Research Project Portfolio

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Exploring the Psychosocial Needs of Adults with Haematological Cancer Under Watch-and-Wait

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Contents

Portfolio Abstract

Background

Understanding patients’ unmet needs has been deemed critical for holistic cancer care provision. However, research reporting the unmet needs of individuals with haematological cancers under watch-and-wait (indolent haematological cancers [IHC]) is scarce, despite reports of high levels of psychological distress in this population. Therefore, the present study aimed to explore the psychosocial needs of individuals living with IHC and when these needs were met, if so at all. To further understanding, the study also aimed to explore if, and if so how, needs changed over a six-month period, and whether needs differed from those identified in individuals with prostate cancer under watch-and-wait.

Method

A longitudinal qualitative design using semi-structured interviews was used. Fifteen participants were each invited to two semi-structured interviews, six months apart. Interviews took place in March 2022 and September 2022 and were therefore in the context of the Covid-19 pandemic. The interview schedule was designed to explore the needs of individuals, and when these needs were met and unmet. Themes were constructed using inductive reflexive thematic analysis and pattern-oriented longitudinal analysis. Secondary codebook analysis was applied to explore how well needs mapped onto the needs reported by individuals with prostate cancer under watch-and-wait. The analysis was also used to examine the applicability of an existing psychosocial needs theory (Self-Determination Theory) and a model of psychosocial adjustment to chronic illness and disease.

Analysis

Of the 15 participants interviewed initially, 12 attended a second interview six months later. The sample was predominantly White and female. One overarching theme: ‘The psychological battle of watch-and-wait’, was constructed. Under this, four themes were generated: (1) Understanding the impossible: cancer that does not require treatment; (2) Sense of abandonment under watch and wait; (3) The importance of peer connection; (4) Trying to live after Covid-19. These themes were found to represent information, communication, peer, emotional, and public awareness needs. Needs appeared to remain relatively stable over time and were most often met when individuals engaged with relevant charities. Deductive analysis generated the understanding that individuals with IHC have some similar and some unique needs, compared to individuals with prostate cancer under watch-and-wait. Finally, the data was found to map onto Self-Determination Theory and the model of psychosocial adaption to chronic illness and disease.

Discussion

People living with IHC not receiving treatment may be at risk of having unmet needs across domains. Future research should aim to develop effective psychosocial interventions that target the unmet emotional and informational needs of people living with IHC. Limitations of the present study include recruitment occurring exclusively through peer support groups and the predominantly White female sample, which may have skewed the needs reported.

Impact on Clinical Psychology

This study was the first to explore the psychosocial needs of individuals with IHCs qualitatively, providing an in-depth analysis of the needs for information, communication, emotional support, and peer connection. These findings add to the growing literature base of how Oncology and Haematology services can holistically support individuals with IHC to live well alongside their diagnosis.

Statement of Contributions

The systematic literature review was completed by Katie Russell, with supervision from Dr Anna Tickle and Dr Nima Moghaddam. The small-scale research project was completed by Katie Russell on a clinical placement, with supervision and support from Dr Anna Tickle, Dr Nima Moghaddam, Dr Gina Campion, and Dr Paul Langthorne.

The following table details contributions to the main research study:

Domain	**Contributor**
Project design	Katie Russell with supervision from Dr Anna Tickle, Dr Michelle Palmer, and Dr Sanchia Biswas
Ethical approval	Katie Russell with supervision from Dr Anna Tickle
Writing the review of literature	Katie Russell with supervision from Dr Anna Tickle and Dr Nima Moghaddam
Recruiting participants	Katie Russell
Data collection	Katie Russell
Scoring questionnaires (HADS)	Katie Russell
Transcription	Katie Russell (aided by the University of Nottingham Automated Transcription Service)
Data analysis	Katie Russell with supervision from Dr Anna Tickle
Write-up	Katie Russell with supervision from Dr Anna Tickle, Dr Nima Moghaddam, & Dr Sanchia Biswas

Under supervision from Dr Anna Tickle and Dr Michelle Palmer, Katie Russell developed and wrote the research protocol, parts of which are now included in the final thesis.

Systematic Literature Review

Examining anxiety and depression in haematological cancer patients in ongoing treatment and under watchful waiting: A systematic review and meta-analysis

Abstract

Introduction: The present review aimed to establish prevalence rates of anxiety and depression in adults with haematology cancer, with a focus on the differences between patients under treatment and patients under watchful waiting.

Method: Five databases (Scopus, Medline, PsycINFO, EThOS, CINAHL) were searched throughout June 2021. Key search terms included haematology cancer, anxiety, depression, in treatment and watchful waiting. Study and sample characteristics, prevalence rates, and mean self-reported scores of anxiety and depression data were extracted.

Results: A total of 18 eligible papers were included in the review. Quality appraisal indicated papers were of adequate standard. Depression data from 2720 participants (14.5% under watchful waiting) and anxiety data from 2520 participants (15.9% under watchful waiting) were analysed through subgroup meta-analyses. The prevalence of anxiety was 34% amongst adults receiving treatment and 24.5% amongst those under watchful waiting. The prevalence of depression amongst adults receiving treatment was 31.3%, significantly higher than 16.1% of adults under watchful waiting.

Conclusion: Overall, adults with haematology cancer were at greater risk of experiencing anxiety and depression than the general population, with greatest risk in those under treatment. The findings indicate the need for future research to examine availability and effectiveness of targeted psychological interventions.

Key words: haematology, cancer, prevalence, depression, anxiety, meta-analysis.

Introduction

Haematology cancer (HC) describes any cancer affecting the blood, bone or lymphatic system (NICE, 2016). The term describes over ninety diagnoses, each associated with different characteristics (Blood Cancer UK, 2019). HC accounts for an estimated 5% of cancer cases globally (Sung et al., 2021) and 9% of those diagnosed in high economically developed countries (Smith, Howell, Patmore, Jack, & Roman, 2011). Though HC affects individuals across the lifespan, there is a marked increase in incidence in individuals aged 50 years and over (Smith et al., 2011).

On average, 50% of people diagnosed with HC in the UK are expected to survive for ten years or more, thanks to advances in treatment development (Foster, Calman, Richardson, Pimperton, & Nash, 2018). The move from viewing cancer as an acute life-threatening illness to a chronic condition means focus has shifted to exploring how individuals can live well alongside their diagnosis (Pitman, Suleman, Hyde, & Hodgkiss, 2018). Anxiety and depression are commonly diagnosed disorders that can significantly increase the psychosocial burden of living with cancer (Gold et al., 2020). It is estimated that depression affects approximately 20%, and anxiety approximately 10%, of people living with cancer, higher than prevalence rates seen in the general population (Pitman et al., 2018). Psycho-oncology theories have aimed to explain mechanisms of increased risk of psychological distress in cancer (Barroilhet, Forjaz, & Landivar, 2005). The Folkman model (Holland, 2002), based on the Stress and Coping model (Lazurus and Folkman, 1984), proposes that a person’s appraisal of the cancer diagnosis, and their coping style, influence the emotional response to having cancer. Appraisals of high threat and unhelpful coping styles have been linked to increased reports of experiencing psychological distress (Greer, Morrey & Watson, 1989). Though such theories may require updating, recent research has found the model remains applicable in cancer settings (Kim, Mitchell, & Ting, 2019; Admiraal, 2020).

The prevalence of anxiety in people living with HC is estimated to be 20%-37% (Clinton-McHarg et al., 2014), compared to 7% in the general population (Steel et al., 2014). In addition to impacting patients’ quality of life, anxiety in cancer has been linked to an increase in pain, vomiting and sleep disturbance (Baqutayan, 2012).

Depression is estimated to affect between 17%-51% (Clinton-McHarg et al., 2014) of the HC population, substantially higher than the estimated 5% in the general population (Steel et al., 2014). A comorbid diagnosis of depression has been linked to poorer adherence to cancer treatment, consequent poorer health outcomes and increased mortality (Sherrill, Smith, Mascoe, Bigus, & Abbitt, 2017). It is important to note that prevalence of anxiety and depression are most commonly assessed through self-report measures (Mitchell et al., 2010), a method which has received criticism. In cancer patients, high base-rates for adjustment disorders are reported, and generic mood questionnaires do not differentiate between these and anxiety and depression (Vodermaier & Millman, 2011). In addition, self-reporting relies on the responder's understanding and openness, and omits clinical judgement. Therefore, the way in which self-report measures have been applied may hold implications for prevalence rates reported. However, research also benefits from such validated tools due to their ease of application and utility in allowing for comparisons across samples (Mitchell et al., 2010).

Comorbid psychological distress has implications for wider society (Mausbach, Decastro, Schwab, Tiamson-Kassab, & Irwin, 2020). Cancer patients diagnosed with anxiety or depression were significantly more likely to attend an emergency department, to require hospitalisations and on average, were hospitalised for 73% longer than cancer patients without anxiety or depression (Mausbach et al., 2020). In total, cancer patients presenting with anxiety and/or depression incurred healthcare costs that were over double cancer patients without anxiety and/or depression. Consequently, anxiety and depression place additional financial pressure on countries with national healthcare systems, such as the UK. For individuals who pay for their healthcare, psychological distress is likely to increase the financial burden of having cancer, which in turn, has been linked to higher risk of anxiety and depression (Hall et al., 2016).

Some HC diagnoses are classed as acute and require immediate and often debilitating treatment, such as chemotherapy, radiotherapy or a bone marrow transplant (NICE, 2016). Side effects from such treatments can include fatigue, nausea, vomiting, neutropenia, and an increased risk of infection (MacMillan Cancer Support, 2020). Aggressive treatments with such side effects have been associated with an increased risk of individuals presenting with anxiety and depression (Allart-

Vorelli, Porro, Baguet, Michel, & Cousson-Gélie, 2015). Other HC diagnoses are slow-growing chronic diseases which may not require immediate treatment. Patients with such diagnoses can be placed under “watchful waiting”, a disease monitoring pathway whereby patients attend regular check-ups with their care team (also known as active surveillance or active monitoring) (Blood Cancer UK, 2019). Whilst patients under watchful waiting do not experience debilitating treatment side effects, managing a chronic HC significantly impacts individuals’ ability to work, plan for the future and maintain a family life (Evans, Ziebland, & Pettitt, 2012).

In the wider cancer population, anxiety and depression are more commonly noted in the early stages of receiving a diagnosis, with symptoms reducing following commencement of treatment (Niedzwiedz, Knifton, Robb, Katikireddi, & Smith, 2019). In contrast, in HC patients, anxiety and depression are reported to remain high over time (Oerlemans et al., 2014) and do not correlate with receiving treatment (Walker et al., 2014). Despite preliminary findings indicating HC patients under watchful waiting and under treatment experience significant levels of anxiety and depression, provision of psychological support differs. Leukaemia Care (2019) surveyed 1152 HC patients about support provision when under treatment and when under watchful waiting. Those under watchful waiting were significantly less likely to be offered information on emotional support (39% versus 69%) or access to a Clinical Nurse Specialist, despite this being identified as a key driver of improved patient experience by NHS England (Leukaemia Care, 2019).

Whilst there is extensive research examining the prevalence of anxiety and depression and associated effective support in the wider cancer population, there are comparatively few studies examining the prevalence in HC patients and even fewer in those under watchful waiting. Moreover, there are several key differences associated with HC which may make findings from the wider psycho-oncology literature inapplicable. Such differences include lack of a solid tumour site, absence of physical signs of illness, and differences in treatment regimens (Swash, 2015). There are also important differences in watchful waiting pathways across cancer diagnoses. For example, in the UK, prostate cancer patients typically have choice between watchful waiting or surgical intervention (NICE, 2019), whereas treatment is predominantly dictated by disease stage in HC (NICE, 2016).

Depression and anxiety can significantly impact the quality of life of people living with cancer (Pitman et al., 2018), as well as increase financial pressure on individuals or healthcare systems. Understanding the prevalence of depression and anxiety is essential for understanding the need for, and development of, evidence-based psychological interventions to address distress. However, prevalence estimates vary across individual studies. Therefore, this paper aims to systematically review literature to answer the question: “What are the prevalence rates of anxiety and depression in adults living with HC in ongoing treatment and under watchful waiting?”. It is hoped that an indication of overall prevalence, as well as differences between treatment pathways, will inform policymakers and service providers in developing effective care pathways in supporting people living with HC.

Method

2.1 Protocol and registration

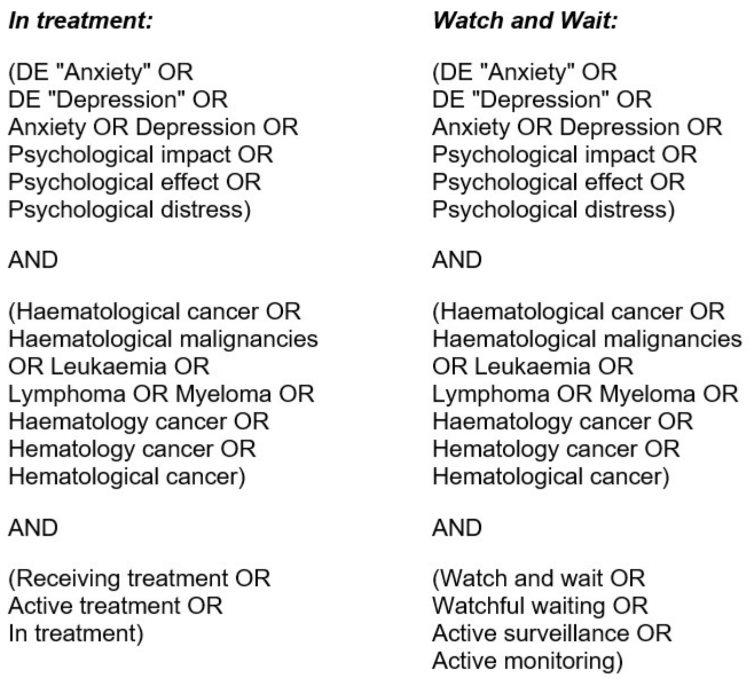
The present systematic review was registered with PROSPERO (registration number CRD42021265435). The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines provided a framework for development of the review protocol (Page et al., 2021).

2.2 Search strategy

PsycINFO, Medline, CINAHL, Scopus and EThOS databases were systematically searched for literature examining anxiety and depression in people with HC. Searches were initiated and completed in June 2021. No date limit was set. On PsycINFO, Medline and CINAHL, both free text and index terms were used; on Scopus and EThOS, only free text search was available. Given the scarcity of research examining patients under watchful waiting and in treatment in a single study, two separate searches were conducted across all databases. Both searches contained terms relating to depression, anxiety and haematology cancer. In addition, one search included search terms relating to the watchful waiting pathway, whilst the other search included terms relating to ongoing treatment. Broad search terms and multiple alternatives to key words were used to increase opportunity to identify relevant literature. A published review was also used as a key terms guide (Watts et al., 2014). An example of a full search strategy can be viewed in Figure 1.

Bibliographies of relevant reviews and included articles were examined to identify additional relevant literature.

Figure 1.
Full search strategies used in PsycINFO database via the EBSCO Host platform.



In treatment:	***Watch and Wait:***
(DE "Anxiety" OR DE "Depression" OR Anxiety OR Depression OR Psychological impact OR Psychological effect OR Psychological distress)	(DE "Anxiety" OR DE "Depression" OR Anxiety OR Depression OR Psychological impact OR Psychological effect OR Psychological distress)
AND	AND
(Haematological cancer OR Haematological malignancies OR Leukaemia OR Lymphoma OR Myeloma OR Haematology cancer OR Hematology cancer OR Hematological cancer)	(Haematological cancer OR Haematological malignancies OR Leukaemia OR Lymphoma OR Myeloma OR Haematology cancer OR Hematology cancer OR Hematological cancer)
AND	AND
(Receiving treatment OR Active treatment OR In treatment)	(Watch and wait OR Watchful waiting OR Active surveillance OR Active monitoring)

2.3 Study selection

Following identification of potentially relevant studies, duplicates were removed, and article titles and abstracts were screened by the main author. Full-text papers were then obtained and screened for inclusion in the review against the eligibility criteria. Grey literature was included to minimise the impact of publication bias, given recruitment issues in this population are not uncommon (Swash, 2015).

2.4 Eligibility criteria

Articles that met the following criteria were considered for inclusion:

1. Sample comprised participants over the age of 18 and diagnosed with a haematology cancer at the time of study participation.
2. Participants were described as being under watchful waiting or in ongoing treatment.
3. Empirical study reporting original quantitative anxiety and/or depression data, determined using a validated measure.

4. Available in English.

Studies were excluded if:

1. Participants had completed treatment and awaiting further treatment. This excluded studies that examined the impact of discrete treatments such as a bone marrow transplant. Patients undergoing such treatments were viewed as being on a third treatment trajectory, beyond the scope of the present review.
2. Participants were identified as having anxiety or depression diagnoses prior to cancer diagnosis.
3. Inappropriate data presentation meaning suitable data could not be extracted:
    a. Depression and anxiety scores were combined, and separate means or prevalence rates were not presented.
    b. Depression and anxiety scores for those under watchful waiting and those in treatment were combined, or the paper did not explicitly state the treatment trajectory of the sample the scores represented.
    c. Depression and anxiety scores included participants with non-haematological cancers.

2.5 Data abstraction

The main author extracted and recorded key data from included papers, including study design, sample characteristics and outcome measures of anxiety and depression.

2.6 Quality appraisal

Each included article was given a quality rating by both authors. Due to lack of a “gold standard” quality assessment tool, one tool was adapted to ensure the included reviews were thoroughly appraised (Quigley, Thompson, Halfpenny, & Scott, 2019). It was anticipated that articles reporting various study designs would be included in the review. Therefore, an adapted version of the Standard Quality Assessment Criteria for Evaluating Quantitative Primary Research Papers from a Variety of Fields (QualSyst) (Kmet, Lee & Cook, 2004) was used. Adaptions included omitting three questions pertaining to randomisation of participants due to the review only considering baseline data (see section 2.4), and therefore, randomisation to intervention group being irrelevant to the quality of the baseline data reported. One question from the Quality Assessment Tool for Quantitative Studies (Thomas, Ciliska, Dobbins, & Micucci, 2004) on sample representativeness was included to capture risk of selection bias. Each article was given a rating out of 2 (2 = criterion met; 1 = criterion partially met or cannot tell; 0 = criterion not met) on each question of the appraisal. A total score was provided for each question and for each article.

2.7 Data analysis

Depression and anxiety data were analysed separately through an identical meta-analysis process. Descriptive data (means, standard deviations [SD], sample prevalence percentages and sample sizes) were extracted and entered into meta-analysis software: OpenMeta[Analyst] (Wallace et al., 2012). Subgroup analyses were conducted for means data and prevalence data. Random effects modelling (Der Simonian & Laird., 1986) was chosen due to non-randomisation of participants to each group and the heterogeneity between samples. Pooled estimates of prevalence of anxiety and depression in each subgroup were computed using 95% confidence intervals (C.I.). Pooled estimates of subgroup means and SDs were computed. Pooled estimates were compared to test for statistical significance through further random-effects subgroup analysis (Borenstein, Hedges, Higgins, & Rothstein, 2009).

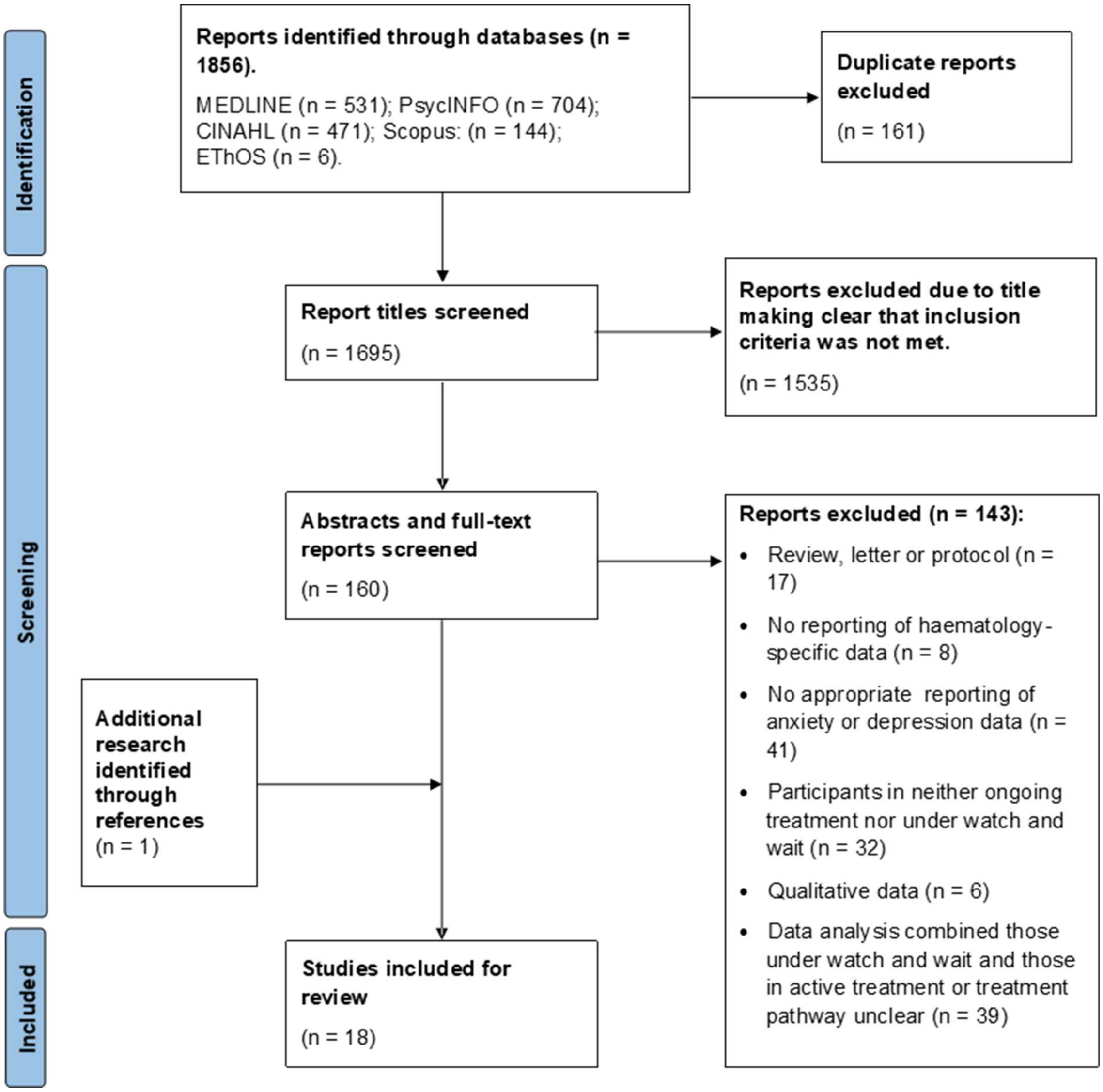
Results

3.1 Systematic search results

Systematic database searching returned 1856 articles. After removing duplicates, 1695 articles remained and 1677 of these were excluded at title, abstract or full-text level, depending on when ineligibility became evident. Manual searching of reference lists returned one previously unidentified article. Following screening, 18 articles met eligibility criteria. Figure 2 illustrates a detailed breakdown of article selection and exclusion.

Figure 2.

PRISMA diagram illustrating article selection and exclusion process (Page et al., 2021)



3.2 Study characteristics

Table 1. outlines study characteristics. Studies comprised cross-sectional and longitudinal designs. All 18 reported depression data (17 reported means; 13 reported prevalence), whilst 17 reported anxiety data (16 reported means; 11 reported prevalence). In total, depression data was extracted from 2720 participants (14.5% under watchful waiting); anxiety data was extracted from 2520 (15.9% under watchful waiting). The difference resulted from one study (n=200) only measuring depression (5). Sample sizes ranged from 17 to 489 participants. The average age

of participants across studies was 53 years with 61% male. Though average age and gender ratios vary depending on diagnosis, generally HC is more commonly diagnosed in males aged over 50 years (Smith et al., 2011), as reflected in the overall characteristics. Only five studies reported ethnicity (2,10,13,14,15), each reporting a majority Caucasian sample (range 75%-100%). Studies were conducted in 11 countries, across 5 continents; however, all studies reporting ethnicity were based in the UK or USA. Therefore, the overall ethnicity of the sample was unknown. Across studies, 11 types of HC diagnoses were reported, with Multiple Myeloma and Chronic Lymphocytic Leukaemia mostly commonly described.

All studies used self-report measures to assess anxiety and depression. Across studies, ten outcome measures were used. The Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983) was most commonly reported (1,3,4, 6,8,9,12,15,16,17,18). Four studies compared psychological distress in those under watchful waiting and those in treatment (13,16,17,18). Two examined distress in those under watchful waiting only (14,15) and the remaining 12 examined only those in treatment (1-12). Ongoing treatments included chemotherapy, radiotherapy and other drug therapies.

3.3 Quality appraisal

Table 2 outlines the quality ratings of each study. Each received a score out of 24, with a higher score indicating higher study quality. A score of 50% or less was deemed a liberal estimate of low quality by QualSyst developers (Kmet et al., 2004). The average study quality score was 21, equivalent to 88% (SD=7.9%; range: 67%-92%). 13 scored above 75% (1, 3-6, 8-12, 14, 16, 18); no study scored 50% or below. Though the tool used in the present review was an adapted version, 11/12 questions were taken from QualSyst and so the 50% mark has been deemed relevant as a general guide. Therefore, the overall study quality was considered good.

All studies stated the research question or aims, and all samples were at least partially representative of the wider HC population in terms of gender, age, or diversity in HC diagnoses. Most lacked detail on sample ethnicity. Studies generally scored poorly on appropriate sample size, which may hold implications for generalisability of individual study findings to the wider HC population. Generally, studies scored highly on analysis and reporting of results, with many offering an estimate of variance of their main findings or controlling for confounding factors.

Table 1.

Study characteristics

No.	Author and country	Study design	Sample size (% men); mean age (age range); sample ethnicity	Haematology diagnosis	Treatment received	Outcome measures	Key relevant findings	
							Anxiety Mean (SD)	Depression Mean (SD)
1	Bellali, Manomenidis, Meramveliotaki, Minasidou & Galanis. (2020) Greece	Cross-sectional	76 (65.8%); 58.4 years (not given); not given	Non-Hodgkins Lymphoma, Chronic Lymphatic Leukaemia, Hodgkins Lymphoma, Multiple Myeloma	In treatment: chemotherapy	Anxiety: HADS[a] Depression: HADS[a]	12.7 (4.5)	11.1 (4.0)
2	Bryant et al. (2018) USA	Longitudinal	17 (62.5%); 50 years (28-69); 76% White, 24% African American	Acute Myeloid Leukaemia, Acute Lymphoblastic Leukaemia	In treatment: chemotherapy	Anxiety: PROMIS[b] Depression: PROMIS[b]	Baseline for intervention group: 58.2 Baseline for control group: 59.4 Prevalence: 58%	Baseline for intervention group: 58 Baseline for intervention group: 59.5 Prevalence: 58%
3	Fukushima et al. (2018) Japan	Longitudinal	44 (47.7%); 68 years (41-86); not given	Acute myeloid leukaemia, Acute lymphoblastic leukaemia, Multiple Myeloma, Chronic Myeloid Leukaemia	In treatment: chemotherapy	Anxiety: HADS[a] Depression: HADS[a]	High exercise engagement: 5.8 (3.2) Low exercise engagement: 6.4 (4.8)	High exercise engagement: 7.0 (3.0) Low exercise engagement: 5.9 (3.9)

No.	Author and country	Study design	Sample size (% men); mean age (age range); sample ethnicity	Haematology diagnosis	Treatment received	Outcome measures	Key relevant findings	
							Anxiety Mean (SD)	Depression Mean (SD)
4	Furzer et al. (2016) Australia	Longitudinal	37 (not given); 49 years (22-68); not given	Non-Hodgkins Lymphoma Hodgkins Lymphoma Multiple Myeloma	In treatment: chemotherapy (100%), radiotherapy (27%), stem cell transplant (13.5%).	Anxiety: HADS [a] Depression: HADS [a]	Baseline for intervention group: 5.3 (2.9) Baseline for control group: 6.8 (4.6)	Baseline for intervention group: 4.7 (3.4) Baseline for control group: 5.1 (4.6)
5	Kapoor et al. (2015) India	Cross-sectional	100 (63%); 41 years (18-70); not given	Chronic myeloid leukaemia	In treatment: Imatinib	Depression: PHQ-9 [c]	*N/A*	Adherence group: 2.48 (2.88) Non-adherence group: 7.16 (5.84) Prevalence: 23%
6	Kiely, Cran, Finnerty, & O'Brien (2017) Ireland	Cross-sectional	41 (59%); 64 years (46-86); not given	Multiple myeloma	In treatment: Thalidomide Lenalidomide Bortezomib Chemotherapy Stem cell transplant	Anxiety: HADS [a] Depression: HADS [a]	Median (SD) 9.8 (3.76) Prevalence: 30%	Median (SD) 10.1 (3.68) Prevalence: 37%

No.	Author and country	Study design	Sample size (% men); mean age (age range); sample ethnicity	Haematology diagnosis	Treatment received	Outcome measures	Key relevant findings	
							Anxiety Mean (SD)	Depression Mean (SD)
7	Koizumi et al. (2018) Japan	Cross-sectional	27 (74%); 60 years (not given); not given	Leukaemia, Myelodysplastic syndrome Non-Hodgkin's Lymphoma, Aplastic anaemia, Multiple myeloma	In treatment: chemotherapy	Anxiety: POMS [d] Depression: POMS [d]	17.0 (7.1) Prevalence: 55%	15.9 (9.5) Prevalence: 33%
8	Mianmian et al. (2019) China	Cross-sectional	180 (56.1%); 51 years (not given); not given	Acute myeloid leukaemia (AML)	In treatment: chemotherapy	Anxiety: HADS [a] Depression: HADS [a]	Relapsed and remitting AML: 9.1 (4.0) De novo AML: 7.5 (3.4) Prevalence: 53.9% Prevalence: 40%	Relapsed and remitting AML: 8.0 (3.7) De novo AML: 6.7 (3.0) Prevalence: 45.6% Prevalence: 29.4%
9	Oerlemans et al. (2014) Netherlands	Retrospective	489 (61%); 57.5 years (not given); not given	Hodgkins Lymphoma (HL), Diffuse large B-cell lymphoma (DLBCL)	In treatment: chemotherapy	Anxiety: HADS [a] Depression: HADS [a]	HL – 4.8 (4) DLBCL – 4.1 (4) Prevalence: 24% (HL) and 17% (DLBCL).	HL – 3.7 (4) DLBCL – 4.3 (4) Prevalence: 18% (HL) and 19% (DLBCL).
10	Robbertz et al. (2020) USA	Longitudinal	106 (67%); 60 years (24-82); 95.6% Caucasian, 2.30% African American.	Chronic Lymphatic Leukaemia	In treatment: chemotherapy	Anxiety: GAD-7 [e] Depression: PHQ-9 [c]	None-mild anxiety: 2.09 (2.40) Moderate-severe: 13.00 (2.45) Prevalence: 10%	None-mild depression: 2.25 (2.00) Moderate-severe: 11.73 (3.43) Prevalence: 14%

No.	**Author and country**	**Study design**	**Sample size (% men); mean age (age range); sample ethnicity**	**Haematology diagnosis**	**Treatment received**	**Outcome measures**	**Key relevant findings**	
							Anxiety Mean (SD)	Depression Mean (SD)
11	Wang, Liu, Shi, & Wang (2016) China	Explorative	227 (51.5%); 45 years (18-83); not given	Leukaemia, multiple myeloma, lymphoma	In treatment: chemotherapy	Anxiety: Zung self-rating anxiety scale Depression: CES-D[f]	47.87 (11.21) Prevalence: 45.8%	20.18 (9.65) Prevalence: 65.0%
12	Zittoun, Achard, & Ruszniewski (1999) France	Longitudinal	178 (55.6%); 44 years (16-83); not given	Acute leukaemia, chronic myeloid leukaemia, Hodgkin's lymphoma, non-Hodgkin's lymphoma, multiple myeloma	In treatment: chemotherapy, bone marrow transplant	Anxiety: HADS[a] Depression: HADS[a]	5.55 (4.14) Prevalence: 33%	5.95 (4.53) Prevalence: 23%
13	Levin, Li, Riskind, & Rai (2007) USA	Cross-sectional	105 (63%); 59 years (not given); 95% White	Chronic Lymphatic Leukaemia	In treatment (48%) Watchful waiting (57%)	Anxiety: BAI[g] Depression: BDI-II[h]	Watchful waiting: < 60 years: 6.18 (5.47) > 60 years: 2.91 (3.04) Ongoing treatment: < 60 years: 4.75 (4.01) > 60 years: 5.38 (6.46)	Watchful waiting: < 60 years: 8.09 (6.07) > 60 years: 4.75 (4.54) Ongoing treatment: < 60 years: 8.62 (6.78) > 60 years: 6.39 (4.54)

No.	Author and country	Study design	Sample size (% men); mean age (age range); sample ethnicity	Haematology diagnosis	Treatment received	Outcome measures	Key relevant findings	
							Anxiety Mean (SD)	Depression Mean (SD)
14	Morrison et al. (2016) USA	Cross-sectional	112 (55%); 61 year (37-76); 100% Caucasian	Chronic lymphocytic leukaemia	Watchful waiting	Anxiety: GAD-7[e] Depression: CES-D[f]	3.8 (6.5) Prevalence: 20.5%	10.2 (8.1) Prevalence: 20.6%
15	O'Byrne (2018) UK	Longitudinal	33 (57%); 70 years (50-89); 96% White, 3% Other	Chronic lymphatic lymphoma, Low grade lymphoma	Watchful waiting	Anxiety: HADS[a] Depression: HADS[a]	Median: 5 Prevalence: 43%	Median: 3 Prevalence: 12%
16	Santos, Kozasa, Chauffaille, Colleoni, & Leite (2006) Brazil	Cross-sectional	107 (55%); 50 years (21-84); not given	Non-Hodgkins Lymphoma, Acute myeloid leukaemia, Acute lymphocytic leukaemia, Multiple Myeloma	In treatment (49%) Watchful waiting (51%)	Anxiety: HADS[a] Depression: HADS[a]	Watchful waiting: 4.63 Ongoing medication: 3.2 Radiotherapy: 3.0 Chemotherapy: 6.45	Watchful waiting: 3.47 Ongoing medication: 2.2 Radiotherapy: 1.8 Chemotherapy: 4.64

No.	Author and country	Study design	Sample size (% men); mean age (age range); sample ethnicity	Haematology diagnosis	Treatment received	Outcome measures	Key relevant findings	
							Anxiety Mean (SD)	Depression Mean (SD)
17	Swash (2015) UK	Longitudinal	71 (46.8%); 61 years (19-97); 97.4% white, 1.3% Black Caribbean, 1.3% Chinese.	Non-Hodgkin's lymphoma, chronic lymphocytic leukaemia, chronic myeloid leukaemia, Hodgkin's lymphoma	In treatment (69%) Watchful waiting (31%)	Anxiety: HADS [a] Depression: HADS [a]	Watchful waiting: 6.00 (1.3) In treatment: 7.6 (0.62)	Watchful waiting: 4.33 (1.05) In treatment: 5.42 (0.56)
18	Van den Broek et al. (2015) Netherlands	Cross-sectional	125 (67%); 61 years (not given); not given	Chronic lymphocytic leukaemia, Small lymphocytic leukaemia	In treatment (46%): chemotherapy, radiotherapy Watchful waiting (54%)	Anxiety: HADS [a] Depression: HADS [a]	Watchful waiting: 4.5 (3.7) Ongoing treatment: Chlorambucil 6.0 (4.2) Chemo/ immunotherapy 3.5 (3.7) Prevalence: 18%	Watchful waiting: 3.6 (3.5) Ongoing treatment: Chlorambucil 4.9 (4.1) Chemo/ immunotherapy 4.1 (4.1) Prevalence: 13%

Outcome measures: Hospital Anxiety and Depression scale (HADS) [a]; Patient-reported Outcome Measurement Information System (PROMIS) [b]; Patient Health Questionnaire (PHQ-9) [c]; Profile of mood states (POMS) [d]; Generalised Anxiety Disorder Assessment (GAD-7) [e]; Centre for Epidemiologic Studies Depression Scale (CES-D) [f]; Beck's Anxiety Inventory (BAI) [g]; Beck's Depression Inventory (BDI-II) [h].

