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**Experiences of living with incurable  
haematological malignancy:**

**A research portfolio**

Ellie M. Caldwell

Doctorate in Clinical Psychology

The University of Edinburgh

August 2013

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## **Acknowledgements**

I would like to firstly thank the people who generously gave their time to take part in this study and to share their experiences for the benefit of others.

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# Thesis Overview

This thesis follows the research portfolio format and is carried out in part fulfilment of the academic component of the Doctorate in Clinical Psychology at the University of Edinburgh. An abstract provides an overview of the entire portfolio thesis. Chapter One contains a systematic review of published research investigating the experience of living with incurable forms of haematological malignancy. Chapter Two is an empirical study exploring adults' experiences of living with follicular lymphoma while being maintained under the 'watch and wait' protocol. Both chapters are prepared for submission to the European Journal of Cancer Care, and follow their author guidelines.

## Word Count

Systematic Review:	5,741
Journal Article:	7,741
Portfolio Total:	13,482

# Thesis Abstract

**Aims:** Despite advances in cancer treatments, many types of haematological malignancy remain incurable. The aims of this research portfolio are: Firstly, to review the published qualitative literature pertaining to the experience of living with any form of incurable haematological malignancy; and secondly, to research the experience of living with a low-grade malignancy, follicular lymphoma, while being maintained under observation without active treatment.

**Method:** A systematic review and meta-synthesis of the literature was carried out. The methodology employed strict inclusion criteria and resulted in the identification of eight qualitative studies for inclusion in the review. For the research study, adults (n=9) diagnosed with follicular lymphoma were interviewed about their experiences of living with the condition. Interpretative Phenomenological Analysis was used to analyse the data.

**Results:** The review highlighted the paucity of research in this area, with the majority focusing on people diagnosed with myeloma. However, the quality of identified research was high, lending confidence to the conclusions of the reviewed studies. Themes identified from the collective body of literature were: The need for information; impact and meaning-making; coping with an incurable condition; and adjustment and integration. The empirical study found an overarching theme of adjustment, encompassing three subthemes: Making sense of the condition in the context of existing and evolving knowledge and experiences; intrapersonal and interpersonal coping strategies; and incorporating the condition into the life narrative.

**Conclusion:** Patients with incurable haematological malignancies in general, and an indolent form of such malignancy in particular, have unique challenges to overcome in making sense of, coping with and integrating the condition into their life narrative and world view. There are subtle and easily missed barriers for understanding and coping with these conditions which healthcare teams must address using an individualised, holistic approach.

# CHAPTER 1

**‘Suddenly, for the first time, somebody has given you a rough map of the rest of your life’: A systematic review and meta-synthesis of the experience of living with incurable haematological malignancy**

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**Abstract**

The aim of this systematic review and meta-synthesis is to examine the experiences of people living with incurable haematological malignancies. Research in the area of psychosocial outcomes for haematology patients largely focus on high-grade, curable conditions, or the experience of specific symptoms or treatments. Some patients with incurable conditions will spend long periods of time being untreated for their condition and having relatively infrequent contact with healthcare services. These patients are also faced from diagnosis with the reality that they will die of or with their condition. By pooling the collective qualitative evidence in this area this review addresses the question of what it is like to live with these incurable conditions. Emerging from the synthesis and interpretation are complex needs for information; the impact and meaning-making that patients face; ways of coping with an incurable condition; and the processes of adjustment and integration patients experience. This provides breadth and a more cohesive picture of the current state of knowledge in this area, revealing gaps in the research that need to be addressed.

**Key words:** leukaemia; lymphoma; myeloma; illness experience; adjustment.

## **Introduction**

Haematological malignancies are a highly complex group of disorders, including the leukaemias, lymphomas, and myeloma. While treatments have developed significantly in the last 30 years the majority of these cancers remain incurable. Although blood cancers are considered diseases of older people, they can affect younger adults and children. Incidence is increasing, and due to the aging population we can expect to see this trend continue. Due to the complexity of these conditions and ever evolving treatment approaches the outlook for patients is highly variable and uncertain (Lichtman, 2008).

Lymphomas and leukaemias are commonly categorised as being either high- or low-grade. High-grade disease is aggressive, may be rapidly fatal without treatment, but is treated with curative intent. Low-grade forms develop slowly and are often advanced by the time they are diagnosed. These conditions may be treated to slow progression but unless caught early are not currently considered curable. They may, however, be survived for a decade or more, and are therefore a chronic illness. In the indolent or low-grade forms of these diseases treatment is given to control symptoms and it is considered advisable to postpone treatment until the manifestation of clinical symptoms (Voliotis and Diehl, 2002). For low grade leukaemias and lymphomas median survival is around 10 years, with large variation from several months to a normal lifespan (Voliotis and Diehl, 2002). Leukaemia survival rates are around 44% at five years, placing them within the average range for cancers; while lymphomas have a relatively high five year survival rate of around 63% (Cancer Research UK, 2013).

Myeloma is an incurable malignancy that has more severe symptoms and a poorer prognosis than the low-grade haematological cancers. It has a relapsing remitting course, with has an asymptomatic indolent or 'smouldering' phase, and an active phase where treatment is given. Again, the aim of treatment is to control disease, prolong survival and maximise patient wellbeing (Sonneveld et al., 2013). Currently, myeloma is considered a life-shortening condition, with a median survival of approximately 33 months (Glass and Munker, 2007). The five-year relative survival rate is amongst the lowest of the 21 most common cancers at around 37%, with survival continuing to tail off after five years (Cancer Research UK, 2013).

Regardless of underlying malignancy and prognosis, the preservation of quality of life is of major consideration in haematological malignancies (Voliotis and Diehl, 2002). However, relatively few studies have investigated this issue (Johnsen et al., 2009). People

with low grade haematological malignancies, despite their higher prevalence, are a significantly under-researched population (Parry, 2011). Johnsen et al. (2009) investigated the prevalence and predictors of symptoms and problems in a representative sample of haematological patients in Denmark. In a random sample of 470 patients with leukaemia, multiple myeloma and advanced lymphoma the most frequent symptoms or problems were fatigue (55%), reduced role function (49%), insomnia (46%), and pain (37%). Older patients and those in active treatment reported more symptoms and problems.

A systematic review of unmet psychosocial needs in patients with haematological malignancies was presented at the International Psycho-Oncology Society World Congress of Psycho-Oncology (Swash et al., 2012). This found only 16 papers whose mixed cancer samples included haematology, and three papers whose participants had haematological malignancies only. The most significant difficulty for patients was identified as fear of recurrence. There were also unmet information needs, and needs relating to healthcare such as having confidence in healthcare professionals.

Unlike patients with potentially curable high-grade malignancies, people with low-grade malignancies or myeloma are faced from the outset with the reality that they will die of or with the condition. However, we have limited insight into what it is like for patients to live with such knowledge. It was suggested in a review of quality of life in patients with non-Hodgkin's lymphoma that qualitative research would enhance the understanding of the impact for survivors (Leak et al., 2011).

This paper reports a systematic review and meta-synthesis of the qualitative literature in an attempt to ascertain the quality and quantity of the current knowledge base relating to patients' experiences of living with incurable haematological malignancies. The aim is to answer the questions: What do we know that can help us understand and explain the experience of living with incurable haematological malignancies, what does this suggest for patient care, and what are the important questions for future research in this area?

## **Method**

A systematic review and meta-synthesis of primary qualitative research was conducted, drawing on the method of framework analysis described by Jones (2004) and developed by Chivers-Seymour et al. (2010).

## ***Search Strategy***

Searches of electronic databases were carried out between May and July 2013. The OVID databases Embase, Medline and PsycINFO were searched using key words, with Boolean operators where applicable, pertinent to qualitative research (*'qualitative research'* or *'grounded theory'* or *'phenomenology'*) and haematological malignancies (*'lymphoma'* or *'non Hodgkin\*'* or *'haematological'* or *'hematological'* or *'leukaemia'* or *'myeloma'*). The same search terms were modified and applied to a search of CINAHL (*'qualitative'* or *'grounded theory'* or *'phenomenolog\*'* in the abstract) and (*'lymphoma'* or *'non Hodgkin\*'* or *'haematolog\*'* or *'hematolog\*'* or *'leukaemia'* or *'myeloma'* in the title). A search was conducted in Google Scholar (a search engine designed for locating scholarly articles) for the exact word or phrase, *'qualitative research'*; any of the words, *'lymphoma'* or *'leukaemia'* or *'myeloma'*; and none of the words, *'acute'*, *'children'*, *'adolescents'*, *'parents'*, *'carers'*, *'mothers'*, and *'fathers'*). The final search strategies were arrived at after an initial 'berry picking approach' (Bates, 1989) and experimentation in all search platforms, using several combinations of specific and general search terms, as well as subject relevant filters, and guided by recommended search terms for locating qualitative research papers (Petticrew and Roberts, 2006). The reference sections of all retrieved articles were also hand-searched for potentially relevant titles.

## ***Inclusion Criteria***

The aim of this review was to examine the qualitative evidence pertaining to the experience of adults living with an incurable haematological malignancy. Studies were graded on the suitability of their sample characteristics in order to gain the greatest possible insight into these experiences. Attempts were made to avoid confusing the picture with the experiences of high-grade malignancies, since the natural histories, treatment approaches and prognoses for such conditions are different. However, this was not a simple task and a pragmatic approach was taken to inclusion and exclusion criteria. There is a paucity of research on psycho-social impact and experiences for individuals with haematological malignancies in general, with very few focusing on individuals with low-grade or incurable conditions. Studies were therefore included with mixed samples of individuals with different types of malignancy where it was considered that people with incurable conditions were reasonably well represented. A further consideration was how to capture the experience of *living with* these conditions. To achieve this aim, studies were excluded which explored the following: experiences of accessing, taking part in or recovering from specific treatments, interventions or the experience of specific symptoms – this was in order to maintain a

holistic perspective in the review and because these areas have had more attention in the research already. Pre-diagnosis or end-of-life experiences were not included because these were deemed not to relate to the experience of knowingly living with an incurable form of cancer. Studies were included regardless of qualitative methodologies used, as this is argued to add to the depth and breadth of the description of the object of study (Jones, 2004) and because of the limited research having been carried out in this area.

### ***Publication Selection***

Qualitative papers' titles can be uninformative; sometimes failing to indicate whether the research is qualitative (Jones, 2004) and as observed by Evans (2002) the relevance of qualitative research is often not clear from the title or abstract alone. Each title was therefore reviewed along with its abstract where the title alone was insufficient to judge the suitability of the paper. Full texts were obtained for potentially relevant papers. The search process yielded 509 papers, of which 24 were retrieved in full. Full texts were examined in detail, and papers were rejected which focused on treatment, intervention or symptom experiences, or where the sample was not representative of people with incurable conditions, or where it was not possible to determine this. Ultimately, eight papers were deemed to be relevant to the review. These were graded as to the degree of relevance: (A) papers focusing specifically on the experience of living with a diagnosis of an incurable form of haematological malignancy (n=5); (B) those with mixed samples but reasonable clarity regarding the relative proportion of such patients, and an adequate representation of people with incurable malignancy (n=2); and (C) papers where the relative proportion of malignancy type was not made clear, but it was possible to determine through examining the text that a reasonable proportion of the sample was likely to have an incurable form of illness (n=1). Figure 1 represents the selection process diagrammatically. See Table 1 for a summary of the aims, method and sample details for reviewed articles.

