John or Fred." David*

Being treated as an ill person was difficult enough for these participants, but being seen as a 'cancer patient' was something even worse as this signified a greater deviation from one's own sense of self and individuality.

*"I didn't want to be defined... I was pretty touchy about it (...)it's a small part of my life but it's, you know, I'm very happy that I'm being checked out every year but... did I want people to know at the time?" Mark*

This feeling of changes to one's very self was mirrored in changes to the body and body image. Physical changes were felt to be a manifestation of the disease that signalled to the world that they were ill.

*"it was just a way of saying really, look there's, there's this problem." Mark*

Feeding from this, there was guilt associated with the perception that body image could impact so greatly on psychological wellbeing, when one's very life was under threat. And yet image was felt to be central to participants' sense of self. While the impact of cancer on body image was not felt to be of importance by friends and family, it mattered to the person who was trying to maintain a sense of self throughout their experience.

*"But it's the support network that...come on it doesn't matter. It does matter. It matters what you... it matters to the person." Daphne*

Other more specific areas of psychological need raised were fear of recurrence, maintaining hope, coping and struggling with emotions such as guilt and anger.

### ***The Need to Feel Supported Throughout the Cancer Experience***

Feeling supported was important to all participants, and where it was absent, the consequent unmet need was felt keenly. Both informal social support and support from healthcare professionals was important. For all participants, support from haematology staff, including both the haematologist and haematology nurses, was felt to be of greater relevance than support from primary care clinicians.

Relationships with family and friends were valued highly, therefore, when support was not forthcoming, the resulting impact was strong.

*"I was a little bit surprised about who kind of put what into the pot." Mark*

However, participants identified too that maintaining relationships was difficult when there was so much else going on both practically and emotionally.

*"I didn't want to make contact cos I just couldn't cope cos I was up to here." Daphne*

Communication between the patient and professional was a key determinant of how well supported participants felt throughout their cancer experience. Successful communication was defined by these participants as the giving of clear and individually-tailored information, and the way in which information was delivered was crucial.

*"even though they kept explaining things... they use big words and names of stuff." James*

Regular contact from clinical staff during the diagnosis and treatment phases was welcomed and created a feeling of being supported. When treatment was completed, however, this sense of support was suddenly absent creating feelings of isolation and uncertainty.

*"And then you're fired off the end. You're at home aren't you? Well, you are, and I think that maybe that's the time when..." Mark*

Given the noted importance of psychological needs, the need to feel that there was support available to address these needs was key. There were differences between participants in the extent to which formal support would have been desired,

*"I'd rather have somebody prescribe something than deep, psycho, self analysis. It's just not something that I felt, I had a really strong support via my own wife and colleagues and friends" Mark*

For those who were more open to receiving support, there was uncertainty around what help was available or how acceptable it was to ask for such help.

*"you don't get any interaction with a psychologist or someone who understands these things, if you are feeling depressed, you would probably tend to keep it to yourself because you're sat in a room with 12 other people." David*

A complicating factor to feeling supported was the perception that haematological cancers are different from other cancers. There was a feeling that lymphoma is less well recognised and understood than other cancer diagnoses.

*"they think cancer's cancer, and it isn't is it?" Mark*

Haematological cancers were perceived not to fit well with other cancer diagnoses, instead feeling more like living with a chronic illness.

*"I'm in remission, and, you know, hope to be so for as long as possible but, there's no outward signs. Now, if you've had aggressive breast cancer and, for instance, you've had a mastectomy... and your body image changes. Whereas here there isn't much to take away, it's all, it's more medicine than surgery and it's more like diabetes that's controlled." David*

This created a sense of isolation and separation both from family and friends who were perceived not to understand what these participants were experiencing, but also from other cancer patients who were perceived to have access to better support services.

*“Now if you’ve got cancer, the Macmillan nurses are superb.” Daphne*

This sense of separation was compounded by a lack of outward signs of the disease. This was felt to be both positive and negative, in that it made it easier to get on with everyday life, but at the same time heightened feelings of difference from both family and peers.