Table 2.

Quality ratings (based on quality assessment tools by Kmet et al., 2004 and CASP 2019)

	1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**11**	**12**	**13**	**14**	**15**	**16**	**17**	**18**	
Question	Bellali et al. (2020)	Bryant et al. (2018)	Fukushima et al. (2018)	Furzer et al. (2016)	Kapoor et al. (2015)	Kiely et al. (2017)	Koizumi et al.(2018)	Mianmian et al. (2019)	Oerlemans et al. (2014)	Robbertz et al. (2020)	Wang et al. (2016)	Zittoun et al. (1999)	Levin et al. (2007)	Morrison et al. (2016)	O'Byrne (2018)	Santos et al. (2006)	Swash (2015)	Van den Broek et al. (2015)	**Total**
1. Was the research question or aims clearly stated? [a]	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	36
2. Were the individuals selected to participate in the study likely to represent the target population? [b]	2	1	2	1	1	1	1	1	1	1	2	2	1	1	1	2	2	1	24
3. Is the method of subject selection described and appropriate? [a]	2	2	0	1	1	2	1	1	2	1	1	2	1	2	2	1	1	2	25
4. Was the sample size appropriate? [a]	1	0	1	1	2	1	0	2	2	1	2	2	2	2	0	1	0	2	22
5. Are the subject characteristics sufficiently described? [a]	2	2	1	1	2	2	2	2	2	2	2	2	2	1	2	2	2	2	33
6. Is the design evident and appropriate to answer study question? [a]	1	2	1	2	2	2	2	1	2	2	2	2	2	2	2	2	2	1	32
7. Was the outcome measure well defined and robust to measurement/misclassification bias? [a]	2	2	2	2	1	2	0	2	2	2	2	2	2	2	2	2	2	2	33
8. Is the analysis described and appropriate? [a]	2	1	2	2	2	2	2	2	2	2	2	1	2	2	2	2	2	2	34
9. Controlled for confounding? [a]	1	0	0	2	2	1	0	0	2	1	2	1	1	2	1	1	2	1	20

10. Is an estimate of variance for the main outcome given? [a]	2	0	0	0	2	2	0	0	0	0	0	0	0	2	0	0	0	2	10
11. Are results reported in sufficient detail? [a]	2	2	2	2	2	1	1	2	2	2	2	2	2	2	1	1	1	2	31
12. Do the results support the conclusions drawn? [a]	2	1	1	2	2	2	1	2	2	2	2	2	2	2	2	2	2	2	33
Total raw score	21	15	14	18	21	20	12	17	21	18	21	20	19	22	17	18	18	21	18.5
Total percentage (%)	88	62	58	75	88	83	50	71	88	75	88	83	79	92	71	75	75	88	77

[a] Item taken from the Standard Quantitative Quality Assessment Criteria for Evaluating Primary Research Papers from a Variety of Fields (Kmet et al., 2004)

[b] Item taken from the Quality Assessment Tool for Quantitative Studies (Thomas, Ciliska, Dobbins, & Micucci, 2004)

2. Papers were judged on sample representativeness of age (wide range and average age above 50 years), gender (roughly equal or slightly more male to female ratio), ethnicity (diversity in ethnic backgrounds) and breadth of haematology diagnoses.

4. Judged on Power calculations if available or on response rate from those identified as eligible for the study.

3.4 Anxiety and Depression

In some studies, an overall sample mean or prevalence was not reported and instead, samples were split by a factor relevant to the individual study, e.g., Kapoor et al. (2015) presented their means for a medication-adherence group and a non-adherence group. In these cases, samples were treated independently and entered separately into OpenMeta. Further details on split samples within single studies can be viewed in Table 1.

Meta-analyses included only studies reporting HADS mean and SD data. This decision was made on the basis that transforming raw scores from several measures into comparable data would weaken the clinical utility of the findings, as clinical cut-offs would be inapplicable. The HADS is a 14-item self-report scale which has demonstrated acceptable internal consistency in a cancer population (Cronbach's α = 0.85) (Rodgers, Martin, Morse, Kendell, & Verrill, 2005). Scoring gives separate scores of anxiety symptoms and depressive symptoms, each out of 21. A score below 8 is deemed "normal"; between 8 and 10: "mild"; 11 and 14: "moderate" and over 14: "severe". Two studies only reported median HADS data (15, 16) and so it was assumed that sample distribution was not normal and transformation from median to mean scores was not possible. Therefore, the samples were excluded from the means meta-analysis. Both studies were included in the prevalence analysis.

Table 3 outlines the key findings relating to anxiety and depression data in HC patients.

Table 3.

Prevalence and symptoms of anxiety and depression across groups

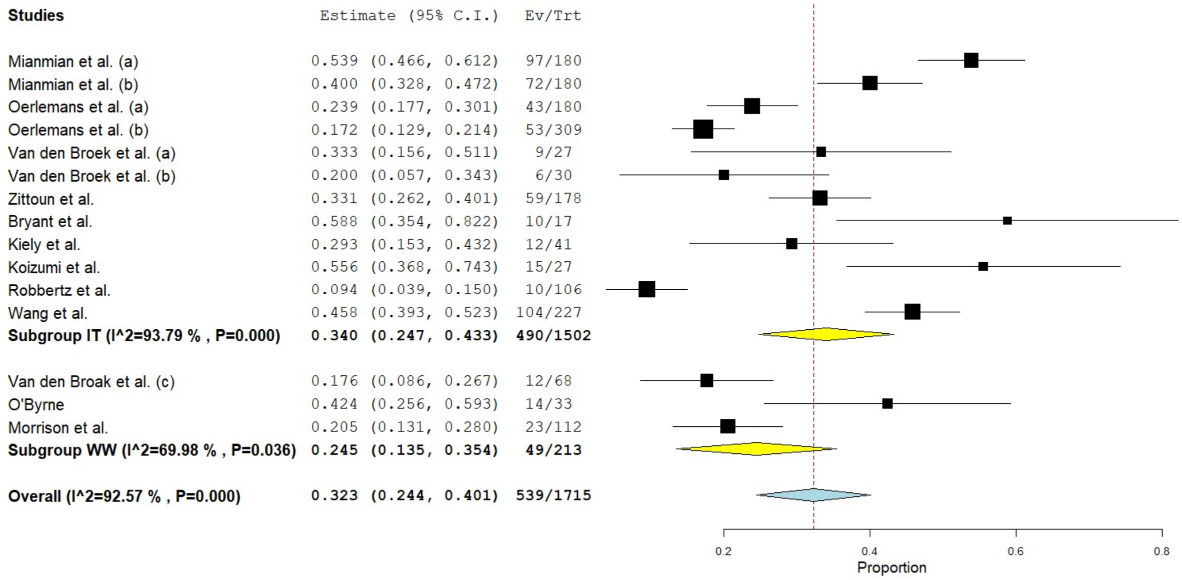
	Anxiety		**Depression**	
	Prevalence % (C.I.)	Mean (SD)	Prevalence % (C.I.)	Mean (SD)
Watchful waiting	24.5 (13.5-35.4)	5.1 (1.1)	16.1 (10.7-22.4)	4.1 (0.7)
Under ongoing treatment	34.0 (24.7-43.3)	6.4 (1.0)	31.3 (22.1-40.7)	6.0 (0.9)
Overall	32.3 (24.4-40.1)	6.1 (0.7)	28.2 (20.2-36.2)	5.7 (0.8)

3.4.1 Prevalence of Anxiety

Across nine studies reporting anxiety prevalence in those in ongoing treatment (2,6-12,18) (n = 1502), sample prevalence ranged between 9%-59%. In the three studies examining those under watchful waiting (14,15,18), the prevalence range was 17.6%-42.4%. Subgroup analysis revealed the pooled estimated prevalence of anxiety in those undergoing treatment was 34.0% (C.I. 24.7%-43.3%; I^2 = 93.8%), higher than the estimated prevalence in the watchful waiting group (24.5%; C.I. 13.5%-35.4%; I^2 = 70.0%), though this difference was not statistically significant (z=1.296, p=0.195). The study reporting the highest prevalence in those under watchful waiting (15) (42.4%), was also deemed to be at highest risk of bias compared to the other studies. Similarly, the studies reporting the highest prevalence rates in those undergoing treatment (2,7) received the lowest quality ratings of the included studies. Therefore, the upper limits of both estimated prevalence rates should be considered lightly. Subgroup and overall analyses revealed the prevalence (I^2) of anxiety in those undergoing treatment at more than 90%, indicating high heterogeneity existed among the reviewed articles. Figure 3 illustrates the prevalence of anxiety across studies.

Figure 3.

Forest plot of prevalence of anxiety based on random-effects model by subgroup (IT = in treatment; WW = watchful waiting)



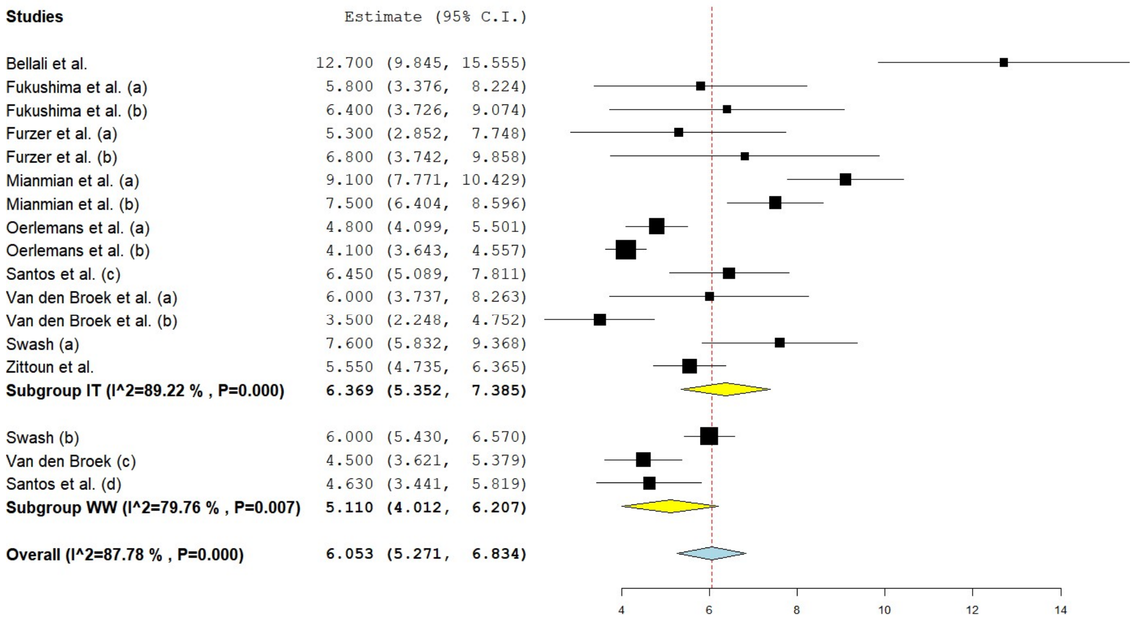
Studies	Estimate (95% C.I.)	Ev/Trt
Mianmian et al. (a)	0.539 (0.466, 0.612)	97/180
Mianmian et al. (b)	0.400 (0.328, 0.472)	72/180
Oerlemans et al. (a)	0.239 (0.177, 0.301)	43/180
Oerlemans et al. (b)	0.172 (0.129, 0.214)	53/309
Van den Broek et al. (a)	0.333 (0.156, 0.511)	9/27
Van den Broek et al. (b)	0.200 (0.057, 0.343)	6/30
Zittoun et al.	0.331 (0.262, 0.401)	59/178
Bryant et al.	0.588 (0.354, 0.822)	10/17
Kiely et al.	0.293 (0.153, 0.432)	12/41
Koizumi et al.	0.556 (0.368, 0.743)	15/27
Robbertz et al.	0.094 (0.039, 0.150)	10/106
Wang et al.	0.458 (0.393, 0.523)	104/227
Subgroup IT (I^2=93.79 % , P=0.000)	**0.340 (0.247, 0.433)**	**490/1502**
Van den Broak et al. (c)	0.176 (0.086, 0.267)	12/68
O'Byrne	0.424 (0.256, 0.593)	14/33
Morrison et al.	0.205 (0.131, 0.280)	23/112
Subgroup WW (I^2=69.98 % , P=0.036)	**0.245 (0.135, 0.354)**	**49/213**
Overall (I^2=92.57 % , P=0.000)	**0.323 (0.244, 0.401)**	**539/1715**

3.4.2 Anxiety means

Meta-analysis of 10 studies reporting HADS data was conducted. Of the studies that examined patients under treatment (1,3,4,8,9,12,16-18), 14 samples were included (n=1354). The remaining three samples (16-18) comprised patients under watchful waiting (n=143). Reported means ranged from 3.5 to 12.7 for those under treatment, and 4.5 to 6.0 in those under watchful waiting. The estimated overall means were 6.4 (SD = 1; I^2 = 89.2%) in those under treatment and 5.1 (SD = 1.1; I^2 = 79.8%) in those under watchful waiting. Both overall means were below clinical cut-off and the difference between the groups was not significant (z=1.650, p=0.099). The overall average mean across treatment pathways was 6.1 (SD = 0.7; I^2 = 87.8%). Visually, one study appeared anomalous (1) (see Figure 4), with a mean two times greater than the pooled estimated mean for those in treatment. However, risk of bias in this study was deemed low. Of the nine studies measuring those in ongoing treatment that did not use the HADS, only two studies reported clinically significant means (2,11). Despite these two studies varying in quality (75% and 88% respectively), both reported means marginally above the cut-off point for clinical significance.

Figure 4.

Forest plot of anxiety symptoms based on random-effects model by subgroup (IT = in treatment; WW = watchful waiting)

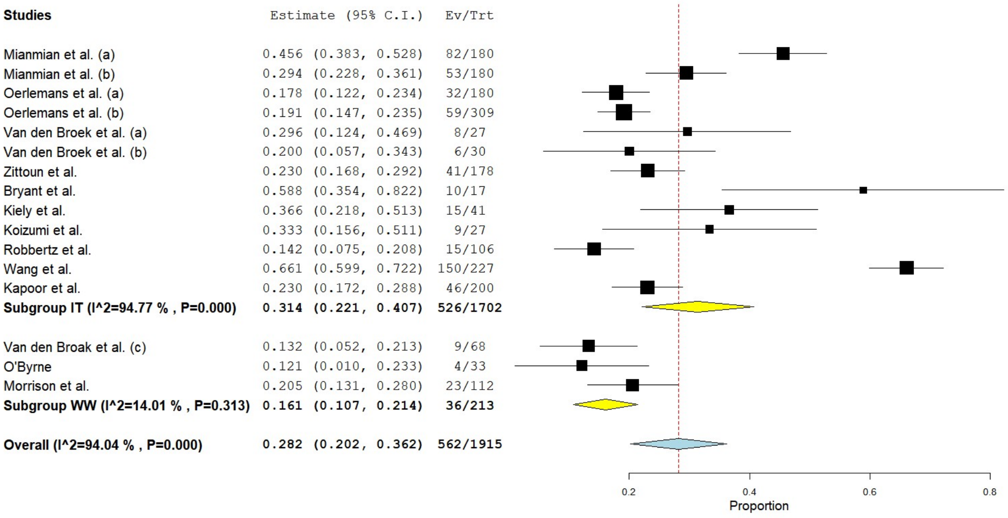


3.4.3 Prevalence of Depression

Prevalence of depression was examined in thirteen samples of patients under treatment (2,5-12,18) (n=1702) and three samples of patients under watchful waiting (14,15,1) (n=213). Reported prevalence ranged between 14.2%-66.1% for those under treatment, and 12.1%-20.5% for those under watchful waiting. Subgroup analysis reported prevalence of depression in those under treatment (31.3%; C.I. 22.1%-40.7%; I^2 = 94.8%) was significantly higher than in those under watchful waiting (16.1%; C.I. 10.7%-22.4%; I^2 = 14.01%) (z=2.800, p<0.05). The overall prevalence across studies was 28.2% (C.I. 20.2%-36.2%; I^2 = 94.0%). Study 11 reported the highest prevalence in those under treatment, with a finding 2.1 times greater than the overall under treatment average. Quality appraisal suggested a strong study design and a comparatively large sample size, with good sample representation. Interestingly, study 2 reported a similarly high prevalence (58.8%) but quality was comparatively low, with a small sample size (n=17) and weak analysis. In Figures 5 displays subgroup and overall analyses with prevalence (I^2) of depression in those undergoing treatment at 94.77% and 94.04% respectively, indicating high heterogeneity existed among the reviewed articles. In contrast, heterogeneity amongst watchful waiting samples was low, despite variation in appraised quality, and all individually reported watchful wait prevalence rates fell below the overall prevalence rate, as illustrated in the forest plot (Figure 5).

Figure 5.

Forest plot of prevalence of depression based on random-effects model by subgroup (IT = in treatment; WW = watchful waiting)



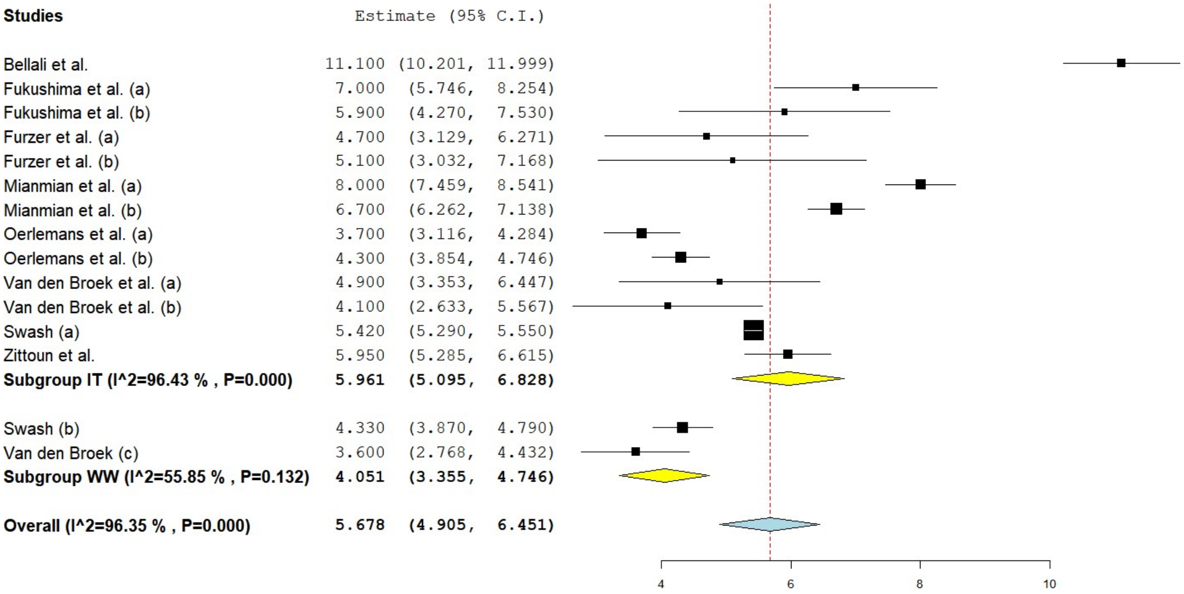
Studies	Estimate (95% C.I.)	Ev/Trt
Mianmian et al. (a)	0.456 (0.383, 0.528)	82/180
Mianmian et al. (b)	0.294 (0.228, 0.361)	53/180
Oerlemans et al. (a)	0.178 (0.122, 0.234)	32/180
Oerlemans et al. (b)	0.191 (0.147, 0.235)	59/309
Van den Broek et al. (a)	0.296 (0.124, 0.469)	8/27
Van den Broek et al. (b)	0.200 (0.057, 0.343)	6/30
Zittoun et al.	0.230 (0.168, 0.292)	41/178
Bryant et al.	0.588 (0.354, 0.822)	10/17
Kiely et al.	0.366 (0.218, 0.513)	15/41
Koizumi et al.	0.333 (0.156, 0.511)	9/27
Robbertz et al.	0.142 (0.075, 0.208)	15/106
Wang et al.	0.661 (0.599, 0.722)	150/227
Kapoor et al.	0.230 (0.172, 0.288)	46/200
Subgroup IT (I^2=94.77 % , P=0.000)	**0.314 (0.221, 0.407)**	**526/1702**
Van den Broak et al. (c)	0.132 (0.052, 0.213)	9/68
O'Byrne	0.121 (0.010, 0.233)	4/33
Morrison et al.	0.205 (0.131, 0.280)	23/112
Subgroup WW (I^2=14.01 % , P=0.313)	**0.161 (0.107, 0.214)**	**36/213**
Overall (I^2=94.04 % , P=0.000)	**0.282 (0.202, 0.362)**	**562/1915**

3.4.4 Depression means

Of the studies that examined patients under treatment (1,3,4,8,9,12,17,18), 13 samples were included (n = 1312). The remaining two samples comprised patients under watchful waiting (17,18) (n=88). The pooled mean average of depressive symptoms in those under treatment (mean = 6.0; SD = 0.9; I^2 = 96.4%) was found to be significantly higher than those reported by patients under watchful waiting (mean = 4.1; SD = 0.7; ; I^2 = 55.85%) (z=3.370, p<0.001). The overall average mean was 5.7 (SD = 0.8; I^2 = 96.4%). All pooled means fell below clinical cut-off. Similar to findings in section 3.4.2, one finding appeared anomalous (1) (see Figure 6), despite quality appraisal indicating a low risk of bias. Heterogeneity across studies was found to be high and this can be observed visually in Figure 6. Of the studies reporting depression means via outcome measures other than the HADS, only one study (11), of high-quality, reported a mean above the clinical cut-off point. No study examining those under watchful waiting reported a clinically significant mean, consistent with studies included in the meta-analysis (17,18).

Figure 6.

Forest plot of depression symptoms based on random-effects model by subgroup (IT = in treatment; WW = watchful waiting)



Studies	Estimate (95% C.I.)
Bellali et al.	11.100 (10.201, 11.999)
Fukushima et al. (a)	7.000 (5.746, 8.254)
Fukushima et al. (b)	5.900 (4.270, 7.530)
Furzer et al. (a)	4.700 (3.129, 6.271)
Furzer et al. (b)	5.100 (3.032, 7.168)
Mianmian et al. (a)	8.000 (7.459, 8.541)
Mianmian et al. (b)	6.700 (6.262, 7.138)
Oerlemans et al. (a)	3.700 (3.116, 4.284)
Oerlemans et al. (b)	4.300 (3.854, 4.746)
Van den Broek et al. (a)	4.900 (3.353, 6.447)
Van den Broek et al. (b)	4.100 (2.633, 5.567)
Swash (a)	5.420 (5.290, 5.550)
Zittoun et al.	5.950 (5.285, 6.615)
Subgroup IT (I^2=96.43 % , P=0.000)	**5.961 (5.095, 6.828)**
Swash (b)	4.330 (3.870, 4.790)
Van den Broek (c)	3.600 (2.768, 4.432)
Subgroup WW (I^2=55.85 % , P=0.132)	**4.051 (3.355, 4.746)**
Overall (I^2=96.35 % , P=0.000)	**5.678 (4.905, 6.451)**

Discussion

4.1 Summary of main findings

The current review aimed to further understanding of anxiety and depression in HC patients, with a focus on differences between those in ongoing treatment and those under watchful waiting. A total of 18 studies involving 2720 adults with HC (14.5% under watchful waiting), carried out between 1999 – 2020, were reviewed.

Meta-analysis reported no significant difference in anxiety prevalence between those under watchful waiting (24.5%) and those under treatment (34%), supporting findings that HC is associated with increased risk of anxiety, regardless of whether immediate treatment is offered (Holtzer-Goor et al., 2015). Both estimated prevalence rates were in line with previous estimations in the HC population (Clinton-Mcharg et al., 2014) and substantially higher than the estimated prevalence in the general population (7%) (Steel et al., 2014).

Prevalence of depression in HC patients under watchful waiting was also found to be greater than that in the general population (16% v 5%) (Steel et al., 2014) and greatest in those undergoing treatment (31.3%). In contrast with previous findings (Walker et al., 2014), a significantly higher proportion of patients under treatment reported depression, compared with those under watchful waiting. Psycho-oncology theories, focusing on appraisal and coping as factors influencing emotional distress, can be used to hypothesise about the observed findings (Barroilhet et al., 2005). It is possible that patients receiving treatment appraised their situation as more severe and had a lower perception of their ability to cope with aggressive treatments, increasing the likelihood of developing depression, compared with patients under watchful waiting. In contrast, both groups may have experienced equal levels of anxiety because a cancer diagnosis may be appraised as threatening and uncertain, regardless of treatment pathway. Such hypotheses require testing and future research should focus on understanding underlying causes of distress in those under watchful waiting and those in treatment.

Across studies, prevalence rates of anxiety and depression in patients under watchful waiting were estimated to be higher than in the general population. This discovery contradicts findings in prostate cancer research where patients are reported to cope well under watchful waiting (Matheson et al., 2019). Psychological theories of needs, where psychological distress is thought to indicate unmet psychosocial needs, can be considered to understand why such a difference has been observed. Self-determination theory (Deci & Ryan, 1985) posits that autonomy is one of three vital needs for psychological wellbeing. A lack of autonomy over treatment pathway could contribute to the differences observed between HC patients and prostate cancer patients under watchful waiting. Future research could test such hypotheses to further understanding of the specific challenges associated with the HC watchful waiting pathway and enable development of effective interventions.

Exploring symptom prevalence revealed HC patients under treatment were more likely to report depressive symptoms than those under watchful waiting, and equally likely to experience anxiety. However, all overall means were under the threshold for clinical significance. The disparity between the substantially increased prevalence rates and the within "normal" mean scores suggest that a proportion of HC patients cope well with their diagnosis and resulting treatment pathway. Study quality did not appear to correlate with level of anxiety or depression recorded, with both high- and low-quality studies reporting highest means.

4.2 Limitations and future research

The most significant limitation of the current review was the dearth of research examining depression and anxiety in those under watchful waiting. Of the six studies included, two constituted grey literature and were of lower quality than other included studies (15, 17), predominantly due to recruitment difficulties. The substantially smaller overall sample size of patients under watchful waiting somewhat limits the ability to comprehensively answer the review question. Future research should focus on increasing understanding of prevalence and symptoms of psychological distress in those under watchful waiting, and consequently, what effective support would comprise.

Other limitations relate to the heterogeneity of the included studies. Whilst breadth in haematology diagnosis was important for generalising findings to the HC population, most studies did not offer prevalence or symptom rate by diagnosis. HC diagnoses can vary in prognosis, treatment intensity and symptom severity (Blood Cancer UK, 2019), which may impact levels of anxiety or depression. In addition, few studies reported ethnicity. Given there is a relationship between psychological distress and ethnicity (Flaskerud, 2000), research should explore this further. The included studies were conducted across 11 countries, indicating potential for cultural variation. The impact of certain cultural factors, such as the quality and availability of psychological support (Niedzwiedz et al., 2019), cultural conceptualisations of anxiety and depression (Maters, Sanderman, Kim, & Coyne, 2013) or healthcare costs (Hall et al., 2016), could partially account for variance seen between study estimations. For example, significantly higher mean scores were reported in a Greek population (1), where access to psychological support is reported as low (Madianos, 2020). Data unavailability and small sample sizes meant that formal analysis of ethnicity, culture or HC diagnosis-related factors was not possible, and this limits the extent to which prevalence estimations can be understood. Future research is required to explore moderating and mediating factors on levels of anxiety and depression in the HC population.

None of the included studies reported whether participants were receiving psychological support or taking mood medication at the time of, or prior to, study participation. Understanding proportions accessing treatment for psychological distress is vital to accurately assessing the risk of anxiety and depression in the HC population. Without accounting for this data, the present review may have underestimated prevalence, as those receiving treatment may have consequently scored out of clinical ranges. Future research should consider recording such information to develop a more comprehensive understanding of distress in HC.

Finally, all studies reported anxiety and depression data via self-report measures, which has acknowledged limitations (Vodermaier & Millman, 2011). Preferably, prevalence estimations should be based on clinical assessment in addition to self-report screening tools (Mitchell et al., 2010). Further, only data from the HADS was included in the means meta-analyses. Pooling estimates from a range of different measures may have increased accuracy in estimations due to increasing the evidence base. Despite these limiting factors, research examining prevalence in HC patients through clinical interviews found that 26% of the sample met criteria for Major Depressive Disorder and 31% for an anxiety disorder (Allart, Soubeyran, & Cousson-Gélie, 2013) – figures very similar to overall prevalence reported in the present review (28% and 32% respectively). Therefore, the current prevalence estimations appear consistent with wider literature.

4.3 Strengths and Implications

Whilst living with cancer is widely understood to be associated with increased risk of anxiety and depression (Pitman et al., 2018), the present review furthers understanding on the impact of treatment pathway. Reviewing the literature has highlighted the scarcity of research exploring psychological distress in HC patients under watchful waiting. To the best of the authors' knowledge, the present review is the first of its kind to evaluate and synthesise current available evidence with a focus on treatment pathway in HC. The use of meta-analysis has the benefit of increasing the accuracy of estimated prevalence rates, compared to considering each study individually (Haidich, 2010). Evidence of estimated prevalence of anxiety and depression for patients on each pathway can inform policymakers and healthcare providers around the need for psychological support in haemo-oncology services. Further, the findings can increase clinicians' awareness of the risk of patients presenting with anxiety or depression in outpatients' appointments and consequently signposting to appropriate support.

4.4 Conclusion

The present review examined prevalence and symptoms of anxiety and depression among adults with haematology cancer, both under watchful waiting, and under treatment. Analysis indicated high prevalence of anxiety and depression in both groups, highlighting the need for evidence-based psychological interventions. Those under treatment were at most risk of experiencing depression, and both groups were equally at risk of experiencing anxiety. Reviewing the literature demonstrated a paucity in studies involving HC patients under watchful waiting. The findings therefore emphasise the need for future high-quality research exploring the experiences of those under watchful waiting, and what effective psychological support would comprise.

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Journal Paper

Exploring the Psychosocial Needs of Adults with Haematological Cancer under Watch-and-Wait

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Journal: This paper has been prepared for submission to the European Journal of Cancer Care. Author guidelines can be found in Appendix A. Please note, as the journal allow any reference style, APA 7th was adhered to. However, as per the journal guidelines, the reference list was arranged in order of citation, and citations are given as the corresponding number in a square bracket.

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Abstract

Background

Research reporting the unmet needs of individuals with haematological cancers under watch-and-wait is scarce, despite reports of elevated levels of psychological distress. This qualitative study aimed to explore the psychosocial needs of these individuals, and when these were met, if so at all.

Method

A longitudinal design using semi-structured interviews was used. Individuals with a diagnosis of haematological cancer living under watch-and-wait were recruited through online support groups. Participants were each invited to two semi-structured interviews, six months apart. Interviews took place in March 2022 and September 2022 and were therefore in the context of the Covid-19 pandemic. All interviews were recorded and transcribed verbatim. Reflexive thematic analysis and pattern-oriented longitudinal analysis were used to analyse the data.

Analysis

Of the fifteen participants interviewed initially, twelve attended a second interview. The sample was predominantly White and female. Across participants and time points, a theme was generated that individuals experienced a ‘Psychological battle of watch-and-wait’. Under this overarching theme, four themes were constructed: ‘Understanding the impossible: Cancer that does not require treatment’; ‘Sense of abandonment under watch and wait’; ‘The importance of peer connection’; and ‘Trying to live after Covid-19’. The themes were understood to predominantly represent needs for information, communication, peer support, and emotional support, and were most often met when individuals engaged with relevant charities.

Conclusion

People living with haematological cancer under watch-and-wait may be at risk of having unmet needs across domains, and without support, these needs will likely remain unmet over time. The findings add to the growing literature base of how Oncology and Haematology services can holistically support individuals with indolent cancers to live well alongside their diagnosis.

Key words: Haematology, Cancer, Watch and wait, Psychosocial needs, Longitudinal qualitative

Exploring the Psychosocial Needs of Adults with Haematological Cancer under Watch-and-Wait

Need hierarchies, such as Maslow's [1], posit that humans have basic needs that must be met for individuals to thrive. Maslow theorised that any unmet need is considered a psychological threat and, therefore, a person with unmet needs is likely to experience some degree of psychological distress. Indeed, correlational studies have found a significantly positive relationship between unmet needs and psychological distress [2, 3].

Across the literature, the term ‘psychosocial needs’ has been applied differently. Maslow’s hierarchy of need [1] defined needs in the following domains: physiological; safety; love and belonging; esteem; and self-actualisation, with only needs in the third and fourth domains (love and belonging; esteem) being considered ‘psychosocial’[1]. In contrast, Thomas et al. [4] conceptualised psychosocial needs as being more broadly defined as any requirement or desire for support, which underlies a person’s psychological wellbeing. Arguably, this definition could incorporate all tiers of Maslow’s needs, given the theory’s assumption that any unmet need may result in psychological threat [1]. Thomas et al.’s [4] definition aligns with recently developed needs assessments, which have positioned psychosocial needs as covering physical health, practical, emotional, relational, spiritual, and information/support domains [5]. Ultimately, the present study took the view that whilst distinctions in domains of need are theoretically helpful, in truth, needs reflect the interconnected desires of an individual and are therefore, self-defined[2] [6].

Specific theories of psychosocial needs have been developed, such as Self-Determination Theory (SDT) [7]. SDT[3], which posits humans need to feel autonomous, competent, and socially connected for psychological wellbeing [7], has been widely used to understand psychological distress and inform intervention development [8]. Research evaluating such an intervention found that meeting the basic needs was associated with reduced worry, improved sleep, and reduced anxiety and depression [9], indicating the theory can inform understanding and management of psychological distress, through addressing individuals’ needs.

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[1] Please see extended introduction (1.1.1) for further explanation of Maslow’s hierarchy of needs.
[2] Please see extended introduction (1.1.2) for further background to psychosocial needs.
[3] Please see extended introduction (1.1.3) for further explanation of Self-Determination Theory.

Receiving a cancer diagnosis poses a threat to life and therefore a threat to the most basic of physical health needs. Amongst the most common cancer diagnoses in the UK are cancers of the blood, bone, and lymphatic systems, termed haematological cancers (HCs)[4] [10]. Some HCs are aggressive and require immediate intervention but approximately 13% are "indolent" (IHCs), meaning they are slow-growing and do not require treatment immediately [11]. In these cases, individuals are placed under "watch-and-wait" (W&W); a pathway whereby patients see their team at set intervals for monitoring[5]. They will only receive treatment if/when the disease progresses to a stage where treatment is found to be most effective [12]. The prolonged nature of IHCs has led to them being considered by some as 'chronic cancers'[6] [13].

In the literature, various models of chronic illness exist [14]. However, despite them fitting diagnostically, most models have excluded cancer diagnoses from consideration [13]. One model that considers cancer and may be useful in identifying unmet needs in such a population, is the Psychosocial Adaption to Chronic Illness and Disability (PACID) model [15, 16]. The PACID model comprises three components: antecedents (medical and contextual factors prior to diagnosis); processes (psychological reactions, coping, appraisals); and outcomes (assessment of functioning and quality of life following illness onset)[7]. As the model aims to conceptualise the psychosocial experiences of living with chronic illness, it may be helpful for identifying unmet psychosocial needs in people with IHC. For instance, exploring an individual's coping skills may identify areas they desire additional support in (e.g., unmet information or emotional needs).