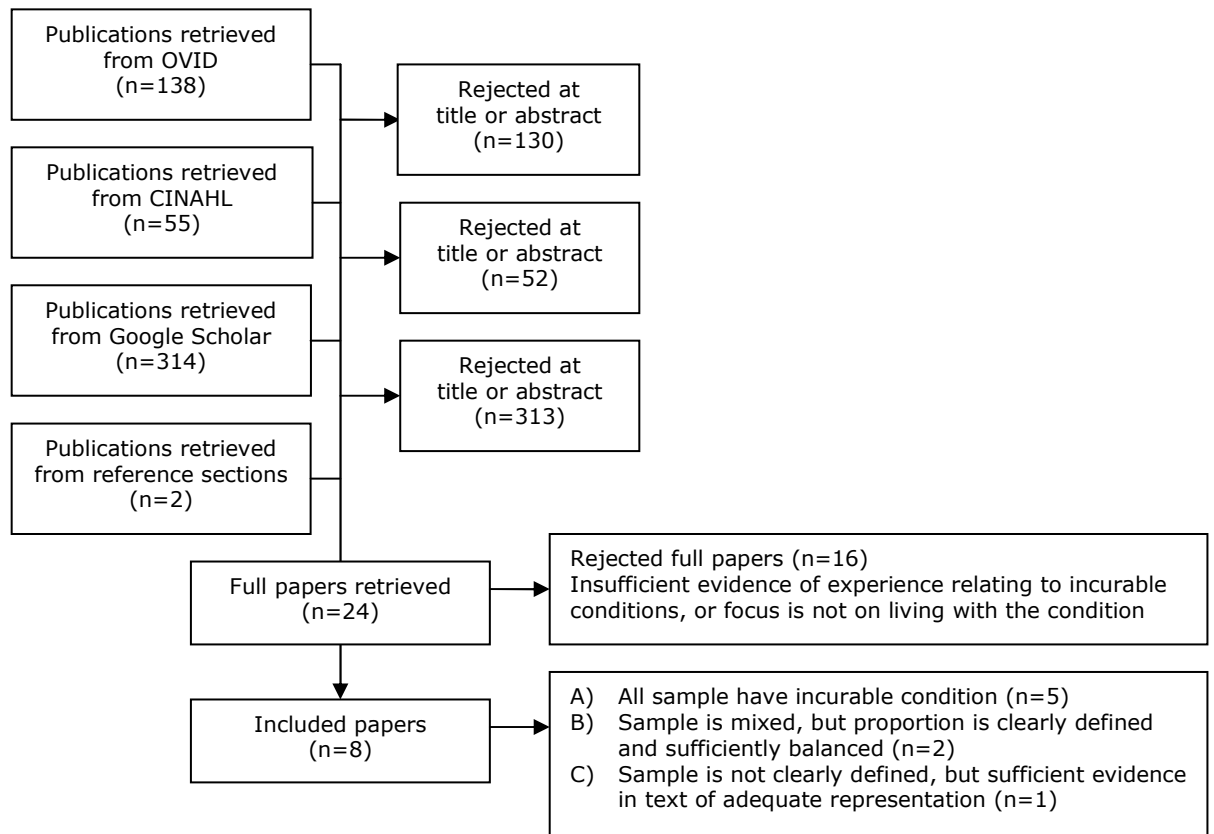


Figure 1. Flowchart of studies selected for systematic review

### *Assessment of Quality*

The studies were appraised for quality using an adapted version of the quality assessment tool developed by Chivers-Seymour et al. (2010). This tool assesses 12 areas of the publication (covering the following areas: *abstract and title; introduction and aims; method and data collection; sampling; data analysis; ethics, bias and rigour; clarity of results; transferability or generalisability; implications and usefulness; discussion of limitations; quality of quotes used; and relevance to review question*) each area is rated on issues such as clarity, rigour and appropriateness of design based on clearly defined criteria, with a numerical score assigned for each rating: ‘good=3’, ‘fair=2’, ‘poor=1’, or ‘very poor=0’ (Appendix A). There was little difference in quality between studies, and ratings were high for all, ranging from 27-34 out of a possible 36, suggesting that there can be reasonable confidence in the research findings (summarised in Table 1, with a full breakdown of quality scores in Appendix B).

Table 1. Summary of aims, method, sample details and quality ratings for reviewed articles

Authors/ year	Aim of study	Sample properties	Sampling	Diagnosis – name of cancer and potential curability	Length of time since diagnosis	Treatment characteristics	Methodological orientation	Quality rating (n/36)
Evans et al. (2012)	Watchful waiting for chronic lymphocytic leukaemia (CLL)	N=12 Male: 4 Female: 8 Age range: 54- 87 Mean age: 68	Purposive	Chronic lymphocytic leukaemia (incurable)	1 year–18 years	All initially maintained on watch and wait Subsequently received treatment: n=6 Never received treatment: n=5	Constant comparison	32
Kelly & Dowling (2011)	Patients' lived experience of being diagnosed with myeloma	N=11 Male: 7 Female: 4 Age range: 42- 83 Mean age: 63	N/S	Myeloma (incurable)	1.5–4 years	'Not currently undergoing treatment'	Hermeneutic phenomenological approach	30
Maher & De Vries (2011)	The lived experiences of individuals with relapsed multiple myeloma (MM)	N=8 Male: 5 Female: 3 Age range: 48- 74 Mean age: N/S	Purposive	Myeloma (incurable)	N/S 'Not recently diagnosed'	N/S	Thematic content analysis	28
McGrath (2004a)	Positive spiritual outcomes for survivors of haematological malignancies	N=12 Male: 8 Female: 4 Age range: 25- 60 Mean age: N/S	N/S	Chronic myeloid leukaemia: n=5 (incurable) Acute lymphoblastic leukaemia: n=3 (potentially curable) Acute myeloid leukaemia: n=2 (potentially curable) Multiple myeloma: n=1 (incurable) Non-hodgkin's lymphoma: n=1 (N/S)	3-15 years	High-dose chemotherapy: n=12 Radiation: n=12 Bone marrow transplant: n=8	Phenomenology	32

N/S: signifies not specified in article

Table 1. *Continued*

Authors/ year	Aim of study	Sample properties	Sampling	Diagnosis – name of cancer and potential curability	Length of time since diagnosis	Treatment characteristics	Methodological orientation	Quality rating (n/36)
McGrath (2004b)	Reflections on serious illness as a spiritual journey	N=12 Male: 8 Female: 4 Age range: 25- 60 Mean age: N/S	N/S	Chronic myeloid leukaemia: n=5 (incurable) Acute lymphoblastic leukaemia: n=2 (potentially curable) Acute myeloid leukaemia: n=2 (potentially curable) Multiple myeloma: n=1 (incurable) Non-hodgkin's lymphoma: n=1 (N/S) Ewings sarcoma: n=1 (potentially curable)	3-15 years	High-dose chemotherapy: n=12 Radiation: n=12 Bone marrow transplant: n=8	Phenomenology	27
Potrata et al. (2011)	Understanding distress and distressing experiences in patients with MM	N=15 Male: 10 Female: 5 Age range: 42- 75 Mean age: 58	Purposive	Myeloma (incurable)	<1 year: n=4 1-5 years: n=2 >5 years: n=9	Stem cell transplantation: n=11	Grounded theory	34
Randall & Wearn (2005)	Patients' reflections on receiving bad news	N=15 Male: 8 Female: 7 Age range: 31- 85 Mean age: 59	Purposive	Curability N/S: Leukaemia: n=6 Lymphoma: n=9 State of illness: Stable (good prognosis): n=4 Stable (bad prognosis): n=1 Progressive: n=7 Unknown: n=3	4 days- 11 years	N/S	Thematic content analysis	33
Vlossak & Fitch (2008)	Multiple myeloma: the patient's perspective	N=20 Male: 13 Female: 7 Age range: 44- 88 Mean age: N/S	Convenience	Myeloma (incurable)	6 months- 6 years	N/S	'Standard content and theme analysis'	33

N/S: signifies not specified in article

### ***Data Extraction and Analysis***

The framework approach used in this review was adapted from Chivers-Seymour et al. (2010): In order to reflect the participant's voice in its purest form, data were extracted only from the 'results' section of each paper. The approach involved: (1) familiarisation through repeated reading of all papers, creating a list of themes and codes from the data; (2) identifying a thematic framework with final themes based on the key issues identified during familiarisation; (3) indexing, where the papers were coded manually, based on the thematic framework; (4) charting and mapping, where data were transferred to a matrix, charting themes against papers; and (5) interpretation, where coded data were extracted from the matrix, clustered by theme, and explored for patterns and contradictions across the papers.

### ***Methodological Rigour in the Review Process***

In order to enhance the quality of this review an expert in qualitative research methodology at the University of Edinburgh was consulted at several points through the review process. In addition, three of the eight papers were reviewed by three independent colleagues for assessment of the quality of these papers and to gauge the reliability of the author's data coding, with 96% concordance between the author's and colleagues' coding. It would have been desirable to have more than one author involved in the development of the thematic framework, however, this was not possible in the present study.

Due to the nature of the population of interest, and in common with other meta-syntheses (Chivers-Seymour et al., 2010), there was heterogeneity in the study samples, and different qualitative approaches and styles used. While the quality of a review is influenced by the quality of the studies reviewed, these factors make it challenging to assess quality and pool data for meta-synthesis (Chivers-Seymour et al., 2010). Quality ratings were high for all articles and restricting analysis to data derived from the results sections of articles was considered to be the most systematic approach for pooling data.

### **Results**

This meta-synthesis attempts to synthesise and understand the qualitative data relating to different aspect of the experience of living with incurable forms of haematological malignancy. The overarching impression was of patients attempting to negotiate a world in which mortality ceases to be an abstract concept and becomes a tangible reality. Participants gave accounts reflecting complex, varied and changing information needs; the impact of cancer and their efforts at making meaning of their diagnoses; attempts to cope with life with incurable conditions; and the process of adjustment and integration of the diagnosis into the self- and world-view. Table 2 displays the studies from which the themes were derived.

Table 2. Emerging themes and studies they derive from

Theme 1. The need for Information	Theme 2. Impact and Meaning-Making	Theme 3. Coping with an Incurable Condition	Theme 4. Adjustment and Integration
Evans et al. (2012)	Evans et al. (2012)	Evans et al. (2012)	Kelly & Dowling (2011)
Kelly & Dowling (2011)	Kelly & Dowling (2011)	Kelly & Dowling (2011)	Maher and De Vries (2011)
Maher and De Vries (2011)	Maher and De Vries (2011)	Maher and De Vries (2011)	McGrath (2004a)
Potrata et al. (2011)	McGrath (2004b)	McGrath (2004a)	McGrath (2004b)
Randall and Wearn (2005)	Potrata et al. (2011)	McGrath (2004b)	Randall and Wearn (2005)
Vlossak and Fitch (2008)	Randall and Wearn (2005)	Potrata et al. (2011)	
	Vlossak and Fitch (2008)	Randall and Wearn (2005)	
		Vlossak and Fitch (2008)	

### *The Need for Information*

A common element of the patient experience was the idiosyncratic, complex and fluid requirements for information. There was variability between individuals and over time regarding how much information participants had wanted to receive; for example, one individual with low-grade disease had been frightened when information was withheld at the time of diagnosis in a misguided effort to protect her from anxiety (Evans et al., 2012). Some participants had wanted to know very little about their condition at the time of diagnosis and appreciated not having information ‘forced’ on them (Randall and Wearn, 2005). However, a study exploring distressing experiences in myeloma patients found that, despite the relatively severe nature of this condition, all participants had wanted to know their diagnosis and to be told directly and as soon as possible (Potrata et al., 2011).

Feeling able to trust healthcare professionals to provide accurate information was important for giving participants a sense of control over their situation and the uncertainty inherent in these conditions (Maher and De Vries, 2011). However, for some participants there was a sense that the information they desired was not always forthcoming and for some with low-grade cancer this was perceived as being due to the relative ‘disinterest’ of consultants in low-grade conditions. These participants also perceived there to be a general absence of information sources for people with haematological malignancies (Evans et al., 2012).