*“If you’ve got, breast cancer, or you have testicular cancer, or prostate cancer or kidney cancer or bowel cancer, or something, you tend to lose, you tend to, you know, I’ve had colleagues and family members who’ve had these other forms of specific cancers like that, and they do tend to look ill... Whereas, I didn’t. I haven’t lost any weight. I haven’t gained any but I haven’t lost any. Um, I looked a bit grey the day after I’d had the chemo... and, what is both a good and a bad thing is that the people who, the people that you meet and who know you’ve got this, forget it.” David*

While many support services would categorise haematological diagnoses as cancer, participants crucially did not and supportive care services were not seen as accessible or relevant to them. Some participants did access haematology-specific support groups that were run by national charities, but this involved travelling long distances to attend. It was also highlighted how accessing peer support could be problematic, as it is difficult to remain positive about your own prognosis when others with the same diagnosis are seen to be becoming increasingly unwell or pass away.

### ***Barriers to Accessing Support***

Psychological needs were repeatedly highlighted as important, yet often remained unmet through treatment as participants described feeling uncomfortable or unsure about raising their concerns with clinicians.

*"I think the support is there if you want it. You just ask. But I think sometimes, do you not think people are afraid to ask? In case, because everyone's busy, I think some people get it in their head, oh I can't, I'd better not ask in case they're busy." Mark*

Repeatedly, the busyness of the clinical environment was noted to be a barrier to expressing needs, with clinicians already juggling many tasks, with some (i.e. treatment) taking priority. As such, participants did not feel comfortable raising a concern that was seen as an aside to their cancer or their treatment, for fear of wasting the healthcare professional's time.

*"I kept saying that I, I'm sorry, I don't like troubling you." William*

Hospitals were deemed places where cancer was treated and medical concerns addressed, therefore the physical aspects took predominance over the supportive, and thus psychologically-related concerns were not raised. Participants instead put on a 'brave face' and maintained the façade that all was well.

*"Unless they've got time to spend speaking to you, they cannot hear what's happening inside you. And it's the bits you can't see." Ray*

### ***Making Sense of the Cancer Experience***

Participants described feeling a need to make sense of their experiences, and forming comparisons with others was found to be a useful way of doing this while also helping to decrease feelings of isolation. Seeing others survive and thrive after cancer was viewed as a powerful source of hope; seeing others struggle on the hospital ward was difficult, however provided some form of comparison to determine how well they were individually coping.

*"looking at others, and the way that some people only get halfway through their first lot of the day and be really struggling... And it's the determination of the staff, I felt that they were going about things in such a way that just added to my own determination... that I was going to deal with this, they were doing so much and dealing with it so well, that, even if I had a problem, there was no way I could let them know."* Ray

While forming comparisons could be positive, it could also create feeling of guilt that others were perceived to be coping with worse treatments, symptoms and prognosis. This had the effect of creating a barrier to asking for help and support from healthcare professionals for these patients who didn't want to take clinicians' attention away from those with greater need.

Taking control of one's own experience was a powerful force in enabling participants to own their experience and to make sense of what was happening to them.

*"I did feel as if we knew exactly where we were and what the next step was, and broadly what the significance of every part of the intervention was."* Mark

For others, surrendering control to their clinicians and deferring to the perceived experts seemed a helpful way of placing the locus of control outside of themselves.

*"There's nothing you can do about it, you're in the hands of other people who will hopefully do the right thing for you."* David

### ***Need for Information***

Two aspects of information giving were deemed important: first, the actual delivery; and second, ensuring that it was personalised to the individual. These participants reported that in their experience



the delivery of information was generally appropriate. However, the need for clearer, concise information was emphasised.

*“words of one syllable... and plain, simple English.” James*

Having information about diagnosis and treatment was highly valued, yet the need for the information given to be relevant and wanted by the individual was highlighted repeatedly.

*“when you first start you get all these generic leaflets on, you know, how do you get a wig. I don’t need a wig. What’s going to happen if..., what’s the likely side effect?” Mark*

A sensible balance between a realistic prognosis while allowing the maintenance of hope was what all participants hoped for.

## **Discussion**

This paper highlights areas of unmet psychological and supportive care needs that are of particular relevance to haematology patients. Broadly, the needs discussed by these participants can be divided into two groups: those that tie in with what we already know about unmet need in cancer, and those that add something new. With the exception of the themes centred around the specific differences innate to being a haematology patient and the barriers to accessing support, the themes drawn from these focus groups indicate a level of similarity in the type of unmet need found in patients with differing cancer diagnoses (Armes et al, 2009). It may be that for some areas of need, for example physical impact, psychological concerns or practical matters, that type of need is common across cancer regardless of the specific diagnosis (Harrison et al, 2009).