Research suggests a particularly high prevalence of psychological distress in individuals with HC, compared to the wider cancer population [17] . Although there is a lack of research exploring this further, several differences between HCs and solid tumours (e.g., lung/breast) exist, including: differences in treatment regimens; often no solid tumour site to monitor; treatment under Haematology rather than Oncology; absence of physical signs of illness; and a lack of understanding in the wider public [18]. Critically, these differences were reported as barriers to accessing further care, as participants reported they did not align

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[4] Please see extended introduction (1.2.1) for further explanation of HC diagnoses and management.
[5] Please see extended introduction (1.2.2) for further explanation of the W&W process.
[6] Please see extended introduction (1.2.3) for further consideration of IHC as a chronic illness.
[7] Please see Figure 2 in extended introduction (1.2.3) for a detailed overview of the PACID.

with being a “cancer patient”, and subsequently, did not believe it was suitable for them to access cancer charities for support [18].

In addition to physical differences, those with HC reported specific unmet psychosocial needs of receiving little information on specific diagnoses; lacking involvement in decisions; poor patient-centred communication; and lacking a documented care plan [19]. As these needs appeared infrequently in the wider psycho-oncology literature, they were deemed more specific to HC patients by the researchers. However, as comparatively few studies have focused on the psychosocial needs of individuals with HC [20], it is difficult to draw firm conclusions about the differences in psychosocial needs between those with HC and the wider population of people living with cancer.

Those with IHC face the additional challenge of not receiving immediate treatment, which often contradicts expectations of having cancer [21]. A large survey recently reported 41% of individuals with IHC did not understand why they were not receiving immediate treatment and 53% expressed concerns about this, indicating potential unmet information and support needs [22]. Results also indicated that those under W&W were less likely to be offered emotional support than those receiving treatment, despite a recent meta-analysis finding a high prevalence of anxiety and depression amongst both groups [23]. Literature has predominantly focused on the experiences of those receiving treatment, and therefore, research exploring whether unmet psychosocial needs underly distress in people with IHC is sparse. A recent study by Damen et al. [24] is exceptional in exploring needs in people with IHC. Their quantitative findings indicated individuals do indeed have several unmet needs, with unmet ‘physical health’ and ‘information and support’ needs being most frequently reported. In line with the wider psychosocial needs literature, those with moderate to high levels of unmet need described significantly higher levels of anxiety and depression than those with low or no unmet needs[8].

The W&W pathway is not unique to individuals with HC and is commonly used for people with prostate cancer (PCa) [25]. A recent meta-synthesis identified unmet psychosocial needs in people with PCa under W&W in the following domains: information needs, peer support needs, emotional support needs, and exercise

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[8] Please see extended introduction (1.3) for further details on the psychosocial needs of people with HC.

needs [26]. Whilst these findings may generalise to people with HC to some degree, there are several key differences to consider, including the potential impact of gender [27] and PCa as a contained solid tumour. In addition, guidance for management of PCa describes offering individuals options, and therefore, increases patient involvement in treatment decisions [25]. In contrast, W&W for HC is determined by the stage of disease, and therefore, people with HC have little choice in when they receive treatment [11]. The increased involvement is an important difference when considered in the context of SDT [7]. Specifically, involvement offers increased autonomy, one of three psychosocial needs posited by SDT and a factor linked to reduced suicide risk in people living with cancer [28]. Therefore, the potential differences in the experiences of W&W for individuals with HC and individuals with PCa needs further exploration before findings can be generalised across populations[9].

Despite the high prevalence of psychological distress found in people with IHC, literature evidencing effective psychosocial interventions is sparse. Identifying unmet psychosocial needs provides a tangible understanding for individuals' psychological distress and consequently can provide the basis for intervention development [3]. Therefore, the present study aimed to explore the subjective identification of psychosocial needs of people with IHC. A common criticism of psychosocial needs research relates to the notion that needs are often context-dependent and can shift between being met or unmet depending on various factors at any one time [29]. Given the present research took place during the evolving Covid-19 pandemic[10] - a factor found to have a significant impact on individuals' wellbeing [30] – it was considered important to incorporate a longitudinal aspect into the research design. Understanding how reported needs fitted with existing models of need in the literature was also deemed important to maximise the utility of the findings in developing effective support. The study aimed to answer[11]:

1. What are the psychosocial needs of people living with HC under W&W and do these needs align with existing knowledge of need in the wider health literature?
2. When are these needs met, if so at all?

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[9] Please see extended introduction (1.4) for further details on the differences between W&W populations
[10] Please see extended introduction (1.5) for further details on the impact of the Covid-19 pandemic
[11] Please see extended introduction (1.6) for further details of the study's rationale.

3. Do these needs change (become met/unmet) over a six-month period, and if so, how?
4. Are the reported needs different to those identified in individuals with prostate cancer under W&W and if so, how?

Method

Approval was granted by the NHS Research Ethics Committee and the Health Research Authority (Appendix B)[12].

Study Design

Due to the limited understanding of individuals' experiences of being under W&W, a qualitative design was deemed appropriate[13]. A 'critical realist' epistemological stance was taken by the researchers[14]. This stance recognises that a social reality exists but that individuals only access this reality through the lens of their own experiences and perceptions [31]. Data was collected through individual semi-structured interviews conducted at two time points, six months apart.

Sample

The study invited individuals to participate if they a) had received a diagnosis of a HC more than six months ago; b) were assigned to the W&W pathway; c) were aged 18 years or older; and d) were able to give informed consent. Individuals were excluded if they had another primary cancer diagnosis for which they were receiving treatment, were not fluent in conversational English, or had a diagnosed memory impairment that would impede their ability to reflect on a six-month period.

All participants were recruited through social media advertisement, using self-select sampling. Interested eligible individuals were provided with study documents (see Appendix C, D, E). The study recruited 15 participants[15]. Participants' self-reported cancer diagnoses and treatment pathways were not formally verified.

Data Collection

All interviews were recorded and took place remotely, either via video call or telephone call, dependent on participant preference. Participants were asked to complete the Hospital Anxiety and Depression Scale (HADS) [32] at both time points to give an indication of the psychological distress in the sample. To contextualise the

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[12] Please see extended method (2.2) for further details of ethical approval and ethical considerations.
[13] Please see extended method (2.1.1) for further details of the study design.
[14] Please see extended method (2.1.2; 2.1.3) for further details of the researcher's position.
[15] Please see extended method (2.3) for further details on the sample size, eligibility, and recruitment.

data collected, demographic information was also gathered during the first interview[16].

The interview schedule at time one (T1) aimed to explore participants' experiences of living under W&W, including what had been helpful and unhelpful in supporting their psychosocial wellbeing since diagnosis (see Appendix F)[17]. The second interview (T2) followed a similar schedule, but with focus on the previous six months. Interviews at T1 ranged from 35 minutes to 60 minutes (n=15). Interviews at T2 ranged from 20 minutes to 70 minutes (n=12). All interviews were transcribed verbatim in full and were pseudonymised to preserve confidentiality[18].

Data Analysis

Thematic analysis (TA) following a reflexive guide [33][19] was applied to the data, through both a semantic and latent approach. Initially, inductive analysis was adopted to generate themes of shared meaning directly from the data. The data at each time point was coded separately. A pattern-oriented longitudinal analysis (POLA) was then applied to the data [34], allowing for both within and between participant comparisons to be made across time points[20]. Finally, a deductive codebook approach was also taken to consider how data fitted with existing theory and literature relating to psychosocial needs, chronic illness, and knowledge of unmet needs in those with PCa under W&W. Consequently, the codebook included codes to denote the components of SDT [7], PACID model [16][21], and needs identified in individuals with PCa under W&W [25]) (see Appendix G).

Qualitative trustworthiness guidance [35] was followed throughout the analytic process, to ensure methodological quality. Accordingly, reflective notes and supervision were used to exercise transparency and recognise biases in analysis. The main researcher approached the study from the position of having worked in Psychology departments of physical health settings. The researcher was aware of how their beliefs around the impact of physical illness on psychological wellbeing may have influenced how they interacted with individuals in the study, and subsequently how individuals responded to the researcher. Theme development was

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[16] Please see extended method (2.4.1) for further details of demographic data collection.
[17] Please see extended method (2.4.2) for further details on interview schedule development.
[18] Please see extended method (2.4.3) for further details on data pseudonymisation.
[19] Please see extended method (2.5.1) for further details on the decision to use reflexive TA.
[20] Please see extended method (2.5.2) for further details of the inductive analysis.
[21] Please see extended method (2.5.3) for further details of the deductive analysis.

supported through discussions of coding and code grouping amongst the research team[22].

Analysis

Sample Characteristics

A total of 15 participants were interviewed at T1 (12 females), and 12 at T2 (nine females). Out of three individuals who did not complete a second interview, a suitable time could not be found with two, and the third did not feel physically well enough. The mean average age of the sample was 62 years (standard deviation = 6.7 years) and the sample was predominantly White British[23]. Table 1 details the demographic information of each participant and Table 2 shows the average responses to the HADS [32] at each time point.

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[22] Please see extended method (2.5.4) for further details on methodological quality assurance.

[23] Please see extended results (3.1) for further details of the recruited participants.

Table 1.

Participant characteristics

Participant	Age (years)	Time under W&W at T1 (years)	Diagnosis	Gender	Employment status	Ethnicity
Ann	65	4.5	CLL	Female	Retired	White British
Bridget	71	8	CLL	Female	Retired	White British
Christine	59	7	S/CLL	Female	Unemployed	White British
Delia	69	6	SMM	Female	Retired	White British
Eileen	67	11	NHL	Female	Retired	White British
Frank	65	2.5	SMM	Male	Self-employed	White British
Gail	69	1	CLL	Female	Retired	White British
Helen	61	8	SMM	Female	Retired	White British
Ian	51	5	CLL	Male	Retired (early)	White British
Julie	60	8	SMM	Female	Retired (early)	White British
Karen	52	5	S/CLL	Female	Self-employed	White British
Lisa	71	3	CLL	Female	Self-employed	White British
Marta	54	8	CLL	Female	Employed	Mixed heritage
Noel	58	0.25	NHL	Male	Unemployed	White British
Olivia	59	4	NHL	Female	Employed	White British

Notes: Chronic Lymphocytic Leukaemia (CLL); Small/Chronic Lymphocytic Leukaemia (S/CLL); Smouldering Multiple Myeloma (SMM); Non-Hodgkin's Lymphoma (NHL).

Table 2.

Participant means and standard deviations (SD) on the HADS [31]

	Anxiety score		**Depression score**	
	Mean (SD)	Range	Mean (SD)	Range
T1 (n=10)	11.3 (3.1)	6-15	7.6 (5.1)	1-17
T2 (n=8)	11 (1.5)	9-13	7.6 (2.8)	4-11

Notes: mean HADS score and standard deviation (SD); each HADS subscale is out of a total of 21, with scores indicating: 0-7 (normal); 8-10 (mild); 11-15 (moderate); 16-21 (severe)

Inductive Analysis

Four related but distinct themes were constructed: ‘Understanding the impossible: cancer that does not require treatment’; ‘Importance of peer connection’; ‘Sense of abandonment under watch-and-wait’; and ‘Trying to live after Covid-19’. Some themes also contained subthemes (see Appendix H). Across all, the overarching theme of ‘The psychological battle of watch and wait’ was evident, with participants frequently using words such as “battle” and “fight” to describe their psychological experiences. The importance of peer connection and the process of moving forward through Covid-19 mirror findings in the wider literature [36, 37]. Therefore, the present paper focuses on the two more novel themes.

Understanding the Impossible: Having Cancer that Does Not Require Treatment[24]

Subtheme: Battling One’s Own Perception That Cancer Must be “Fought Off”. Going through a process of understanding W&W was described by all, with several sharing that W&W was “very difficult to get your head around” (Helen, T1; Gail, T1; Julie, T1). Prior to diagnosis, cancer appeared to be understood by most as an acute illness that warranted urgent medical input, and therefore, it is perhaps unsurprising that participants reported difficulty in comprehending a diagnosis that did not require immediate treatment.

> “You’re told you’ve got cancer. And it’s like you expect chemotherapy. I couldn’t get my head round it, I just couldn’t. I kept saying, you’re lying to me” (Julie, T1)
>
> “I was really angry that I couldn’t have the treatments […] If I was having treatment, I could fight it” (Marta, T1)

The distress caused by hearing a diagnosis of cancer and being told treatment was not necessary appeared exacerbated by individuals receiving little information on W&W or the decision-making process.

> “If someone had told me and said look the national standard for people like you is watch and wait and this is what we do, and this is why we do it. That probably for me would have been a lot more helpful” (Olivia, T1)

Understanding did not seem to improve from T1 to T2, except for Noel, who was most recently placed under W&W. Noel described an increase in his

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[24] Please see extended results (3.2.1) for further details of theme generation and analysis.

understanding of W&W during the second interview and this appeared to result from increased communication with his Haematology team: “they’re open and frank with me now” (T2). In line with this, positive relationships with one’s healthcare team, such as having regular communication, was associated with fewer informational needs and consequently, greater understanding and acceptance of not receiving treatment. Lisa reported “You need that interaction from your team, because otherwise I think it would just finish you off, they tell you you’ve got cancer, but they’re not going to treat you, it’s a lot” (T1).

Subtheme: “There’s Nothing Wrong with You”: Managing and Internalising Others’ Perceptions. Concerns about other’s misunderstanding their diagnosis and/or misunderstanding the W&W process were common, with some feeling disbelieved when sharing they had cancer.

> “How do you say to people… By the way, I’ve got blood cancer […] but they’re not doing anything about it and I’m not on any treatment. People don’t understand that, they think “well, you can’t really have cancer then” (Helen, T1)

Others felt dismissed by people who underestimated the psychological impact of a diagnosis irrespective of whether treatment was needed immediately or not, with some being told by friends and family that they had a “good cancer” (Gail, T1) or had “won the cancer lottery” (Ian, T1). Olivia shared “Someone even said to me “Oh cancer really suits you. You look amazing”” (T2). Individuals appeared to rationalise the experiences of having the cancer minimised as being a result of “not looking like a cancer patient” (Olivia, T2; Ian, T1) and not having anti-cancer treatments.

Whilst present in both datasets, managing other’s expectations was more prominent at T2, and this was perceived to be linked to the ‘resolving’ Covid-19 pandemic. Specifically, individuals experienced hostility and confusion from others who did not understand the risks remaining to people living with cancer once cases reduced and the vaccine rollout had been completed.

> “I said, unfortunately, I can’t go, I daren’t go. He’s says but why not? I says because of Covid, he said well you’ve had your jabs, and I said but I’m still vulnerable, he said well I don’t understand that” (Julie, T2)

Seemingly resulting from others’ perceptions, individuals seemed to internalise stigmatised identities, for example, viewing themselves as a “malingerer” (Frank, T1), “fraud” (Olivia, T2), or “a drama queen” (Marta, T1). These identities were associated with increased low mood and feeling undeserving of support from cancer services. Consequently, the lack of understanding from others and resulting internalised stigma was understood to lead to individuals having unmet emotional and relational needs.

Sense of Abandonment Under Watch-and-Wait[25]

Subtheme: Staying Healthy is a Personal Responsibility. In relation to looking after their health, individuals described having no choice but to be "their own best advocate" (Lisa, T1). Shared experiences ranged from needing to explain their diagnosis to their General Practitioner doctor (GP) and having to seek out health information from peers in online forums, to writing to their local MPs to "fight" for vaccines. These shared experiences suggest individuals do not feel adequately cared for by healthcare professionals, indicating unmet health needs.

> "The only way that [GP practice] know anything about my cancer and my diagnosis, is the fact that I keep every single bit of paperwork. So I can, shall we say, *enlighten* my own doctors, which is not really my job" (Noel, T1)

Here, Noel captured the increased burden of responsibility felt by individuals resulting from poor communication between healthcare systems. The psychological burden of responsibility was particularly evident in those who reported a sense of being "abandoned" and "forgotten" (Bridget, T2; Lisa, T1) by their healthcare teams. Ian described having "no real support" from his healthcare team, and later reported the responsibility was so great, that he felt his life was threatened if he was not proactive: "I don't think you should really have to be that involved in your own care in many ways, but you do. And if you don't, you feel like you're going to die basically" (T2).

Experiences in keeping with this theme became more apparent at T2, with participants reporting to battle healthcare providers for the right care and vaccines.

> "Recently I wanted to get my booster for pneumonia. I had to kind of be quite firm with the nurse because she kept saying no, you don't need it. And I kept saying yes, I do need it. It's in the notes. And I find myself constantly preparing to battle to just to have normal healthcare now" (Marta, T2)

Ultimately, the sense of personal responsibility to stay healthy was shown across participants to lead to increased anxiety and exhaustion, a lack of trust in

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[25] Please see extended results (3.2.2) for further details of theme generation and analysis

professional opinions, and a sense of needing to be "prepared to battle" to have their physical health, emotional, and informational needs met.

Subtheme: "If My Bloods Are Fine, They Think I'm Fine". Whilst many participants recognised that monitoring blood markers must be the main priority for their Haematology team, they also felt that no space was given to the emotional impact of living with cancer. Adjustment to living under W&W was not seen as important to professionals and resulted in participants feeling "abandoned" (Helen, T1; Ian, T1, T2; Bridget, T2; Lisa, T1; Delia, T1, T2) by their team in relation to anything beyond basic monitoring.

> 'They do the necessary, but there's no one to ask you how you're feeling about it. Or are you coping with it? Or is the family alright? There's just nothing about the mental side of it at all' (Frank, T1)

The perceived professional perception that patients not requiring treatment are (medically) doing well appeared to contrast participant perception. All described struggling psychologically at one stage with having cancer and not receiving treatment, indicating an "ill but not ill" (Frank, T1) conflict that resulted in emotional and information needs being overlooked.

> "I don't think any of them could quite understand that I felt quite set adrift. [They] give me this huge diagnosis that to them perhaps wasn't because my numbers were really low, and then just left me to get on with it" (Marta – T1)

Some described reaching out for emotional support through their GP. This resulted in varying degrees of success, with some not being able to access any support at all and others completing Cognitive-Behavioural Therapy (CBT) courses, again to varying degrees of success. Most described a desire for better signposting to where they could access emotional support.

> "I just wanted to know a number, you know for someone to talk to, other than just about the blood results. I was desperate for someone to listen to me and someone to tell me you know what you're thinking is okay" (Marta, T2).

In the six-month interview gap, Delia reported the gap between blood tests had reduced in time, Olivia reported the time gap had increased, and the remaining ten reported the time remained the same. However, the sense of abandonment remained a prominent theme regardless of change. This remained even for Delia, whose blood test results had indicated the cancer was advancing, as she stated "I just don't think they're interested anymore. I have to cope alone" (T2).

Whilst there was a common sense of being 'abandoned', Delia also highlighted the crucial contextual factor of participants being a generation of predominantly Western older adults, who are commonly “against counselling” and who have “always just been told to just suck it up and get on with it”. The culture of stoicism may make it more challenging for individuals to indicate to professionals the need for support to manage the emotional impact of W&W, highlighting the importance of healthcare professionals asking questions that explicitly consider both physical and emotional needs of patients.

The Importance of Connection with Peers

Perhaps unsurprisingly, connection with others going through similar experiences was highly valued and reported consistently across time points. The need was most frequently met through online forums and local groups. Those that reported having accessed support from others were “amazed at the difference it made” (Olivia, T1) and noted benefits including improved emotional wellbeing and increased understanding of various components of W&W.

> “Watch and wait, it’s totally all-consuming and nobody else knows how you feel about it unless you speak to other people on the support groups and then you feel like you’re there for each other and you share hints and tips about how to handle things” (Karen, T1)

In contrast, those less engaged in peer connection described W&W as “lonely” (Helen, T1; Frank, T1 & T2; Lisa, T1; Ann; T1; Ian, T1 & T2; Marta, T1), suggesting that contact with others under W&W is fundamental for supporting social and emotional needs in individuals with HC[26].

> “I think meetups with other patients would be lovely. I want to meet up with people, just to talk, a bit like we’ve talked today, about their feelings and thoughts and how they’re coping. It’s an isolated business being under watch and wait” (Frank, T1)

Trying to Live After Covid-19

This theme reflected a within-participant shift in needs around Covid-19 over time. For some, testing positive for Covid-19, receiving vaccinations, and talking with others appeared to have reduced anxieties regarding the potential dangers of catching the virus: “Having Covid, […], it actually took away a lot of the fear that I

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[26] Please see extended results (3.2.3) for further details of theme generation and analysis.

had" (Gail, T2). Others indicated a pattern of increasing anxiety, with a sense that society was moving forward regardless of the remaining danger to them. This appeared to leave individuals feeling worthless and anxious, with Bridget (T2) sharing "Covid has been a nightmare. The majority [of the general public] don't care anymore, they don't give a damn". These experiences were interpreted as representing unmet emotional and informational needs, as individuals reported to be unclear on the risks remaining to them, consequently experiencing increased fears of Covid-19[27].

Deductive Analysis[28]

Analysing the data using a deductive framework generated an understanding that people living with IHC have some similar and some unique needs compared to people living with PCa under W&W. As in the PCa review [26], unmet emotional needs were frequently reported, with participants desiring support to manage the psychological burden of living with cancer not requiring treatment. Similarly, many commented on receiving inadequate information. This related to understanding their diagnosis, W&W, and receiving results from blood tests and scans. In contrast, only a minority shared that they found information confusing or inaccurate. Those that did most commonly referred to viewing misinformation online, rather than receiving confusing or inaccurate information from healthcare professionals.

In congruence with the inductive findings, information needs were mostly met through charities and peer connection. Peer needs were the fourth domain of need found in the PCa literature and mapping onto the theme generated through inductive analysis, peer needs were found to be frequently reported in the present sample. This need was most commonly met when individuals were able to join online forums or attend support groups. Finally, unlike in the PCa review, exercise needs were infrequently identified in the present sample. Whilst several discussed making attempts to live healthier, such as making changes to their diet and increasing exercise, no reference to needing or desiring support with exercise was made, indicating a difference between HC and PCa patients under W&W.

All three basic needs of SDT [7] were found to map onto the data and inductive analysis. Represented in participants feeling abandoned by healthcare, autonomy appeared to be forced upon individuals, through their need to self-monitor

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[27] Please see extended results (3.2.4) for further details of theme generation and analysis.
[28] Please see extended results (3.3) for further discussion of the deductive findings.

and self-manage. On the other hand, individuals shared experiences indicating they lacked autonomy, with decisions around treatment typically being made solely by healthcare professionals, leading to a sense of having no control over their future. Described experiences of autonomy were also found to fit particularly well with aspects of the "process" domain of the PACID model, such as managing the emotional impact of uncertainty and self-managing the physical symptoms of illness [16].

Individuals reported feeling forced to become experts in their own condition, and this was interpreted as a need to feel competent in understanding and monitoring the cancer. The extent to which individuals reported feeling competent varied across the sample, but rarely across time. Several individuals reported having medical backgrounds and some also described having supported family members to live with HC. The impact of such contextual factors on how competent individuals may be are helpfully considered in the first domain "antecedents" of the PACID model [16]. Specifically, the space allowed for consideration of how prior knowledge (e.g., from prior medical occupation/familial experience of HC) may impact an individual's perception of HC and their ability to comprehend and feel competent in monitoring their condition.

Finally, the need for 'relatedness' was found across participants and consistently across time, mapping strongly onto the inductively constructed theme of needing peer connection. In contrast to peer connection needs, which were often met, individuals rarely reported feeling connected to their healthcare teams. The need for relatedness with peers was also amplified by friends and family struggling to understand their diagnoses. The 'interpersonal' domain of the PACID model [16] was found to consider relatedness, and this was explicitly in terms of both peer connection and connection with friends and family, adding to its pertinence to both the data and SDT. However, the applicability of the PACID model would be enhanced further by an additional component that considers relatedness with one's healthcare team.

Discussion

This study aimed to explore the psychosocial needs of adults with IHC, and when these were met, if so at all. Secondary aims were to understand if/how needs changed over a six-month period, and whether these needs differed from those identified by people with PCa under W&W. The themes constructed were interpreted to represent the following areas of need: information on diagnosis, symptoms, and W&W; communication with healthcare professionals; public awareness of chronic cancers; and peer connection. Aspects of needs reported mapped onto autonomy, competence, and relatedness, as identified in SDT [7]. Further, the psychological impact of living under W&W was present throughout the data, with anxiety, internalised stigma, and difficulties managing uncertainty being frequently reported, strongly indicating the presence of unmet emotional needs[29]. The deductive analysis demonstrated: (1) three out of five key unmet needs identified in the PCa literature [26] were identified in the present HC sample; (2) SDT [7] was applicable to understanding individuals' reported needs; (3) IHCs may be understood as "chronic illnesses", as highlighted by the applicability of the PACID model [16]. These findings contribute to the early literature on the needs and experiences of people living with HC under W&W, and advance knowledge in where to target psychosocial interventions to support the wellbeing of this population.

Information and Communication Needs

The incomprehensibility of having cancer that does not require treatment was commonly discussed and remained prevalent across time points. The theme highlighted the lack of information participants reported receiving both at diagnosis, and throughout the W&W process. This was exacerbated further by poor communication with healthcare teams and little opportunity to ask questions[30]; a finding in line with previous research [38]. These unmet information and communication needs become particularly problematic when considered in the context of individuals who are self-monitoring under W&W. This is a responsibility that requires them to understand their condition and how cancer progression may present [39]. This need was considered as 'competence', as identified in the basic needs of SDT [5]. Increasing individuals competence in understanding and managing cancer has been found to reduce levels of anxiety and depression, and decrease physical symptoms, such as fatigue [40]. In the wider health literature, increased health competence through intervention was associated with increased quality of life [41]. In line with these findings, individuals in the present sample who engaged with blood cancer charities, and particularly webinars, more commonly reported their information needs as met.

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[29] Please see extended discussion (4.1) for further discussion of unmet emotional needs under W&W.

[30] Please see extended discussion (4.2) for further discussion of the impact of Covid-19 on unmet needs.

Managing others' expectations of what a cancer diagnosis means (i.e., having treatment/looking 'ill') was also frequently referenced. This misunderstanding was experienced as burdensome, and individuals expressed a desire for greater awareness in the general public. These experiences were associated with internalised stigma, low mood, and feeling unworthy of support from cancer charities and services. Perhaps due to differences in public awareness, this need was not identified in the PCa literature, indicating a potentially unique need for people with IHC[31]. The need for greater awareness was also not identified in recent quantitative exploration of needs in individuals with HC [24], perhaps due to the use of measures restricting participants' ability to respond freely. It is possible that increasing patients' competence would aid their confidence in explaining their diagnosis and its chronicity to others. However, further research is required to assess this, or whether alternative strategies would best meet this need (e.g., through development and distribution of information resources).

Unmet information and communication needs were also understood to underpin individuals feeling abandoned by their healthcare teams. Specifically, abandonment was perceived through individuals feeling forced to take responsibility for their own health and the belief that Haematology teams were concerned only with blood test results. This appeared to result in a sense that their wider wellbeing was neglected and resulted in feelings of anxiety and anger. Findings relating specifically to feelings of abandonment do not appear to be reported in the IHC or wider W&W literature. However, there are reports that people living with HC desire to be treated as a whole person, rather than as a cancer patient [24], and the meaning making of abandonment may partially explain this need. Interpreting the sense of abandonment through the SDT perspective led to the notion that autonomy was forced upon some, and went unmet for others, with both outcomes relating to increased psychological distress and reduced sense of control. Research has reported that good patient-clinician communication is vital for promoting patient autonomy, ensuring that decision-making processes are collaborative with individuals feeling well-informed [42]. Such an experience was not reported by the sample and therefore, this holds

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[31] Please see extended discussion (4.3) for further comparison between W&W populations.

implications for how healthcare teams could adapt their communication to meet individuals' needs in the future.

Emotional Needs

Across the sample, increased psychological distress and limited access to psychological support were described. These reports are in line with findings both within the IHC population [24] and in the wider W&W population [26]. Further, the qualitative results build on quantitative research by finding that distress was in part due to a combination of unmet information needs and poor communication with healthcare teams, resulting in distress. Resulting unmet emotional needs were identified in desires to discuss the psychological impact of living under W&W through professional counselling. Individuals who had received formal psychological support (e.g., CBT) described having to seek this out for themselves, rather than through signposting by their Haematology team, further demonstrating the burden of unmet informational needs.

Desires for emotional support should be considered in the context of IHCs being most frequently diagnosed in older adults (i.e., those aged over 65 years) [10]. Older adults' mental health is suggested to be particularly at risk of being overlooked, with depressive symptoms being normalised and consequently not treated [43]. When coupled with the understanding that older adults are less likely to seek emotional support themselves, due to barriers such as fearing stigma [44], it becomes clear that it is imperative for Haematology teams to follow routine procedures for assessing psychological wellbeing [45] and signposting to support as necessary. Additionally, recent findings suggest that cancer care staff feel inadequately trained to support patients' psychological wellbeing [46]. Future research could explore the impact of brief psychological interventions training for Haematology staff on patients' emotional support needs, and subsequently, their reported need for external support.

Peer Needs

The benefits of peer connection and formal peer support have been well-documented across psycho-oncology [47] and chronic health literature [48]. Further, peer connection features as fundamental in theories of human need, as demonstrated by the inclusion of "relatedness" in SDT [7] and "belonging" in Maslow's hierarchy of need [1]. Surprisingly however, the finding has not previously been reported in the IHC literature. In contrast, Swash et al. [18] reported on the potentially problematic nature of peer connection in people with HC, given it can highlight the graveness of one's own diagnosis. However, in the current study, peer connection was found beneficial not only for meeting specific needs of feeling connected to peers, but also for gaining information and emotional support from those in similar positions. The findings could represent a change caused by the Covid-19 pandemic, which temporarily reduced individuals' connectedness to family and friends [49]. Alternatively, it could be related to the method through which individuals accessed support (e.g., online vs. in-person). Knowledge in this area would be advanced further through research specifically exploring the barriers and facilitators to effective peer support in the IHC population.

Implications, Limitations, and Future Research

Whilst it is not an aim of small-sample research to produce generalisable findings [34], the breadth of HC diagnoses covered through recruitment means that findings can be considered in the broad context of IHCs. This builds upon previous findings in diagnostically homogenous populations [38]. In addition, the longitudinal nature of the research allowed for exploration of how needs change over time[32]. The finding that needs found to be unmet at T1 largely remained unmet at T2 contributes to understanding that, without specific psychological intervention, unmet needs, such as emotional and information needs, may remain relatively stable over time in this population. This stability strengthens the argument for the development of interventions specifically targeting unmet needs to support patients' psychological wellbeing.

Previous research has mostly used SDT [7] to explain motivation and health behaviour in people with chronic health conditions [50]. The present study found the theory's posited basic needs map onto the needs reported by the sample, advancing theoretical understanding of how the model can be used to consider the unmet needs of individuals with IHC. In addition, the applicability of the PACID model [16] was explored. Whilst this model focuses on psychosocial adaption, and not specifically psychosocial need, the domains covered were found to fit well with both the needs and experiences of people living with IHC. Taken together, the findings indicate that literature using SDT to improve the wellbeing of individuals living with chronic conditions may well be applicable to those living with IHC[33]. This also holds

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[32] Please see extended discussion (4.4) for further discussion of unmet needs over time.

[33] Please see extended discussion (4.5) for further discussion of the theoretical implications of the study.

clinical implications for healthcare professionals considering how service processes can be adapted to promote psychological wellbeing, with the SDT and wider chronic illness literature base being available to draw upon.

Several limitations are important to note[34]. Firstly, all participants were recruited through social media support groups and therefore, the study findings were likely skewed towards the views of those who valued and accessed peer connection. If recruitment had occurred through healthcare channels, it is possible that opposing experiences of unmet or undesired peer connection needs may have been heard. It is possible that wider recruitment may have also resulted in a more clinically distressed sample, since satisfied peer needs have been found to reduce distress in people with cancer [51].

Aside from diagnoses, the study recruited a relatively homogenous sample. Firstly, the recruited sample were predominantly women, despite IHCs being more commonly diagnosed in men [52]. This is particularly pertinent given men with HC have been found to report significantly fewer unmet needs compared to women [53], though the survey study design of these findings does not allow for deeper exploration of this. Secondly, 14 out of 15 participants identified as White British. Whilst research indicates people from White backgrounds are at highest risk of developing HC [54], racial discrimination has been found to have a significant negative impact on individuals' health outcomes [55]. This holds implications for potential differences in levels of unmet physical health needs between individuals from 'White' and 'Black and Minority Ethnic' backgrounds. Future research should explore these differences further and consider any potential differences during intervention design.

Finally, the decision not to use a formal needs measure, such as the Holistic Needs Assessment [5], could be considered a limitation. Such a tool was not used to avoid influencing participants' own perceptions of their needs. However, completion of the tool after interviewing may have allowed for clearer comparisons to be made between the present findings and extant literature. Further, using a mixed-methods approach may have enabled examination of the applicability of such measures, which are most commonly developed in people with solid-tumour cancers [56], rather than people with HCs. Given the findings that people with IHC may have some

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[34] Please see extended discussion (4.6) for discussion of an additional study limitation.

unique needs, it may be beneficial for future research to examine the applicability of needs assessments further, and work on developing a HC-specific measure if deemed necessary. Meanwhile, individuals with IHC may benefit from healthcare professionals taking a qualitative, person-centred approach to needs assessments, wherever possible, in addition to quantitative questionnaires.

Conclusions

People living with IHC described several domains of need: informational, communicational, emotional, and peer connection. These needs remained relatively stable over time and were most commonly met when individuals engaged with charities or had positive relationships with their healthcare teams. Whilst some areas of need already have good avenues of support (e.g., peer connection), other areas require increased targeted interventions (e.g., emotional needs). The present findings provide insight into the under-reported experiences of people living with IHC, and advance understanding of how services can develop to improve support for patients’ psychological wellbeing, with particular reference to the utility of SDT [5] and PACID model [16].

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Extended Paper

1. Extended Background

1.1 Psychosocial Needs

1.1.1 Theory of Human Motivation (Maslow, 1943)

Maslow (1943) proposed that human behaviour can be understood as being motivated by at least five sets of ‘goals’, termed ‘basic needs’. The theory posits that the most basic needs will dominate human behaviour, until these needs are largely satisfied. Consequently, when needs lower down the hierarchy are unmet, needs further up will be minimised or denied. Only once the more basic needs (e.g., physiological needs) are mostly met, then needs in the ‘higher’ domains will emerge (e.g., safety needs). The theory acknowledges that human behaviour is complex, and thus, it is hypothesised that humans will likely attempt to meet multiple needs at any one time, with most humans being partially satisfied and partially unsatisfied. A final important facet of Maslow’s theory is the notion that any barrier, or potential barrier, to a need being met can be understood as a psychological threat. That is, when one is not able to meet or maintain meeting a need, they are likely to experience psychological distress (Maslow, 1943).

1.1.2 Defining ‘Psychosocial Needs’ and Their Relevance to Psychological Distress

Research into the psychosocial needs of people living with cancer has been rapidly increasing since the early 2000s (evident through exponentially increasing citations as recorded on the Scopus database). Consequently, there are multiple definitions and conceptualisations of ‘psychosocial needs’ across the literature. Frost et al. (1997) described psychosocial needs as representing any social, developmental, spiritual, or mental need resulting from a cancer diagnosis. Within this, they included a decline in physical or intellectual functioning, responses to treatment, emotional responses to their diagnosis, and impact of the diagnosis on family and friends. Whilst this definition sets out a range of areas that unmet needs may be present in, the definition appears hard to operationalise. Later, Thomas et al. (2001) offered an alternative definition, with importance placed on needs being separate from distress. That is, psychological distress is not a need in itself, but rather, may represent the presence of one or more unmet psychosocial need. Their full definition was as follows:

> Psychosocial needs are embedded in features and qualities of life and social relationships that, from the viewpoint of patients and informal carers, are necessary, important, or critical to their psycho-emotional ability to live with the knowledge and social consequences of cancer, and thus to their ability to hold themselves and their social worlds together. (Thomas et al., 2001, p184)

In short, this definition conceptualises psychosocial needs as any need that patients (or their carers) require for them to maintain their psychological wellbeing when living with cancer (Swash et al., 2015). Finally, having the *desire* for support is a key difference between a psychosocial need and other concerns where the patient does not wish for external support (Swash et al., 2015). For example, Swash et al. found that not all individuals who reported to feel anxious desired help to manage it. This distinction further highlights the value of assessing and understanding unmet needs, over and above simply using psychological distress screening tools.