The provision of information leaflets and written consultation summaries had helped some participants understand and maintain a sense of control over their information. However, many participants spoke of seeking information from sources other than their healthcare team. Participants across studies reflected on the frightening nature and potential inaccuracy of much of the information available to them. They spoke of finding ways to limit their exposure to worrying information, for example, by avoiding certain areas of the internet, or appointing a family member to ‘filter’ information for them.

Another important factor was the way that information is presented to patients. This was critical for helping patients feel comfortable and respected. For example, the use of technical language or long or complicated words was confusing and frightening for participants, leading them to feel uneasy about asking questions for fear of appearing ‘stupid’ or of being unable to understand the answer. A common experience was feeling that professionals were ‘too busy’ to provide the time and level of input required. Consultations during which patients receive ‘bad news’ are particularly stressful, and several participants spoke of having difficulty finding the words to express their feelings or to formulate questions. Some participants also spoke of concealing their emotions from professionals in order to appear courageous (Maher and De Vries, 2011). This may limit the mutual understanding between patients and their healthcare team.

Knowing how to use the information they had gained was a further challenge for patients. This is reflected in participants’ accounts around decision-making regarding their healthcare. In a mixed-sample study many had little desire to contribute to treatment decision-making, feeling unqualified to make such choices (Randall and Wearn, 2005). For participants with myeloma, treatment often commences immediately after diagnosis, leaving patients feeling they had little time to consider their options. Some participants saw themselves as having little choice regarding their treatment due to the relative severity of this condition (Vlossak and Fitch, 2008).

### ***Impact and Meaning-Making***

Participants’ meaning-making involved combining existing knowledge, assumptions, and attributions regarding ‘cancer’ with newly acquired information regarding their diagnosis. However, haematological malignancies are a complex collection of conditions with variable courses and outcomes, and many participants struggled to make sense of their diagnosis. For example, some people who received a diagnosis of myeloma did not initially realise that it was a type of cancer (Kelly and Dowling, 2011). For individuals with low-grade disease even the provision of information did not always help them understand their diagnosis (Evans et al., 2012) and many made assumptions and created ‘worst case scenarios’ during their diagnosis, sometimes leading them to negatively misinterpret information. Some also had difficulty coming to terms with the indolent nature of the disease and of not having received treatment. Some individuals with incurable conditions also wondered what it would mean when their time came for treatment, and whether this signified the ‘beginning of the end’.

A common experience for those who had experienced symptoms was the wide-ranging impact these had, including a loss of independence, leaving participants feeling like a burden, useless and inadequate, but also resentful of those around them. Changes in appearance resulting from illness also affected how participants’ thought about themselves and how others viewed them, and the realisation that they could no longer conceal their cancer had a major psychosocial impact for some (Kelly and

Dowling, 2011). While all patients with haematological malignancies can experience debilitating and distressing symptoms, these findings are particularly significant for people with myeloma, who are more likely to experience symptoms which also tend to be more severe and visible. These patients talked of multiple losses as a result of their illness: of their former self, their identity, sense of value, friendships and the ability to participate in life, sometimes leading to depression, anxiety and social isolation (Maher and De Vries, 2011).

Across studies, participants spoke of the difficulty they and their healthcare team could have in identifying whether symptoms they experienced could be attributed to their conditions. This appeared to be particularly significant for patients with low-grade disease, whose symptoms may be milder and more vague (Evans et al., 2012). A common experience was the 'rollercoaster' of emotions around routine checkups with preceding anxiety being replaced by intense relief if the condition had not progressed.

Patients without symptoms had other issues to contend with: some found it confusing that they had begun to think of themselves as 'ill' while feeling well (Evans et al., 2012). For patients with low-grade disease, particularly those who had comorbid health conditions, the condition could be perceived as insignificant, preventing participants sharing their diagnosis with loved ones (Evans et al., 2012). While participants were aware of stigma associated with cancer, one study with a mixed sample found that the word 'cancer' was seen by participants as preferable to 'disease'. They also preferred 'illness', 'condition', or the proper medical name for their condition (Randall and Wearn, 2005). This may be particularly significant for patients with asymptomatic low-grade disease who may not identify with the concept of being 'diseased'.

Participants' accounts across several studies reflected their attempts to understand how they had come to have their condition. There was a sense for some people that it was 'fated to be', or to be due to their own actions, while some ascribed a spiritual purpose to their condition, such as being 'tested'. Many participants, even individuals with myeloma, talked about a sense of being lucky in some way: to be alive, that treatment options were available to treat symptoms, or in their perceptions of their own situation in relation to others'.

### ***Coping with an Incurable Condition***

A variety of coping strategies were reported across studies: Some individuals spoke of the importance of maintaining hope, and how this could be damaged when participants perceived that clinicians did not believe in their ability to fight their illness. Randall and Wearn's (2005) participants with incurable conditions found it harder to come to terms with treatment, for whom it is non-curative, than participants with curable conditions. It was still helpful for these patients to be offered some form of reassurance about what the future might hold. The hope of curative treatments becoming available

in the future was mentioned by some participants. Some also spoke of the importance of maintaining a sense of normality, despite having a lifelong condition, but this was hampered for some by family and friends being overprotective. Belief in an afterlife provided comfort for some but there was also a sense of participants being aware of their powerlessness in the face of an incurable illness, and so avoiding the 'long view' when it came to coping, with some avoiding thinking about their condition altogether.

Factors relating to individuals' support networks were central to participants' attempts to cope with their condition. They derived strength and comfort from family and extended social networks, particularly for some with myeloma who spoke of how heavily they relied on others due to their symptom burden. However, the diagnosis of cancer can interfere with the life of every member of the family, and some family members coped through avoidance. It appears from this body of research that friends might play a greater role for cancer patients than is generally recognized, providing emotional, practical, and financial support. However some participants experienced dissolution of relationships with family or friends who had not been able or willing to be supportive.

Participants described withholding information and hiding their feelings to protect family and friends from distress or themselves from the stress of having to repeat their 'story'. Patients with low-grade leukaemia spoke of their condition being 'invisible', finding that sympathy (or even recognition) could be hard to obtain (Evans et al., 2012). This reflected a broader sense among study participants that their experiences could not be understood by members of their social network. Because of this, expressions of concern were sometimes perceived as disingenuous, as well as coming as unbidden reminders of conditions that some were trying to 'forget'. Some participants spoke about the benefits of talking to other patients with the same condition, but for many who took part in these studies this option had not been available or sufficiently accessible.

Patients with incurable conditions will remain engaged with healthcare teams for the rest of their lives and the importance of the patient-doctor relationship was apparent in participants' accounts. The relationship was felt to be particularly important for these participants who perceive their conditions to be different to other cancers in showing no visible signs of progression. It was vital to them to know they would be seen regularly and kept informed about their condition (Randall and Wearn, 2005). The ability of the consultant to individualize their patient's experience was fundamental to the relationship. Continuity of care was perceived to allow clinicians to develop an understanding of patients' idiosyncratic needs for information and how best to communicate this to them (Randall and Wearn, 2005). However, for patients with low-grade leukaemia there was a perception that even their doctors did not always appreciate how patients felt and how the condition could affect their lives (Evans et al., 2012)

The literature indicates that patients feel it is important to be made aware of the possible psychological impact of their condition (Randall and Wearn, 2005). There was a perceived absence of support groups for people with haematological conditions, or difficulty accessing them due to the need to travel. There may be barriers to patients accepting one-to-one counselling due to this being seen as ‘dwelling on their condition’, or because of it being offered too soon after diagnosis for the patients to be ready to consider the offer.

### ***Adjustment and Integration***

Adjustment was found to be a challenging, fluid process occurring over a period of time, and involving participants recognising the limitations posed by their illness and managing their lives accordingly. Support, particularly from family members, was a vital component in promoting adjustment (Maher and De Vries, 2011). There is a confrontation with death experienced by those diagnosed with an incurable condition that makes one acutely aware of the fragility of life and one’s own mortality, with the consequence that patients are challenged to think closely about the meaning and purpose of their life.

Many participants’ had a sense of having been given ‘the gift of extra life’, and of being more conscious of making the most of life. Many had re-examined their priorities and re-evaluated their lives, making changes that allowed them to focus on what was important. Personal relationships were explored, strengthened and deepened and some participants spoke of an enhanced ‘sense of personhood’ (McGrath, 2004a) with increased assertiveness and confidence, greater ability to focus on one’s own needs, with less feeling of responsibility for others and dependence on others’ approval. Some felt that their illness experiences had given them insights and skills that were relevant and transferable to their daily life.

It was recognised by participants that, due to the nature of their conditions, their illness journey would extend for their full lives, with some reporting that they had examined their past and managed to come to a position of peace with their future. This reflected a sense of acceptance of mortality with some patients even having a sense that they were ‘fortunate’ to have experienced the spiritual aspects of the illness journey. However, it was noted that the experience of distressing physical symptoms impacted on the ability of participants to take a broad and positive perspective on their situation or to derive a sense of spiritual growth from their experiences.

### **Discussion**

As far as it has been possible to determine, this is the first systematic review and meta-synthesis of qualitative research exploring the lived experiences of people with incurable haematological malignancies. The reviewed studies represent a range of stages and experiences along the patient journey, with patients diagnosed between four days and 18 years previously. Studies

focused on: receiving the diagnosis of haematological malignancy (Randall and Wearn, 2005); spirituality in patients' meaning-making and positive illness experiences (McGrath, 2004a; 2004b); the experience of living with a low-grade leukaemia in which patients had to come to terms with a lack of immediate treatment and living with symptoms of an 'invisible' condition (Evans et al., 2012). Half of the reviewed studies related to experiences of living with myeloma: Vlossak and Fitch (2008) found the most difficult obstacle for patients and family members to be the sudden confrontation with mortality; Kelly and Dowling (2011) emphasised the 'preciousness of time' for patients living 'in limbo' in a changed body; Potrata et al. (2011) found that distress in myeloma related to the experience of symptoms and the meaning patients made of them; and Maher and De Vries (2011) found patients with relapsed myeloma trying to cope with the uncertainty of an 'ever-changing' perspective between illness and wellness.

Adjustment to serious illness refers to psychological processes occurring over time as the individual, and those in their social world, manage, learn from and adapt to the changes they have gone through (Brennan, 2001). Adjustment, therefore, is an ongoing process that does not equate to the absence of psychopathology and does not represent the end-point of the coping process. The concept of 'liminality' can be used as a framework for understanding cancer experiences, referring to a transition between two states, where people become 'structurally invisible', being 'no longer classified, and not yet classified' (Blows et al., 2012). Patients across studies are involved in a delicate balancing act of seeking the information they need in order to understand their situation while protecting themselves from becoming overwhelmed. Participants use new information and existing beliefs to make sense of their situations and for all participants the role of both personal and professional support networks were crucial for helping or hindering them in their illness journey. Patients with low-grade conditions appeared to juggle two conflicting ideas: Cancer as terrifying, deadly, and stigmatising, against a condition that goes largely unnoticed, unacknowledged and untreated. For participants with myeloma, with its more severe symptoms and poorer prognosis, the increased sense of fear and threat was palpable in the body of research. Despite these differences there was a general overall picture of participants struggling with the uncertainty of their future, fear of recurrence, and fear of the unknown.

According to 'crisis theory' (Moos and Schaefer, 1986) people faced with major life crises and transitions experience disruption to their established personal and social identities and in order to cope with these challenges, psychological systems are driven towards maintaining equilibrium. In the present review, universal coping strategies emerged with patients attempting to maintain hope and a sense of normality, while balancing defiance towards their condition with acceptance of an incurable diagnosis. Acceptance of their diagnosis appeared to allow participants to place the condition within the broader life story and to use this as a platform for becoming more in tune with their values and priorities. Ciarrochi et al. (2011) identified that greater success at 'living one's values' was

significantly related to improved wellbeing and distress-related outcomes for cancer patients. However, according to this review such positive growth may be stalled or blocked by distressing symptoms.