There were recurrent indications that, as haematology patients, participants felt themselves to be different from 'cancer patients': there was the lack of outward signs and the absence of looking 'ill'; the separation in treatment and associated terminology, for example being treated by haematologists rather than oncologists; and, for some, the modality of treatment was felt to differ, with lymphoma being likened to a chronic health condition, rather than an acute cancer. These perceived differences were a cause of frustration. Feelings of isolation, of being misunderstood by others, and of being less able to access appropriate support services compared with other cancer patients negatively impacted these participants' cancer experiences. Feelings of isolation or loneliness as a result of a cancer diagnosis have been highlighted previously (Helgason et al, 2001; Refsgaard and Frederikson, 2013), yet this has commonly been in relation to changing lifestyles or altered relationships with significant others, not as a result of diagnostic categorisation. Across this sample no participant identified themselves as a 'cancer patient'. Participants perceived their diagnosis to be poorly understood by both the general

public (from which their informal social support is drawn) and by some healthcare professionals, notably non-cancer professionals such as general practitioners: this was believed to be not the case for other cancers. But, perhaps more importantly, participants did not identify *themselves* as being cancer patients and this was evident in two distinct ways. First, a widely held belief was that they were primarily haematology (or specifically lymphoma) patients: the perceived differences between haematological and other cancers affected their views of both how acceptable services such as generic cancer support within the hospital or external charity-led support programmes were, and whether they felt comfortable accessing those support services when they do not identify as a 'cancer' patient.

Second, some patients simply did not wish to be associated with a 'disease label' at all, and the suggestion that they should adopt the label of 'cancer patient' was felt to be unreflective of who they believe themselves to be, and the self that they wish to portray to the world. If existing support services are designed with cancer patients in mind, a group to whom participants did not feel a sense of belonging, then the applicability of such services to those with a haematological diagnosis may be questioned. These participants were clearly unsure about whether these existing cancer services were available, or even relevant, to haematology patients. In the absence of formal support services, participants were accessing support through their own social support networks or, in two cases, via disease-specific support groups. It is not clear however, whether these choices were made out of preference for this type of support, or as a result of the perceived lack of alternatives. These findings are novel and have not been reported elsewhere in the psychosocial oncology literature. What we were unable to ascertain from this study, however, was whether this perceptual difference comes from the patients themselves, or whether healthcare and support staff working in both oncology and haematology settings perceive this difference too.

Patients reported feeling uncomfortable about raising psychosocial issues with their clinicians, a situation that was compounded by a perceived reluctance from clinicians who also did not typically raise discussion of these kinds of concerns in the oncology clinic; the implication of this bi-directional reluctance is that psychosocial concerns often simply weren't discussed with anyone. It has been recognised that clinicians can find it difficult to raise psychological issues with cancer patients, yet NICE (2004) have proposed a model of stepped-care to illustrate how clinicians at all levels can contribute to the maintenance of psychological wellbeing in cancer patients. Unmet needs assessments such as the Holistic Needs Assessment (HNA) and the distress thermometer (National Comprehensive Cancer Network, 2013) have been developed as tools to help clinicians detect distress, yet there is a great deal of variability in their use with the National Cancer Patient Survey in 2011/2012 finding that only 24% of cancer patients were offered a needs assessment and subsequent care plan (Department of Health, 2012). Training packages have been developed that aim to improve clinician efficacy at detecting and managing distress within a general healthcare setting (Merckaert et al, 2005; Fallowfield et al, 2002). While these kinds of training programmes do seem to improve clinician confidence in their abilities and short-term competence (Fallowfield et al, 2003), there is less convincing evidence as to whether there are also improvements in ability to accurately detect distress or whether ultimately patient experience is improved (Moorey, 2013). The idea that cancer professionals do not always accurately detect the presence of psychological morbidity is not new (e.g. Fallowfield et al, 2001) and further work is needed to extrapolate the current evidence base in order to improve clinician confidence in raising psychological concerns with patients and to ultimately improve the patient experience.

This work also highlights barriers that are preventing patients who would benefit from psychological support from attempting to access this. If healthcare professionals do not raise psychosocial concerns

within the clinic, and patients do not feel able to do so themselves, these needs will inevitably be left unaddressed. The need for HCPs to raise concerns and to feel confident in their abilities to do so is key. Existing research highlights the fact that many HCPs feel a lack of confidence in their ability to manage psychological distress (Moorey, 2013), as such there has been an influx of training programmes that aim to improve confidence and efficacy. Evaluations of these programmes have found that they do improve confidence but it is unclear as to whether there are also improvements in clinician ability to accurately detect distress and whether patient experiences are ultimately improved.