In practical terms, psychosocial needs can be identified in many areas of life. The reason domains of the Holistic Needs Assessment (HNA) (Appendix I) (MacMillan Cancer Support, 2018) fall more broadly under psychosocial needs is that any unmet need could, arguably, be associated with psychological distress. For example, both financial difficulties and poorly managed physical symptoms were significantly related to clinical levels of psychological distress in people living with cancer (Ebob-Anya & Bassah, 2022). Similarly, another study into the needs of those living with cancer found the presence of anxiety to be a strong predictor of unmet spiritual needs (Höcker et al., 2014). Despite both research and health bodies endorsing the use of needs assessments in people living with cancer, approximately only 31% of those with cancer, and 28% of those with HC, received a HNA in the UK in 2017 (NHS England, 2018).

Findings have established that the presence of unmet psychosocial needs correlates with a poorer quality of life, increased low mood, and increased anxiety in people living with cancer (Pereira et al., 2020). Psychological distress has been linked to poorer adherence to anti-cancer medication and consequently, increased mortality, compared to individuals without clinical levels of psychological distress (Sherrill et al., 2017). Chan et al. (2014) reported that improving anxiety and depression in people living with cancer has the potential to improve survival rates.

This finding is supported further by a recent review examining the impact of anxiety and depression in genitourinary cancers (Dinesh et al., 2021). Researchers concluded that both disorders were associated with significantly worse overall survival rates. Taken together, these findings indicate that meeting individuals' psychosocial needs may not only improve quality of life and reduce psychological distress, but could also increase treatment adherence, and consequently, improve chances of surviving a cancer diagnosis.

1.1.3 Self-Determination Theory (Deci & Ryan, 1985)

Self-Determination Theory (SDT; Deci & Ryan, 1985), a theory of human motivation, posits that humans have three fundamental psychological needs: autonomy, relatedness, and competence. Autonomy refers to individuals feeling in control of their own decisions and behaviours. Competence relates to individuals edge required to work towards their goals. Finally, relatedness refers to the importance of individuals having a sense of attachment to others. Applied to health contexts, SDT research has focused predominantly on understanding how healthcare teams can support individuals to increase adherence to positive health behaviours (such as eating healthily) using the three fundamental needs (Osei-Frimpong, 2017; Ryan et al., 2008). This has revealed positive effects, with a meta-analysis finding that supporting these three needs was associated with reduced psychological distress and higher positive physical health behaviours (e.g., increased exercise; Ng et al., 2012).

More recently, researchers reviewed the literature exploring the needs of people living with chronic health conditions through the SDT framework (Eassey et al., 2020). Through meta-synthesis, three themes were developed: the need to feel empowered, the need to feel a sense of belonging, and perceived ability to self-care. These themes were understood to map onto autonomy, relatedness, and competence, respectively, suggesting SDT can be used to understand patient experiences of living with chronic conditions. Supporting its utility further, a meta-analysis examining the effectiveness of SDT-informed health interventions found that meeting needs of autonomy and competence resulted in significant improvements in individuals' physical and psychological health (Ntoumanis et al., 2021). Whilst these findings are promising for the use of SDT in healthcare more widely, no studies appear to have explored these three basic psychological needs explicitly in people with chronic cancer diagnoses. Given the limited understanding of unmet needs in the IHC population, and the promise which SDT has shown in other populations, further studies are required to understand how SDT can be applied and used to support people with chronic cancers.

1.2 Haematology Cancers

HC is an umbrella term used to describe a diverse range of cancers, covering over 90 different diagnoses (Blood Cancer UK, 2022a). These diagnoses fall within three overarching categories: leukaemia, lymphoma, and myeloma. Whilst all diagnoses fall under the "haematology" label, they vary significantly in their characteristics and consequently, in treatment options and survival rates.

1.2.1 Epidemiology and Risk Factors

Globally, approximately 5% of all cancer cases are haematological in nature (Sung et al., 2021), with this rising to 9% in high economically developed countries (Smith et al., 2011). Due to recent advancements in treatments, an average of 50% of people with HC are now expected to survive for at least ten years (Foster et al., 2018), though survival rates vary significantly depending on the diagnosis. Some diagnoses, including myelomas, have a significantly reduced rate, with the five-year survival rate estimated to be less than 50%.

Whilst some HCs account for the most common cases of childhood cancer, in general, risk of HC increases with age. Approximately 40% of all people living with HC are aged over 75 years (Blood Cancer UK, 2022a), with a marked increase in cases in those aged over 50 (Smith et al., 2011). Some diagnoses, such as myelomas, are found to be more common in males and in people from African-Caribbean backgrounds (Blood Cancer UK, n.d.a), though generally, risk factors for developing HC are not well understood. Unlike in other cancers, research has not found evidence of lifestyle factors, such as diet or smoking, to significantly increase the risk of developing HC. Further, individuals appear to be at increased risk of developing HC if their parent has a HC, but it is not known whether this directly relates to genetic factors or shared environmental factors. For example, working in occupations involving the use of chemicals, such as hairdressing or farming, have been found to increase the risk of developing HC (Sergentanis et al., 2015; Thandra et al., 2021), and this is hypothesised to be a possible cause of familial cases.

1.2.2 Watch and Wait Pathway

As is the case for survival rates and epidemiology, treatment options for HC vary widely depending on the diagnosis. The present research was focused solely on individuals diagnosed with slow-growing “indolent” HCs (IHCs), placed under the watch-and-wait pathway (W&W) in the UK. Therefore, treatment options were not discussed here, and the following W&W information was based on typical processes that occurred under the UK’s National Health Service (NHS) at the time of writing.

W&W, also referred to as ‘active monitoring’, involves patients having periodic blood tests and seeing either their General Practitioner (GP) or their Haematologist for reviews. The time period between appointments can vary from once a year to once every few weeks, depending on how stable a person’s results are. Similarly, whether an individual remains under the care of a Haematologist or is discharged into the care of their GP depends largely on the stability of the cancer and the Haematology department’s policy. Between appointments, individuals are advised to self-monitor for new symptoms such as weight loss, worsening fatigue, or persistent fevers (Leukaemia Care, 2020).

The rationale for W&W is complex. In brief, cancers suitable for W&W are typically not curable and therefore, few advantages have been found to offering treatment immediately (Blood Cancer UK, n.d.b). Further, cancer treatments such as chemotherapy are associated with long-lasting side effects that can reduce quality of life (Lewandowska et al., 2020). Consequently, the decision to start treatment is taken only when the risks of treatment and subsequent side effects outweigh the risk of allowing the cancer to progress further. For some, the disease may never progress to this point, and they may be on W&W for many years before dying of another cause. Others may only be under W&W for a short period of time before needing treatment. The length of time on W&W depends largely on the diagnosis subtype, genetics, and individual characteristics, meaning it is very hard for professionals to estimate the length of time an individual is likely to be under W&W for. Consequently, living under W&W is associated with high levels of uncertainty (Byrne, 2018).

1.2.3 Understanding HC as Chronic Illnesses

Thanks to advancements in treatments, a growing proportion of individuals are living with active cancer that may never be cured but can be managed for long periods of time. This has led to the notion that some cancers should be considered ‘chronic’. Harley et al. (2012) defined ‘chronic cancer’ as an incurable cancer that is not considered ‘end-stage’ and has available anticancer treatment that can assist with symptom control, slow progression, or prolong life. According to the definition, the chronic phase is deemed to end when no further treatment options are effective, and the patient has “‘only months” (p. 3) left to live. The definition of chronic cancer seems to fit with IHCs: the immediate threat to life is very low, and treatment options are available once they become symptomatic.

In the literature, various models of understanding the psychological impact of chronic illness exist (Smedema et al., 2009). One such model, the model of Psychosocial Adaption to Chronic Illness and Disability (PACID) (Livneh, 2001), has recently been updated to incorporate new theoretical and empirical findings, including consideration of cancer as a chronic illness (Livneh, 2022). The tripartite model considers: (1) antecedent features, comprising both medical and contextual factors; (2) psychosocial adaption processes, considering adaption to illness characteristics, the experienced psychological reactions, coping skills, and cognitive appraisals of the illness; and (3) adaption outcome, comprising intrapersonal, interpersonal, and extrapersonal considerations (see Figure 1 for a comprehensive overview of the model). Taken together, the model suggests that the experience of chronic illness is a complex interaction between physical symptoms, emotional wellbeing, and one’s social environment, and thus, unique to each individual.

Santos et al. (2019) used the PACID model as a theoretical framework to examine factors contributing to quality of life in patients with Multiple Sclerosis (MS). They concluded the model aided consideration of factors that moderated and mediated the impact of MS on psychological wellbeing and quality of life. Such factors included marital status, caregiver burden, and understanding of MS; issues that could be considered in terms of need (i.e., social support needs, caregiver support needs, information needs). Researchers have also examined the model’s utility in understanding wellbeing in people with skin tumours (Pereira et al., 2017). Similar to Santos et al. (2019), researchers reported that the PACID model facilitated understanding of the mediating impact of psychosocial factors (such as body image, social support, and illness representation) on the quality of life of people with skin cancer. In turn, they recommended these identified psychosocial factors should be the focus of psychological interventions to support people to live well with skin cancer. These findings highlight the potential utility of using a psychosocial adaption model to identify unmet needs and consequently, consider where to target psychosocial interventions to support people with chronic conditions (Pedras et al., 2018).

Perhaps due to the updated version only being published very recently, no studies appear to have examined the applicability of the PACID model to people living with IHC. Understanding whether IHCs fit into the PACID model as “chronic cancers” may increase both researchers and healthcare professionals’ understanding of what factors influence psychological wellbeing. If it is found that the PACID is appropriate for considering individuals adaption to IHC, then the model may provide a useful framework for the development of interventions to target areas of unmet need.

Figure 1.

A model of psychosocial adaption to Chronic Illness and Disability (Livneh, 2022)

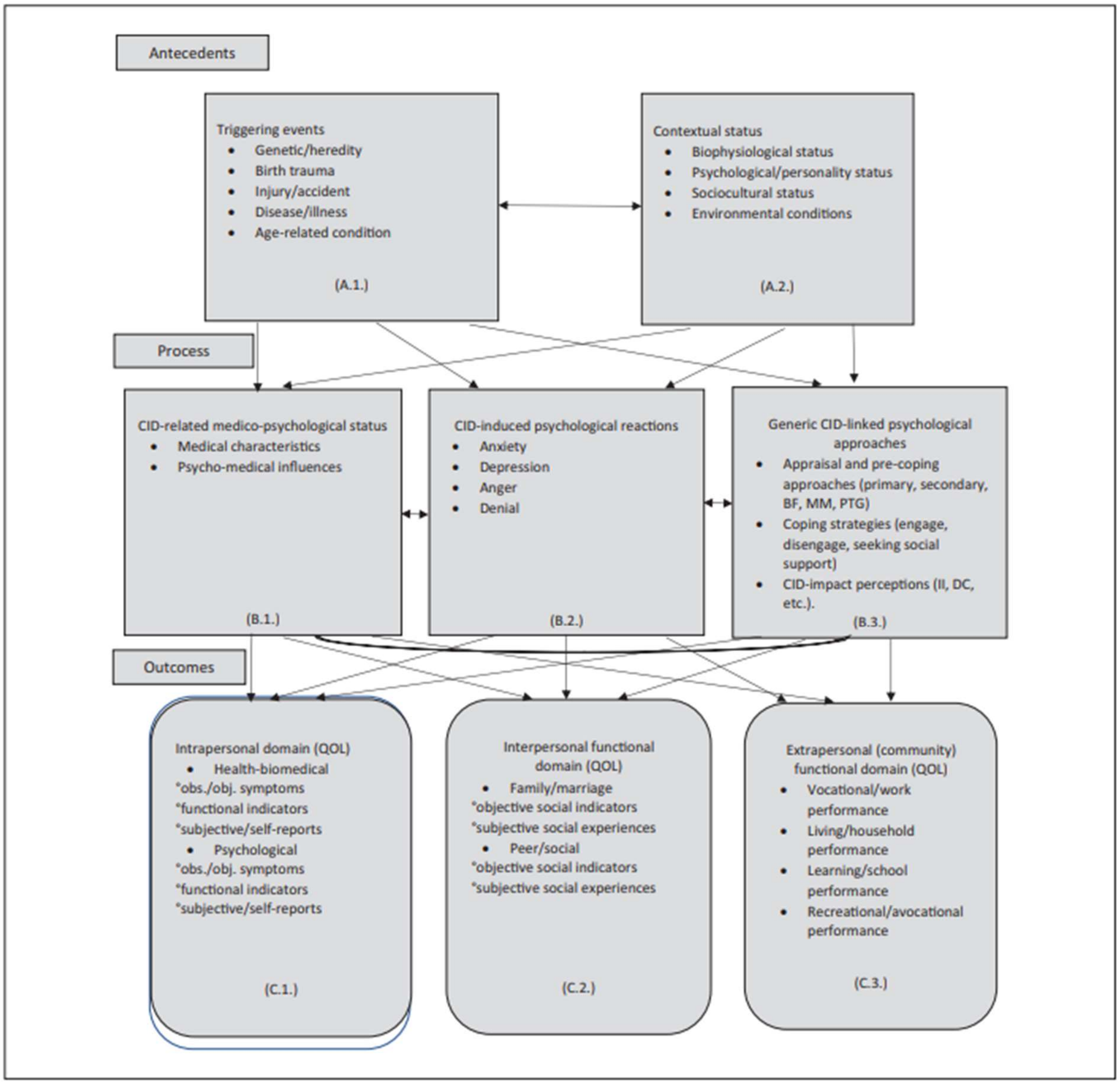


Figure 1. A model of the structure, content, and process of psychosocial adaption to CID.

Note. A double-headed arrow (↔) represents a bi-directional relationship between two or more sets of variables (e.g., Triggering events and Contextual status [Antecedents]; CID-related medico-psychological status, and CID-induced psychological reactions [Process]).

A single-headed arrow (→) represents a unidirectional relationship between a set of variables (presumed to be the cause) and a second set of variables (presumed to be the effect; e.g., Triggering events [Antecedents] and Generic CID-linked psychological approaches [Process]; CID-induced psychological reactions [Process]; and QOL intrapersonal domain [Outcomes]). CID = chronic illness and disability. BF = benefit finding, MM = meaning-making, PTG = post-traumatic growth; II = illness intrusiveness; DC = disability centrality.

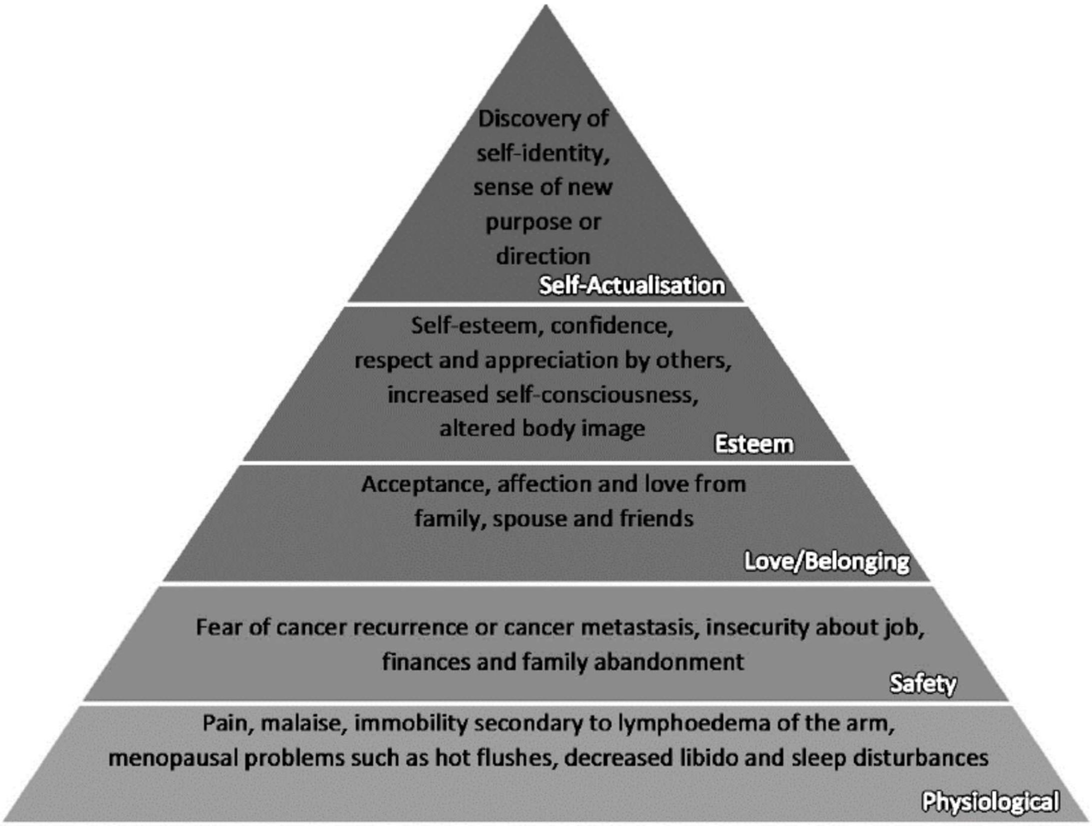
1.3 Psychosocial Need in People with Haematological Cancers

1.3.1 Maslow’s Hierarchy of Needs Applied to Cancer

Maslow (1943) considered the impact of illness on needs during discussion of ‘safety’ needs, suggesting that illness typically leads people to feel threatened and unsafe. Consequently, individuals focus their attention on safety needs. Maslow hypothesised that becoming unwell may lead to new needs, such as needs for protection and reassurance, which weren’t present prior to illness. The hierarchy has been applied to understanding the needs of people with breast cancer, with an adapted model developed (Ng et al., 2017; see Figure 2). At the most basic level, the model considers cancer-specific physiological needs including pain, sleep disturbances, and treatment side effects. Safety encompasses needs of fearing cancer metastasising, financial concerns, and family abandonment concerns. Less specific factors were included at the ‘love/belonging’ level, with acceptance, affection and love being cited as generic needs. Esteem needs included factors such as increased self-consciousness and changes to body image (such as breast removal or hair loss). Finally, self-actualisation was conceptualised as incorporating the cancer diagnosis into one’s new identity, along with finding a new sense of purpose. Ng et al. proposed that the adapted model holds benefits for moving towards healthcare systems delivering holistic cancer care, and away from focusing solely on the physical health condition of an individual.

Figure 2.

Maslow's (1943) hierarchy of needs adapted for people living with cancer (Ng et al., 2017)



1.3.2 Distress and Needs in People with Haematological Cancers

The understanding that some cancer diagnoses can be chronic, rather than solely acute, has led to increased focus on supporting individuals with cancer to live well alongside their diagnosis (Pitman et al., 2018). One factor found to significantly worsen the psychosocial burden of living with cancer is psychological distress (Gold et al., 2020), a notion potentially mediated by the previously described link to unmet needs. People living with cancer have been found to be at increased risk of experiencing clinical levels of anxiety and depression, with an estimated 20% experiencing depression, and 10% experiencing anxiety; rates higher than those found in the general public (Pitman et al., 2018). In HC specifically, an estimated 32.2% of individuals experience clinical levels of anxiety, and 28.2% experience clinical levels of depression (Russell et al., 2022). Whilst elevated levels of psychological distress have been consistently reported across cancer populations, and across cultures (Carlson et al., 2019; Rao et al., 2019), it is important to note that anxiety and depression prevalence rates have been predominantly measured through self-report measures (Mitchel et al., 2010). Generic mood questionnaires do not differentiate between mood disorders and adjustment disorders (Vodermaier & Millman, 2011), which are also commonly reported in people living with cancer. In addition, findings based on self-report measures are commonly criticised for heavily relying on the responder's understanding and willingness to be open, limiting opportunity for clinical judgement. Therefore, a degree of caution is needed when basing understanding of prevalence rates on self-report measures only.

In contrast to findings in the wider cancer population, psychological distress has been found to remain high in people with HC, even following a period of adjustment (Oerlemans et al., 2014). Interestingly, in people with HC, levels of psychological distress were not found to correlate with the commencement of treatment (Walker et al., 2014), indicating both those under W&W and those receiving treatment experience elevated levels of psychological distress. Support for this notion was provided by a recent meta-analysis that examined prevalence rates of anxiety and depression, separating out those with HC under W&W and those receiving treatment (Russell et al., 2022). Findings revealed significantly elevated levels of anxiety and depression in both groups, compared to the wider cancer population. In addition, anxiety levels between those receiving treatment and those under W&W were not found to be significantly different.

According to psychosocial needs theorists (Maslow, 1943; Thomas et al., 2001), the high levels of psychological distress reported in HC patients under W&W may be indicative of underlying unmet needs. Indeed, research examining this found that over half a sample of individuals with IHC reported unmet needs, with 19% reporting low levels of unmet need and 35% reporting moderate to high levels of unmet need (Damen et al., 2022). The most commonly reported unmet needs as identified on the 'Supportive Care Needs Assessment' (Boyes et al., 2009) included: fears of the cancer spreading, needing self-help information, wanting a contact point at the hospital, and wanting access to professional counselling. This study appears to be the only one to have measured psychosocial needs in individuals specifically under W&W with HC, and the quantitative design limits the depth to which these experiences can be understood. Additionally, as described in the main journal paper, research has found people with HC may have unique unmet needs, compared to the wider cancer population (Herrmann et al., 2020). This may have implications for the validity of research using needs questionnaires, given these are most commonly developed on the basis of needs identified in solid tumour and acute populations (Boyes et al., 2009; MacMillan Cancer Support, 2018). For example, previously reported HC needs such as 'receiving a documented care plan' or 'being involved in healthcare decisions' (Herrmann et al., 2020) were not considered in the Supportive Care Needs Survey (Boyes et al., 2009) used in Damen et al.'s (2022) study.

Questioning the applicability of existing measures further, Evans et al. (2012) qualitatively explored the experiences of people living with a specific IHC: Chronic Lymphocytic Leukaemia (CLL). A theme relating to the invisibility of IHC was constructed. Whilst the study did not explicitly explore psychosocial needs, having an invisible illness was associated with receiving reduced support and a desire for others to understand the diagnosis. However, neither the Supportive Care Needs Assessment (Boyes et al., 2009) nor the HNA (MacMillan Cancer Support, 2018) indicate any need category relating to coping with an invisible diagnosis.

Despite the similarities in levels of distress and unmet need, Leukaemia Care (2019) found support for those receiving treatment, compared to those under W&W differed substantially. The survey of 1152 people living with HC revealed that the majority of patients under W&W were not allocated a Clinical Cancer Nurse Specialist, despite this being named as a critical driver of improved experiences for individuals living with cancer (NHS England, 2007). Further, compared to individuals receiving treatment, individuals under W&W were significantly less likely to receive information on available psychological support, such as charities and helplines (69% compared to 39%). Taken together, the literature suggests that those under W&W are at similar risk of experiencing psychological distress and unmet needs, compared to those receiving treatment, but are less likely to be adequately assessed or supported.

1.3.3 Social Identity Needs

Social identity theory posits that individuals define themselves in terms of the groups they perceive themselves as belonging to (Tajfel & Turner, 1979). Having a cancer diagnosis has been found to impact an individual's social identity (Park et al., 2009), with the word "cancer" being imbued with sociocultural connotations (Stephens & Thorne, 2022). These subsequent social identity changes have been associated with a subset of key psychosocial needs of people living with cancer (e.g., "support in dealing with changes to the way I look", "support in dealing with changes in the way others see me"; Soothill et al., 2001).

Preliminary research has suggested that HC patients experience identity change differently to the wider cancer population. For example, survivors of Non-Hodgkin's lymphoma (a type of HC) described how they did not identify as a "cancer patient" due to reasons such as receiving treatment under "haematology" rather than "oncology" (Swash et al., 2018). Swash et al. reported that identifying as a "haematology patient" rather than an "oncology patient" deterred individuals from accessing cancer support, resulting in greater unmet needs in psychological and peer, and information/support domains. These findings are supported by recent research specifically examining the impact of HC on the self (Stephens & Thorne, 2022). Stephens and Thorne reported that people with chronic HCs seemed to share a feeling that they did not identify with the word "cancer", or even "blood cancer". Rather, they chose to identify with their specific diagnostic subtype (e.g., harry cell leukaemia) and subsequently preferred to access support from groups targeting their subtype, even when this was difficult to come by. A second factor identified as influencing individuals' social identity was the invisibility of HC. The invisibility meant they were not perceived by the general public as having cancer, due to not having the expected appearance (e.g., noticeable weight loss). Finally, participants discussed the challenges of having a cellular-level cancer, as opposed to a solid tumour, and how this made separating out their “self” from the cancer difficult, thus impacting their self-identity. The researchers concluded that re-claiming and re-developing social identity was an important need for supporting the wellbeing of people living with HC. These findings further highlight the potential for individuals with HC to have unique needs to those in the wider cancer population.

1.4 W&W in Other Populations

As explained in the journal paper, W&W is not uniquely used in HC. A similar process of disease-monitoring is used in people with colorectal cancer. However, similarly to IHC, studies examining the psychosocial consequences for people with colorectal cancers not requiring treatment are sparse. In contrast, several studies have focused on the experiences of people with prostate cancer (PCa) under W&W, with varying findings. Some have concluded that people with PCa under W&W maintain good quality of life and do not experience significantly greater psychological distress than the general population (Bellardita et al., 2015; Matheson et al., 2019; Sypre et al., 2022). In contrast, others have reported increased psychological burden and distress in PCa patients under W&W, even compared to those receiving treatments (Orom et al., 2017; Tan et al., 2016; Watts et al., 2014). Though not explored explicitly, Tan and colleagues reported unmet needs of uncertainty and poor symptom management as underlying reasons for distress.

Exploring this further, the recent meta-synthesis referenced in the journal paper reported on the unmet psychosocial needs of people with prostate cancer under W&W (McIntosh et al., 2019a). They reported the following unmet needs: inadequate, inconsistent, or confusing information available (information needs); lack of emotional support (emotional support needs); lack of contact with others with similar diagnoses (peer needs); and finally, a desire for increased support with exercise (physical health needs). On one hand, these findings seem non-specific to PCa, and therefore, may hold relevance to individuals with IHC. However, there are differences between HC and PCa that may mean the findings are not generalisable. Firstly, PCa under W&W generally denotes a solid tumour contained within the prostate. The individual may be able to monitor this physically, through noticing changes in its size or shape. In contrast, HC typically refers to cancers occurring on a cellular level, meaning there is often no tumour (i.e., a lump) to monitor. The cellular nature also means that the cancer is not contained to a specific location, but rather, in cells throughout the body. A second difference relates to the curability of IHC and PCa. HCs suitable for the W&W pathway are not typically curable. A person may receive treatment to manage symptoms and to prolong life, but the cancer will most often remain present to some degree (Cancer Research UK, 2021; Jeong, 2022). In contrast, PCa in people under W&W is often curable (National Institute for Health and Care Excellence [NICE], 2019), with medication or surgery available that will result in the cancer being cured. Finally, prostate cancer research, by nature, focuses only on the experiences of biological males. This is pertinent given women have been found to report a greater number of unmet needs than men (Morrison et al., 2012).

In addition to the differences in diagnoses, there are also important differences between the W&W pathways for PCa and HC. Typically, people with PCa can choose whether to undergo W&W or active treatment (NICE, 2019). Even once placed under W&W, they may request to receive treatment at any time (NICE, 2019). In contrast, W&W is predominantly dictated by disease stage in HC and the individual has little choice in deciding when they begin treatment (NICE, 2016). As described in the journal paper, this difference in the individual's ability to be involved in their own care plan may have significant implications for meeting needs such as autonomy and control.

Finally, there is the previously discussed difference in distress. Reports of psychological distress in people with PCa under W&W vary, with some papers finding that individuals generally cope well under W&W (Matheson et al., 2019). This contrasts the consistently reported finding that psychological distress in those with HC under W&W is high (Russell et al., 2022). Given the relationship between unmet need and psychological distress, these differences may indicate differences in needs in each group.

1.5 Covid-19 Pandemic

In February 2020, the Covid-19 virus was detected in the UK for the first time (Williams et al., 2020). Following this, nearly two years of intermittent measures were imposed to manage and mitigate the spread of the virus. Initially, most of these restrictions were lifted in July 2021. The vaccine rollout began in December 2020 and all adults had been offered their two vaccines and booster jab by December 2021. However, by December 2021, a new variant of the coronavirus, Omicron, had begun to circulate, resulting in the UK Government reintroducing compulsory mask-wearing indoors and the use of NHS Covid Passes to enter some venues (Institute for Government, 2022). These restrictions lasted four weeks, until the end of January 2022. Finally, self-isolation rules stopped being compulsory in March 2022.

Blood plays a vital role in the human immune system and consequently, those with HC, regardless of whether they were receiving treatment or not, were found to be at significant risk of death if they contracted Covid-19 (Lennard et al., 2020). Consequently, most individuals with HC were classed as “extremely clinically vulnerable”. This meant they were provided with additional “stay at home” guidance and should have been offered vaccines and boosters as a priority.

1.6 Rationale

Research has highlighted that people with IHC require additional psychological support, evidenced by elevated psychological distress in this population, compared to the wider cancer population. Despite this, there is a dearth of literature exploring their needs, and consequently, what interventions should comprise (Liptrott et al., 2020). Instead, studies reporting the psychosocial needs of individuals with HC have either excluded those not receiving treatment or combined those receiving treatment with those under W&W. Further, the only study that has examined psychosocial needs of people with IHC used a pre-defined needs questionnaires, and the applicability of this to IHC has been questioned here. Whilst research has explored the psychosocial needs of individuals with PCa under W&W, it is not yet clear whether it is possible to generalise results due to the identified differences between the two groups. Similarly, as the W&W pathway is associated with unique challenges, caution is also required when generalising findings from research reporting the psychosocial needs of individuals with HC receiving treatment.

Finally, the SDT model has demonstrated value in providing a framework for intervention development to support psychological wellbeing, and the PACID model provides a comprehensive framework for understanding the impact of chronic illnesses. Therefore, understanding whether the sample's needs align with the basic psychological needs of SDT and elements of the PACID model, may prove valuable for furthering both theoretical and practical understandings what effective psychological support should comprise. In addition, testing the models in this new environment (i.e., chronic cancers) expands the current literature base on the utility and applicability of the models.

2. Extended Method

2.1 Study Design

2.1.1 Rationale for the Qualitative Longitudinal Design

The present study aimed to inductively and deductively explore the psychosocial needs of people living with HC under W&W. Whilst there are clearly defined categories of psychosocial need detailed in the literature, such as the HNA (MacMillan Cancer Support, 2018), individual needs are ultimately subjective. Consequently, quantitative studies that have used pre-defined assessments (e.g., the HNA) to explore individuals with HCs' psychosocial needs are bound by the limits of the questionnaire. The present study aimed to explore needs through qualitative methods to allow for a more rich and nuanced understanding of individual experiences to be developed (Pope & Mays, 1995). Specifically, semi-structured interviews were used to enable the researcher to understand the factors surrounding psychosocial needs (such as the impact of time and the psychological impact) beyond simply understanding whether specific needs were reported as met or unmet. Further, research examining the experiences and needs of people living with HC specifically under W&W is scarce. Developing insight from a small number of individuals using qualitative methods can be useful in informing future design of large-scale quantitative research, such as intervention studies (Pope & Mays, 1995). The qualitative design was further supported by a review that concluded that further research, specifically qualitative, was required to increase understanding and consequently advance knowledge in relation to this population's psychosocial needs (Statham & Davis, 2018).

Psychosocial needs can shift between being met and unmet depending on various contextual and environmental factors at any one time (Swash et al., 2014).

Whilst interviewing multiple participants gives variety on individual contextual differences, such as time since diagnosis, interviewing all participants at one time-point offers little understanding of the impact of wider societal factors such as the Covid-19 pandemic. Therefore, the researchers interviewed participants a second time, utilising a longitudinal qualitative approach, with the aim of strengthening the understanding of needs and the conditions under which they are more likely to be met or unmet. Longitudinal qualitative research guidance was used to shape the study design (Calman et al., 2013; Tuthill et al., 2020).

The use of longitudinal qualitative designs has become more common in recent years (Thomson & McCleod, 2015). Calman et al. (2013) suggested that repeating interviews over time has the benefit of moving away from descriptive understanding and towards analytical understanding, by allowing exploration of drivers and consequences of change. Longitudinal qualitative research has also been cited as advantageous in understanding individuals changing experiences of physical illness (Murray et al., 2009). Murray et al. reported that repeating interviews is particularly useful in research exploring processes that may change over time. For individuals under W&W, time can be viewed as central to the experience: the more time that passes, the closer individuals become to needing treatment.

Several factors were considered when deciding on the time frame between interviews. In the present study, it was assumed a priori that most participants would have at least one check up with their General Practitioner (GP) or Haematology/Oncology team during a six-month period. Secondly, available longitudinal needs literature has reported a change in needs over six-month period (McDowell et al., 2010). Finally, six months was thought to be the maximum gap feasible within the time constraints of a doctoral thesis. Although there were reasons for the chosen time frame, the researchers acknowledge that time is simply a convenient metric, rather than a direct cause of change (Ployhart & Vandenberg, 2009). Therefore, the timeframe chosen was somewhat arbitrary, with other timeframes likely being equally appropriate.

2.1.2 Epistemological Stance

Epistemology concerns the philosophical framework from which researchers understand the acquisition of knowledge (i.e., how beliefs about reality are developed). In some disciplines, such as medical research, new knowledge is understood as developing through positivism: knowledge is built from objective observations of reality. Other disciplines take a constructivist approach, understanding knowledge acquisition as a socially constructed process, relying on individual experiences, and irrespective of an objective reality. Out of the these opposing paradigms, Bhaskar (1978) developed critical realism. From a research perspective, critical realism accepts that it is not possible to develop a theory of "true reality", but rather, research develops understanding and explanation of social phenomena (Fletcher, 2016).

It has been suggested that a relationship exists between an individual's physical illness, and the meaning they have formed around it (Murray & Chamberlain, 1999). Taking a critical realist approach to understanding individuals' experiences of living with chronic cancer embraces the understanding that what individuals report will be shaped by their past experiences, opinions, personal expectations as well as wider cultural and societal factors of having cancer. However, whether these experiences represent met or unmet needs will hold real implications for the individual's reality. Taking a positivist stance would risk neglecting the importance of the individual narratives around having a chronic cancer. In contrast, a social constructionist position may overlook the relevance of the physicality of illness and the objective reality of having cancer. Therefore, the researcher adopted a critical realist framework throughout the research process. Consistent with critical realism, the researcher was aware that both data collection and analysis would be influenced by their personal beliefs and experiences, and previous experience of working in physical health settings.

2.1.3 Researcher's Position

Elliot et al. (1999) advise that researchers should describe their beliefs about the study phenomenon, and their personal experiences and training in relation to the topic, to allow readers to contextualise the research findings. Further, by recognising these interpretation biases early, the researcher aimed to be aware of their impact throughout through using supervision and reflexivity (including a reflective journal).