### ***Implications for Clinicians and Healthcare Teams***

The key findings of this review are that: (1) Information and support needs are idiosyncratic and change over time; (2) patients may have unarticulated assumptions about cancer affecting their ability to understand and cope with their diagnosis of an incurable cancer; (3) patients may not express their thoughts and feelings about their situation to either social or professional support networks; and (4) ambivalence, poor timing of support offers, and barriers to accessing support services may prevent patients obtaining support and information that would help them understand and cope with their condition.

These findings suggest that clinicians need to negotiate and re-visit information requirements for every patient throughout their cancer journey. Schapira and Tulsky (2008) provide a guide to help oncologists deal with the complex communication needs of cancer patients.

Participants' accounts reflected difficulty coping with the ongoing nature of their conditions as well as, for some, fear regarding end-of-life experiences. Patients' beliefs should be openly explored, allowing the healthcare team to understand and address the individual psychological challenges faced by patients and helping them to address these.

Maguire et al. (1996) suggest that patients can be helped to disclose their concerns by being allowed time to express their feelings, by showing them empathy, using open questions, asking about psychosocial issues, seeking clarification of any psychosocially significant comments or non-verbal communications, summarising what they have said and offering 'educated guesses' as to how they might be feeling. For medical professionals this might result simply in the patient feeling heard and understood, in frank discussions about palliative care, or referrals to specialist psycho-social support services.

Joined-up working within multidisciplinary teams will be crucial for helping patients to understand and cope with their illness experiences. With patients reporting that they conceal their feelings from healthcare professionals and social support networks it is important that systems are in place for monitoring adjustment and distress in patients, with opportunities for support offered repeatedly throughout the patient journey. It is hoped that developing a plain language summary of this review will provide patients and healthcare professionals with information that can help to normalise and validate the patient experience as well as inviting discussion of individual experiences that may represent difficulty coping or adjusting to the diagnosis, warranting referral to specialist support services.

## ***Limitations***

As noted by Chivers-Seymour et al. (2010) the final selection of studies for meta-synthesis can represent a biased sample. In the present review, two papers referred to the results of one study, and of the papers purely relating to experiences of incurable conditions, four relate to the experience of multiple myeloma, and only one to an indolent condition (chronic lymphocytic leukaemia).

The haematological malignancies represent a diverse collection of diseases, and the distinction between low- and high-grade disease is not clear cut. Despite this, patients are generally categorised as having either a more slowly developing disease, which is unlikely to be curable, or a quickly developing disease that may be curable with the right treatment. Due to the limited research in this area three studies were included in this review that referred to samples with both high- and low-grade conditions. While examination of the sample characteristics suggests reasonable representation of people with incurable conditions this was not made explicit in the articles. Indeed, McGrath (2004b) refers to the significance of survival at five years for their participants in considering themselves 'cured'. This highlights the issue of combining diagnoses within samples making it difficult to draw conclusions about the unique experiences of those who have been told they are living with an incurable condition, as opposed to those who believe a cure is possible.

## ***Future Directions for Psychological Research***

This review emphasised the scarcity of research that has been carried out into patient experiences in the area of haematological malignancies. In particular, there has so far been only one study exploring the experiences of people living with a low-grade incurable haematological malignancy, despite the unique and potentially challenging existential issues faced by this population. Therefore, there is a need for more knowledge regarding the psychosocial experiences of patients living with indolent disease.

The use of language around cancer continues to use the 'military metaphor' of fighting and losing battles with cancer. Potential problems with this were discussed in a seminal text by Susan Sontag (1978) which proposed the danger of framing the experience of cancer as a battle in which there are winners and losers, with 'good' patients fighting their disease to the death. This use of language may be particularly unhelpful for patients with incurable disease. Patients in this review also expressed discomfort with the word 'disease' being used to describe their condition and it may be beneficial to further explore the impact on patients of the language used around long-term incurable cancers.

Considering the issue of 'fighting against' curable cancer versus 'accepting and living with' incurable cancer, there is potential utility in psychotherapeutic approaches aimed at supporting individuals' acceptance while supporting their value-congruent living. Acceptance and Commitment

Therapy (Hayes et al., 1999) is a psychotherapeutic approach with a focus on helping patients accept distressing physical or psychological experiences in the service of 'valued' living. Research has begun to provide evidence for its effectiveness for people with cancer (Páez et al., 2007; Branstetter et al., 2004; Feros et al., 2013), but it has not been trialled with patients with indolent cancers for whom it may particularly appropriate, given their incurable status, ongoing investigations and treatment episodes with good long-term prognosis.

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## **CHAPTER 2**

### **‘Lymphoma’s different’: A qualitative exploration of living with follicular lymphoma and the experience of ‘watchful waiting’**

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**Abstract**

A study is reported that used the qualitative approach of interpretative phenomenological analysis (IPA) to explore the experiences of participants (n=9) living with a low-grade form of incurable haematological malignancy: follicular lymphoma. Participants' accounts reveal an overarching theme of adjustment, comprised of making sense of the condition in the context of existing and evolving knowledge and experiences; intrapersonal and interpersonal coping strategies; and integrating the condition into the life narrative. Findings reinforce the importance of patients' relationship with healthcare providers, and holistic, individualised care. The diagnosis can have subtle and far-reaching implications for social networks and the patient's sense of self. Patients are involved in an intricate task of maintaining and relinquishing control, balancing their needs for support and self-reliance, and managing their concerns about illness with their enhanced sense of the preciousness of life. Suggestions are made for how healthcare teams can understand and respond to the unique needs of each patient.

**Key words:** lymphoma, indolent, illness experience, cancer, adjustment.

## **Introduction**

Lymphomas and leukaemias are types of haematological malignancies that are commonly categorised as being either high- or low-grade. High-grade disease is aggressive, may be rapidly fatal without treatment, but is treated with curative intent. Low-grade forms develop slowly and are often advanced by the time they are diagnosed. These conditions may be treated to slow progression but unless caught early are not currently considered curable. They may, however, be survived for a decade or more, and are therefore a chronic illness. Myeloma is another form of haematological malignancy, which is incurable and has a relapsing remitting course, but has more severe symptoms and a poorer prognosis than the chronic haematological cancers.

Patients with low-grade malignancy are commonly maintained under a 'watch and wait' protocol, whereby they undergo regular routine examinations to monitor for progression of their disease. If symptoms increase or there are other signs of progression, treatment may be given with the intention of reducing the disease. Once a treatment has been given it becomes ineffective and alternatives must be used at later treatments. Patients may be treated initially at diagnosis or may not receive their first treatment for several years. The average time from diagnosis to treatment is two to three years, with similar lengths of time between treatments. However, intervals between treatments are likely to decrease over time.

Time spent waiting at any point of cancer diagnosis and treatment is often emphasised as being highly stressful (Saegrov and Halding, 2004). It has been argued that cancer patients have a critical 'need for action' (Jakobsson et al., 2005), which patients under watch and wait may not feel is happening. These patients also have less contact with professionals than individuals with high-grade disease, perhaps missing out on support that may aid adjustment to the diagnosis (Horn and Campbell, 2010).

Haematological malignancies are under-researched in the psychological literature, with the majority of research that does exist focusing on aggressive diseases and their treatment. There is little known about psychological outcomes for patients with low-grade disease. Chronic lymphocytic leukaemia (CLL) is one of the most common lymphoid malignancies. A survey comparing the quality of life (QoL) of CLL patients to the general population found that while the physical, social/family, functional, and overall QoL scores of CLL patients were similar to or better than population norms, their emotional well-being was dramatically lower than that of both the general population and patients with other types of cancer, with younger patients having lower wellbeing (Shanafelt et al., 2007).

A recent review of QoL outcomes in people with non-Hodgkin's lymphoma (NHL) which can be high- or low-grade, found that people with NHL had higher levels of posttraumatic stress symptomatology than population norms, but comparable levels of mental health functioning, although

this was poorer in younger patients (Leak et al., 2011). The review authors highlighted that qualitative methods would more adequately capture the totality of a survivor's experience compared with using one QOL measure.

Patients with prostate cancer are commonly maintained under watchful waiting, and significantly more research, including use of qualitative methodologies, has been carried out with this group. For example, Hedestig et al. (2003) found prostate patients experienced solitariness and uncertainty, and tended to avoid burdening friends and family by not talking about their condition, reducing their sources of support. These patients preferred to talk to other patients or healthcare professionals.

A systematic review of qualitative literature pertaining to all forms of incurable haematological malignancy (Caldwell, 2013) identified only one study exploring the experiences of patients living with a chronic haematological malignancy: Evans et al. (2012) interviewed 12 patients under 'watchful waiting' for CLL. Their participants reported finding it difficult to come to terms with a condition which is incurable, but for which no treatment is recommended in its early stages. In common with the men with prostate cancer, the invisibility of CLL made some participants selective about whom they told, limiting the social support available to them. An email was circulated to members of the Special Interest Group in Oncology and Palliative Care (SIGOPAC, UK) community to ascertain whether any members were aware of qualitative research having been conducted with individuals with lymphoma living under watch and wait – this yielded no further research, although interest was expressed in the area.

Follicular lymphoma (FL) is the most commonly occurring low-grade lymphoma. Compared with CLL, patients with FL are likely to be younger, to receive more frequent check-ups, and to ultimately require treatment (XXX Chair of XXX Cancer Network Haematology Group, personal communication, July 2012). Because of the different clinical characteristics, individuals with FL may have different experiences of watch and wait compared to those with CLL. No research to date has explored the experiences of individuals with follicular lymphoma who are not undergoing active treatment. We therefore have little knowledge about the support needs of this patient group during the majority of their life-long cancer journey.

The present study aims to explore the lived experience of patients maintained under the watch and wait protocol for follicular lymphoma, in order to improve our understanding of the particular challenges and needs of this group of patients. Due to the limited research in this area, a qualitative approach (interpretative phenomenological analysis) will be used to explore how participants perceive and make sense of the world around them, and the meanings they construct regarding their personal and social world (Smith & Osborn, 2003)

## **Method**

### ***Sampling***

Purposive sampling was used to recruit a relatively homogenous group of individuals who were able to reflect upon the phenomenon of interest (Smith and Osborn, 2003), i.e. the experience of living with follicular lymphoma under the watch and wait protocol. Nine individuals with a diagnosis of follicular lymphoma were recruited via consultant haematologists at a UK Regional Cancer Centre. Consultant Haematologists were asked to identify eligible patients from their caseloads. Inclusion criteria were stipulated as: adults (over the age of 18 years) who were currently not in active treatment for their lymphoma, i.e., were being maintained under the watch and wait protocol; who had never been diagnosed with another form of cancer; and who did not have comorbid severe mental health or neurocognitive difficulties that would inhibit their ability to participate. Haematologists identified 15 eligible patients who were then approached by letter, signed by their consultant, inviting them to contact the researcher to arrange an interview at their convenience, either at the Cancer Centre or in their own home. Four individuals did not respond to the invitation, and one individual was not able to participate due to his work schedule. Non-participants were two males and three females, aged between 32 and 74 years.

Participants were five males and four females between the ages of 45 and 74 years (mean 62 years). Time since diagnosis ranged from under one year to over seven years. All participants were white British; socio-economic status data were not collected. At the time of interview four described themselves as retired, three were in employment, and two identified themselves as being retired but working. Five participants had received no treatment, although two of these had received lymph node removal for testing. One person had received radiotherapy and three had had chemotherapy (one following therapeutic node removal). One participant had progressive disease but did not believe she would imminently be receiving treatment for this. Two suspected progression and were shortly to undergo investigations (see Table 1). The interviews lasted for an average of 70 minutes (range: 36 to 157 minutes) and were conducted by EC either in the Cancer Centre or in participants' own homes.