While this study provides a valuable insight into the lived experiences of psychosocial needs in haematological cancer patient, it also highlights the need for ongoing and systematic quantitative assessment of unmet need in haematology, just as is recommended for other cancer groups (Watson et al, 2012). From a research perspective, there is a need for large cohort studies, ideally with multiple types of haematological diagnoses, recruited to inform the sector about the unmet needs of different patient groups, and to supplement this work on ideographic patient experiences. Recommendations by the National Cancer Survivorship Initiative (2010) include the use of cohort studies as a way of mapping areas of need within cancer survivorship and as a method to develop priorities for future studies. There is also a need to better understand the supportive care preferences of this patient group. It became apparent within this sample that participants had not accessed support services that were designed for 'cancer patients', despite their unmet needs not appearing to differ greatly. Future research should seek to establish whether a change in how existing support services are marketed to patients would increase uptake, or whether haematological cancer patients would prefer to access support services that are targeted towards their specific patient group.

There are both benefits and limitations of conducting a study with a small sample size. The intention of this study was to better understand patient experiences of need during cancer and how unmet needs impacted upon overall wellbeing; however, this does mean that applicability to the wider patient population is problematic. Indeed, given the qualitative epistemology of this study, application of the findings to a whole patient population was not the objective of the work. Rather, this study was designed to provide a depth and richness that could fit alongside subsequent quantitative works from which wider generalisation could be inferred. The small sample was, in part reflective of challenges encountered when attempting to recruit participants into the study. While homogeneity within the sample was appropriate given the use of IPA, it does reflect a wider problem within psychosocial oncology research in attempting to recruit diverse samples that reflect society within the UK today. However, the dominance of males within the sample was deemed positive as men are typically harder to engage in psychosocial oncology research than women. Indeed, difficulty recruiting cancer patients into psychosocial studies is a challenge beyond that presented within this paper and is a challenge for psychosocial research in the UK today.

In conclusion, this work demonstrates a clear perceived difference between haematological cancer patients and other cancer patient groups. Though drawn from a small sample, this work is novel and has direct implications for both how these patients identify themselves, and in reducing the perceived acceptability of support services that are designed for general cancer patient populations.

Understanding which unmet needs are most prominent is the crucial first step in designing interventions and clinical services to begin to meet those needs, and this work clearly demonstrates the potential psychological impacts of such needs remaining unmet.

The Author(s) declare(s) that there is no conflict of interest.

## Reference List

Armes J et al (2009) Patients' Supportive Care Needs Beyond the End of Cancer Treatment: A

Prospective, Longitudinal Survey. *Journal of Clinical Oncology*, 27(36), 6172-6179.

Cancer Research UK (2014) Cancer mortality statistics. Available at:

<http://www.cancerresearchuk.org/cancer-info/cancerstats/mortality/>. Last accessed on 01/01/2015.

Caldwell, E (2014) Experiences of living with incurable haematological malignancy: A research portfolio.

Available at: <https://www.era.lib.ed.ac.uk/bitstream/handle/1842/9881/Caldwell2014.pdf?sequence=1>

Last accessed on 26/05/2016

Department of Health (2012) National Cancer Patient Experience Survey 2011/12 - National Report.

Available at:

[https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/212860/Cancer-](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/212860/Cancer-Patient-Experience-Survey-National-Report-2011-12.pdf)

[Patient-Experience-Survey-National-Report-2011-12.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/212860/Cancer-Patient-Experience-Survey-National-Report-2011-12.pdf) Last accessed on 13/05/2016.

Elphee, E (2008) Understanding the concept of uncertainty in patients with indolent lymphoma.

*Oncology Nursing Forum* 35(5): 449-454.

Evans J, Ziebland S, and Pettitt A (2012) Incurable, invisible and inconclusive: watchful waiting for

chronic lymphocytic leukaemia and implications for doctor–patient communication. *European Journal of*

*Cancer Care* 21, 67–77.

Fallowfield L, et al (2001) Psychiatric morbidity and its recognition by doctors in patients with cancer. *British Journal of Cancer*, 84(8), 1011-1015.

Fallowfield L, et al (2002) Efficacy of a Cancer research UK communications skills training model for oncologists: a randomised controlled trial. *Lancet*, 359, 650–656.