Whilst I did not have any prior personal experience of HC, in 2021 I completed a systematic literature review examining psychological distress in individuals with

HC. The review found that clinical levels of anxiety and depression were higher in people with IHC than the general public (Russell et al., 2022), and this shaped my perceptions towards the study phenomenon. In addition, I have had personal experiences of family members having non-haematological cancers. For instance, both my grandads are survivors of prostate cancer. Whilst one was treated immediately, the other opted to spend a short period under monitoring, before being treated, and this meant I had some prior beliefs about what W&W meant in relation to prostate cancer (mainly, that it was a patient-led decision). More recently, my mother received urgent surgery for the removal of a melanoma and my grandma had radiotherapy for breast cancer. These events consolidated my previous understanding and belief that cancer is an acute medical emergency that requires immediate attention.

I also believe my work in physical health settings (paediatrics and epilepsy) may have shaped my understanding of the study phenomenon prior to beginning the research. These roles exposed me to individuals presenting with high levels of psychological distress, resulting from chronic conditions such as diabetes, epilepsy, and renal conditions. These past experiences and prior knowledge could have had the potential to influence how distressed I perceived individuals living with IHC to be and how I interpreted their emotional support needs (e.g., potentially overestimating the psychological impact of IHC). On the other hand, my mother has lived with a chronic condition, MS, for many years, with fortunately little impact on her day-to-day life. Therefore, I also have a personal understanding that not everyone with a chronic condition will present with high levels of unmet psychosocial needs or high levels of distress. I believe these prior conflicting perceptions around both cancer and chronic conditions encouraged me to take an open and critical stance to understanding participant experiences.

2.2 Ethical Approval and Considerations

Recruitment was planned to take place through social media and NHS channels. Due to the intention to recruit partly through the NHS, ethical approval for recruitment through all channels was sought from the NHS Research Ethics Committee and the Health Research Authority. Ethical approval was granted on 8th March 2022 by the Health Research Authority and the South Central – Oxford A

Research Ethics Committee (REC reference: 22/SC/0044) (Appendix B). In addition, approval was sought from the following NHS Trusts Research and Development departments: Nottinghamshire Healthcare Foundation Trust, Sherwood Forest Hospitals NHS Foundation Trust, United Lincolnshire Hospitals NHS Trust, and Chesterfield Royal Hospital NHS Foundation Trust. However, recruitment was completed through social media before all individual Research and Development departments completed their approval assessments and therefore, no participants were recruited through the NHS. Further details on the recruitment process are given in section 2.4 below. No ethical amendments were made during the research process. Prior to beginning, the study was registered on the Open Science Forum.

2.2.1 Confidentiality

At the start of each interview, the researcher explained confidentiality, and its limits, to the participant. In line with guidance, the researcher treated all data collected in the interview confidentially, and with care and respect (British Psychological Society, 2014). The participant was free to discuss the interview with whomever they wished.

2.2.2 Data Protection and Storage

A University of Nottingham Data Management Plan was completed prior to research beginning. In line with the General Data Protection Regulation 2018 and the Data Protection Act 2018, anonymised interview transcripts and researcher notes were stored securely on an encrypted, password-protected USB drive. Anonymising transcripts (including removing all personal identifiers and assigning pseudonyms) ensured participants were not identifiable in the written research report. Access to the data was restricted to the researcher, research supervisors, and a small necessary number of course staff.

Identifiable data, including consent forms, a list of participant details (including demographic information and their corresponding pseudonym), and their contact details were securely stored separately to the anonymised data, on the researcher's password-protected University of Nottingham drive. After study completion, all study documents will be stored electronically by Administration staff at the University of Nottingham. Only Administration staff and research supervisors will have access to this data. All identifiable information will be destroyed three months after study completion. In line with GDPR and University of Nottingham data management policy, all data will be destroyed seven years after the study has ended.

2.2.3 Participant Information and Informed Consent

The researcher explained the details of the study and provided a Participant Information Sheet (Appendix C) and the Study Procedure Flowchart (Appendix D) to all participants prior to sharing the consent form. The Participant Information Sheet made clear that participation was entirely voluntary and declining to participate would not result in any penalty. The researcher ensured participants had sufficient time to consider participating or not. The researcher answered any questions that the participants had concerning study participation.

Prior to participation, all participants provided informed consent. In line with the University of Nottingham guidelines for remote studies, participants were sent an electronic version of the consent form (Appendix E) and asked to return this via email. The returned copy of the consent form was retained in the study records and participants were asked to keep a copy for their own records. Some participants were not able to access the consent form virtually and therefore, they were posted hard copies of the consent form along with a stamped and addressed envelope to return the form to the University. Scanned copies of these hard copy consent forms were retained in the study records.

2.2.4 Participant Withdrawal

Participants were made aware prior to participation (through the information sheet and the consent form) that they could have withdrawn from the study at any point, at their own request, without penalty and without reason. Throughout the study, the researcher ensured participants were regularly reminded that their participation was entirely voluntary. Participants were made aware that they may have contacted the researcher up to one week after participating in each interview to withdraw from the study. Participants would have been offered the opportunity to remove part or all of their data; however, no participant withdrew or requested to withdraw their information from the study.

2.2.5 Debriefing

After participation in the study, participants were provided with debriefing information. This summarised the aims of the research and included the researcher’s contact details and contact details of the University of Nottingham research support and complaints team (Appendix J). Participants who wished to receive a summary of the research upon completion will do so once the research paper has been finalised.

2.2.6 Interview Management

The researcher recognised that recruiting and interviewing participants to discuss their cancer diagnosis and unmet needs could have been upsetting and difficult at times for both the participant and the researcher. The researcher monitored participant distress throughout interviews and was aware of support available to offer participants if it was felt to be necessary (such as MacMillan cancer support helpline). Participants were reminded that their participation was voluntary and that they had the right to decline to answer any questions. Recruiting through social media support groups meant that participants had access to support after participation, should they have needed it.

2.2.7 Participation Reimbursement

Participants received a £5 Love2Shop voucher for each interview they participated in to thank them for their time. This amount was not considered sufficient to affect financial support and participants were informed they would still receive a voucher if they chose to withdraw.

2.3 Sample

2.3.1 Sample Size

Unlike in quantitative work, establishing sample size in qualitative research cannot rely on statistics-based rules. Rather, sample size is decided through considering methodological, epistemological, and practical factors (Vasileiou et al., 2018), with the aim being to determine a sample size large enough to develop new and detailed conclusions, but small enough to allow for deep analysis of each participant (Sandelowski, 1996). Previously, one of the most widely used criterion for determining when to close recruitment was saturation (Saunders et al., 2018). Saturation, originally developed for use in grounded theory (Glaser and Strauss, 1967), refers to the point at which further data collection is deemed unnecessary to answer the research question (Saunders et al., 2018). However, outside theoretical development, claims of achieving saturation are being increasingly criticised as being ‘articles of faith’, rather than based in evidence (Thorne, 2020). Instead, alternative concepts of aiming for ‘theoretical sufficiency’ (Dey, 1999) and ‘information power’ (Malterud et al., 2016) have been suggested. Both concepts refer to the point at which researchers are likely to have heard *enough* rather than heard *it all* (LaDonna et al., 2021). Given the growing criticisms around claiming saturation (Thorne, 2020), and its lack of specific applicability to the study methodology, the researchers chose to instead aim for sufficiency.

Literature recommends the number of interviews needed to achieve sufficiency to be between six and ten (Guest et al., 2006; Hennink et al., 2017). However, longitudinal research carries the risk of participant attrition. A systematic review of longitudinal qualitative research in healthcare found attrition rates varied from 0% through to 50% (Smith-Battle et al., 2018). Though it was reported that reasons for attrition were rarely stated, the researchers identified the following actions reduced attrition rates: rapport building, offering a participation incentive, and telephone calling participants between interviews. The researcher considered this guidance and focused particularly on rapport building with participants to reduce the risk of attrition. As there was little other evidence available to predict the attrition rate for the study, the researcher oversampled at T1, aiming for 12-15 participants, to accommodate for possible attrition at T2.

2.3.2 Eligibility Criteria

Inclusion criteria:

- Must have a diagnosis of haematological cancer and be at least six months post-diagnosis (to allow for an adjustment period, as advised by a DClinPsy Service User and Carer Advisory Panel [SUCAP] member).
- Assigned to the “watch-and-wait” pathway.
- Aged 18 or above.
- Conversational level of English (to allow them to take part in the interview without the need of a translator).
- Ability to give informed consent.

Exclusion criteria:

- Diagnosis of another primary cancer - this may mean they are having additional support and monitoring, even if assigned to the “watch-and-wait” pathway for haematological cancer.

- Diagnosis of a memory impairment, which would hinder their ability to reflect on a six-month period (e.g., a dementia).
- Individuals unable to give informed consent.

There is a marked increase in risk of IHC in individuals aged over 50 years (Smith et al., 2011), and being placed under W&W under the age of 40 is extremely rare (Ferrajoli et al., 2010; McNamara et al., 2012). Further, it was assumed that children may have significantly different psychosocial needs to middle to older aged adults (e.g., psychosocial perceptions around retirement versus education). Therefore, to ensure a level of useful homogeneity in the sample, only adult participants were invited to take part in the study.

Whilst research has found that anxiety and depression remain high after diagnosis (Shanafelt et al., 2007), it was hypothesised that individuals would likely go through a natural process of adjustment immediately after diagnosis, which may lead to specific support needs being identified. Therefore, the decision was taken to only recruit individuals who had been diagnosed at least six-months prior to the first interview.

2.3.3 Recruitment

Previous research into individuals with IHC referenced recruitment difficulties when recruiting through NHS channels (Swash et al., 2015; Byrne, 2018). Further, recruiting through local NHS trusts would have likely resulted in all participants living within relatively close proximity, risking hearing experiences specific to a small geographical area. Therefore, the initial recruitment strategy was two-pronged to maximise reach: recruitment through identification by Cancer Nurse Specialists working in NHS oncology/haematology teams, and recruitment through social media. Ethical approval was sought to cover both recruitment strategies. Once ethical approval was confirmed, confirmation of capacity and capability was sought from each healthcare site’s Research and Development departments and the recruitment poster (Appendix K) was shared with administration members of the following Facebook groups:

- Blood Cancer Uncensored – Leukaemia, Lymphoma, Myeloma, Myelodysplasia
- UK Hodgkin’s Lymphoma Support Group

- UK Non-Hodgkin's Lymphoma Support Group
- UK Myeloma Support Group
- CLL Support Group – UK

Snowball sampling was also used, whereby participating individuals were encouraged to share study information with other potentially interested parties. To the researcher's knowledge, participants shared the recruitment poster in an additional Facebook support group, and in a support WhatsApp support group.

Within three weeks of social media advertisement, 22 individuals requested further information about the study. Out the interested participants, three were ineligible due to being under active treatment and two did not wish to take part after receiving the study information documents. The first fifteen participants were invited for interviews and the remaining two were thanked for their interest and informed the study had closed. During this time, no research site had completed the capacity and capability assessment and so NHS recruitment had not begun. Each site was thanked for their support and informed that recruitment through their systems was no longer necessary.

2.4 Data Collection

2.4.1 Collecting Demographic and Mood Information

Demographic information was collected at the start of the first interview. The specific data collected was guided by previous research and included the participant's age, gender, ethnicity, employment status, and haematological cancer diagnosis (Swash et al., 2017). The length of time the individual had spent under W&W was also recorded. In addition, the researcher asked each participant to complete the Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983) at each time point, to give an indication of the level of psychological distress in the sample. Psychometric analysis of the HADS has demonstrated it has acceptable internal consistency (Cronbach's $\alpha = 0.85$) in a cancer population (Rodgers et al., 2005). Understanding the sample demographics and reported psychological distress was deemed important for the researcher to identify the context in which the data was collected (Corbin & Strauss, 2015).

2.4.2 Semi-Structured Interviews

Common qualitative data collection methods include semi-structured interviews, focus groups, and open-ended questionnaires. A DClinPsy SUCAP member offered guidance on the most appropriate data collection method, through discussing their experience of both facilitating and participating in qualitative research. The advantages and disadvantages of various methods were discussed, and the advisor recommended the method of semi-structured interviews. Semi-structured interviews are considered to provide a deeper more nuanced understanding of phenomena than can be gained from purely quantitative data (Gill et al., 2008). Further, interviews allow participants to discuss any areas they feel are relevant to their experience, enabling the researcher to expand their understanding of the topic area, beyond their pre-defined interview schedule (Adams, 2010). After considering the literature, the research question, and the SUCAP member's advice, one-to-one semi-structured interviews were chosen as the method of data collection.

Interview schedules for each time point were developed using relevant literature and the research team's prior knowledge of psychosocial needs in cancer. The aim of the schedule was to yield as much relevant information as possible about the needs of people under the W&W pathway. Therefore, questions were phrased to broadly explore what experiences had been helpful or unhelpful for living well under W&W (see Appendix F for the full interview schedule). Whilst interviews were semi-structured, with pre-set questions chosen to cover topic areas of interest, the researcher was flexible in using follow-up questions to explore individual experiences.

2.4.3 Preparing the Data

All interviews were recorded using Microsoft Teams, with the recordings automatically saving to KR's University of Nottingham password-protected OneDrive. Due to the time constraints associated with completing doctoral research, interviews were transcribed using the University of Nottingham's Automatic Transcription Service (GDPR compliant). The first researcher (KR) then immersed themself in the data whilst checking the accuracy of each transcription against the original audio recording. It was also ensured that all personal identifiers were removed (e.g., a hospital name became "[hospital]") and pseudonyms were assigned. Qualitative data can be anonymised through either assigning participants a number or giving participants a pseudonym. It has been argued that assigning pseudonyms can lead readers to make powerful assumptions about factors such as a participant's age, race, and class (Corden & Sainsbury, 2006). However, the alternative of using numbers is thought to depersonalise reported experiences and make it more difficult for individual narratives to be followed (Saunders et al., 2014). Through discussion of each option with the primary research supervisor (AT) and a review of relevant literature (Naccache et al., 2014), it was decided that pseudonyms would be used. To attempt to reduce the impact of inaccurate assumptions, it was agreed that pseudonyms that generally reflected the overall participant demographics, particularly age (within a UK context), would be selected. The researcher acknowledges that readers make assumptions based on their personal experiences, and thus, may still make inaccurate assumptions about participant demographics. It was hoped that the impact of this would be minimised further by the provision of demographic information.

2.5 Data Analysis

2.5.1 Choosing Reflexive Thematic Analysis

The decision to use reflexive thematic analysis was taken after discussions during research supervision. When making the decision of which methodology would be best suited to answering the research aims, several different types of qualitative analysis were considered.

Grounded theory, first developed by Glaser and Strauss (1967), is an inductive qualitative research methodology that was considered at the start of the research process. Through the approach, data is systematically collected and analysed, and new theory is generated, aiding understanding of complex processes under specific circumstances (Strauss & Corbin, 1994). The method is therefore useful for research aiming to produce explanations of phenomena about which little is known (Tie et al., 2019). Whilst there is little understanding of the specific experiences of people living with IHC, there are existing theories of psychosocial needs (e.g., Deci & Ryan, 1985; Maslow, 1943) and theories of adjustment to health conditions (e.g., Livneh, 2022). The present study aimed to explore the needs in people living with HCs, and to understand how these findings are similar or different to individuals with prostate cancer under W&W. Further, the study aimed to identify shared patterns of meaning that could be used to inform future intervention or support pathways. Given the knowledge already available, and the lack of emphasis on developing a new theory, grounded theory was not deemed to be an appropriate method of data analysis for the study.

Interpretative Phenomenological Analysis (IPA) is another qualitative approach that aims to deeply explore participants’ perceptions of experiencing a major life event, such as a diagnosis of cancer. IPA is concerned with inductively and intensively analysing each participant’s data, aiming to highlight unique personal experiences, in addition to shared meanings. Due to the intensity of analysis, studies using IPA typically use a small number of participants (Smith & Osborn, 2015). The analysis then involves a two-stage interpretation process involving (1) the participant making sense of their experience and sharing these perceptions and (2) the researcher making sense of the participant’s shared perceptions. Perhaps due to its focus on developing deep and personal understanding of complex experiences such as illness, IPA is increasingly used within health psychology research (Peat et al., 2019). The methodology is congruent with the researchers’ critical realist position and could be useful in providing detailed accounts of the experience of having cancer and not receiving treatment immediately. However, the present study’s objective was to develop an understanding of the most commonly experienced unmet needs amongst people living with IHC, with the hope of informing future intervention studies. Further, IPA methodology has been criticised for focusing heavily on individuals’ perceptions of their lived experience but neglecting to explore the factors that have triggered or contributed to specific experiences (an aspect that relates to the second aim of the present study). After discussion amongst the research team, it was decided that, compared to IPA, thematic analysis would provide greater opportunity to identify shared experiences amongst a larger and more heterogenous sample.

Thematic analysis (TA), first named by Merton (1975), is a method of noticing, analysing, and later explaining patterns in qualitative data. Since 1975, various versions of TA have been proposed (e.g., Boyatzis, 1998; Braun & Clarke, 2006). Arguably, the most widely used method of TA is Braun and Clarke’s (2006) six phase process, described by the authors as a theoretically flexible method of analysis. The process involves the researcher recursively analysing textual data until patterns, named ‘themes’, are generated. Like other qualitative methodologies, TA is inescapably bound by the researcher’s own subjectivity; coding and theme generation are interpreted through the lens of the researcher’s own beliefs and understanding of the world (Lincoln, 2005). Braun & Clarke understand this subjectivity as a key driver of TA and report critical reflection on personal subjectivities an “essential resource” to reflexive TA. In contrast with grounded theory and IPA methodologies, reflexive TA does not prescribe specific data collection methods, or theoretical or epistemological positions (Braun and Clarke, 2013). This flexibility means that TA can be positioned within the researcher’s critical realist stance.

TA allows data to be analysed in two ways: inductively (data-driven) and deductively (theory-driven). Inductive analysis involves generating codes, and subsequently themes, directly from the data. In contrast, deductive analysis involves analysing data using a pre-defined codebook. Codebooks are typically developed using available literature and theory of interest; thus, deductive analysis is “theory-driven” (Fereday & Muir-Cochrane, 2006). Inductive analysis was believed to be appropriate for the present study, due to the lacking literature exploring the needs of people with HC under W&W. However, given the availability of research into the needs of individuals with other cancer diagnoses under W&W, namely prostate cancer literature, pre-existing psychosocial needs theories, and psychosocial theories of managing chronic conditions, a deductive approach was also considered to be useful.

In addition to identifying shared patterns of met and unmet needs, the researcher was also interested in how needs changed over time, and the factors and contexts around these changes. Whilst TA produces themes that represent shared patterns across the sample, it has less utility in identifying variation within individuals arising from contextual changes (e.g., the evolving Covid-19 pandemic). Looking at individual changes was understood to be important for deepening understanding of factors leading to changes in needs over time (Kneck & Audulv, 2019). Pattern-Oriented Longitudinal Analysis (POLA), developed by Kneck and Audulv (2019), is one method of analysing within-participant changes in longitudinal qualitative research. The authors cite inductive TA as one method of structuring the data during this longitudinal analysis (i.e., through data coding). Given the flexibility in analysing the data inductively and deductively, its applicability in the POLA method, and its fit with the researcher's epistemological position, reflexive TA was decided upon as the most appropriate method of analysis.

2.5.2 Inductive Analysis

Data was analysed following Braun and Clarke's (2006) six phase process. Since their seminal paper, the authors have updated and refined the approach. Therefore, Clarke and Braun's (2022) guide to reflexive TA was used to inform the researcher of how to engage in each phase of the process. Table 1 outlines of the researcher activity associated with each phase.

Table 3.

Thematic analysis six-phase process (Braun & Clarke, 2006)

Phase	Researcher activity, guided by Clarke & Braun (2022)
1. Familiarisation with the dataset	The researcher simultaneously listened to the audio recording and read the corresponding transcript; this served the dual purpose of familiarising the researcher with the data through immersion, and also ensured the transcription was correct. A second important component of familiarisation requires the researcher to 'critically engage' with the data (Clarke & Braun, 2022). The researcher critically engaged with the data by attempting to understand the meaning behind the data, aided by asking questions of the data (e.g., "how is the person making sense of this experience?"). Finally, the researcher noted down ideas of potential patterns and meanings in the data generated from both immersion and critical engagement, ensuring reflexivity through holding in mind questions such as "are there different ways I could understand this

	data?” and “what personal biases might my ideas be being influenced by?”.
2. Data coding	After ensuring the transcription was correct, the researcher openly coded each transcript. This involved the researcher thoroughly reading each transcript and adding a code to any text that was interesting or potentially relevant to the research question. Each time a code was needed, the researcher considered whether an existing code captured the text, or whether a new code was needed. To do this, excel spreadsheets were used for each transcript, with the data in one column, and codes added in the corresponding row of the next column. At this point, a different colour font was selected for each dataset (including codes) to differentiate which codes came from which participant later in the analysis.
3. Initial theme generation	To generate themes, the researcher spent time looking at all of the codes across the dataset. Candidate themes were generated through looking at how codes potentially connected to one another and considering the different meanings patterns in codes represented. The generated candidate themes were then placed in a third column, in the row corresponding to the code (see Appendix L), and in the corresponding font colour. Not all codes related to a candidate theme. In line with guidance, “miscellaneous” codes were kept track of on a separate excel spreadsheet to ensure these were available for later theme revision. Finally, initial theme mapping was used to explore the differences and similarities between candidate themes.

4. Theme development and review	The aim of phase four was to develop richness and nuance in the analysis and to check the validity of the initial themes . This began with the researcher discussing the initial themes with the research team. Through collaborative discussion, an overarching theme was constructed, and other themes were dropped when lacking in evidence, or collapsed into one when overlapping. The researcher then re-engaged with the data to consider whether this had led to higher quality pattern development. As advised in guidance, a recursive process of moving back and forth between the analysis and the data was used to develop themes. Finally, the researcher returned to the research team to ensure the final theme ideas were agreed upon and felt reflective of the key recurring patterns in the data.
5. Theme refining, defining, naming	The aim in this phase was to finalise the themes for the write up, using a two-stage process. Firstly, the researcher tweaked the names of the themes, refining them until it was agreed that the theme title captured the essence of the shared meaning it represented. Secondly, theme definitions were written for each theme. Question prompts provided by Clarke and Braun (2022, p111) were used to test the richness and nuance of the themes (e.g., “what are the boundaries of this theme?”). Whenever the researcher struggled to answer these questions clearly, they returned to reworking the analysis and discussing the challenges with the primary research supervisor AT.

6. Writing up	The final phase of the process was to write up the findings. It was important that the written report contained (pseudonymised) participant quotes for two reasons: (1) to provide evidence for the themes presented and (2) to allow readers to consider the fit between the researchers understanding of the data, and the data itself. Therefore, quotes were used, and selected using the guidance provided by Clarke & Braun (2022).

Once interviews at each time point had been inductively coded following Braun and Clarke’s process, the researcher created a new excel spreadsheet to begin the POLA. For each participant, candidate theme codes generated through TA at T1 and T2 were placed in adjacent columns (see Appendix M). This enabled the researcher to compare the codes generated at T1 and T2 for each participant (within participant changes) and across participants (between participant changes). As advised by Kneck and Audulv (2019), an analytical question was chosen to focus the researcher on identifying relevant changes within each dataset: “what changes have occurred over the last six months and what factors are associated with this change?”. This enabled the researcher to focus the analytic interpretation on the research question. Using the excel spreadsheet, in a third column, summaries of changes noticed between T1 and T2 for each individual were recorded (e.g., “more fearful of Covid-19”). Finally, the researcher studied the change-related shared patterns across the participant datasets by noting any additional changes to needs reported between the complete T1 dataset and the complete T2 dataset. To maintain trustworthiness of the analysis, the same processes were followed as throughout the initial inductive process. That is, the researcher kept a reflective log, maintained an audit trail, and used research supervision to monitor bias and reflect on interpretations made.

2.5.3 Deductive Analysis

A coding framework for the deductive analysis was developed a priori, based on literature and theories of interest (see Appendix G). The first codes aimed to answer the fourth study aim ‘Are the reported needs different to those identified in people living with prostate cancer under W&W and if so, how?’. Therefore, the codes in the coding frame represented each key need identified in a recent systematic review exploring the needs of individuals under W&W with prostate cancer (McIntosh et al., 2019a). PCa was chosen as a focus because the literature exploring needs in individuals under W&W with other cancers was very limited at the time of study development. To explore the data against an existing psychosocial needs theory, the three components of the SDT (Deci & Ryan, 1985) (autonomy, competence, relatedness) were included in the framework. Finally, as previously described, the present study questioned whether HCs not requiring immediate treatment could be considered to be ‘chronic cancer’. Consequently, the researcher was curious as to whether the experiences of the study sample would align with a psychosocial theory of chronic illness. Therefore, codes representing each aspect of the PACID model (Livneh, 2022) were included in the coding frame.

The researcher had previously become familiar with the data through simultaneously listening to the audio of each transcript, whilst reading and correcting the transcription produced by the automated transcription service. Further familiarisation then occurred through the inductive analysis process. Following inductive analysis completion and theme construction, each transcript was re-coded using the coding framework. Coding was completed using an excel spreadsheet (see Appendix N), with each column alongside the data corresponding to each domain of the coding framework (e.g., a column for each “autonomy”, “relatedness”, “competence”). Next, each deductive code was transferred onto a separate spreadsheet formatted to denote each code in the framework (e.g., the code “emotional wellbeing not supported” would be transferred into the corresponding column: “Emotional support needs”). Finally, how the data fit the literature and theory was explored, including where the data aligned and where it did not.

2.5.4 Ensuring Methodological Quality

Researchers have combined literature on quality control measures in qualitative research to create a trustworthiness guide (Korstjens & Moser, 2018). This guidance has been used to influence the researcher’s analysis and interpretation procedures to ensure the research produces credible findings. In line with the guidance, the researcher immersed themself in the data, firstly through correcting the transcription, and secondly through reading, coding, re-reading and recoding the data until the researcher and supervisors agreed on final themes. The researcher worked closely with supervisors, providing them with a record of code and theme development using Microsoft Excel. Korstjens and Moser's guidance also recommends maintaining an audit trail to record a transparent description of the study process. Throughout, the researcher kept records of the decision processes throughout study development and data collection and analysis processes.

One concern associated with longitudinal qualitative analysis is the risk of bias when analysing second interviews, once codes of first interviews have been developed (Kneck & Audulv, 2019). Ideally, each participant's T1 and T2 interviews would have been transcribed and coded together. However, given the time constraints of the project, T1 interviews were transcribed and partly coded in the six-month period prior to T2 interviews. To monitor bias, the researcher kept a reflective log throughout the analytic process, recording the their reflections and pulls during coding and theme development (Appendix O), and discussed these with the primary research supervisor AT. Finally, Clarke and Braun's (2022) '15-point checklist for good reflexive TA' was used to monitor quality throughout study development and execution (Appendix P). The checklist helpfully guided the researcher through quality assurance measures at each stage of the research process.

3. Extended Analysis

This section provides further detail of each theme with additional illustrative quotes that were not shared in the main journal paper. The section also provides greater detail of the deductive analysis findings.

3.1 Recruited Participants

In the sample, nine participants were retired, with three having taken early retirement. Out of the four that were working, three were self-employed. Two described themselves as unemployed, though both were seeking voluntary work. All participants resided in England, with relatively equal spread across the country. Two had previously received anti-cancer treatment and had since been placed on W&W. At the time of T1 interviews, time between blood tests ranged from six weeks to one year.

Two thirds of individuals responded to the HADS (Zigmond & Snaith, 1983), with 10/15 returning the questionnaire at T1, and 8/12 at T2. At both time points, anxiety was reported to be in the clinical range, with an average score of 11.3 at T1 and 11 at T2. Compared to anxiety symptoms, depressive symptoms were less common and in the borderline range, with a score of 7.6 being reported at both time points.

3.2 Inductive Analysis Findings

3.2.1 Understanding the Impossible: Having Cancer That Doesn't Require Treatment

Subtheme: Battling One's Own Perception That Cancer Must be "Fought Off". All shared the shock they felt at being told they had cancer but that they were not going to be treated immediately. Understandably, this contradicted prior conceptions that cancer is an illness that requires a "fight".

> "There's the sort of cancer narrative that you have this fight. You have an operation, bit of chemo maybe. Maybe radiotherapy[…], Well, you don't have that" (Ian, T1)
>
> "The idea that I had cancer, and no one was doing anything, just felt really weird. You know, normally, my mum had breast cancer previously and you know as soon as they discovered it, it was like in chemo, radiotherapy, you know you get along with things, so suddenly being told 'we're not doing anything', was a real shock" (Olivia, T1).

Prior to being given the final diagnosis, Olivia described equipping herself with knowledge of treatments, giving the sense that she was preparing to fight.

> "I'd then sort of been on the lymphoma website over the weekend and downloaded all this stuff about chemo and radiotherapy and immunology. And I'm a bit of a gung-ho person so I was like well if I've got cancer, I'll just get on with it" (Olivia, T1).

Coming to terms with and accepting the W&W process was described by several as taking a long time. Many commented on the difficulty of understanding W&W immediately after being diagnosed, and this was often related to receiving little to no information at the initial appointment.

> "It's really hard to get your head around watch and wait, it really is. It took me a good two or three year" (Julie, T2)

> “She just said it's not curable, but it's manageable and you'll have tests and she said I won't give you any information today. And she didn't forward me any support or anything” (Christine, T1)

Comparisons were made between having a HC and other cancers in relation to treatment pathways. Helen reported one of the more positive diagnosis experiences of the sample, whereby a Nurse spent time with her after the initial appointment to check her understanding of the diagnosis, and her understanding of not receiving treatment. Later, a sense was gained from Helen that she felt a need to trust her healthcare team, even if she did not fully comprehend the process.

> “In most other cancers they say the earlier you get it we can do something straight away, but this is different, it’s something to get your head around […], but I sort of carried on with it and thought well, I’ve got to trust what they're doing” (Helen, T1).

In addition, the physical difference between IHCs and solid tumour cancers was referenced by some as an extra factor to comprehend. The fact that HC, by nature, is all over the body, rather than contained to a solid tumour site, was associated with increased fear and confusion with Haematologist’s decision that treatment was not yet required.

> “You know they told me I've got cancer in every drop of blood in my body. And yet they don't want to do anything about it, and it's scary because every time a cell divides, you know it could also mutate. That cancer can get worse, […], you're left with this sort of burden of feeling vulnerable, feeling unsafe” (Ian, T2)

Across timepoints, participants continued to reference difficulty understanding W&W and the psychological impact of not receiving treatment. A change was noted for Noel, who was placed under W&W most recently. Through longitudinal analysis, an increase in his understanding of W&W and trust in his team was perceived.

> “I don't get any more [anti-cancer treatment], and that worries me because that was for my immune system, with a blood cancer, my immune system has no boost, so I think that leaves me with a lot of questions in my head” (Noel, T1)

> “Well, if [healthcare team] are not concerned, then there's no need for me to be concerned. The time to worry is when they worry. So that's my method and way of looking at things. If they're worried, I'm worried, if they’re not, I’m not.” (Noel, T2)

Another change was noted for Delia, who’s blood tests had become more frequent over recent months, and therefore, she was aware that she was nearing needing treatment. Her account encapsulates the conflict indicated by others: the urge to wish for treatment whilst understanding that under W&W, treatment inevitably means the cancer is advancing.

> “I wish they could start [treatment] soon. I don't want it, but I want to stop it getting any worse and I can't comprehend why they don't do that” (Delia, T2)

Interestingly, a third of participants had a parent who had had a HC. In some cases, this increased individuals’ understanding of W&W, as they had prior knowledge and exposure of IHCs and W&W. Ann witnessed her father pass away from the same diagnosis, and this initially impacted her trust in W&W and her healthcare team.

> “They said all the same things to him, you know. This is the long, slow disease, and it's no more than high blood pressure. And then he died of CLL, so of course when they told me all the same things I was thinking, *yeah right* I’ve heard this before” (Ann, T1)

Others had experiences of their parent having an acute HC that required intensive and immediate treatment, and this was interpreted as increasing fear and decreasing understanding of not receiving treatment.

> “Lots of GPs or medical people say you don't need to worry about it, but of course hearing that you've got cancer, and to me it was quite a worry because my mum actually died of leukaemia” (Gail, T1)

Subtheme: “There’s Nothing Wrong with You”: Managing and Internalising Others’ Perceptions. Reports of family, friends, work colleagues, and even healthcare professionals misunderstanding or underestimating the impact of living with an IHC were discussed by most. Individuals perceived others as “dismissive” (Ann, T1; Gail, T2; Marta, T1) when talking about having cancer. Ultimately, this appeared due to others associating not being treated with not being ill, and consequently, underestimating the possible psychological impact of living with cancer. Ian described an interaction with a friend who, due to Ian not receiving treatment, thought the diagnosis had been tenuous rather than confirmed.

> "He said to me 'Did you actually have that? I thought they just thought you had it and it went away?' I said yes, I have it. I'm going to have it for the rest of my life, you know, and it's like people don't get that" (Ian, T1)

The need for greater awareness of IHC in the general public was frequently inferred and verbalised explicitly by Olivia.

> "I think it would be good if the wider public knew more about it" (Olivia, T1)

A sense was gained that concerns that others did not take their diagnosis seriously was a barrier to accessing support. Without the visible signs associated with having cancer, such as losing hair or weight, Olivia found it difficult to access counselling at a local hospice, where her GP had referred her to for psychological support.

> "I feel like a fraud going into the hospice and saying I've come to my [counselling] appointment, you know, and they'll look at me as if to say, well you look perfectly healthy. What are you doing here, you know?" (Olivia, T2)

Individuals reported that friends interpreted the lack of treatment as meaning they were physically well, and subsequently, psychologically well. These inferences were perceived as dismissive and led to individuals describing an avoidance of talking to friends about the diagnosis and its physical and psychological impact. Managing others' underestimations of the impact of the diagnosis indicates a potential barrier to gaining informal support from friends and family.

> "Friends that I've told, now I get things like well, so there's nothing wrong with you because you haven't had any treatment then and you know, it's a lack of understanding on their part, but now I very rarely mention it" (Gail, T1)

> "It's difficult to know what to say to friends, I don't want to be a malingerer to my friends and say ohh, you know I'm ill but I am actually ill and I'm not being treated but they think cancer has to be treated" (Frank, T1)

Interestingly, several reported that they wished they had told fewer people about the diagnosis.

> "I think I might have told, definitely told fewer people because […] some people can be very dismissive" (Gail, T2)

> "It's other people' reactions to it sometimes can be almost more difficult than just managing it" (Olivia, T1)

A desire to protect family by avoiding the use of the word 'cancer' (and related words) was interpreted as a second facet of managing others' perceptions. This seemed due in part to the emotionally loaded perceptions people hold towards cancer, and the difficulty explaining to others that their diagnosis was chronic. Some managed this by avoiding talking about the diagnosis with those closest to them.

> "My husband's not very good with it, um, so we don't really talk about it too much" (Marta, T1)

Others chose to use alternative, seemingly less emotive words to refer to the cancer.

> "When I first got this, I said to my daughter, well I was struggling for the words to say leukaemia, and we came up with cooties. So she says to me now, well, of course you're tired because you've got your cooties" (Ann, T1)

> "I thought if I told her I'd got leukaemia she'd just freak out, it's difficult to explain to people that's chronic, […], I just say I've got funny blood" (Bridget, T1)

Choosing to protect family and friends from the diagnosis left individuals with the psychological battle of managing the impact of the diagnosis alone, with several commenting on the need for more formal and external support.

> "I think definitely some sort of counselling, talking, talking to somebody face to face, because it's a lot, you need someone to talk to" (Karen, T1)

3.2.2 Sense of Abandonment Under Watch-and-Wait

Subtheme: Staying Healthy is a Personal Responsibility. A sense that individuals had a personal responsibility to manage their diagnosis and ensure they received adequate healthcare was prominent across the data. A feeling was shared that they were given a cancer diagnosis and "left to get on with it" (Marta, T1), with infrequent contact with their Haematology team and little information on self-management provided.