### ***Procedure and Data Collection***

Permission for the study was gained from National Health Service (NHS) Research and Development (R&D) management, the University of Edinburgh School of Health in Social Science Ethics Committee, site-specific R&D offices and the Lothian NHS Research Ethics Service. An interview schedule was prepared to guide interviews, which consisted of general guiding questions such as ‘‘has anything changed since you were diagnosed with follicular lymphoma’’, ‘‘what has helped since being diagnosed?’’ and prompts to gain more depth of information when needed, such as, ‘‘has anything changed in how you think of yourself since your diagnosis?’’. However, the aim was to

maintain a ‘conversational’ atmosphere and to allow the participant to direct the content of the interview, so an inductive process was adopted, using reflection (e.g. ‘you spoke about...’) and probes (e.g. ‘can you tell me more about...’). Frequently, further details and clarification were asked for to elicit rich, insightful accounts. While time was allowed for each participant to express their own narrative, the interview guide was developed iteratively, with participants being queried about elements of the experience that others had considered important (e.g. ‘some people have said... I wondered if you had experienced anything like that?’). This method was used to ensure that participants were able to tell their own story in their own words, without missing potentially important aspects of the experience that they may not have considered relevant without prompting. Interviews were recorded on a digital voice recorder and transcribed verbatim.

### *Analysis*

An interpretative phenomenological analytic (IPA) approach was used in order to analyse transcripts for important themes for individual participants, and to further explore the similarities and differences between participants’ experiences. This method has its origins in hermeneutics and phenomenology, taking the position that people interpret and actively make sense of their world rather than passively perceiving an objective reality. IPA is a ‘double hermeneutic’ process involving two stages of interpretation: the participant interprets their own experiences, and the researcher attempts to make their own sense of the participant’s interpretations (Smith and Osborn, 2003). As such, the interaction between the participant’s narrative and the researcher’s interpretation is seen as fundamental to the aim of exploring the individual’s personal account of a phenomenon of interest: it is not an attempt to produce an objective record of the phenomenon. The intention in this study is to present themes in the form of insightful and transparent narrative accounts, using verbatim extracts to evidence the researchers’ interpretations (Smith, 2011).

Each transcript was read several times in order to become familiar with the accounts and each was analysed individually before examining the transcripts for similarities and differences across participants. In each transcript, significant words, phrases or descriptions were highlighted, with emerging themes documented. Transcripts were coded according to emergent themes which were then clustered into one overarching theme of Adjustment, comprising three subthemes reflecting participants’ experiences of making sense of, coping with, and adapting to a diagnosis of follicular lymphoma: (1) *Making sense of the condition in the context of existing and evolving knowledge and experiences*; (2) *Intrapersonal and interpersonal coping strategies*; and (3) *Incorporating the condition into the life narrative*. Extracts are presented to illustrate key elements of each theme and to allow the reader to assess the author’s interpretations. All names are pseudonyms. The first author analysed all transcripts, with credibility checks carried out by three independent colleagues for a third

of transcripts to ensure coding was appropriate, with 98% agreement. All three subthemes were present in the account of each participant.

Table 1. Participant background information

Participant pseudonym	Age	Sex	Years since diagnosis	Treatment received to date	Participants' perception of lymphoma progression status at time of interview
'Cath'	64	F	4 years	Chemotherapy following diagnosis	Possible progression (being investigated)
'Lynda'	67	F	7 years	Excision with chemotherapy following diagnosis and again one year ago	No progression suspected
'Gary'	65	M	6 years	Participated in chemotherapy trial for two years following diagnosis	No progression suspected
'Carol'	71	F	3 years	None	No progression suspected
'Dave'	65	M	4 years	Radiotherapy to groin following diagnosis	No progression suspected
'Alistair'	45	M	3 years	None	Possible progression (being investigated)
'Gordon'	45	M	2 years	None	No progression suspected
'Maggie'	62	F	4 years	Abdominal radiotherapy following diagnosis	Recent progression but decision to watch and wait
'Robert'	74	M	<1 year	None	No progression suspected

## Results

### *Theme 1. Making sense of the condition in the context of existing and evolving knowledge and experiences*

All participants described having to reconcile the diagnosis of low-grade lymphoma with their assumption that cancer is a terrifying disease that must be fought to be survived. These were based on both personal experience and social constructs:

*Dave: Initially, all you hear is 'cancer'. You don't hear about the type of cancer, what the overall prognosis is, eh, you're only hearing the word 'cancer', and you're thinking back to, yeah, my father, or what I've read about it in the past.*

Maggie did not fully identify with being a cancer patient due to the absence of symptoms and indolent nature of the condition:

*Maggie: [at first] I really thought that I did have full blown cancer. You know, to me this isn't full blown ... because it is so low grade ... I do feel well and that's the problem, I've never felt ill!*

Misunderstanding about the purpose of treatment occurs in the context of society's discourse about cancer, as highlighted by Alistair:

*Alistair: I think it's the fact that when people are diagnosed with something like this they want treated, and they want cured and they want to get on with their life, whereas if somebody tells them that, 'actually, we're not going to treat you right now' ... that's like, sort of ... difficult because everybody drums into you in the- all the publicity about cancer is you need to get it quick ... you need to treat it quick ... whereas lymphoma's different.*

Several participants acknowledged that they were 'lucky' in comparison to those affected by more profoundly life altering conditions such as stroke or Alzheimer's. However, there was a shared realisation that their diagnosis was fundamentally different to the experience of serious but curable conditions:

*Carol: I suppose it's no different to a lot of things in life, but you're not going to get past it, it's going to at some point develop, because it's not curable. Um, so it's more concrete than some things that you come up against and you can deal with them, you can put them behind.*

The impact of the diagnosis varied widely. The eldest participant was reassured by being told that the cancer was unlikely to be rapidly fatal and he could continue with his life with little change. However, for one of the youngest participants, the impact of diagnosis three years previously was profound:

*Alistair: It was the most bizarre day, my whole world just turned upside down in the space of about 10 seconds.*

This reflects the significance of life context in participants' meaning-making. The importance of life stage came up for a number of people. Most participants were over the age of 60 and felt that the condition was easier to understand and cope with than if they had been younger, reflecting Alistair's

experience. Previous experiences of illness or adversity gave several participants a reference point and resources for coping, and for some the presence of comorbid illness or stressful life events made the lymphoma seem relatively insignificant:

*Gary: If you've got something else wrong with you, you don't notice you've got it. I think maybe I would be more frightened if- I don't know what other people, if they've got it, what they feel like ... because I've got all the other complications.*

There were more subtle effects on participants' sense of identity and cohesion. These were complex ideas to grapple with:

*Carol: I must admit I fear becoming my illness... I don't want to be identified only through the illness. I don't know if I even understand that one myself...*

*Alistair: There was a point where I felt that I was actually no longer a part of the human race. You felt like you were up here, everybody else was going about their normal life, and you're no longer part of that.*

*Maggie: When I was out, and I know this sounds very strange, I felt everybody was pointing the finger, I thought they knew that there was something wrong with me.*

Some felt conscious about how others might perceive them or react to the diagnosis, and there was a strong sense of not wanting to be pitied or offered empty reassurances:

*Lynda: ... it's amazing how many people didn't know. Didn't know at all. Cause I didn't tell everybody ... Not their business, its mine. And I didn't want- I didn't want sympathy ... And what really bothered me was this 'oh you'll be fine, I know you'll be fine'. You know? You don't know.*

An important but unanswerable question for participants was why they had developed the condition, particularly since most viewed themselves as having had a healthy lifestyle. Attributions included psychological stress, spiritual challenge (being 'tested'), genetic (and therefore 'inevitable') causes, and a vague sense of fate or sacrifice:

*Alistair: It's kind of weird, it was almost like, I don't think it was being given to me for a reason, I'm not into all that kind of airy fairy stuff, but I have had a, um.. I've had a great life ... Not a reason, but I think, if it was a choice between me and any of the members of my family I would take it, because I think I can deal with it better than they can.*

All participants' accounts conveyed a sense of living with uncertainty and threat. Participants found that they could no longer interpret bodily sensations or changes, and often their consultants could not either. While some felt able to contact their consultant or GP to seek reassurance some lived with feelings of anxiety until their next appointment.

*Dave: I've put on about a stone since Christmas ... if my weight hasn't gone down [at my next appointment] there won't be a problem at that check-up, but the next check up I go to, because I will have lost that stone ... they'll say 'you've lost weight' ... The last time that happened they sent me for a scan, because they're unsure of whether it's the cancer that's causing a loss of weight, or whether it's ... me on a diet, and they can't trust me (laughs) so they send me for a scan. Which is great, cause it means that I know for sure it's not cancer.*

Routine checkups were a universally emotive experience for participants, bringing both anxiety and relief:

*Carol: I forget that I've got anything wrong with me until it comes to just before the check-up and then you start to think, well, it's routine but, you know, um ... I'm always anxious to get the blood test over and done with and they say the magic words 'your bloods are fine'.*

Participants spoke about the various ways they tried to source, understand and filter information to help them make sense of their situation. There was consensus that the internet was likely to be unhelpful and frightening, however, some felt the need to supplement or confirm the information offered by their doctors. Participants mistrusted statistics, feeling generalisations were unhelpful. Despite attempts to control the flow of information many found this was not always possible and at times were forced to confront uncomfortable issues:

*Cath: What [the pension advisor] was saying was ... if your life expectancy is shorter they can give you a bigger payout because they know you're not going to live that long, relative, and at that time I hadn't got all the information, so that, I found, was very difficult.*

In the absence of concrete information participants described making interpretations about their condition, often as a method of reassurance although it could also lead to frightening misunderstandings:

*Maggie: I had to go to [the chemotherapy ward]. I was probably putting two and two together but that's where I saw [my consultant] ... I thought, you're going to tell me that I'm going to have to have chemo and I'm going to be shown round - that's what I thought.*

*Interviewer: What was that like?*

*Maggie: Horrible, really bad.*

*Interviewer: Did you mention that to him? That that's what you'd thought?*

*Maggie: No.*

## ***Theme 2. Intrapersonal and interpersonal coping strategies***

Issues around information also came through in participants' dialogue around coping with their lymphoma, with participants trying to arm themselves with sufficient knowledge to know how to cope, without becoming overwhelmed:

*Lynda: I just like to compile as much information as I possibly can, and make informed decisions. But everybody is different.*

Participants appeared to feel it was important to view the condition as a challenge rather than as a threat. However, elements of challenge, threat and loss were apparent in participants' narratives:

*Alistair: It was this whole kind of rollercoaster. Which was interesting, it was definitely character building ... I don't do unhappy, but this was a challenge for me, this was, and I think that was the biggest thing, I think I thought I'm never going to be that same person, it was*

*going to change me, I didn't want to change because I liked who I was, I liked that person who was always happy, and always cheery, and very rarely letting things get me down.*

While problem-focused coping styles are generally considered adaptive, one participant spoke of his initial attempts to 'problem-solve' his diagnosis, which on reflection he thought had been unhelpful and unhealthy:

*Alistair: My initial feelings when I was first diagnosed was one of sheer panic... and I did do some rather stupid things. I went down to see a specialist in London, who [is] part of this Oasis of Hope hospital in Mexico ... there's so much pressure on you to try and do something.*

*Interviewer: where did that pressure come from, do you think?*

*Alistair: I think it came from myself, you know, I'm an engineer, that's what I do, I fix things. Um, and I tried to fix myself.*

Robert, the eldest and most recently diagnosed participant, appeared to have found a way to be problem-focused while relying on the expertise of clinicians to be the problem-solvers:

*Robert: Oh, I watch myself like a hawk! Anything's that's untoward I'll go and get it investigated, very rapid, because my philosophy now is, if there's something wrong with you get it fixed as quick as possible, because the longer you delay the worse it can become.*

The helplessness that is inherent in this life-long condition led many to use coping strategies involving distraction, distancing, avoidance and attempting to maintain a sense of normality:

*Gordon: I don't know [how I deal with it]... just got to get on with it. I go out for a cycle or do my weights – take the aggression out ... I don't know how you explain it, it can crack you up. I'm not going to crack up. It might eventually get on top of me, but- how I view it is, things that are causing you stress, get away from them.*

Most participants coped with the lack of control by firmly placing themselves in the hands of professionals:

*Dave: I can do a lot to a motorcycle or car or whatever, but when it comes to the modern cars and motorcycles, they've all got their on board computers and you need specialist equipment, and that's sort of analogous to them across there.*

Maggie appeared to cope by not fully taking on board the incurable nature of the condition, acknowledging that she kept such thoughts from her mind, living, as she described it, in a protective 'bubble'. This led her to become acutely distressed when the 'inevitable' happened:

*Maggie: [I had thought] I've had the radiotherapy and now I'm getting better ... The minute she said [it had come back] that was it. The bubble was burst. It was very hard. 'God, here we go again', that was my words. You didn't know what you were going to go and do or what you were going to get.*

Robert, on the other hand, acknowledged his condition while appearing able to put this advice from his consultant into practice:

*Robert: He says, 'you can go home and worry about it if you like, but it won't make any difference', so he says, more or less this is what he says anyway, 'we'll do what we can for you, when we need to do it, and in the meantime get on with your life'. That's exactly what I did.*

A degree of acceptance is likely to be essential for coping with an incurable condition, and most participants made statements that indicated they recognised the potential risk of not confronting reality. Lynda spoke about monitoring herself for progression:

*Lynda: You have to be proactive. You don't just say 'if I don't acknowledge it it'll not happen' you can't be like that. I know a lot of people that are like that, 'oh don't talk about it' or, 'it'll just settle – go away'. You have to investigate, but I'm not paranoid either! I'm not paranoid. I'm just, I'm sensibly cautious, I would say.*

Ultimately, participants had to somehow accept their powerlessness in the face of an incurable condition – most participants spoke of the importance of maintaining a hopeful and positive attitude. This included the use of humour and, for some, hope that a long-term condition such as this may one day have a cure:

*Alistair: ... the adverts on television are basically saying they will beat it – they're confident they will beat it. So there is a confidence I think from the whole of society that we are in an era where we're close ... which is good for people like myself - they might have something that I can take next year and it will go and that will be it.*

The social context emerged as central to coping with the condition. Participants spoke of the importance of support from friends, the difficulty of gaining support from family while feeling compelled to shield them from worrying information, and the ambivalence towards gaining support from fellow patients due to the danger of 'focusing' on the condition and allowing it to take over their lives. The place of intimate partner relationships was a complex issue for this group – seen as particularly important but also uniquely fraught or nuanced. One aspect of this related to feeling 'alone' without a partner, regardless of other support that was available. For the youngest two participants, both 45 years old, relationships had dissolved since diagnosis. It was common for participants to be fearful of becoming too dependent on their partners. However, for Carol, whose husband had previously been diagnosed with a lymphoma, the very closeness of the intimate partner relationship was a barrier:

*Carol: We don't talk. I mean we talk, but we haven't really gone very deeply into- ... we don't talk deeply about it, it's just one of these- I have friends [laughs]. I don't know why, your partner just, I don't know, sometimes to verbalise something makes it real.*

This stance reflected a broader sense of the need for self-reliance and self-preservation:

*Lynda: I've got two friends who've been diagnosed with cancer since I had mine, and what I did say to them was, 'remember this is you, it's got noth- it's not your family', because you find you spend time dealing with other people's emotions. You know? And they've got no right to do that to you, because you're dealing with something that is purely pertinent to you.*

The relationship with the care team members had a special place in participants' accounts of their experiences, with the long-term nature of their condition meaning that relationships with staff developed over time. While some experienced distressing investigative procedures or treatments, the overwhelming sense was that participants felt well cared for by their healthcare team. Potentially, however, this leaves patients (who will have lifelong involvement with the team) vulnerable to changes. For example, a sense of loss was expressed about a consultant who retired unexpectedly.

*Dave: You feel better cared for if it's people that, or faces that you know. You feel as though you can speak to them a lot easier than a stranger.*

The importance of maintaining these relationships left some participants feeling uncomfortable about raising difficulties they had experienced as part of their healthcare:

*Cath: I did say to the [consultant], whoever it was, I said, 'you know, I don't want any repercussions, because I'm going to be coming here for the next however long, and I don't want to be meeting this young man [a junior doctor] and him going 'ha ha, that's her that complained'.*

In terms of specialist psychological or emotional support, participants generally did not recognise the value of this, and were suspicious about what it might involve:

*Interviewer: When you say you're not sure you have dealt with it, does that mean... that you would want to talk to somebody about it?*

*Gordon: I don't know how it would- to deal with it, you understand... sitting round holding hands has never- somebody might get comfort out of it but I cannae see myself- the point of it, eh.*

This made sense in the context of an underlying need for individuals to maintain their self-image of resilience and strength, and a reluctance to be defined by the condition:

*Alistair: ... the type of person I am I think I'll be able to deal with it a lot better than some other people. Maybe not, maybe I'm not dealing with it that well. But I think some people would probably find it a lot harder*

*Interviewer: What makes you think that?*

*Alistair: I don't know, just the type of person I am I think I do just tend to- I mean I'm not saying it's easy but, er, if I was the type of person that constantly worried about things I think it would be quite difficult. I think it would be quite stressful.*

The need to conceal 'weakness' may negatively impact on the availability for support. This is illustrated by the case of Gary who suffers from chronic fatigue syndrome that has left him house-bound and at times parasuicidal. The extract below relays his 'bravado' in communicating with his consultant at the time of his cancer diagnosis, an attitude which may potentially have concealed a need for psycho-social support to help him cope with his complex medical situation:

*Gary: I went to the hospital myself... and my doctor says 'is there somebody with you? I have to tell you, you've got lymphoma'. And I said 'aye, right, fine, that's too bad. What do I do*

now?’ he says, ‘what do you mean?’ he says ‘all the rest of the patients are like- usually they break down “you’ve got cancer”’. I says ‘no, you know, if I’ve got it I’ve got it’.

### **Theme 3. Incorporating the condition into the life narrative**

The final theme relates to the sense participants were able to make of their condition, through understanding and coping with it, placing it in the broader narratives of their lives. There was an overall sense of heightened awareness of the fragility and preciousness of life, and a desire to live life to the full:

*Lynda: It’s made me more aware of doing as much as I can. Enjoying my life as much as I can. Getting as many experiences in my life as I can ... I’m very grateful of the fact that I’ve survived, and I’m very grateful to be alive, every day ... I think that cancer was a wake- up call. Made me realise that, you know, life’s precious.*

*Dave: Since I was diagnosed with this I’ve said ‘right, hell I’m doing this’. So we’ve been to India on bikes, we’ve been to Poland, northern Spain on motorcycles, this year we’re going to do Russia ... But it’s, it’s things like that where you think- I suppose it’s a bucket list. It’s things that, you say ‘ach, I’ll do that someday’ but someday never comes, unless you actually decide ‘right, I’m doing that!’.*

Several participants felt frustrated by people who did not appear to appreciate the value of life:

*Interviewer: Do you think anything’s changed since you’ve had your diagnosis?*

*Cath: I’m a little bit more intolerant of people. Particularly in the medical aspect, when they make fusses about stuff which really ... I’ve got to work hard at being as sympathetic to certain things now. Somebody that smokes, non-stop, that is worried because they’ve got to go and have a chest x-ray in case they’ve got something nasty ... and I’m like, you know, some people want to live.*

For many participants there was increased salience of values and priorities:

*Alistair: I’ve always been a very family-orientated person, but I do definitely feel that you kind of hang on to- you don’t cling on to people, but I think you appreciate the people that are close in your life...*

Robert, who had prepared for and was thoroughly enjoying his retirement, appeared to have established his values prior to his diagnosis and seemed to find the whole experience less challenging than other participants:

*Robert: No. Nothing’s changed. It’s just something that they’ve told me I’ve got, and I’m dealing with it. It hasn’t had any effect on my life at all. None whatsoever.*

However, despite the new awareness of their values and priorities, several participants spoke of the decreased opportunities they perceived as a result of their diagnoses. For example, Cath felt unable to travel to exotic locations because of the poorer medical care. Alistair felt that his diagnosis limited his chances of finding a partner:

*Alistair: I try to focus on the present [now] but I used to always plan for the future. I used to always have my great ideas and what it was going to be like, where I was going to be in the*

*future, but I don't think you can focus on that too much now, because ... I'm a potential time bomb.*

Unfortunately, for Gary, life felt limited by being housebound and reliant on people who were not prepared to meet his needs. He was therefore perhaps prevented from having the revelatory experiences that others reported:

*Interviewer: Do you think anything's changed for you since you've found out that you have cancer?*

*Gary: Not really, I mean the wife says she's retired now and she'll not be in so you have to look after yourself, and I can't ... I never thought I was going to be like this when I retired. [Before becoming ill with ME I had] never been off my work.*

With their experiences of personal growth and challenge, participants felt that they had developed a healthier sense of perspective on life:

*Carol: There's a lot of things in life that are icing on the cake, and you don't need to bother about them ... I think all this squabbling between relatives and sisters and things, they're not a priority either. I don't get involved if I don't need to. You just think 'what are they bothering about?'*

Ultimately, there was awareness among participants that whatever direction their lives would take, the cancer would be there, and the sense of underlying threat would remain:

*Carol: It's not something that you can deal with and put away because it stays there, the illness itself, you just don't know whether it's going to develop.*

## **Discussion**

The aim of this study was to explore patients' experiences of living with a diagnosis of follicular lymphoma while not receiving treatment. An overarching theme of adjustment reflected participants' attempts to make sense of the condition in the context of existing and evolving knowledge and experiences relating to cancer in general and this particular diagnosis, intrapersonal and interpersonal strategies used to cope with the condition, and incorporation of the condition into the life narrative.

Faulkner and Maguire (1994) suggest that psychological adjustment to cancer is associated with six 'hurdles' for the patient: managing uncertainty about the future, searching for meaning, dealing with a degree of loss, having a need for openness, and the needs for emotional and medical support. For this group of patients uncertainty related primarily to the uncertain progression of the illness, not whether it would progress. This led to a sense of looming threat for some, although life stage and previous and current life events affected participants' illness experiences.

Of the six 'hurdles', the need for emotional support was perhaps the most complicated for these participants: most had experienced some sort of barrier to discussing their feelings, either with

those closest to them (especially partners) or with clinicians. This was most often related to the importance of self- and others' perceptions of their ability to cope. Participants were hesitant about the possibility of receiving specialist support from NHS or Third Sector agencies. There were also mixed feelings relating to accessing peer support. Interestingly, those who appeared to feel the least distressed by their lymphoma diagnosis were more curious about meeting others with the same diagnosis, while participants who were struggling more were reluctant to reveal their concerns or expose themselves to this potential source of worrying information regarding their condition.

The search for meaning was reflected in all participants having attempted to reconcile their preconceptions about cancer as an immediately life-threatening condition that must be fought, with the information they had accrued relating to indolent lymphoma. For some participants an illness that is treatable but not curable continued to be confusing. This appeared to be in part due to participants' attempts to maintain a sense of normality by allowing little space in their thoughts for their diagnosis. Most also made attempts to understand what had caused their condition.

For many participants there was a determination to remain 'positive' and maintain their self-image of being defiant and able to cope. Coping technically refers to actions that function to reduce the stressfulness of a challenging situation, however, the term is generally used more loosely to refer to any responses to a challenge. Coping can be an automatic response or a conscious, considered strategy, and an individual's ways of coping with illness reflect their previous experiences of coping with adversity (Salmon, 2000). Coping strategies have been classified as either problem- or emotion focused (Lazarus and Folkman, 1984): Problem-focused coping involves behavioural or cognitive attempts to meet a challenge. The latter may involve, for example, coping 'self-talk' and for individuals with follicular lymphoma this may be a more effective strategy, considering that there is little the individual can do behaviourally to influence their illness. As discovered by 'Alistair', fruitless attempts to do so may result in more cost than benefit.