Fallowfield L, et al (2003) Enduring impact of communication skills training: results of a 12-month follow-up. *British Journal of Cancer* 89: 1445-1449.

Harrison J D, et al (2009) What are the unmet supportive care needs of people with cancer? A systematic review. *Supportive Care in Cancer*, 17(8), 1117-1128.

Helgason AR, Dickman PW, Adolfsson J, et al. (2001) Emotional isolation: Prevalence and the effect on well-being among 50-80-year-old prostate cancer patients. *Scandinavian Journal of Urology and Nephrology*, 35, 97–101.

Holland J and Alici Y (2010) Management of distress in cancer patients. *The Journal of Supportive Oncology*, 8, 41-12.

Howell DA, et al (2011) Haematological malignancy: are patients appropriately referred for specialist palliative and hospice care? A systematic review and meta-analysis of published data. *Palliative Medicine*, 25(6), 630-641.

Manitta VJ, Philip J, and Cole-Sinclair MF (2010). Palliative Care and the Hemato-Oncological Patient: Can We Live Together? A Review of the Literature. *Journal of Palliative Medicine*, 13(8), 1021-1025.

Molassiotis A et al (2011) Unmet supportive care needs, psychological well-being and quality of life in patients living with multiple myeloma and their partners. *Psycho-Oncology*, 20, 88-97.



Montgomery C, et al (2003) Predicting psychological distress in patients with leukaemia and lymphoma.

*Journal of Psychosomatic Research* 54(4): 289-292.

Moorey S (2013) 'I know they are distressed. What do I do now?' *Psycho-Oncology*, 22, 1946–1952.

Morrison V, et al (2012) Common, important, and unmet needs of cancer outpatients. *European Journal of Oncology Nursing*, 16(2), 115-123.

Merckaert I, Libert Y, and Razavi D (2005) Communication skills training in cancer care: where are we and where are we going? *Current Opinion in Oncology*, 17, 319–330.

National Cancer Survivorship Initiative (2010) Priorities for research on cancer survivorship. A report from the NCSI Research Workstream June 2010. <http://www.ncsi.org.uk/wp-content/uploads/NCSI-Research-Priorities-Report.pdf> (accessed December 2015).

National Comprehensive Cancer Network (2003) Distress management clinical practice guidelines. *J Natl Comp Cancer Network* 1: 344–374.

NICE (2003) Improving outcomes in haematological cancers. Available at:

<http://www.nice.org.uk/guidance/ta251/documents/leukaemia-chronic-myeloid-first-line-dasatinib-nilotinib-and-standarddose-imatinib-appraisal-consultation-document2> Last accessed on 10/07/2015.

NICE (2004) Improving supportive and palliative care for adults with cancer. Available at:

<https://www.nice.org.uk/guidance/csgsp>. Last accessed on 13/12/14.

Palmer M, et al (2010) Developing an Interpretative Phenomenological Approach to Focus Group Data.

*Qualitative Research in Psychology*, 7, 99-121.

Pitceathly C and Maguire P (2003) The psychological impact of cancer on patient's partners and other key relatives: a review. *European Journal of Cancer*, 39, 1517-1524.

Refsgaard B and Frederiksen K (2013) Illness-related emotional experiences of patients living with incurable lung cancer: A qualitative metasynthesis. *Cancer Nursing*, 36(3), 221-228.

Sanson-Fisher R, et al (2000) The unmet supportive care needs of patients with cancer. *Cancer*, 88(1), 225-236.

Sherman R, et al (2005) Dialogue among survivors of hematopoietic cell transplantation: Support group themes. *Journal of Psychosocial Oncology*, 23(1), 1-24.

Smith JA (2004) Reflecting on the development of interpretative phenomenological analysis and its contribution to qualitative research in psychology. *Qualitative Research in Psychology*, 1, 39-54.

Smith J and Osborn M (2008) Interpretative phenomenological analysis. In JA Smith (Ed) *Qualitative Psychology: A Practical Guide to Methods* (second ed) London: Sage.

Swash, B, Hulbert-Williams, NJ & Bramwell, R (2014) Unmet psychosocial need in haematological cancer: A systematic review. *Supportive Care in Cancer* 22 (4): 1131-1141.

Watson E, et al (2012) Personalised cancer follow-up: risk stratification, needs assessment or both? *British Journal of Cancer*, 106, 1-5.