> “There's nothing… there's no real feedback... I'm my own... to be honest, I'm my own best advocate, you've got to be proactive with this, both psychologically and physiologically, you have to advocate for yourself” (Lisa, T1)

> “Now all I'm thinking about is I'm going to relapse and I've got no idea when it's gonna happen and the fact that there's nobody now until August, monitoring what the hell is going on” (Noel, T1)

Several described the urge to become competent in understanding and managing their condition by educating themselves. Both Ann and Delia had medical backgrounds and were able to find reliable sources of information.

> “[Consultant] said we'll keep an eye on you, but we won't see you, and so you're a bit like well who's keeping an eye on me? So I thought well I'll keep an eye on myself and I'll learn, […], so I go on the webinars that Leukaemia Care put out about CLL. They're all very interesting” (Ann, T1)

> “I mean, I'm reading papers, checking out things as my numbers change and everything, but proper scholarly papers, you know” (Delia, T2)

After receiving the diagnosis, it was common for individuals to be discharged back into the care of their GP. Understandably, it was reported that GPs often did not have any expertise in the individual’s diagnosis, given they are not haematology experts. Those that reported a positive relationship with their GP shared experiences of their GP listening and trusting them as an expert in their condition. For example, Delia reported a good relationship with her GP and shared “My GP reckons I know more about myeloma, MGUS and smouldering than he does. He just says to me you know more about it than I do” (T2). Whilst GPs acknowledging the patient’s expert position seemed helpful for increasing individual’s autonomy, there was also an emotional toll of needing to become a “patient expert” (Delia, T2).

> “I think the GPs need to understand the emotional impact on their patients and how tiring and frightening it is when they don’t know what they should know. It’s scary and it’s battling away” (Marta, T1)

Individuals also reported to take on responsibilities of communicating between healthcare teams, and ensuring their GP was aware of recent test results.

> "I rang up to discuss the results, and the GP hadn't got the results yet and the doctor said to me, it's so good talking to you because you know what's what […], when she hadn't got the results, I managed to get them speaking to the [Haematology] secretary, so I was trying to read out these tiny results off the chart to my GP. These were scan results from back in April, but you know when you ring up the GP the receptionists say 'ohh don't worry cause if there's anything wrong you'll hear from the doctor'. I have to say no, that's not the case at all" (Karen, T1)

Here, Karen's response to the GP surgery that hearing from a doctor if there was something wrong was "not the case at all" highlighted a common pattern of individuals feeling compelled to ensure they were being proactive in their own care, and not relying on others to take care of them.

> "I make sure I get all the blood results and everything so I can monitor it myself" (Delia, T1)

> "You just can't rely on anything that anybody tells you. You just have to be in control and be proactive" (Karen, T1)

Tying into the lack of understanding identified in the previous theme, a sense of individuals being unequipped to self-monitor for symptoms was gained, with poor communication with healthcare teams seeming to exacerbate this further. This lack of competence in understanding how to self-manage conflicted with the need to be responsible for one's own health.

> "I've been getting chills the last two months, and then I thought why, so I asked [haematologist] you know, but nothing. You gotta watch yourself, but there's no explanation of things" (Christine, T1)

> "You just don't know what's going on. You get an ache in the armpit and you think is that a lymph node? […] You know you've got nobody to ask" (Bridget, T2)

Out of the sample, Noel was most recently placed under W&W. At T1, he seemingly felt unequipped to observe his own symptoms, stating "I can't self-manage. I'm not medically trained. I don't know what I'm looking for" and "I left the hospital burning, feeling quite anxious, all sorts of things go around in my head, but there's nobody there to answer my questions". At T2, he was no longer under the care of his GP, after requesting to be cared for under his cancer team again. A sense was gained that having specialists available to ask questions relieved the psychological strain of the personal responsibility he had previously felt.

> "It don't matter how small the thing is, if I'm concerned to them it's not a small concern. Nothing is too small for them. it helps me. Mentally is the bigger issue. So now things don't play on my mind too much" (Noel, T2)

Finally, a pattern of responsibility relating specifically to accessing vaccines was observed. It is possible that this was a particularly salient topic of conversation due to the interviews timing with the recent rollout of the Covid-19 vaccine. Individuals reported to face challenges with accessing booster jabs and described having to provide their GP surgeries with evidence of being eligible. These experiences were understood to represent the lack of understanding and awareness of chronic cancers even within healthcare services.

> "I'd sent an email to the clinical commissioning group for my area, and they contacted the doctor and thereafter, my doctors did actually arrange for me to go and have, well that would have been the third [jab]" (Gail, T1)

> "To begin with, I wasn't on the extremely vulnerable list. I had a conversation with the doctor at our surgery and they said "well, you're not, are you on treatment?" No? "Well, you're not clinically extremely vulnerable then" and I had to get a letter… Leukaemia Care wrote me a letter about CLL and our risks, which I then sent to the doctor and then I got on the list" (Bridget, T1)

Whilst the difficulties with Covid-19 vaccines were ongoing at T2, discussion at both timepoints was extended beyond the Covid-19 vaccines to challenges relating to the Shingles and Pneumonia vaccines too, with the theme of battling healthcare to receive the correct protection continuing.

> "I had to take a screenshot from the webinar which said that people who were immuno-compromised should have their pneumonia antibody levels checked. So I showed the nurse this screenshot and she said "well that's the NHS guidelines so we'll organise that"" (Bridget, T2).

> "I said to my doctor I know I'm not supposed to have the live vaccine, I should have the Shingrix, he just said no, it's okay, you can have the ordinary one.

> So I actually asked Leukaemia care that. And they said under no circumstances should you be having a live vaccine” (Gail, T2)

Ultimately, the combination of unmet information needs and infrequent or poor communication with healthcare teams gave a sense that individuals were left feeling abandoned, and with no choice but to take on sole responsibility for their health.

Subtheme: “If My Bloods Are Fine, They Think I’m Fine”. The notion that haematologists were concerned solely with blood levels was shared by most, with several suggesting a perception that if their blood results were fine, doctors perceived them to be well. This indicated holistic care approaches were lacking for the sample, with little consideration or assessment of wider healthcare needs, such as their psychological wellbeing.

> “It's just sometimes I think they look at the numbers and don't always look at the person. And alright, they might say well look your numbers have stayed stable this time but it's more than numbers, isn't it? It's how you feel and how you're dealing with it. And I don't sometimes always feel like I'm dealing with it very well” (Helen, T1)

> “They go with the numbers. Um, they don't think about the fact that once they’ve delivered the numbers, you know, we put the phone down and how is the patient then? Then what? How's he feeling about it? And I'm not saying… I know that they're blood doctors, not psychologists, but I think there could be an element of sensitivity that could be improved upon” (Frank, T2)

In contrast to this medical perception that people under W&W are “well”, many commented on the psychological struggle they experienced as a result of the diagnosis.

> “It’s huge and to be honest, I wish I could say that I've been able to sort it out and integrate it and all the rest of it but I haven’t. I've just been left with a huge sense of failure actually and a lack of identity, a lack of esteem” (Ian, T1)

> “It's made me feel less of a woman, less attractive, and you know, I just feel like because sometimes I ache and I'm tired. I feel like it's aged me before my time […] I’m just not the person that I used to be” (Marta, T1)

Despite the apparent psychological impact, healthcare teams were perceived to neglect the detrimental impact poor mental health can have on individuals. Delia reflected on the fact that in the six years she has been under W&W, she could not recall anyone asking her about her psychological wellbeing, commenting “No one's ever thought, other than having spoken to you, no one's ever thought of me mentally at all. They're just interested in the numbers and nothing else” (T2). The impression that both Haematology teams and GP practices did not routinely provide information on emotional support further highlighted this perception of neglect.

> “You are diagnosed and um, and then if you've not got any particular problems, you're just left to float about in the ether and there’s no concern about the psychological problems that you may have” (Bridget, T2)

> “I feel there's not a lot of support available during watch and wait. They've never said as part of your treatment, you’ve got XYZ. You should feel free to contact them at any time or e-mail them” (Frank, T2)

The lack of consideration for individuals’ psychological wellbeing possibly stems from Haematology teams’ medical reference point that if individuals’ physical health markers are within acceptable limits, then they are “healthy”. Ian used an analogy to highlight this disparity between the patient experience of being ‘ill’ and healthcare professionals’ perceptions that they are ‘well patients’.

> “The way it feels, it's like someone's just pushed you out of an aeroplane. It wasn't your choice. You've been thrown out of an aeroplane. You've got a parachute on your back, but you're free falling. And they're saying to you, you don't want to pull the shoot. You want to enjoy the fall, you know, just enjoy it. And of course, I suppose some people do manage to enjoy it, but maybe you're not particularly keen on parachuting. If you pull the cord too quickly with a parachute, that can almost be a problem because you get blown off course and maybe into the mountains or whatever. So they want you to let it go, but all you can think is the ground is getting closer and closer and closer” (Ian T1)

Infrequent contact with Haematologists appeared to increase the psychological battle of living with cancer, particularly given HC cannot typically be physically monitored in the same way as solid tumours can (i.e., being able to monitor the size of a lump). Relying mostly on blood test results seemed to make the period between tests more anxiety-provoking, with great uncertainty of whether the cancer had progressed. This psychological burden further highlights the need for those under W&W to receive holistic care that considers their psychological wellbeing, in addition to their physical health needs.

> "I think watch and wait is more stressful than having treatment because it's the not knowing. It's the not knowing what's happening. If I had breast cancer you'd see a lump, or you'd feel a lump, and you know you should feel it grow. Whereas with blood, you've got nothing. And it's psychologically, it's hard" (Julie T1)

> "They judge by the number of people they've seen, not by the quality of care that the people get at the other end and they could measure that in psychological terms, not just physical terms" (Frank, T1)

The sense that healthcare teams focus solely on blood test results, and neglected wider health needs, was interpreted as resulting in several unmet needs, particularly in relation to emotional support and information needs.

3.2.3 The Importance of Connection with Peers

Peer connection spaces provided opportunity for individuals to share information about various aspects of having cancer, such as differences between diagnoses, self-management under W&W, and managing infection risks. This finding is particularly pertinent in the context of many describing receiving inadequate information from their haematology healthcare teams. Some described using patient-managed chat groups and others referenced using online regulated forums to learn new information.

> "[The WhatsApp group] keeps you up to date with new treatment, keeping you up to date regarding all these covid jabs, what we should and shouldn't be doing" (Karen, T1)

> "The health unlocked CLL forum, that's great, I've found that there's lots and lots of questions asked and they answer everything" (Ann, T1)

Speaking with those going through similar experiences also provided opportunities to seek reassurance from others. This need appeared particularly pertinent when individuals experienced changes, such as noticing new symptoms or changes being made to the length of time between blood tests. When Gail believed her haematology team "dismissed" her fatigue as unrelated to the cancer, she sought reassurance from the support group:

> "It was good to discuss these sorts of things in a group and find out that most people have those same issues and that it's just adjusting to it, […]. We can be failed sometimes [by doctors] and have to find the reassurance from people in similar circumstances that have had the same experiences and have gone through it all" (Gail, T1)

Several had tried charity-ran "buddy" programs, whereby individuals were paired together to support each other. The extent to which these pairings were successful varied. Olivia recounted a positive experience of meeting a person diagnosed at a similar time to her with the same diagnosis.

> "If you've got any anxiety or worries about things we can e-mail, we can text each other and say does this sound normal or do you think I should worry about it? It was amazing what difference it made" (Olivia, T1)

Others commented on the benefit of supporting peers on the groups. This appeared to provide them with a sense of purpose that they lacked in other areas of their life (e.g., not working).

> "That's part of the reason why I do the Facebook groups and things, so I feel like I have got some purpose, but it's funny how, when in my low moments I can feel like I'm no good to anyone because I don't do what I should be doing as a 50-something-year-old chap" (Ian, T2)

Being under W&W was frequently described as lonely and isolating, indicating unmet emotional support needs. Particularly, the lack of understanding in the general population seemed to result in individuals finding it harder to talk to their friends and family, and instead, connect with others with IHC.

> "Even though you've got friends and family, even though you know these people [on the group] are kind of strangers, you've never met them, but they just know, they totally get where you're coming from" (Karen, T1)

A small number of participants had accessed limited peer support. Those with a myeloma diagnosis (SMM) appeared to access peer support the least. This was possibly due to the rarity of indolent myeloma diagnoses, resulting in a smaller online community compared to diagnoses where W&W is more typical, such as chronic Leukaemias (e.g., CLL). Helen, who had smouldering myeloma, described being part of an online myeloma group. She shared that the group was helpful for finding out about future treatment options, but unhelpful for connecting with others under W&W, given most members were receiving treatment.

> “Sometimes it's just really lonely. I only really talk to my husband […], And I don't really talk to anybody else about it. And like I said, I don't really feel I can just ring [healthcare team] and take a nurse's time up just basically getting things off my chest” (Helen, T1)

Interaction with others with IHC was described by all as either valued or desired, indicating a need for peer connection. Most individuals appeared to have this need met through charities and online forums. Peer connection was described as serving two key domains of needs: (1) providing information and (2) providing emotional support.

3.2.4 Trying to Live After Covid-19

During longitudinal analysis, changes in individuals’ perceptions of the pandemic was evident. In the majority of cases, a sense was gained that individuals’ perceptions had shifted towards beginning to accept the risks of Covid-19 and were choosing to begin living their lives again. For Julie, an increase in risk-taking was noted between T1 and T2, when she had begun meeting her friends again.

> “It's like I'm in a knit and natter group and I've purposely not been going there because of Covid. I started going back when things started getting better, and then obviously they decided to stop wearing masks. So I decided to step back a bit, saying look I don't feel comfortable” (Julie, T1)

> “I don't know how many years left I've got. I'm not gonna keep in the house and bottle myself up. I've got to face this, I just wear a mask when I go out” (Julie, T2)

Whilst Julie reported to be acting in ways congruent with moving forward from Covid-19, she still reported to find this “scary” and “a worry”, echoing others’ experiences that trying to live life again was a psychological battle of risk-assessing every decision that involved leaving home. This burden was understood to indicate unmet emotional and information needs in the sample.

> “I still feel anxious, it's probably at night when you wake up and think oh have I done the right thing, but then you think you've got to live life. You’ve gotta balance it out” (Christine, T2)

Some discussed practical strategies that helped them to feel safe living alongside the virus. For example, at T2, Marta described “still staying masked up” and Julie shared “I’ve got hand sanitizer everywhere, on my house keys, on my handbag, on my car keys”. Others reported that having had the virus or their booster vaccinations had resulted in them feeling more confident about socialising with others. Frank had Covid-19 at the time of the T1 interview and Gail had had the virus just shortly afterwards.

> “I think it's mainly my wife that's very protective and nervous about going out. I, I feel actually having had COVID and I now know that the antivirals work, I feel much more confident going out” (Frank, T2)

> “I think having had it and having the antivirals, it actually took away a lot of the fear that I had about it. I feel very differently about it. I think now it is good to remember actually how I was six months ago, the last six months have been better, it's not been at the fore of my mind” (Gail, T2)

Contrasting the majority, some were left with a feeling that society was moving forward without regard for individuals who were immunocompromised, like those with HC. Tying in with the theme of abandonment, there was an essence of individuals feeling left behind by society, with masks and self-isolation becoming recommended, but not enforced.

> “There’s a feeling that it's not safe, you know, that it’s got worse and for people with blood cancer specifically who are aware of their compromised immunity, we now live in a time where it really feels like society has kind of written us off, like we’re an acceptable loss” (Ian, T2)

Bridget shared similar views to Ian, with an increase in fear of Covid-19, and greater frustration towards other people noted during T2. Interestingly, both Ian and Bridget had medical backgrounds and appeared to have in depth knowledge of the survival rates of HC patients who contracted the virus over the course of the pandemic. It could be interpreted that this greater level of understanding of risk resulted in them being more fearful of Covid-19, than others who were less aware.

> “With COVID. It's staying away from groups of people. I used to sing with church choir and the local church choir, and I've not gone back to that yet” (Bridget, T1)
>
> “The worry about COVID is just a nightmare. There is no protection for the immuno-compromised. It’s worse than in March 2020. Because everybody else is out there not wearing face masks, getting on with their life […], it makes me very angry with the world” (Bridget, T2)

This theme highlights the impact of an environmental factor on the presence of unmet needs, with individuals’ access to information on risk being reduced, and increases in worries and concerns over uncertainty and infection risks (indicating unmet psychological, safety, and information needs). Further, the minority view that living alongside Covid-19 became more difficult over the six months, rather than easier, highlights how complex and varied experiences and perceptions of Covid-19 were.

3.3 Deductive Analysis Findings

3.3.1 Comparisons to the Needs of Those with Prostate Cancer

The first section of the deductive framework aimed to answer the fourth research question: “Are the reported needs different to those identified in individuals with prostate cancer under W&W and if so, how?”. The needs identified in the prostate cancer literature were compared to those identified by the present IHC sample. Table 4 expands on the summary of the findings given in the main journal paper, by displaying illustrative quotes and summaries for each need.

Table 4.

Deductive analysis comparing the needs of those with IHC to those with prostate cancer under watch and wait

Deductive code	Summary of analysis	Illustrative quotes
Inadequate information provided	Unmet information needs were frequently reported, as highlighted throughout the inductive analysis. Many described receiving little information at diagnosis and thereafter, experiencing poor communication with their healthcare team. Charity-ran webinars and information sessions were valuable in meeting individuals' needs for information. However, the availability and frequency of these depended on the individual's diagnosis.	"It's a bit like in the old days when your mother told you about periods or didn't tell you about periods and handed you a booklet and said, just read that, that's your lot" (Bridget, T1) "They give me the leaflets on myeloma, and it mentioned it briefly in there, but they do all of these publications. If they could do something around just watch and wait, you know if they could get talking to you, and do a booklet for it, that'd be really helpful" (Julie, T2)
Inconsistent or confusing information	In contrast to the experiences of people living under W&W with prostate cancer, receiving confusing or inconsistent information was rarely experienced. When this was the case, it resulted from inconsistencies between different sources of information (e.g., the internet and a consultant). Individuals did not report any confusions around their prognosis or receiving	"I looked up my condition online and that told me that I'd got maximum 7 years, but when I spoke to my consultant they said "No, that's a load of rubbish". So then I don't know, you know, does the Internet know or does my consultant know?" (Noel, T1) "I said to my GP I know I'm not supposed to have the live vaccine, I should have the Shingix, he just

	conflicting information from their healthcare team.	said no, it's okay, you can have the ordinary one. So I actually asked Leukaemia care that. And they said under no circumstances should you be having a live vaccine” (Gail, T2)
Emotional support needs	In line with the inductively generated overarching theme of W&W being a psychological battle, unmet emotional support needs were identified throughout the data and at both time points. This most commonly related to managing the anxiety of living with constant uncertainty, particularly in the time leading up to receiving blood test results. Two participants reported to have accessed Cognitive Behavioural Therapy through their GP, but the lack of specificity of this to living with chronic cancer seemed to limit its effectiveness.	“There was this illustration of somebody walking around with a gun to your head and that's how it feels on watch and wait, you just don't know when they're gonna pull the trigger. It's just horrific, really. You spend the rest of your life like that with the gun pressing in your temple sort of thing” (Ian, T2) “In a nutshell, my own feelings are that that psychological support offered was nil in reality by the NHS” (Frank, T2)
Need for peer interaction	Mapping directly onto the inductively developed theme around the importance of peer connection, wanting to connect with others was described by all. Unlike in men with prostate cancer, most of the sample appeared to have this need met through charities and online	“There's this little core group of people that sort of support each other, and it's really helpful” (Ian, T2) [When banned from a Facebook group] “I lost that extra bit of support, finding people who had gone through the same experiences as me” (Noel, T1)

	support groups. In those that reported unsatisfied peer connection needs, W&W was described lonely.	
Need for support with exercising	Unlike in the prostate cancer literature, a desire for support with exercising was not expressed by any of the sample. Instead, individuals referenced enjoying exercise and finding it a helpful strategy to cope with having cancer. Some commented on wanting to exercise more but seemed able to manage this themselves, indicating the absence of an unmet need.	"My main coping is exercise at the moment, and it has always been with me. You know, irrespective of the cancer, well before then" (Frank, T1) "I've coped by just getting on with life really just trying to do the stuff you normally do. We like a lot of exercise, we've got big dogs" (Lisa, T1) "I'm not doing as much exercise as I want to. I mean , I'm walking, but I am going to start doing some chair exercises" (Eileen, T2)

Note: deductive codes represent the needs identified in a systematic review of the psychosocial needs of people with prostate cancer under W&W (Mcintosh et al., 2019a).

3.3.2 Self-Determination Theory

As described in the journal paper, the basic needs posited by SDT (Deci & Ryan, 1985) were found to fit well with the needs identified by the sample. The needs of autonomy and competence were mostly understood as unmet, whereas the need for relatedness was reported as mostly met, particularly in those who engaged with peer support groups.

Autonomy. Feeling autonomous under W&W appeared to be a complex process. Frank described the freedom he felt under W&W, compared to how he imagined being under treatment would be, and this was interpreted as him having a sense of autonomy over his life. However, Frank also referenced the difficulties that were associated with this. For example, he described tensions arising between him and his family when he wished to complete voluntary work at a school. For him, voluntary work gave him purpose and he valued doing this, whereas his family were concerned that it put him at increased risk of contracting an infection.

> “When you're being treated it's very defined, with watch and wait, once they've looked at your blood, you go off and it's down to you, which gives you a lot of freedom, but also I would say a lot of potential issues with family and stuff” (Frank, T1)

Ian also discussed issues with infection risks limiting his autonomy, though these were his own worries, rather than others around him.

> “I've got friends who've moved to Southern Africa. They've got this lovely life living on a lake with beautiful hippos, and they’re like come over, but I'm like, yeah, but what if I get an infection?” (Ian, T1)

A shared-meaning pattern around the psychological battle of having IHC was identified through inductive analysis, and this related largely to the uncertainty of W&W. This uncertainty was related to individuals lacking control over if or when treatment would begin. Frank described the difficulty of not being able to take new roles on in case he suddenly entered treatment.

> “I didn't think it was fair for me to be all trained up and become an expert in that area and then have to retire. So there's a lot of uncertainty involved with

> the watch and wait I think, and that is quite difficult to live with I think, and you do because you don't have a choice" (Frank, T1)

Helen appeared desperate for her healthcare team to treat her, and this lack of autonomy over being a part of this decision appeared to result in increased psychological distress.

> "I get more anxious now since obviously things are looking like they're changing. I'm getting more anxious. You know, you just think, please will you just do something" (Helen, T1)

Competence*.* In line with the theme that IHC was difficult for patients, their families, and the general public to comprehend, feeling competent in understanding and managing their condition was rarely reported. Generally, healthcare teams were reported as poor at supporting individuals to develop competence. Instead, individuals reported their knowledge and confidence grew through engaging with charities and attending charity-led events, such as webinars.

> "I've learned in the last year that we can't fight infections, and we respond very poorly to vaccines I've also learned through Leukaemia Care. They've done a series of webinars, particularly through lockdown so I've learned more and more about what we need to be careful about" (Bridget, T1)

> "I've had a couple of queries once or twice and I've emailed the myeloma UK they've got like a helpline. I've not rung but I have emailed and I've got answer back" (Helen, T1)

Gail described a common experience, where the unmet information needs resulted in increased anxiety and reduced confidence in their ability to cope with having cancer.

> "You know to face your fears, you've got to understand what you're up against really. So it didn't really do me any good, not being told this information and trying to find out things myself and why the reason why they might have thought it was mantle cell and why it wasn't" (Gail, T1)

For some, even actively seeking out information was difficult, particularly when a diagnosis was a rarer condition, such as for Frank, who was diagnosed with Smouldering Myeloma.

> “One of the big anxieties, is establishing where you are in the chain of events, for me anyway, […], I wanted to be kind of reasonably expert in my condition, but I've learned that there’s very little... there's only a modest amount that one can learn from what's out there about one's experience” (Frank, T1)

This basic need of competence also relates to the inductive findings that individuals felt their health was their personal responsibility. Lisa described learning for herself that having a HC increased her risk of developing skin cancer, but that this learning was not facilitated through her Haematology team.

> “The dermatologist said yes, you have... you have got to watch out [for skin cancer], she said did nobody ever tell you, and I said nobody ever told me, I just said that I have to do my own research” (Lisa, T1)

Relatedness. As described in the journal paper, this code strongly mapped onto the inductively constructed theme “the need for peer connection”, with benefits noted in meeting information, social, and emotional support needs.

> “I've learned a lot from a lot of people on the group” (Delia, T1)

> “I would recommend anybody on watch and wait to get into the support group. Talk to somebody” (Julie, T1)

> “Nobody else knows how you feel about it unless occasionally speak to other people on the support groups and then you feel like you're there for each other” (Karen, T1)

The need also extended beyond connecting with peers, to the need for closeness with friends and family. As previously described, some discussed how difficulties understanding the W&W process appeared to be a barrier for gaining support and closeness from friends and family. Noel had recently moved to a retirement home, where he knew no one and felt he was much younger than the other residents. He had no contact with his friends or family, which resulted in him having little social support. In line with SDT theory, lacking relatedness was understood to have a negative impact on his psychological wellbeing, with little daily meaningful activity or social support.

> “What my issues are, I’ve got no support nobody to support me, nobody to see how I am, the only support, literally my only support is my cancer team, I do miss the interaction” (T2)

It was clear that Noel had tried to increase his closeness with others through attempting to gain voluntary work. Unfortunately, the ongoing pandemic was making this difficult for him. Voluntary employment was referred to by several, and in each case, it seemed to serve a dual purpose of giving a sense of purpose whilst offering connection with others.

> “It some it's made me urm, I have to organise the online session what is needed, so organising it, it’s giving me purpose and it’s fulfilling knowing that I'm helping someone” (Christine, T1)

> “And I love seeing people that work with me grow, […],Why do I do it, I do it voluntarily, I slog to all these meetings, and you know why am I doing it? It's for meeting all these teachers, and so it makes me feel good” (Frank, T1)

> “I've got a bit involved with this community group that runs a mobility scooter scheme in the park. I might sort of end up with some opportunities there to meet people” (Ian, T2)

3.3.3 IHC as a Chronic Illness

The following details the deductive analysis whereby the data was analysed against the core components of PACID model (Livneh, 2022). The aim of this was to examine whether experiences of IHC fitted a model of chronic illness, to further inform future intervention development.

Antecedents. “Triggering events” is the first domain considered in the antecedent section. This domain was difficult to identify in the data due to the triggers for IHC being largely unknown. The main triggering event identified was age, as older age is associated with higher rates of HC. Several participants referenced they initially put symptoms of HC, such as pain and fatigue, down to the natural aging process, potentially resulting in a delay in them visiting their GP about concerns.

> “I was what, 68, so you get tired, probably a bit more than normal, but at the time I thought that was just my age” (Lisa, T1)

Another aspect that was considered in the ‘triggering events’ domain was the finding that several individuals reported to have had a parent with a HC (both active and indolent diagnoses were reported). Although the extent to which HC is hereditary is not yet fully understood, this factor was considered significant in shaping individuals’ initial perceptions of HC and their information needs around this.

> “When I was first diagnosed, I really went into a real decline because suddenly I thought I've done 16 years of going through my mother’s, and then she was down to three monthly blood tests before she died. And then I thought, there I am starting on four monthly, it’s got to be bad, so it’s been huge” (Delia, T1)

> “They said all the same things to him, you know. This is the long, slow disease, and it's no more than high blood pressure. And then he died of CLL, so of course when they told me all the same things I was thinking, *yeah right* I’ve heard this before” (Ann, T1)

The second domain of the antecedent section covers an individual’s “contextual factors”. Considering an individual’s context in which they were diagnosed and living with IHC provided space to consider factors that may impact their level of psychosocial need, such as their occupational and socioeconomic status. Several individuals had medical backgrounds and this was understood to have influenced factors such as their ability to access reliable sources of information and their trust in healthcare.

> “I mean, I'm reading papers, checking out things as my numbers change and everything, but proper scholarly papers, you know, I used to work for the Journal of Bone and Joint Surgery. So I know about, you know, published papers and everything, like that” (Delia, T1)

> “I don't know if you're aware of this, but anytime a GP tries to prescribe something, if it potentially interacts with one of your other drugs, it flashes up a warning […]. And so, of course, I'm on 15 different tablets, and I know full well they can't possibly have all the interactions in their head, but I also know that they don't have that same system that the GPs have, so I ring up my GP and say look can you just have a look and see if there's any interactions please?” (Ian, T2)

Another contextual factor considered in this domain was individuals' financial status and access to healthcare. Some individuals described feeling lucky that they could afford and access private healthcare.

> "In a year or so time, I'll see what my bloods are because I get checked once a year, I will pay for another haematology visit myself, but I'm lucky, I can afford to do that. There are thousands who don't have those resources" (Lisa, T1)
>
> "I was complaining of back pain, and the Haematologist said 'well your bloods are fine, see your GP'. So, I went to my GP. He said oh I don't know. So I'm in the lucky position. I will use my pension and I'll see someone privately" (Delia, T1)

In contrast, Noel described the cost of travelling to his hospital as an additional stressor: "Bearing in mind I live in [city], my teams in [different city] so it costs me a lot to get there. It's just another added concern, to be honest, as if I haven't got enough stress" (T1). Similarly, Gail referred to travel costs as a reason against accessing in-person support: "It's just the actual travelling and you know the cost of it and everything else that that would put me off" (T2). Understanding such financial and access considerations may also help professionals to better understand individual contexts and how these may affect individuals' ability to access support.

Process. The first domain of the 'process' section covered 'medico-psychological status'. This gave space to consider individuals' prognosis, severity, stage, and symptoms such as pain and fatigue. Anxieties around managing pain and fatigue were frequently reported as a challenge.

> "You just don't know what's going on. You get an ache in the armpit and you think is that a lymph node? […] You know you've got nobody to ask" (Bridget, T2)

Secondly, the domain gave space to consider uncertainty and stigma arising from a chronic illness. The data found to fit with this domain mapped onto the inductively constructed understanding of the psychological battle reported to be experienced under W&W.

> "I've no idea whether I'm likely to be someone who would be on watch and wait for five years. 10 years. You know, and I'd like to know" (Gail, T1)

> "So like next time I'm due to go in there will be August, and how do I know that something doesn't manifest itself within that next four months?" (Noel, T1)

> "It's the emotional, the psychological impact, we're somewhere on a sliding scale as it were or on escalators that are going down. And we're not really quite sure how fast it's going and why we're going there and why things are speeding up" (Frank, T2)

Next in the 'process' section of the model is 'CID-induced psychological reactions'. As described across inductive and deductive analysis, feelings of anxiety, low self-esteem, and anger were described in relation to managing living with IHC. The model proposes that, as time progresses, individuals should begin to develop a level of acceptance of living with a CID. This was observed in the sample to some degree, though as previously discussed, this seemed to depend more on the individual's met needs (e.g., information needs, social support, fulfilling activity) rather than simply length of time under W&W. For example, Olivia had been under W&W for four years and described some level of acceptance. In contrast, Delia had spent six years under W&W but reported increasing feelings of anger.

> "The first year I was panicking about a lot of things […]. Now I feel a bit more informed and a bit more distant from it. So although I still worry about things, and I said again, the buddy system helped a lot I think" (Olivia, T1)

> "I'm angry now. I think I've tried to block it out. This is where I'm trying to be fair and not be angry. Because I think I'm sort of trying to deny that [the cancer] is happening, but I know it's happening" (Delia, T1)

The final domain in the 'process' section considers appraisal of and coping with an illness, with focus placed on understanding how an individual mediates and mitigates the psychological impact following a diagnosis. Individuals' experiences of attempts to cope were considered under this domain, with several describing their attempts to continue living life and to reduce the diagnosis' disruption on their life.

> "Now I just get on with things. I don't moan about things. I don't worry about things unless I see I've got a reason to worry. I just get up and get on with things" (Noel, T2)

> "I was thinking I can't get a dog now because maybe I won't be here in five-years-time and that kind of thing, when my attitude now is sort of totally different. It's just like, well, I could get run over by a bus tomorrow and you know life goes on" (Olivia, T2)

In addition, this section allowed for incorporation of individual appraisals and perceptions of IHC. Several described perceiving identity losses resulting from the diagnosis. Ian described having "a lack of identity" since being diagnosed and Marta shared "I feel not the person that I was before". Frank talked about having to reject work opportunities due to fearing he would be unable to complete these if anything changed in the future.

> "I felt I really honestly couldn't join it because I just don't know where I'm going to be in a year's time and I didn't think it was fair for me to be all trained up and become an expert in that area and then have to retire" (Frank, T1)

These appraisals highlight the power of the psychological impact and uncertainty of the diagnosis, even when individuals remained physically able to complete most, if not all, tasks they were able to prior to the diagnosis.

Outcomes. The final section of the model, 'outcomes', helped to consider the extent to which individuals have adapted to their diagnosis across three domains. The first domain refers to 'intrapersonal factors'. Throughout interviews, outcomes suggestive of individuals adjusting both well and with difficulty were observed, suggesting the domain is applicable to the IHC population. Overall, it was perceived that individuals were generally poorly adapted, with data predominantly indicating ongoing psychological difficulties of anxiety, low mood, and low self-esteem. This maps onto the inductively constructed theme of the psychological battle of W&W, and highlights the unmet emotional needs experienced by this population.

> “It’s huge and to be honest, I wish I could say that I've been able to sort it out and integrate it and all the rest of it but I haven’t. I've just been left with a huge sense of failure actually and a lack of identity, a lack of esteem” (Ian, T1)

> “It's made me feel less of a woman, less attractive, and you know, I just feel like because sometimes I ache and I'm tired. I feel like it's aged me before my time […] I’m just not the person that I used to be” (Marta, T1)

In terms of intrapersonal outcomes of reduced anxiety and increased mood, Olivia described “I pretty much do try and do whatever I want to do really and not let [the cancer] affect me too much at all”, indicating a sense of autonomy was important to her adapting to living her life alongside IHC. In others, these outcomes appeared to result from emotional support needs being met.

> “I'll tell you what else has helped me. It is the CLL charity, I did the acceptance and commitment therapy. I had one to one with a lady. That was really, really helpful. Really really good. She listened to how I felt and really personalised it for me” (Christine, T2)

> “I ended up being involved with mindfulness and that sort of thing and it certainly did help and it does help occasionally now as well to be fair” (Frank, T1)

The second domain of analysis related to ‘interpersonal’ outcomes, and strongly mapped onto previously discussed roles of relatedness and peer connection needs. As described, individuals desired peer connection and most accessed this through online forums and social media platforms. The domain also considered the individual’s functioning in terms of family/marital status, and this was helpful for considering the more maladaptive interpersonal outcomes individuals may have developed, such as avoiding talking about the cancer with others in a bid to protect them.

> “I mean if I talked to her she'd burst into tears so I have to keep it from them. It’s not ideal. I have felt very angry” (Delia, T1)

Another interesting facet of this domain related to the consideration of ‘social roles’ individuals held, as this allowed for reflection of care-giving roles and the needs these may have served (e.g., sense of purpose, relatedness).

> “I look after [grandson] two days a week now. So that's a positive, he helps me forget about everything” (Julie, T1)

Finally, the extrapersonal outcomes considered the extent to which individuals were functioning and engaged in the community. IHC is often associated with few symptoms and little impact on physical ability, meaning individuals theoretically should be able to engage in their community in relatively equal capacity to before their diagnosis. Given this, the domain was found to be applicable in considering how functional individuals were and whether unmet needs underlaid poor functioning. For example, Ian described not returning to his church and limiting the number of friends he had seen since being diagnosed, due to infection risks with a compromised immune system. Whilst it was important for him to be aware of increased infection risks, he also described a lack of trust in the healthcare system to treat him adequately. This indicated that his reduced functioning potentially resulted from unmet safety needs.