Emotion-focused coping refers to attempts to manage the emotions, including avoidance, distraction and a range of defensive strategies. Avoidant strategies may be a helpful short-term approach in certain situations, such as during medical procedures (Salmon, 2000) and there is the potential for adaptive longer-term strategies, such as 'downward comparison' (Helgeson and Taylor, 1993) which a number of participants in this study used, helping them to view their own situation favourably in relation to other imagined illness. The risk of this strategy was that participants appeared to view themselves as having an illness that is not as deserving of sympathy or support as more aggressive forms of cancer.

'Emotional support' refers to the availability of people in whom one can confide feelings or difficulties. This relies on the quality, not just the existence, of relationships, requiring supportive others who can facilitate disclosure and are able to listen without needing to be protected themselves

(Salmon, 2000). Several participants seemed to perceive emotional support to be provided in a unique way by an intimate partner; however, for a variety of reasons most participants had not felt that this support was available to them. This may represent unique characteristics of the study sample, where several participants had recently separated from partners and several were in relationships that they described as being difficult.

In the present study 'Maggie' referred to having been 'in denial' and of her 'bubble bursting' leading to her feeling 'devastated' when she was confronted with the reality of disease progression. However, the signs of this were very subtle due to her cheerful demeanour and her self-perception that her coping strategy was a healthy determination to 'stay positive'. Denial is conceptualised as a maladaptive response in which unconscious attempts are made to protect oneself against emotional threat. This may be revealed when patients appear to forget or misunderstand information relating to their illness (Salmon, 2000). 'Maggie's' situation suggests that subtle forms of denial may easily be missed by clinicians. Considering this, it should be noted that avoidance of thoughts related to a stressor do not, according to Salmon (2000), represent a coping strategy in itself but rather an aspect of the experience of distress. That is, avoidant coping does not cause distress – it *is* distress.

'Gary' spoke of the distress he felt through being dependent on others due to his comorbid ME, feeling his emotional and practical support needs were not recognised. On the other hand he spoke with some bravado about the nonchalant way he had responded when faced with his lymphoma diagnosis. 'Reaction formation', another form of defensive emotion-focused coping, occurs when an individual emphasises the opposite to how he or she actually feels (Salmon, 2000). This reaction in 'Gary' may mask his distress from clinicians who would otherwise be in a position to suggest avenues for support.

'Rationalisation' takes place when patients interpret ambiguous information favourably in attempts to provide a logical explanation for events that prevent them having to confront possible threats. This occurred, for example, when participants interpreted postponements to appointments as a sign that they were better than expected. It may be that patients with follicular lymphoma have a tendency to use this approach because of the need to manage anxiety in a condition with vague symptoms.

'Displacement' was evident in the account of 'Lynda' who reported enduring anger towards a GP who had phoned her to wish her luck with an appointment before she knew that she had cancer, forcing her to realise that this was a possibility. While she denied feeling angry about any other aspect of her experiences she was unwilling to relinquish the anger she felt towards this individual. She was, however, reluctant to confront the GP out of respect for her professional status. The urge to be a 'good' patient is recognised as a response in patients who find themselves in positions of

powerlessness (Salmon, 2000). ‘Cath’ – herself in the nursing profession – had expressed reluctance to complain about what she saw as substandard treatment from a junior doctor for fear of repercussions.

Most participants had experienced a heightened awareness of the fragility and preciousness of life, giving them a ‘healthier’ sense of perspective and spurring them to prioritise and live their lives to the full. However, for participants living with concurrent social or medical stressors these potential benefits appeared to be overshadowed and they felt their options for ‘valued living’ were limited despite not suffering symptoms from their FL.

### ***Clinical Implications***

Results pooled from multiple studies suggest that approximately 40% of cancer patients report significant distress (Carlson et al., 2012). Clinical practice guidelines in oncology distress management (National Comprehensive Cancer Network, 2012) recommend that patients are routinely screened for distress, and referrals made or support offered as appropriate. Psycho-oncology services can play a key role in facilitating and supporting the use of psychosocial screening procedures, however, all multidisciplinary team members must be prepared to play a part in implementing these best practices.

Attempts should be made to identify the most personally threatening aspect of their situation for each patient (White, 2001). The assessment of psychosocial problems requires clinicians to take account of the unique aspects of each patient’s experiences and participant accounts reinforce the need for holistic care. Patients can be helped to disclose emotional material by allowing them time to express their feelings, empathising, using open questions, asking about psychosocial issues, seeking clarification of patients’ psychosocial comments or emotional non-verbal communications, summarising what they have said and offering ‘educated guesses’ as to how they might be feeling (Maguire et al., 1996). It is hoped that this research can contribute towards the educated guesses that clinicians can offer.

Salmon (2000) suggests that patients do not generally see themselves as ‘coping with a challenge’ but as ‘responding to a situation’, and that simply introducing the concept of coping can help patients to think differently about their situation and develop more adaptive coping responses. While there is little, behaviourally, that patients can do to influence the progression of their illness, it may be helpful to encourage patients to behave in ways that help them cope with the emotional impact of having this incurable condition, for example, maintaining a healthy lifestyle, maintaining social networks, engaging with their values, and being open to talking about their experiences.

According to theories of stress-coping, the degree to which challenging events are experienced as being stressful depends on intervening psychological and social processes of appraisal, ways of coping and social support (Lazarus and Folkman, 1984). These characteristics of coping suggest that,

while patients cannot and should not necessarily be protected from the ‘challenge’ of their diagnosis, they can be offered some protection from stress by modifying the intervening factors (Salmon, 2000). Helping patients to appraise their condition as a challenge rather than a threat may help, as well as ensuring psychosocial factors are considered and supported by all members of the healthcare team.

The importance of the patient-doctor relationship may leave patients vulnerable to feeling a responsibility to maintain it at personal cost, and to feeling a sense of loss if it terminates for reasons outside their control. The healthcare team is not only involved in healthcare tasks with each patient – they are in a relationship that is a vital part of patients’ coping. Teams must be aware and give attention to this important aspect of care for patients with long term conditions. Participants’ accounts suggest that as much continuity of care as possible should be offered patients, who should receive clear and timely information about any changes that are likely to occur in these important relationships.

### ***Limitations and Future Directions***

In the present study the sample consisted of British Caucasian people. It is possible that some of the findings relating to interpersonal support and the importance of appearing to cope has cultural elements. It would therefore be relevant to repeat the research with culturally different patients with follicular lymphoma. The small sample size used in qualitative research does not lend itself to making generalisations, however, the depth and richness of data that is permitted by this approach allows aspects of the patient’s experience to be discovered which may otherwise remain hidden. Research focusing more specifically on elements of the patient experience highlighted in this research would allow a more thorough understanding, for example: the impact of life stage and life stressors on patients’ appraisals and coping ; and patients’ and their significant others’ perceptions of changing roles and relationship dynamics when an individual develops a low-grade cancer. The present study suggests directions for developing psycho-educational materials and psychosocial support provision for patients living with this type of malignancy. These should be developed, piloted and evaluated with this population before potentially extending their use with other groups of patients with long-term incurable conditions.

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**Appendix A: Quality Assessment Tool for Qualitative Papers (adapted from Seymour et al., 2010)**

<b>Rating</b>	<b>Score Conversion</b>
Good	3 points
Fair	2 points
Poor	1 point
Very poor	0 points

**1. Abstract and title: Did they provide a clear description of the study?**

<b>Good</b>	Structured abstract with full information and clear title.
<b>Fair</b>	Fair abstract with most of the information.
<b>Poor</b>	Inadequate abstract.
<b>Very poor</b>	No abstract.

**2. Introduction and aims: Was there a good background and clear statement of the aims of the research?**

<b>Good</b>	Good full but concise background to discussion/study containing up-to date literature review and highlighting gaps in knowledge. Clear statement of aim AND objectives including research questions.
<b>Fair</b>	Some background and literature review. Research questions outlined.
<b>Poor</b>	Some background but no aim/objectives/questions, OR Aims/objectives but inadequate background.
<b>Very Poor</b>	No mention of aims/objectives. No background or literature review.

**3. Method and data collection: Is the method appropriate and clearly explained?**

<b>Good</b>	Method is appropriate and described clearly (e.g. interview guide included). Clear details of the data collection and recording.
<b>Fair</b>	Method appropriate, description could be better. Data collection described.
<b>Poor</b>	Questionable whether method is appropriate. Method described inadequately. Little description of data collection.
<b>Very Poor</b>	No mention of method, AND/OR method inappropriate, AND/OR no details of data collection.

**4. Sampling: Was the sampling strategy appropriate to address the aims?**

<b>Good</b>	Details (age/gender/race/context) of who was studied and how they were recruited. Why this group was targeted. The sample size was justified for the study. Response rates shown and explained.
<b>Fair</b>	Sample size justified. Most information given, but some missing.
<b>Poor</b>	Sampling mentioned but few descriptive details.
<b>Very Poor</b>	No details of sample.

**5. Data analysis: Was the description of the data analysis sufficiently rigorous?**

<b>Good</b>	Clear description of how analysis was done. Description of how themes derived/respondent validation or triangulation.
<b>Fair</b>	Descriptive discussion of analysis.
<b>Poor</b>	Minimal details about analysis.
<b>Very Poor</b>	No discussion of analysis.

**6. Ethics, bias and rigour: Have ethical issues been addressed, and what has necessary ethical approval gained? Has the relationship between researchers and participants been adequately considered?**

<b>Good</b>	Ethics: Where necessary issues of confidentiality, sensitivity, and consent were addressed. Bias: Researcher was reflexive and/or aware of own bias. Rigour: Attempts made to ensure the rigour of the research
<b>Fair</b>	Lip service was paid to above (i.e. these issues were acknowledged).
<b>Poor</b>	Brief mention of issues. At least, evidence that ethical approval has been sought.
<b>Very Poor</b>	No mention of issues.

### **7. Results: Is there a clear statement of the findings?**

<b>Good</b>	Findings explicit, easy to understand, and in logical progression. Tables, if present, are explained in text. Discussion of results relate directly to aims. Sufficient data are presented to support findings.
<b>Fair</b>	Findings mentioned but more explanation could be given. Data presented in discussion relate directly to results.
<b>Poor</b>	Findings presented haphazardly, not explained, and do not progress logically from results. Qualitative data presented with stats or percentages with only limited suggestion that results were used within a qualitative paradigm.
<b>Very Poor</b>	Findings not mentioned or do not relate to aims. Qualitative data presented as stats or percentages only (e.g. 4/8, 50% participants said...).

### **8. Transferability or generalisability: Are the findings of this study transferable (generalisability) to a wider population?**

<b>Good</b>	Context and setting of the study is described sufficiently to allow comparison with other contexts and settings, plus high score in Question 4 (sampling).
<b>Fair</b>	Some context and setting described, but more needed to replicate or compare the study with others, PLUS fair score or higher in Question 4.
<b>Poor</b>	Minimal description of context/setting.
<b>Very Poor</b>	No description of context/setting.

### **9. Implications and usefulness: How important are these findings to policy and practice?**

<b>Good</b>	Contributes something new and/or different in terms of understanding/insight or perspective. Suggests ideas for further research. Suggests implications for policy and/or practice.
<b>Fair</b>	Two of the above.
<b>Poor</b>	Only one of the above.
<b>Very Poor</b>	None of the above.

### **10. Limitations: Are the limitations of the study discussed?**

<b>Good</b>	Clear description of limitations with critical analysis of impact.
<b>Fair</b>	Descriptive list of study limitations.
<b>Poor</b>	Minimal details of study limitations.
<b>Very Poor</b>	No mention of study limitations.

### **11. Quotes: Are direct quotes of participants used to illustrate qualitative findings?**

<b>Good</b>	Directs quotes used with full explanation of context and meaning and who they were made by (e.g. male, carrier). Quotes linked back to results to clearly illustrate points.
<b>Fair</b>	Direct quotes used with some explanation of meaning.
<b>Poor</b>	Minimal quotes used with little or no explanation
<b>Very Poor</b>	No quotes used.

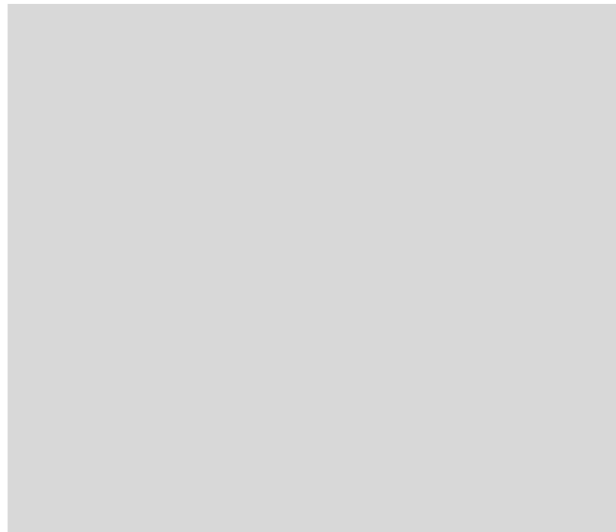
### **12. Relevance to Systematic Review research question.**

<b>Good</b>	Study explicitly based on a type of haematological cancer that is incurable (myeloma, chronic leukaemias, indolent lymphomas – see below)
<b>Fair</b>	Study based on a mixed sample, but sample is clearly defined and sufficiently balanced
<b>Poor</b>	Sample is unclearly defined, but sufficient evidence in text of adequate representation of people with incurable condition
<b>Very Poor</b>	Insufficient information, although is not explicitly based on a sample of people with aggressive/high grade curable conditions

**Appendix B:** Quality Assessment of Reviewed Studies (adapted from Seymour et al., 2010)

Quality Criterion	Evans et al. (2012)	Kelly & Dowling (2011)	Maher & De Vries (2011)	McGrath (2004a)	McGrath (2004b)	Potrata et al. (2011)	Randall & Wearn (2005)	Vlossak & Fitch (2008)
Abstract and title	3	3	3	3	3	3	3	3
Introduction and aims	2	2	2	3	2	3	3	3
Method and data collection	3	2	2	3	3	3	3	3
Sampling	3	2	2	2	2	3	3	3
Data analysis	3	3	2	3	3	3	3	3
Ethics, bias and rigour	2	2	3	3	3	2	2	2
Clarity of results	3	3	3	3	3	3	3	3
Transferability or generalisability	3	2	2	3	2	3	3	3
Implications and usefulness	3	2	2	3	2	3	3	2
Discussion of limitations	1	3	1	3	1	3	3	2
Quality of quotes used	3	3	3	2	2	2	2	3
Relevance to Review question	3	3	3	1	1	3	2	3
<b>Overall rating</b>	<b>32</b>	<b>30</b>	<b>28</b>	<b>32</b>	<b>27</b>	<b>34</b>	<b>33</b>	<b>33</b>

## Appendix C: Letters of Ethical Approval



05 November 2012

Miss Ellie Caldwell  
Trainee Clinical Psychologist



Dear Miss Caldwell

**Study title:** The experience of 'watch and wait' for people with  
follicular lymphoma: A qualitative investigation  
**REC reference:** 12/SS/0185  
**Protocol number:** N/A

Thank you for your letter of 02 November 2012, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered by the chair on behalf of the REC

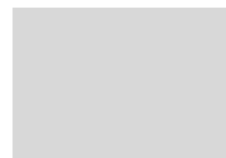
### Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

### Ethical review of research sites

NHS sites





Response to Request for Further Information	Cover Letter	02 November 2012
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### Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

### After ethical review

#### Reporting requirements

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

#### Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

<b>12/SS/0185</b>	<b>Please quote this number on all correspondence</b>
-------------------	---

With the Committee's best wishes for the success of this project

Yours sincerely



Enclosures:

"After ethical review – guidance for researchers" [\[SL-AR2\]](#)

Copy to:



## University Hospitals Division

[REDACTED]

DN/SS/approval

20 November 2012

Miss Ellie Caldwell

[REDACTED]

Dear Miss Caldwell

**Lothian R&D Project No:** 2012/W/ON/39

**Title of Research:** The experience of 'watch and wait' for people with follicular lymphoma - A qualitative investigation

**REC No:** 12/SS/0185

**Patient Information Sheet:** Version 2 dated October 2012      **Consent Form:** Version 2 dated October 2012

**Protocol:** Version 2 dated October 2012

I am pleased to inform you that this study has been approved for NHS [REDACTED] and you may proceed with your research, subject to the conditions below. This letter provides Site Specific approval for NHS [REDACTED]

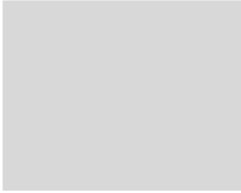
Please note that the NHS [REDACTED] R&D Office must be informed if there are any changes to the study such as amendments to the protocol, recruitment, funding, personnel or resource input required of NHS [REDACTED]. This includes any changes made subsequent to management approval and prior to favourable opinion from the REC.

Substantial amendments to the protocol will require approval from the ethics committee which approved your study and the MHRA where applicable

Please inform this office when recruitment has closed and when the study has been completed

I wish you every success with your study.

[REDACTED]



## Participant Information Sheet

The Experience of 'Watch and Wait' for People with Follicular Lymphoma:

A Qualitative Investigation

### ***What is the purpose of the study?***

*The aim of this study is to find out more about what it is like for people to be kept under observation for their follicular lymphoma, without currently receiving treatment. This is often called 'watch and wait' or 'watchful waiting'. We hope this will help us develop ways to inform and support patients through this experience.*

### ***Why have I been asked to take part?***

*You have been asked to take part because you have been diagnosed with follicular lymphoma and are currently on 'watch and wait'.*

### ***Do I have to take part?***

*No, it is up to you to decide whether or not to take part. You will be phoned by the researcher so you can ask questions and discuss the possibility of taking part, only if you have agreed to be contacted. If you do decide to take part you will be asked to sign a consent form when you come for interview, this will also be signed by the researcher who is running this study. You will still be free to withdraw at any time and without giving a reason. Deciding not to take part or withdrawing from the study will not affect the healthcare that you receive. This information sheet is yours to keep.*

### ***What will happen if I take part?***

*You will be asked to take part in one interview of about one hour in length with the researcher, who is a member of the clinical psychology team in the XXX Cancer Centre. The interview will be a discussion about your own individual experiences of what it is like being on watch and wait. The interview will be arranged to take place at the XXX Hospital at a time that is*

### ***What are the possible benefits of taking part?***

*By taking part you will help us to understand what it is like for our patients to be on watch and wait and so help us develop services for people who are in a similar situation to you. There is evidence that some people find it helpful to talk about their experiences, which is what is involved in taking part in this study. We would also be able to guide you in accessing additional support if you need it, although this guidance and support would be available whether you take part or not.*

### ***What are the possible disadvantages and risks of taking part?***

*Taking part in the study would mean you having a discussion with the researcher, which will take about an hour. This interview will be recorded so the researcher can listen to it again and draw out important themes. It is not thought that there are many disadvantages of taking part; however, it is possible that some upsetting issues might come up in the discussion. As a psychologist the researcher is very used to helping people talk about difficult issues and managing the feelings that arise. If it seemed that you may benefit from additional support from the clinical psychology service, and you would like to receive this, it can be arranged. You can also be informed of other ways to receive support.*

### ***What happens when the study is finished?***

*Interview recordings will be typed up as transcripts and the recordings destroyed. Any details that could be used to identify you will be removed from the transcripts. Anonymised data from the study will be stored securely for a period of ten years to allow for review of the*

convenient to you. If you are not able to attend the hospital for an interview we can try to arrange to interview you at your home or at XXX Hospital in XXX .

**Will my taking part in the study be kept confidential?**

All the information collected during the course of the research will be kept confidential and there are strict laws which safeguard your privacy at every stage. Your name will be removed from the data so that you cannot be recognised from it.

**What will happen to the results of the study?**

The study will be written up as a doctoral thesis in part fulfilment of the researcher's Doctorate in Clinical Psychology. The intention is also to publish the findings in a scientific peer reviewed journal. The results may also be presented to colleagues in cancer services and at other events, such as conferences. There will never be information about you included in documents or presentations which would allow you to be identified. All participants will be sent a summary of the findings if they have indicated that they would like to receive this.

data.

**Who is organising the research and why?**

This study has been organised by Ellie Caldwell, Specialist Psychological Practitioner, under the supervision of Dr XXX, Clinical Psychologist, based at the University of Edinburgh, and Dr XXX, Clinical Psychologist, based in the Clinical Psychology Department at the XXX Cancer Centre. Consultant Haematologists and Oncologists at the XXX Cancer Centre are also helping with this research. The research is being organised to help the XXX Cancer Centre develop better ways to inform and support patients with follicular lymphoma who are being kept under observation without currently receiving treatment (known as watch and wait).

**Who has reviewed the study?**

The study proposal has been reviewed by both clinical and academic supervisors, and independently by the Clinical Psychology programme team at the University of Edinburgh. A favourable ethical opinion has been obtained from XXX REC, the University of Edinburgh, and a representative from NHS XXX Research and Development. NHS management approval has also been obtained,

**Thank you for taking the time to read this information**

If you have any further questions about the study please contact Ellie Caldwell via the Clinical Psychology Department secretary, XXX.

If you have any concerns about the study you can, in the first instance, discuss these with Dr XXX by contacting her via XXX.

**XXX, secretary for Department of Clinical Psychology in Oncology, XXX Cancer Centre**

**Tel: XXX**

**Email: XXX**

If you would like to talk to a person about this research who is independent of the study, you may contact XXX, email: XXX. XXX is a researcher in the Department of Clinical Psychology who is not involved with this particular study.

If you wish to make a complaint about the study please contact NHS XXX:  
XXX

## **Appendix E: European Journal of Cancer Care: Author Guidelines**

### **Submission**

Manuscripts should be submitted online at <http://mc.manuscriptcentral.com/ecc>. Full instructions and support are available on the site and a user ID and password can be obtained on the first visit. Support can be contacted by phone (+1 434 817 2040 ext. 167) Monday-Friday, or at <http://mcv3support.custhelp.com>. If you cannot submit online, please contact Maurine Balansag in the Editorial Office by e-mail ([ECCedoffice@wiley.com](mailto:ECCedoffice@wiley.com)). A covering letter must be submitted as part of the online submission process, stating on behalf of all the authors that the work has not been published and is not being considered for publication elsewhere. A Title Page **must** also be submitted as part of the submission process (please see below).

When submitting a manuscript to the Journal authors are required to nominate at least one referee. The nominated referee will not necessarily be assigned to review the author's manuscript.

### **Copyright Assignment**

If your paper is accepted, the author identified as the formal corresponding author for the paper will receive an email prompting them to login into Author Services; where via the Wiley Author Licensing Service (WALS) they will be able to complete the license agreement on behalf of all authors on the paper. *European Journal of Cancer Care's* Open Access option, OnlineOpen, is available to authors of primary research articles who wish to make their article available to non-subscribers on publication, or whose funding agency requires grantees to archive the final version of their article. With OnlineOpen, the author, the author's funding agency, or the author's institution pays a fee to ensure that the article is made available to non-subscribers upon publication via Wiley Online Library, as well as deposited in the funding agency's preferred archive.

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