> “I need to go to sort of more specialist hospital, otherwise I'm not going to feel safe, and there's a whole fear about will the NHS let you down at that moment when you need them most” (Ian, T1)

The domain also helped consider the extent to which individuals had purpose and meaningful activity in their daily lives (e.g., met psychological needs), such as working or volunteering.

> “I started doing a pub job in the village as well because they were looking for staff and I wanted to get to know more people in the village, but yeah, it's going quite well, I’m enjoying that” (Olivia, T2)

4. Extended Discussion

4.1 Unmet Emotional Needs Under Watch-and-Wait

According to MacMillan (2019), almost half of all people living with cancer experience unmet emotional needs, such as experiencing loneliness and isolation. As demonstrated in Table 2, results from the HADS suggested that the sample was experiencing higher levels of anxiety than depression. This fits with findings in the literature, which estimated 25% of people under W&W experience anxiety, compared to 16% experiencing depression (Russell et al., 2022). Interestingly, average scores were almost identical across the two time points. This suggests that psychological distress remained present over time. This is perhaps unsurprising, given very little change in support was reported over the six months. The findings add to the discussion that more formal support to address distress is required for people living with IHC.

Congruent with the literature and the high levels of reported distress, throughout interviews, unmet emotional needs were evident. When discussing the psychological impact of IHC, words such as “battle” and “fight” were frequently used. This was with reference to internal needs, such as accepting cancer that does not require treatment, and external needs, such as communicating with healthcare teams. A longstanding history of the use of military language in Oncology has been reported (e.g., America’s National Cancer Act declaring “war” on cancer in 1971) (Malm, 2016). The problematic nature of such language is particularly pertinent to IHC patients, who diagnostically do not have any option to “fight”, but rather, must make peace to coexist with the diagnosis, until it progresses further. Considering this language in the context of individuals’ emotional need to feel safe, it is understandable why the sense of inaction and nonurgency may lead to increased fear and psychological distress. It is also possible that the combat-related narratives around cancer contributed to the difficulties individuals reported to experience in understanding their indolent diagnoses. Finally, Nie et al. (2016) argued that the entrenched use of military language in cancer services places great emphasis on treating the physical cancer and neglects the impact on an individual’s wellbeing. This forms an interesting argument for the meaning generated in the present study that participants felt their holistic wellbeing was mostly abandoned by healthcare teams.

4.2 Impact of Covid-19

The Covid-19 pandemic was found to result in reduced contact with healthcare teams (as appointments moved to be via telephone), increasing personal responsibility for self-monitoring (e.g., physical checks) and seeking out information. Increased personal responsibility arguably relies on the individual's competence in self-monitoring skills and their knowledge of how to access reliable information. This highlights how new healthcare regulations, such as virtual appointments, may lead to increased unmet physical health and information needs. These findings fit with a recent exploration of the impact of the pandemic on people with both active and indolent HC (i.e., requiring and not requiring treatment; Zomerdijk et al., 2022). Zomerdijk and colleagues reported individuals experienced reduced communication with their healthcare team and inadequate information on where to receive external support during the pandemic, resulting in them experiencing increased unmet emotional needs such as uncertainty.

In addition to new practical regulations introduced to manage Covid-19, information on risks and protective measures for people with compromised immune systems frequently changed (British Medical Association, 2022). This seemed to further increase the personal responsibility on individuals to ensure they knew their risks and when they were entitled to additional booster vaccines. In the present study, GPs were often reported to rely on the patient's knowledge of their specific diagnosis and were guided by the patient in terms of providing additional vaccines and/or referrals to other healthcare teams. This suggests the impact of new health regulations on individuals' levels of need may be particularly pertinent to conditions managed under GP care, rather than a specialist department (e.g., Haematology).

In addition to increasing unmet physical health and information needs, Covid-19 measures seemed to increase unmet emotional needs of uncertainty for the future, fear of contracting the virus, and social isolation. Perhaps unsurprisingly, this finding is not unique to the experiences of people with IHC. Similar findings have been reported in people undergoing haemodialysis during Covid-19 (Sousa et al., 2021) and in the wider cancer population (Legge et al., 2022). Interestingly, the longitudinal aspect of the present study allowed for observation of these needs reducing for some over the six-month period, as cognitive shifts were facilitated by the vaccine rollout and lived experiences of Covid-19. For others, unsatisfied emotional support needs only became more prominent as feelings of autonomy and relatedness further decreased.

4.3 Comparisons to People with Prostate Cancer Under Watch-and-Wait

The main journal paper discussed the deductively constructed understanding that most of the needs identified in people with PCa were applicable to those with IHC. The main exception to this was the need for support with exercise, identified in the PCa literature, but not in the present IHC sample. The lack of need for support with exercise found in the present study fits with the wider HC research, which has also not identified exercise support as a common unmet need (Damen et al., 2022; Tsatsou et al., 2021). There are several possible reasons why this difference may exist between people with HC and people with PCa under W&W. Firstly, exercise has been linked to slowing PCa progression (Galvão et al., 2016), and thus, is recommended for those with PCa under W&W. In contrast, no specific benefit of exercising has been reported for managing the progression of HC, other than the generic benefits (e.g., increased cardiovascular fitness, reduced stress levels). McIntosh et al. (2019b) hypothesised that a second reason exercise needs may be more prominent in the PCa population than other populations is the masculine values associated with exercise. They suggested that, in the context of poor uptake of psychological support in men with PCa under W&W (Victorson et al., 2017), exercise may be a more accessible channel to satisfy their emotional needs.

Several needs were found in the present IHC sample that have not been reported as common needs in the PCa literature. Difficulties with others underestimating or stigmatising individuals with PCa do not seem to have been reported, as they have been in this study and the wider IHC literature (Evans et al., 2012). Even studies exploring the impact of Covid-19 – a factor reported to increase experiences of stigma in the present sample – have not specified increased stigma as an experience of men with PCa under W&W (Eymech et al., 2022). It is possible that differences in public awareness partly explain this difference in need. Following the completion of a large UK survey study, Blood Cancer UK (2022b) declared the lack of public awareness of HC a ‘massive crisis’. In contrast, the NHS recently published news indicating prostate cancer awareness was at an ‘all time high’, thanks to high-profile charity-led campaigns (NHS England, 2022). Finally, the sense of abandonment that was inductively constructed in the present sample, and found to some degree in the wider literature (Herrmann et al., 2020), does not seem to appear as an experience of those with PCa under W&W. In the present study, this abandonment was perceived to relate to a lack of involvement in one’s own care and poor communication with healthcare teams, leading to reduced perceptions of autonomy, competence, and relatedness. In addition to the potential role of autonomy in those with HC compared to those with PCa (discussed in the main journal paper), other research has concluded that clear communication and providing accurate information strengthened the relationship between individuals with PCa under W&W and their healthcare team, and consequently improved their quality of life (Dickey & Grayson, 2019). This fits with the present findings in which meanings of unmet communication and information needs were constructed, supporting the notion that meeting these needs in those with IHC may in turn meet needs of relatedness, and subsequently reduce feelings of abandonment.

Throughout the literature, and supported by the present deductive analysis, findings suggest that people with IHC may have different unmet needs to the wider cancer population, and even the wider W&W cancer population. For instance, items such as “fear of cancer recurring” and “being informed about treatment side effects” were reported as amongst the most common unmet needs for people with cancer (Paterson et al., 2022), but these hold less relevance for those with incurable diagnoses who are not receiving treatment. On the contrary, uncertainty of the future has been reported as a key unmet need in people with chronic cancers (Boele et al., 2019), but this was not included as a need on some versions of the HNA (MacMillan Cancer Support, 2018). Further, the HNA does not include consideration of peer needs, a need strongly indicated by the present sample. Therefore, future research should explore the applicability of existing needs questionnaires to people living with IHC and develop amended versions if necessary.

4.4 Changes in Need Over Time

The journal paper focused predominantly on the primary aims of understanding what and when unmet needs were present in people with IHC. The following section offers further discussion on aim three of the study, considering how needs changed or remained the same over the six-month period between interviews.

The six-month period between interviews (March 2022 to September 2022) captured an interesting timepoint in terms of moving forward from Covid-19. During the time, restrictions were fully lifted, with more individuals attending for their booster jab each month. Most participants described experiencing a semblance of normality returning at T2. However, whilst the threat of Covid-19 appeared to reduce for most, the cost-of-living crisis was beginning, with fuel prices rising and talks of financial hardship becoming more common in the media. These contextual factors were understood to be the biggest influence of needs changing over time. Whilst it was not deemed to be a theme across the data, at the second time point, several participants referenced the potential impact of the increasing costs of living, particularly in the context of being either retired or self-employed. This demonstrates that throughout individual's lives, various circumstances will arise on both the national and personal level, and these will impact the extent to which individuals have unsatisfied needs.

In addition to contextual factors, research has found that the needs of people with HC change over the course of living with the diagnosis, with unmet needs being found to be most profound immediately after diagnosis (Herrmann et al., 2020). However, Herrmann et al. did not look specifically at people under W&W, and did not give details of whether any participants were under W&W. Given the noted differences in experiences between those with active HC and those with indolent HC, it is not certain whether needs reduce over time for those not requiring treatment. In the present study, the time participants had spent under W&W varied, from three months to eleven years. No pattern of reduced need was constructed in those that had been diagnosed longer, and this maps onto the finding that psychological distress often remains high throughout W&W (Shanafelt et al., 2007). Rather, an individual's level of unmet need was understood to depend on their level of engagement with peers/charities, their wider social support network, their relationship with their healthcare team, and their sense of purpose in life. This holds implications for future research and intervention development, with a need to examine whether individuals would benefit from interventions at certain points in their diagnosis, or whether needs can remain consistently high, regardless of time under W&W.

The longitudinal nature of the study design was considered a strength, given it allowed for deeper consideration of how needs remained stable over time and the understanding of how the contextual factor, Covid-19, changed needs over time. Further, the study provided support for the guidance (Calman et al., 2013; Tuthill et al., 2020; Kneck & Audulv, 2019), which allowed the longitudinal data to be systematically analysed. However, a flaw of the research, and a learning point for future longitudinal qualitative designs pertains to the validity of participants' recall over the six-month period. Whilst participants were encouraged to record any changes in support or noticed desires for support over the six months, this aspect could have been improved upon further by providing participants with a prompt sheet for them to record their reflections on over the time period.

4.5 Clinical and Theoretical Implications

4.5.1 Clinical Implications

The results of the present study hold several implications for clinical practice. Firstly, the finding that individuals with IHC may have unique needs compared to the wider cancer population indicates that healthcare professionals should ensure that they are assessing patients' needs from a qualitative person-centred perspective, in addition to any formal measure of needs used. This is important for ensuring needs specific to those with IHC (e.g., needs relating to not receiving treatment) are considered and appropriate support is provided. In addition to those directly involved in an individuals' physical healthcare, those working in mental healthcare should also hold an awareness of the psychological impact physical health diagnoses can have on an individual, regardless of whether or not the condition causes symptoms (e.g., pain) or requires intensive treatment.

Secondly, the deductive analysis holds clinical implications for the integration of SDT and PACID into clinical practice. Specifically, the analysis highlighted how the theories and related evidence base were applicable to individuals' needs, and therefore, it may be appropriate to draw upon them to assess needs and consider what effective interventions may comprise. For example, SDT and its evidence base could be used to consider how interventions targeting information needs may do so through increasing individuals' understanding of their condition and how to manage it (competence), ability to easily access necessary resources (autonomy), and through increasing connection with peers (relatedness). Whilst further research is needed, the findings suggest that the PACID model may hold promise for clinicians to use as a guiding framework to monitor areas of unmet need relating to a chronic cancer diagnosis.

Finally, most participants referenced how several blood cancer charities had useful resources available and support networks in place, but few described being signposted to these. Similarly, oncology psychological support services exist in the UK, but few participants were given details of where to find this should they need it. A simple but potentially significant clinical implication of this finding is the difference healthcare professionals may be able to make by simply providing patients with support information, both at diagnosis and at frequent points following.

4.5.2 Mapping onto Theories of Need

Needs for competence, autonomy, and relatedness were constructed both inductively and deductively throughout the data, indicating SDT (Deci & Ryan, 1985) can be used to understand what support individuals with IHC may need. In the present sample, competence and autonomy needs were generally unmet. Whilst peer relatedness needs were largely found to be satisfied through online forums, relatedness to care teams, family/friends, and the wider public could be improved upon. According to Livneh's (2022) PACID model, appropriate social functioning would indicate good psychosocial adaption to IHC. However, individual's social functioning appeared to be limited by others understanding, with stigmatising responses resulting in individuals withdrawing from some friends and family. Aside from charity campaigns that target increasing public awareness, it is largely on the individual to explain the chronicity of IHCs to others. However, through inductive analysis, the researcher constructed the meaning that individuals faced their own difficulties with understanding the diagnosis and W&W, and this may have led to barriers in them explaining this to others. Therefore, improving individuals' own understanding and competence of IHC and W&W may in turn result in them feeling more able to explain the nature of IHC to family and friends. Further research, potentially of qualitative explorative nature, is needed to explore the challenges of connecting with friends and family in the face of chronic cancer diagnoses.

Meeting the need for competence would likely be improved upon by meeting individuals' needs for accurate and comprehensive information, and fully equipping them to self-monitor. Previous research has recommended the use of 'infection prevention self-care' educational programs to increase self-management competence in people with HC (Han & Choi, 2018). Increasing this competence may in turn enable individuals to make informed decisions around infection risk-taking and reduce unmet needs across informational, social/relatedness, and emotional domains. Supporting this notion, a recent report detailed six key actions healthcare professionals should take to support people with cancer to self-manage effectively (Howell et al., 2021). Included in these six was the need to 'prepare and empower' people with cancer to self-manage, through educating both individuals and staff in effective self-management techniques. In addition to increasing competence, preparing and empowering individuals to self-manage also acknowledges the importance of autonomy. However, the report also recognised the fundamental role of collaboration between patients and their care teams. This highlights the need for balance between encouraging and empowering individuals to self-manage, and ensuring patients feel adequately supported. Sadly, reflecting the experiences of the present sample, Howell et al. acknowledged the lag in cancer services offering self-management support to individuals, compared to provision in other chronic illness services. Therefore, future research should explore the integration and uptake of self-management support in oncology/haematology services and assess barriers and facilitators to effective implementation, with aims of meeting individuals' needs to feel competent and autonomous.

Experiences of need found in the present study could also be considered in terms of Maslow's (1943) hierarchy of need, another prominent need theory that has been applied to living with cancer. In Ng et al.'s (2017) adapted version, the "physiological" needs related to symptoms of having cancer and anti-cancer treatments. Whilst individuals in the present study described issues with fatigue, and occasionally pain, most were living relatively asymptomatically and due to not receiving treatment, were not experiencing any treatment side effects. Therefore, physiological needs were not commonly referenced as unmet. Maslow hypothesised that when needs at the bottom of the hierarchy (physiological) were mostly met, individuals would focus their attention on the next level (safety). Ng and colleagues suggested that safety needs in people with breast cancer related to fears of the cancer recurring or spreading, financial and job insecurity, and fear of being abandoned. Interestingly, individuals in the present sample did not describe a *fear* of being abandoned, but rather, a sense that they *had been* abandoned. As would be expected by an unmet need, this was associated with psychological threat, evidenced through individuals experiencing anxiety and low mood. The sample did not explicitly describe fears of cancer recurrence or metastasising, perhaps due to the different nature of IHCs. However, as described throughout inductive and deductive analysis, the challenge of living with uncertainty of whether the cancer was progressing was referenced by all and was associated with anxiety and low mood.

The third level of need posited by Maslow relates to needs of belonging and love. Ng et al.'s (2017) included needs did not appear cancer-specific, with needs of acceptance, love, and affection being cited. This level maps onto Deci & Ryan's (1985) broader basic psychological need for relatedness, and as described, this was a commonly discussed need amongst the sample. Interestingly, Rasskazova et al. (2016) attempted to synthesise SDT and Maslow's theory. This resulted in retainment of the two most basic levels of need posited by Maslow (physiological and safety needs) and integrating the remaining three levels into the needs of relatedness, autonomy, and competence. Indeed, these three overarching needs were found to be highly applicable to the present sample.

Finally, needs relating to esteem and self-actualisation, forming the two top tiers of the hierarchy, were less commonly reported than needs in the previous three levels. According to Maslow, the ultimate self-actualisation needs would not have been a focus whilst needs lower down the hierarchy were unmet. However, despite them being rarer, some experiences could still be considered in this domain. For example, efforts to find new voluntary positions could be partially understood as attempts to meet needs of having purpose or direction. Similarly, though infrequent, needs in the 'esteem' domain were present, such as challenges of losing one's identity and internalising stigma. However, in contrast to Ng et al.'s (2017) applied version, needs relating to changes in body image were not applicable, due to no visible signs of illness. On the contrary, needs relating to the challenges of living with an invisible illness were noted (e.g., not feeling understood or respected by others). The fact that needs were described throughout the hierarchy ties into the complexity of human beings and the likelihood that at any one time, individuals are likely partially satisfied and partially unsatisfied.

4.5.3 Understanding Indolent Haematological Cancers as Chronic Conditions

Considering IHCs as chronic illnesses, rather than acute cancers, may hold implications for the research base used to develop effective interventions (e.g., using other chronic illness needs literature, rather than or in addition to acute cancer needs literature, to develop support programmes). However, determining whether IHC fits within a chronic illness model was not an aim of the present study and, therefore, the analysis was not discussed at length in the journal paper. Instead, the findings are discussed in greater detail here.

On the whole, the model was found to be a useful fit for considering participant experiences of living with an IHC. A common exception to this was the "triggering events" domain. Unlike many chronic illnesses, where genetic and lifestyle factors can contribute to the development, little is known around the risk factors for developing IHC. Nevertheless, the factors that were considered – aging and parental history of HC – may be helpful in supporting professionals to consider individuals' needs within their specific contexts. Particularly, and as discussed, the predisposing nature of having a parent with HC impacted individuals' competence in their understanding and management of HC. Coupling this understanding with the second domain of antecedents, "contextual factors" such as occupation, increased understanding of the context in which individuals were living with their diagnosis. Understanding an individual's wider context has been found to be an important factor not only for identifying unmet needs, but also for understanding how best to meet them (Okediji et al., 2017).

The 'process' section of the model was where the bulk of individuals' experiences and unmet needs were considered, and these mapped onto several aspects of the inductive analysis. Meanings around uncertainty of one's future and perceived stigma – components of the ‘CID-related medical status’ domain – were deduced from the data, mapping onto the inductively constructed subtheme ‘“There’s nothing wrong with you”: managing and internalising others’ perceptions’ and the overarching theme ‘The psychological battle of watch and wait’. These qualitative findings support previous research that individuals under W&W have unmet needs of managing uncertainty (Damen et al., 2022) and experience stigmatised identities (Evans et al., 2012), aligning with needs identified in the chronic illness literature.

Relating to the second domain, psychological distress (anxiety, depression, anger), particularly associated with the psychological battle of W&W, were reported throughout the interviews and consistently across time. Prevalence of anxiety and depression in those living with chronic illnesses are well-documented across the literature (DeJean et al., 2013). This ties into Maslow’s (1943) theory that threat to health leads to unmet needs in the safety domain (including psychological safety) resulting in psychological distress. One noted difference between the model and the sample pertains to the model’s assumption that over time, psychological distress should reduce, and, in its place, acceptance of the illness should increase. This contradicts both findings in the present sample, where little decrease in distress was observed across the two time points (qualitatively or on the HADS), and previous literature, which has reported psychological distress remains high throughout peoples’ time under W&W (Shanafelt et al., 2007).

The final domain of the ‘process’ section was also found to be relevant to the experiences of the sample, allowing space for consideration of coping and appraisals around the diagnosis. These coping strategies could be understood as individuals attempting to meet their basic psychological needs, posited by SDT (Deci & Ryan, 1985). For example, coping through becoming an expert in one’s condition not only maps onto the inductive findings (and thus represents the need for accurate information), but also the basic need for competence. Similarly, coping through attempting to gain normality and live in line with one’s values could be considered as attempts to live autonomously, and not ruled by the IHC. Finally, coping strategies involving desiring peer support and spending time with friends and family can be considered as the need for relatedness.

The practical nature of this domain, considering precisely how an individual attempts to reconcile having a cancer diagnosis and still being able to live a fulfilled life, may be a target for psychosocial intervention. Specifically, the model may have potential to help professionals and individuals identify if unhelpful appraisals or coping skills have been developed to manage the diagnosis, and if the individual desires support to change this. Further, linking the domain to consider the needs posited by SDT may help professionals to consider what kind of support is needed (i.e., through targeting either increasing competence, autonomy, or relatedness). For example, psychological therapies targeting improving individuals' capability to self-manage (i.e., increasing competence) reduced psychological distress in people with chronic conditions (Kidd et al., 2017; Whitebird et al., 2018). However, no research appears to have intentionally attempted to combine these theories, in neither an exploratory nor interventional capacity.

The final section of the model, the 'outcome' section, was also found to represent experiences of the sample, with each domain representing a different area of functioning. With relation to the research questions, the domains could also be considered in terms of representing different areas of psychosocial need. As previously referenced, the intrapersonal domain considers the ongoing psychological distress resulting from the diagnosis, but in addition, it considers the resulting physical health impact. Consequently, this domain could be understood as representing needs in the emotional support domain (e.g., anxiety management skills) and the physical health domain (e.g., symptom management). The second domain, 'interpersonal' outcomes, maps strongly onto both the inductively constructed need for peer connection and the broader need for relatedness. The inclusion of this domain in the model strongly indicates the utility of the model for assessing and identifying social and peer support needs in people with IHC. Finally, the 'extrapersonal' domain broadly identifies how well individuals are independently engaging in daily living, seemingly linking to the extent to which individuals are able to be autonomous. The domain was found to be represented in the data in terms of individuals desiring voluntary work and engagement in their community; understood as representing psychological needs such as having purpose and reducing social isolation. However, whilst 'work performance' was considered in this domain, consideration of the impact of a diagnosis on individuals' ability to continue working and the feasibility of taking early retirement was lacking, perhaps questioning the applicability of the model to older adults.

Compared to the inductive findings, one domain that appeared missing from the model was the impact of one's relationship with their team. In the present sample, strong feelings of abandonment were shared under W&W, and it is possible that this impacted individuals' level of adaption to their diagnosis, and subsequently, the level of unmet need they experienced. Given all chronic conditions need managing by medical professionals to some degree, it is interesting that this is not considered in the PACID model. This begs the question of whether the strong negative perceptions towards healthcare professionals are only particularly relevant to individuals with chronic cancers, or whether it was not deemed important to the adaption process. It may be helpful for research to explore this further to determine whether learning can be transferred from support processes used in chronic illness management to those used in IHC.

In summary, the findings preliminarily suggest that Livneh's (2022) model can provide a relatively thorough understanding of an individual's adaptive processes to living with IHC and that IHC can be considered a chronic illness. Further, problems occurring in this process could be conceptualised as unmet need, if identified by the individual as such. This holds implications for the extent to which wider chronic illness literature can be utilised to support individuals with IHC. However, the present study was not designed around assessing the extent to which the model fit the data, and therefore specific questions, such as around appraisals and perceptions, were not asked. Therefore, the literature would benefit from further research assessing model fit specifically, and subsequently, considering how the model could be used in tandem with SDT to develop effective psychosocial support for people with IHC.

4.5.4 Social Identity

The need for peer connection was strongly indicated throughout interviews, and it forms a key feature of both SDT (Deci & Ryan, 1985) and the PACID (Livneh, 2022). The benefits of peer connection have been linked to self-identity theory. Specifically, Guan and So (2016) argue that when an individual feels supported by a group they identify with (in this case, the group of people with IHC), they perceive themselves as having greater abilities to cope (i.e., increased self-efficacy). The authors report this works in a dose-dependent fashion, with individuals who most strongly identify with a specific social group perceiving the most social support, which subsequently results in highest levels of perceived self-efficacy. The findings hold implications for understanding the fundamentality of peer support not only for increasing individuals' sense of relatedness, but also their sense of autonomy and competence.

The findings also hold relevance when considering how individuals with IHC may identify and how teams can meet their peer needs. In the present study, individuals described needs associated with others not understanding their diagnosis, due to it not fitting an acute cancer presentation. In other studies, this has been linked to people with IHC not identifying as part of the wider population of people living with cancer (Swash et al., 2018). This understanding of social identity has been used to posit that asking individuals who they most identify with is critical when considering how their peer support needs may best be met (Stephens & Thorne, 2022).

4.6 Consideration of Socioeconomic Status

Whether there is a relationship between an individual's socioeconomic status and the level of unmet psychosocial need they report is not clear. A study of Australian HC survivors found that socioeconomic status did not significantly predict whether an individual reported multiple unmet needs or not (Lynagh et al., 2018). In contrast, a recent study into the needs of Canadian cancer survivors reported those with higher incomes described significantly fewer unmet needs, than those with lower annual incomes (Shakeel et al., 2020). It is possible that these findings highlight a difference between the impact of socioeconomic status on those with HC compared to those with other cancers. However, it is also possible that this contradiction stems partially from methodological differences, with researchers choosing to measure unmet needs through different questionnaires. Further, geographic factors, such as access to free healthcare and the quality of a country's benefits system, may affect the impact of one's socioeconomic status on their ability to access required support. Unfortunately, UK-based studies exploring the relationship between socioeconomic status and the needs of those with IHC do not appear in the literature.

Although individuals’ socioeconomic status was implied throughout interviews (e.g., one participant discussed their experiences of being homeless prior to diagnosis and two others discussed their use of food banks, whilst several others described feeling fortunate that they could afford private healthcare), status was not assessed through a validated measure. Measuring this formally may have advanced knowledge in whether there is a link between socioeconomic status and unmet needs. The knowledge would also have allowed for further contextualisation of the data, and therefore, it is considered a limitation of the present study. Future research should consider building on the present understanding through examining if and if so, how, unmet needs are experienced and changed, depending on individuals’ socioeconomic status. This may hold further implications for how to develop accessible psychosocial interventions for individuals with IHC.

5. Critical Reflection

5.1 Reflections on Qualitative Research

Prior to training, my only research experience was quantitative. I have always enjoyed mathematics and statistics and therefore, considered myself as aligning more with quantitative approaches than qualitative. However, once on training, I made a conscious decision to choose a research study that would align with qualitative methodology to give me applied experience before qualifying. Although I am very glad to have done this and believe I have learned a lot, I did experience 'hurdles' along the way.

The first hurdle presented at the very start of the research process: deciding on the research question. Through background reading and discussions with Dr Biswas (field supervisor who, at the time, worked in Oncology), I had established the need for a qualitative exploration of the experiences of people with IHC. Given the drive for implementing holistic needs assessments for all individuals under cancer services (NHS England, 2020), we decided to explicitly explore psychosocial needs. However, this quickly raised questions around how to define 'psychosocial needs', with many different conceptualisations being offered across the literature. After reading several different definitions and justifications, I chose to keep the definition broad, and in line with my epistemological position and qualitative methodology. That is, I took the view that psychosocial needs were complex, person-specific, and interconnected desires (e.g., peer needs may influence information needs), rather than defined by pre-existing questionnaires and set domains.

I believe the broad definition benefitted data collection, as individuals were not constrained by set topics. However, through write-up, it was difficult to navigate the broad definition in terms of relating to extant literature. Therefore, I chose to discuss the identified needs within commonly reported domains (e.g., 'emotional needs'). On reflection, I think my experienced discomfort represents the reality that humans are complex beings, with many different aspects of life impacting psychological wellbeing, and this highlights the need for healthcare services to follow existing guidance for providing person-centred care based on holistic assessments of their needs.

Throughout the analytic and write-up process, I found not being able to take a ‘positivist’ stance a challenge. Whilst I certainly feel my own beliefs about ‘knowledge’ in the world align with a critical realist position, I found it difficult to draw conclusions from non-numerical data that lacked defined limits (e.g., significance from p-values). Reflecting on this, I considered how I held a fear of “getting it wrong” – likely stemming from years of taking exams with definitive answers – that was preventing me from fully engaging in the qualitative process. Research supervision and reading guidance around TA was crucial to my development in this area. I particularly found Clarke and Braun’s (2022) guidance on managing anxiety during the analytic process helpful (p.92). This allowed me to focus on moving my attention from looking for the “right” themes to instead exploring the overall patterns I was constructing, whilst acknowledging how my own experiences may have influenced my perceptions of the data. For example, within Clinical Psychology, a specialist area I am interested in is the relationship between physical health and mental health, and how these can impact one another. Throughout data collection and analysis, I was aware that I was likely to be drawn to any indication of the impact of physical health on individuals’ mental health and I initially generated the overarching theme ‘the psychological battle of living with IHC’. However, being aware of my potential bias, and returning to the data with this candidate theme in mind, I noticed that the psychological impact being described stemmed more from the process of W&W than the diagnosis itself (e.g., sense of abandonment from healthcare teams, lack of understanding of not receiving treatment, uncertainty between blood tests). Therefore, I refined the wording to ‘the psychological battle of living under W&W’.

5.2 The Interview Process

Completing interviews in a research capacity was a new experience for me. Prior to beginning, I considered the differences between taking a ‘data-collecting’ researcher position compared to a clinical interviewing role (such as when completing assessments on placements) in research supervision. Based on my knowledge of previous research and HC being most common in later life, I suspected my participants would likely be older adults. Prior to training, I worked in an Older Adult Mental Health service and one of my favourite aspects of the role was hearing individuals' life stories, particularly as they typically differed significantly from my own (e.g., growing up in the 1950s). I was aware how this drive in me may influence any follow-up questions I asked during interviews and so I discussed this potential draw with my primary research supervisor. They advised me to keep a sticky note on my laptop screen with the main research question written down, to help keep the interviews focused on the aim of the study. I think this strategy helped me significantly, and it is a strategy I will use in any future qualitative research.

Throughout the research process and on the course more widely, I have reflected on what my values are, both personally and professionally. During interviews, I noticed how these values impacted how much I was drawn to different participants. For example, "Delia" described being the first woman to achieve a management position in a large motor business. This struck a chord with my feminist values, and I found myself being drawn to her ambition and desire for independence. In contrast, "Noel" raised some concerns around his care provision and placed emphasis on his belief that the poor care was a direct result of the race of his healthcare professionals. I found this conversation very uncomfortable as I perceived this as racism. During analysis, I was conscious of the different perceptions I held of individuals and how this had the potential to bias the analysis. Consequently, I made use of research supervision and journalling my analytic processes in attempts to recognise and reduce biases resulting from these perceptions.

5.3 Taking a Longitudinal Approach

The longitudinal approach was taken to incorporate understanding of how needs may change over time. Due to the timing of the project, this allowed for comparison of the impact of Covid-19 on needs, as the country moved towards "living alongside the virus". I am fortunate to be generally healthy, with no conditions that make me particularly vulnerable to the virus. In addition, I only live with my partner, who was also not classed as vulnerable. Subsequently, my anxieties around the virus had begun to significantly reduce over the course of 2021 and into 2022 (though I was still regularly testing due to working in the NHS). This significantly contrasted the perceptions of the sample, within whom fears of the virus were high. Particularly after T1 interviews, I noticed a sense of guilt set in within me and I began wearing a mask again on public transport and in supermarkets. This stemmed not from my own anxiety of catching the virus, but from the sense of duty I felt towards supporting and protecting those who were immunocompromised. As described, by T2, most individuals had begun attempting to live their lives again, though many still reported to use multiple infection prevention methods. This again elicited a sense of duty in me to ‘do my part’ for those more vulnerable in society. The direct impact of participants’ experiences on my own thoughts, feelings, and behaviour was not something I had noticed in previous research undertakings, and I wonder if this resulted from the more personal nature of qualitative data-collection, compared to quantitative data-collection.

During the six-month gap between interviews, I expected some participants to have entered treatment and I was surprised that all participants, even those who did not take part in a second interview, reported to still be under W&W. I found this assumption an interesting one to reflect on, considering how my short experience of this uncertainty was anxiety-provoking at times (e.g., thoughts such as “I wonder if Frank’s blood results were okay?”), and that was without such serious implications for myself. People under W&W experience this uncertainty for extended periods of time, up to many years. This led me to reflect on the use of the phrase “watch and wait”, and how this seems intrinsically related to uncertainty (particularly, the use of the word “wait”). I am curious as to why this phrase is used consistently in haematology, as opposed to the phrase “active monitoring”, which seems to be used in most other oncology services (e.g., rectal, prostate).

5.4 Implications for Clinical Practice

In addition to improving my research understanding and skills, I think the knowledge I have gained from the study will positively impact my future clinical practice. I hope to gain a qualified role in either Older Adult mental health, or in a physical health department. In both settings, I believe my increased awareness of the impact of physical health on emotional wellbeing and of the PACID model (Livneh, 2022) will be relevant. I hope my future formulations will now be more holistic and include increased consideration of the burden of living with and managing any physical health conditions. I also hope that I will consider how physical health conditions may impact an individual’s needs, such as accessing support, their ability to socialise, and their sense of identity.

The research findings have also strengthened my belief in the power of social connectedness. If appropriate for the service, I would consider the feasibility of setting-up and/or facilitating peer support groups to increase relatedness to those in similar positions. In addition, I will continue to strive to build therapeutic alliance with clients, whilst bearing in mind the complexities of client-service relationships, particularly in the current context of the NHS.

In the wider context of healthcare provision, participants seemed to hold the view that the NHS provided only ‘basic care’, and for anything further, accessing private or charitable services was necessary. From my position as a researcher, it was important to understand whether needs were being met by the NHS or private/charity sectors to understand factors influencing when needs were met (e.g., involvement in charities). However, the study was not an evaluation of the NHS, and therefore, different avenues of support were not viewed as being weighted in value. Yet, as an NHS employee, the lack of support being provided through the NHS raised a sense of moral discomfort in me, particularly around the perceived necessity for private healthcare. During both interviews and analysis, I noticed a draw to focus on improvements that could be made to provision in the NHS, despite this not being an aim of the study. I wonder if this resulted from the sample’s experience of receiving unsatisfying care conflicting with my personal and professional values of being proud to work in the NHS. Increasingly, the NHS appears to be making use of external services to combat internal services being reduced. I think that, rather than viewing these external services, particularly charities, as “sweeping up shortcomings” of the NHS, I will attempt to reframe these as useful pockets of expertise that can provide valuable support. In line with this, in my future roles, I will aim to be aware of local and virtual support that may be of benefit to the client group I am working with, and I will share this knowledge with both clients and teams as appropriate.

My main reason for wanting to develop my qualitative skills on training was to increase the range of skills I could draw on when engaging in research in a clinical role, such as service evaluations and small-scale research studies. I feel that my experiences completing this study have increased my understanding and confidence in using qualitative methods, including research question development, study design, analytic process, and reporting of the results. I feel very grateful to my sample for enabling me to have contributed to the psychological perspective of a largely medical literature base around the experiences of people with IHC, and I hope the skills I have learned will enable me to stay research active once qualified.

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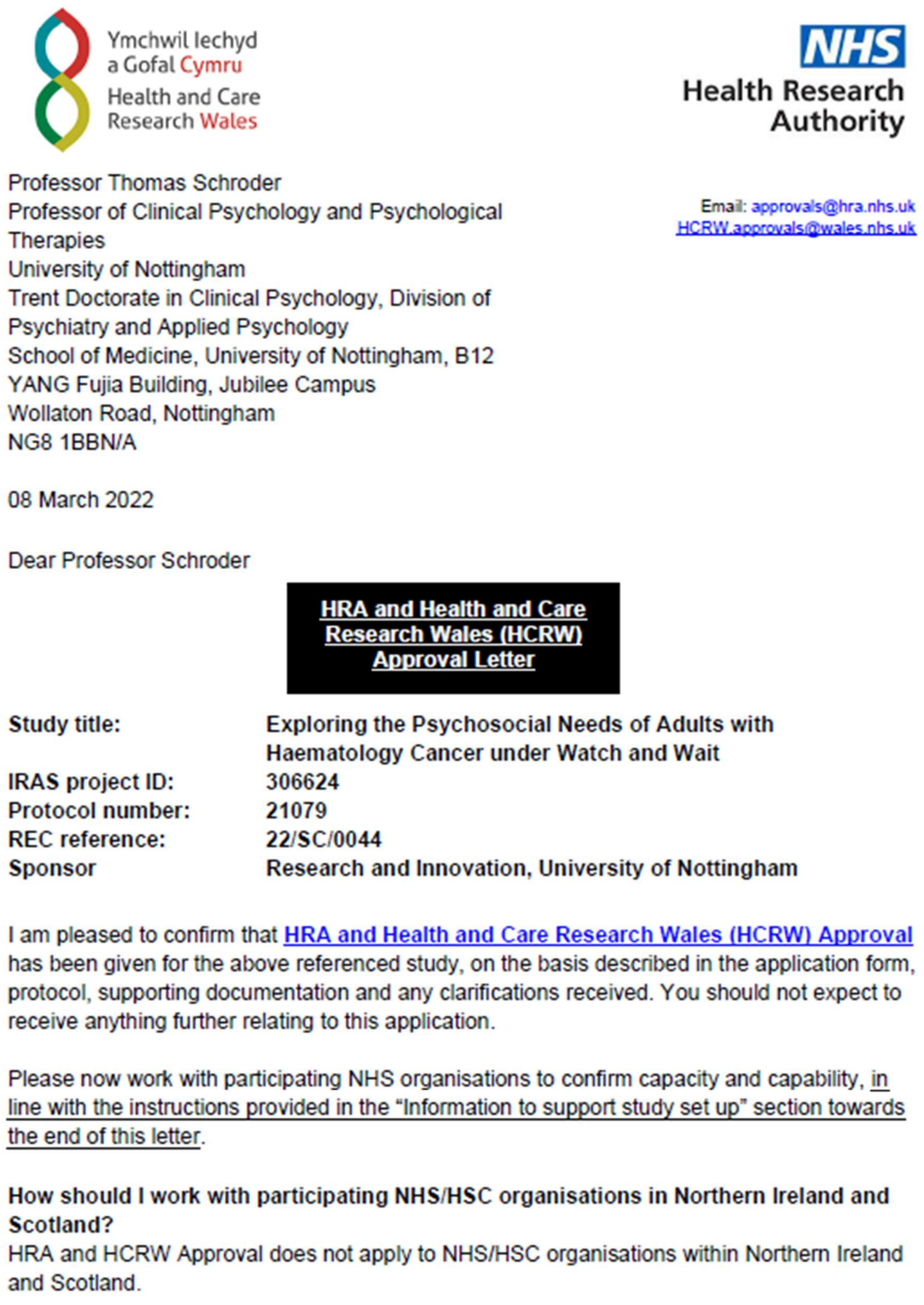
Appendices: Contents

Appendix A: Journal author guidelines

The main journal paper has been written up for submission to the European Journal of Cancer Care. Author guidelines were obtained from: https://www.hindawi.com/journals/ejcc/guidelines/

Appendix B: Ethical approval letter



Ymchwil Iechyd
a Gofal Cymru
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08 March 2022

Dear Professor Schroder

HRA and Health and Care Research Wales (HCRW) Approval Letter

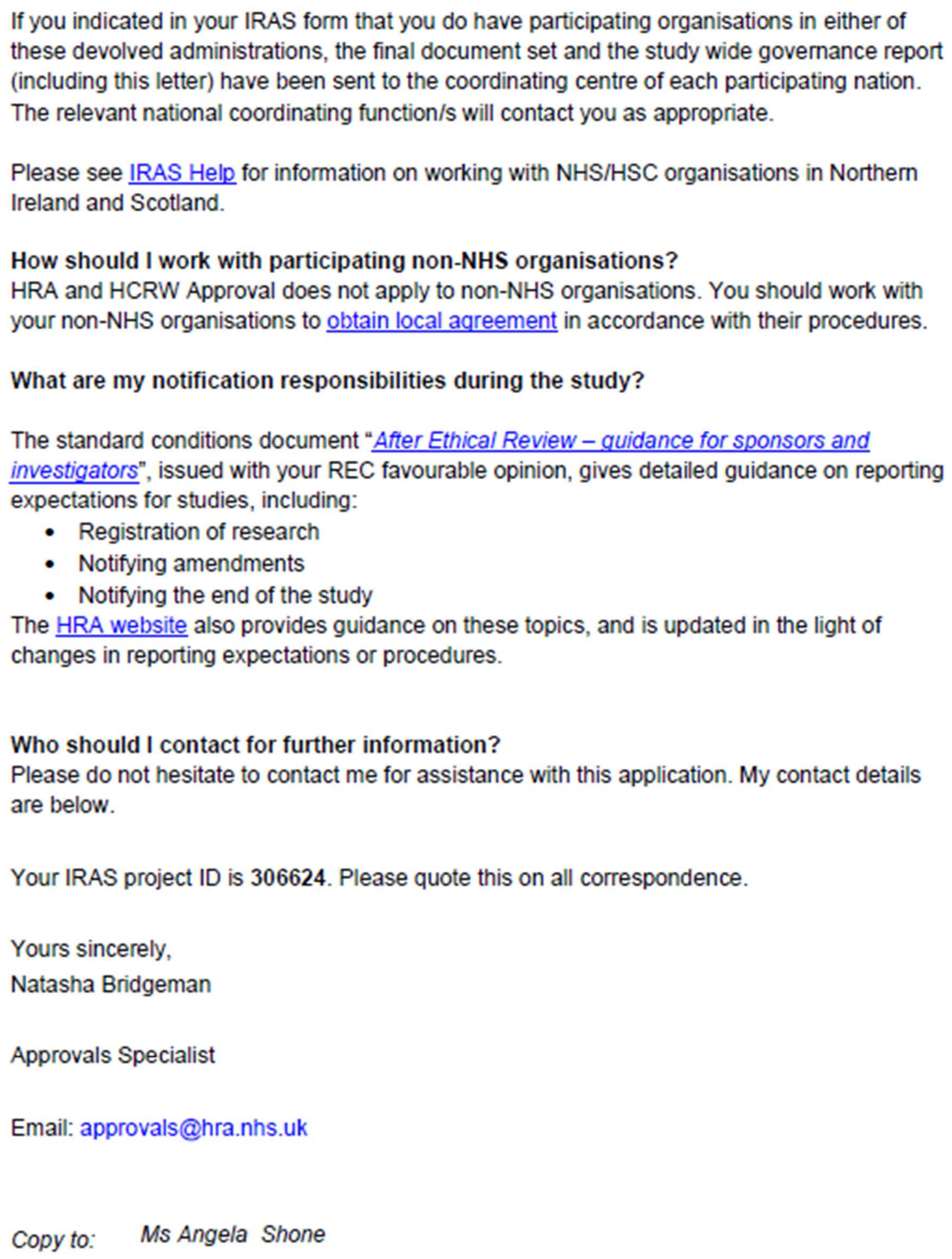
Study title:	**Exploring the Psychosocial Needs of Adults with Haematology Cancer under Watch and Wait**
IRAS project ID:	**306624**
Protocol number:	**21079**
REC reference:	**22/SC/0044**
Sponsor	**Research and Innovation, University of Nottingham**

I am pleased to confirm that HRA and Health and Care Research Wales (HCRW) Approval has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?

HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.



If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?
HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?

The standard conditions document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

Who should I contact for further information?
Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **306624**. Please quote this on all correspondence.

Yours sincerely,
Natasha Bridgeman

Approvals Specialist

Email: approvals@hra.nhs.uk

Copy to: *Ms Angela Shone*

Appendix C: Participant Information Sheet

School of Medicine
University of Nottingham
Medical School
Division of Psychiatry and
Applied Psychology
Nottingham
NG7 2UH

Final Version: 2.0
Date: 15.02.2022

Participant Information Sheet

IRAS Project ID: 306624

Title of Study: Exploring the psychosocial needs of adults with haematology cancer under watch and wait.

Name of researcher: Katie Russell

Chief Investigator: Prof. Thomas Schroder

Contact Details of the Researcher(s) are given at the end.

We would like to invite you to take part in our research study. Before you decide, we would like you to understand why the research is being done and what it would involve for you. Please take your time to read the following information carefully and discuss it with others if you wish. If you would like any further information, or if anything is not clear, please ask us.

Thank you for taking the time to read this information sheet.

What is the purpose of the study?

The study aims to increase understanding around the psychological and social needs of people diagnosed with haematology cancer and placed on the watch and wait pathway. We would like to look at how these needs change over six months, to better understand if further support is needed, and if it is, what this should comprise. This study is being completed as a partial requirement of the Doctorate in Clinical Psychology.

Why have I been invited?

You are being invited to take part because you have been identified as someone who may wish to take part. We are looking for participants who have a diagnosis of haematology cancer and are under the watch and wait pathway and who would be willing to share their experiences of this.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part, you are still free to withdraw at any time and without giving a reason.

What will taking part involve?

The study will involve taking part in two interviews, approximately six months apart. The length of the interview will depend on how much you would like to share but may last up to 60 minutes. It will involve talking about your experiences of being under the watch and wait pathway. The interview will be with one researcher and yourself and can take place either over the phone, or via video call, whichever you would prefer. The interview will be audio recorded and transcribed by an automated service.

What are the possible disadvantages and risks of taking part?

Taking part in this research will involve giving up your time to talk to the researcher about your experiences. In total, this may be up to two hours. The researcher will be interested in your experiences of accessing and receiving support whilst under watch and wait and this could raise difficult feelings for you. You don’t have to discuss anything you don’t want to, and you may decline to answer any question. If the discussion does cause you distress, we will be able to signpost you in the direction of appropriate support.

What are the possible benefits of taking part?

You will have the opportunity to share your experiences under the watch and wait pathway. By sharing your experiences, you will be contributing to increasing understanding of living under the watch and wait pathway. In the long term, it is hoped that increasing this understanding will help to develop effective support.

What if I am unhappy with the study process?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. The researchers’ contact details are given at the end of this information sheet. If you remain unhappy and wish to complain formally, you can do this by contacting the Patient Advice and Liaison Service at PALSandComplaints@nottshc.nhs.uk.

Will my taking part in this study be kept confidential?

We will follow ethical and legal practice and all information about you will be handled in confidence.

If you join the study, we will use information collected from you during the course of the research. This information will be kept **strictly confidential**, stored in a secure and locked office, and on a password protected database at the University of Nottingham. Under UK Data Protection laws the University is the Data Controller (legally responsible for the data security) and the Chief Investigator of this study (named above) is the Data Custodian (manages access to the data). This means we are responsible for looking after your information and using it properly. Your rights to access, change or move your information are limited as we need to manage your information in specific ways to comply with certain laws and for the research to be reliable and accurate. To safeguard your rights we will use the minimum personally – identifiable information possible.

You can find out more about how we use your information and to read our privacy notice at: https://www.nottingham.ac.uk/utilities/privacy.aspx.

The data collected for the study will be looked at and stored by authorised persons from the University of Nottingham who are organising the research. They may also be looked at by authorised people from regulatory organisations to check that the study is being carried out correctly. All will have a duty of confidentiality to you as a research participant and we will do our best to meet this duty.

Your contact information will be kept by the University of Nottingham for three months after the end of the study so that we are able to contact you about the findings of the study and possible follow-up studies (unless you advise us that you do not wish to be contacted). This information will be kept separately from the research data collected and only those who need to will have access to it. All research data will be kept securely for 7 years. After this time your data will be disposed of securely. During this time all precautions will be taken by all those involved to maintain your confidentiality, only members of the research team given permission by the data custodian will have access to your personal data.

In accordance with the University of Nottingham's, the Government's and our funders' policies we may share our research data with researchers in other Universities and organisations, including those in other countries, for research in health and social care. Sharing research data is important to allow peer scrutiny, re-use (and therefore avoiding duplication of research) and to understand the bigger picture in particular areas of research. Data sharing in this way is usually anonymised (so that you could not be identified) but if we need to share identifiable information, we will seek your consent for this and ensure it is secure. You will be made aware then if the data is to be shared with countries whose data protection laws differ to those of the UK and how we will protect your confidentiality.

Although what you say to us is confidential, should you disclose anything to us which we feel puts you or anyone else at any risk, we may feel it necessary to report this to the appropriate persons.

What will happen if I choose to stop taking part in the study?

Your participation is voluntary, and you are free to withdraw at any time, without giving any reason, and without your legal rights or health care being affected. If you withdraw, we will no longer collect any information about you or from you. After each interview, you may contact the researchers up to a week after to request that the information given in the interview is withdrawn. After one week, information will be made anonymous, and it will no longer be possible to remove it from the study. You may contact either the researcher (Katie Russell), or the supervisor (Dr Anna Tickle), via the email addresses given below. To safeguard your rights, we will use the minimum personally-identifiable information possible.

What will happen to the results of the study?

The results of the study will be submitted to the University of Nottingham. The research findings may also be shared with haematology cancer charities such as Blood Cancer UK and Myeloma UK. It will not be possible to identify you in any presentation of the study. A summary of the findings can be provided to you, if you so wish.

Expenses and payments

As a thank you for your time, a £5 Love2Shop voucher will be offered to each participant for each interview.

Who is organising and funding the research?

This research is being organised and funded by the University of Nottingham.

Who has reviewed the study?

All research in healthcare is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by South Central - Oxford A Research Ethics Committee.

For further information, please contact:

Katie Russell (Trainee Clinical Psychologist)

msxkr13@exmail.nottingham.ac.uk

Supervised by:

Dr Anna Tickle (DClinPsy Academic Tutor)

lwaat@exmail.nottingham.ac.uk

Trent Doctorate in Clinical Psychology (DClinPsy)
Division of Psychiatry and Applied Psychology
University of Nottingham

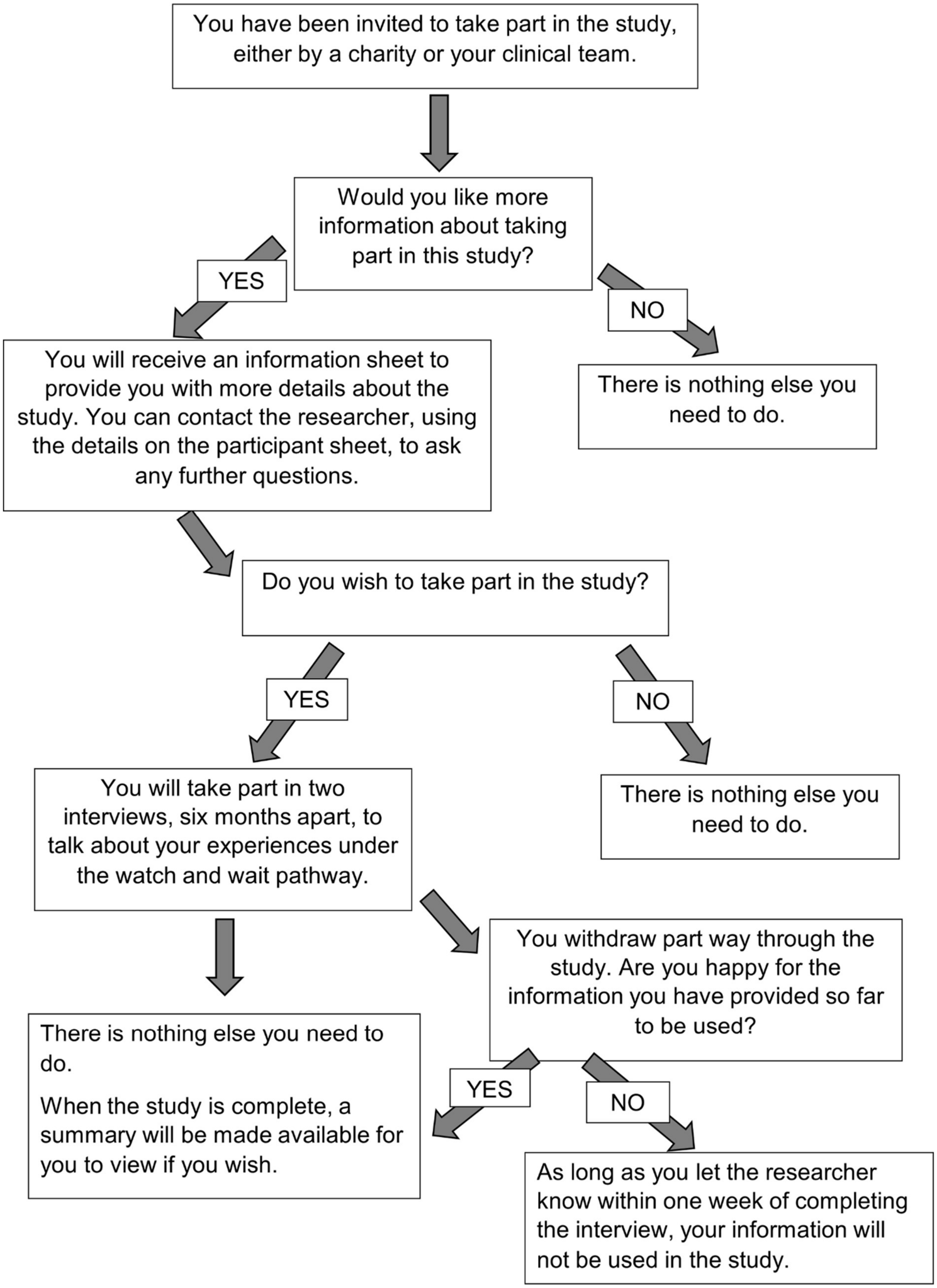
YANG Fujia Building, B Floor
Jubilee Campus
Wollaton Road
Nottingham
NG8 1BB

Supporting services and helplines:

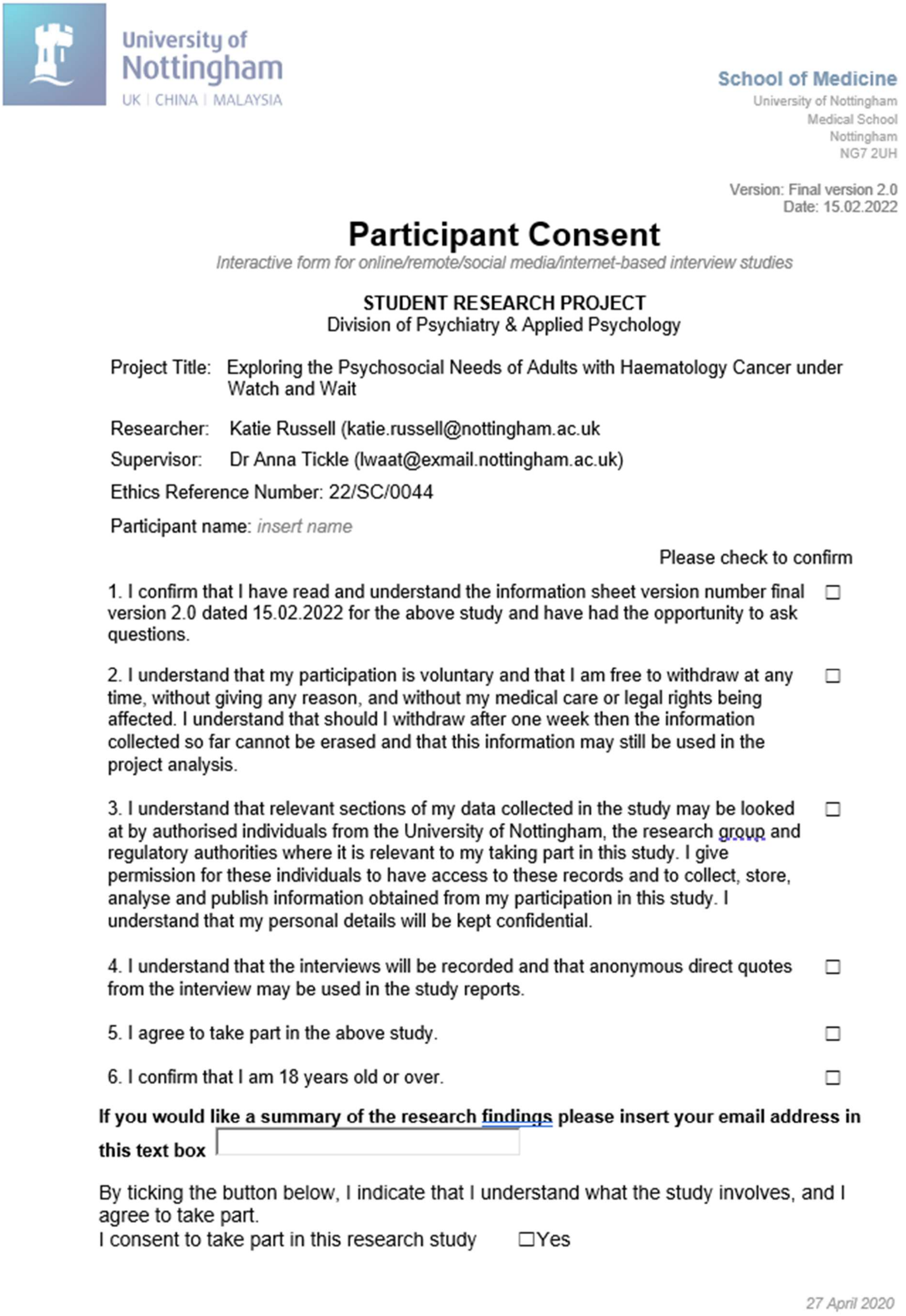
- MacMillan Cancer Support: 0808 808 00 00
- Blood Cancer UK: 0808 2080 888
- Lymphoma Action: 0808 808 5555
- Myeloma UK: 0800 980 3332

Alternatively, you can contact your haematology team or GP.

Appendix D: Study flow chart



Appendix E: Consent Form



University of Nottingham
UK | CHINA | MALAYSIA

School of Medicine
University of Nottingham
Medical School
Nottingham
NG7 2UH

Version: Final version 2.0
Date: 15.02.2022

Participant Consent

Interactive form for online/remote/social media/internet-based interview studies

STUDENT RESEARCH PROJECT
Division of Psychiatry & Applied Psychology

Project Title: Exploring the Psychosocial Needs of Adults with Haematology Cancer under Watch and Wait

Researcher: Katie Russell (katie.russell@nottingham.ac.uk

Supervisor: Dr Anna Tickle (lwaat@exmail.nottingham.ac.uk)

Ethics Reference Number: 22/SC/0044

Participant name: *insert name*

Please check to confirm

1. I confirm that I have read and understand the information sheet version number final version 2.0 dated 15.02.2022 for the above study and have had the opportunity to ask questions. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without my medical care or legal rights being affected. I understand that should I withdraw after one week then the information collected so far cannot be erased and that this information may still be used in the project analysis. ☐

3. I understand that relevant sections of my data collected in the study may be looked at by authorised individuals from the University of Nottingham, the research group and regulatory authorities where it is relevant to my taking part in this study. I give permission for these individuals to have access to these records and to collect, store, analyse and publish information obtained from my participation in this study. I understand that my personal details will be kept confidential. ☐

4. I understand that the interviews will be recorded and that anonymous direct quotes from the interview may be used in the study reports. ☐

5. I agree to take part in the above study. ☐

6. I confirm that I am 18 years old or over. ☐

If you would like a summary of the research findings please insert your email address in this text box

By ticking the button below, I indicate that I understand what the study involves, and I agree to take part.
I consent to take part in this research study ☐Yes

27 April 2020

Appendix F: Interview schedule

School of Medicine
University of Nottingham
Medical School
Division of Psychiatry and
Applied Psychology
Nottingham
NG7 2UH

Final version: 2.0
Date: 15.02.2022

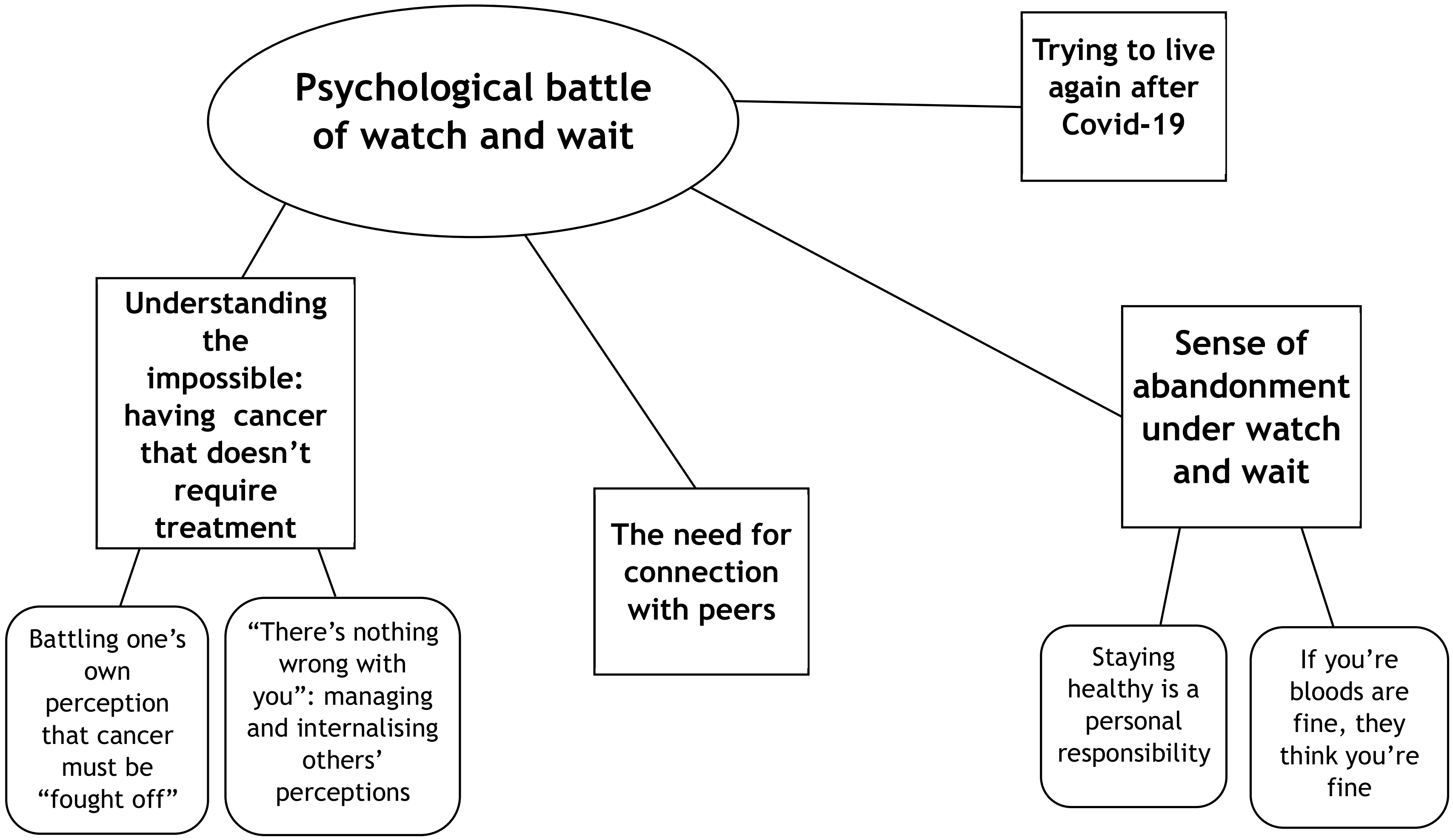
Interview Schedule

Interview at time one	➢ Introduction + Confidentiality ➢ Explanation of psychosocial needs ➢ What is your experience of being under watch and wait? ➢ What would you say are areas you require further support in? What would improve your psychological wellbeing? ➢ What has been helpful in supporting you to live well on watch and wait? ➢ What has been unhelpful in supporting you to live well on watch and wait? ➢ Is there any support you think you would benefit from that you haven't been offered so far?
Interview at time two	➢ Introduction + Confidentiality ➢ Reminder of psychosocial needs ➢ Has there been any major life changes for you in the last six months? ➢ Has your diagnosis changed or progressed in the last 6 months? ➢ Are you still under the watch and wait pathway? ➢ Has your experience of being under watch and wait changed over the last six months? If so, how? ➢ What would you say are areas you require further support in? What would improve your psychological wellbeing? ➢ What has been helpful in supporting you to live well on watch and wait? ➢ What has been unhelpful in supporting you to live well on watch and wait? ➢ Is there any support you think you would benefit from that you haven't been offered so far?

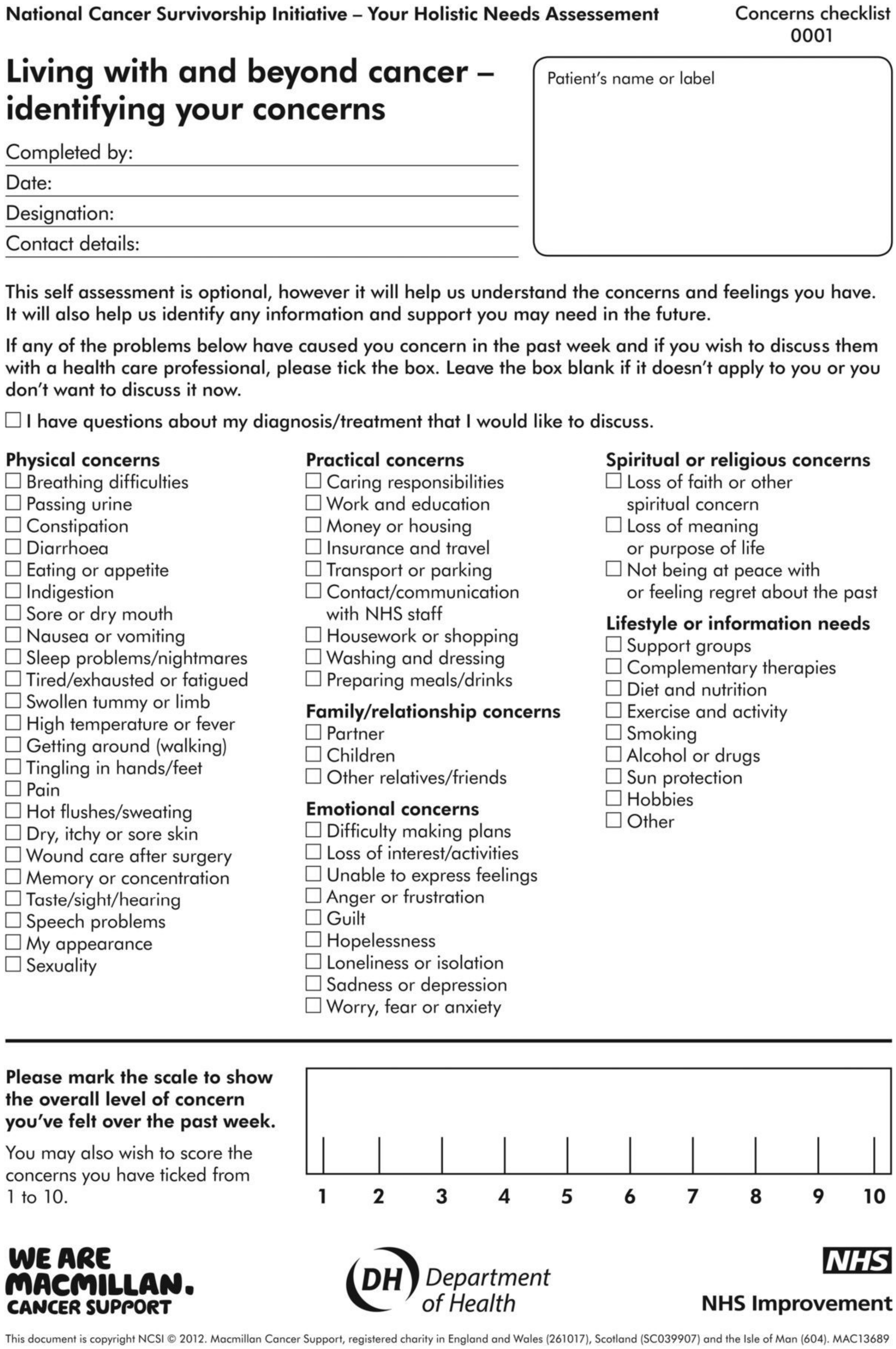
Appendix G: Deductive analysis coding framework

Model of Psychosocial Adaption to Chronic Illness and Disability (CID) (Livneh, 2021)	Antecedents: triggering events
	Antecedents: contextual status
	Process: CID-related medico-psychological status
	Process: CID-induced psychological reactions
	Process: generic CID-linked psychological approaches (appraisals, coping)
	Outcomes: intrapersonal functioning
	Outcomes: interpersonal functioning
	Outcomes: extrapersonal functioning
Psychosocial needs identified in prostate cancer patients under watch and wait pathways (McIntosh et al., 2019a)	Information available is inadequate
	Information available is confusing and inconsistent
	Emotional/Psychological needs
	Social needs
	Physical exercise needs
Self-Determination Theory (Deci & Ryan, 1985)	Autonomy
	Competence
	Relatedness

Appendix H: Thematic map



Appendix I: Holistic Needs Assessment (MacMillan Cancer Support, 2018)



National Cancer Survivorship Initiative – Your Holistic Needs Assessement

Concerns checklist
0001

Living with and beyond cancer – identifying your concerns

Completed by:
Date:
Designation:
Contact details:

Patient's name or label

This self assessment is optional, however it will help us understand the concerns and feelings you have. It will also help us identify any information and support you may need in the future.

If any of the problems below have caused you concern in the past week and if you wish to discuss them with a health care professional, please tick the box. Leave the box blank if it doesn't apply to you or you don't want to discuss it now.

☐ **I have questions about my diagnosis/treatment that I would like to discuss.**

Physical concerns
- ☐ Breathing difficulties
- ☐ Passing urine
- ☐ Constipation
- ☐ Diarrhoea
- ☐ Eating or appetite
- ☐ Indigestion
- ☐ Sore or dry mouth
- ☐ Nausea or vomiting
- ☐ Sleep problems/nightmares
- ☐ Tired/exhausted or fatigued
- ☐ Swollen tummy or limb
- ☐ High temperature or fever
- ☐ Getting around (walking)
- ☐ Tingling in hands/feet
- ☐ Pain
- ☐ Hot flushes/sweating
- ☐ Dry, itchy or sore skin
- ☐ Wound care after surgery
- ☐ Memory or concentration
- ☐ Taste/sight/hearing
- ☐ Speech problems
- ☐ My appearance
- ☐ Sexuality

Practical concerns
- ☐ Caring responsibilities
- ☐ Work and education
- ☐ Money or housing
- ☐ Insurance and travel
- ☐ Transport or parking
- ☐ Contact/communication with NHS staff
- ☐ Housework or shopping
- ☐ Washing and dressing
- ☐ Preparing meals/drinks

Family/relationship concerns
- ☐ Partner
- ☐ Children
- ☐ Other relatives/friends

Emotional concerns
- ☐ Difficulty making plans
- ☐ Loss of interest/activities
- ☐ Unable to express feelings
- ☐ Anger or frustration
- ☐ Guilt
- ☐ Hopelessness
- ☐ Loneliness or isolation
- ☐ Sadness or depression
- ☐ Worry, fear or anxiety

Spiritual or religious concerns
- ☐ Loss of faith or other spiritual concern
- ☐ Loss of meaning or purpose of life
- ☐ Not being at peace with or feeling regret about the past

Lifestyle or information needs
- ☐ Support groups
- ☐ Complementary therapies
- ☐ Diet and nutrition
- ☐ Exercise and activity
- ☐ Smoking
- ☐ Alcohol or drugs
- ☐ Sun protection
- ☐ Hobbies
- ☐ Other

Please mark the scale to show the overall level of concern you've felt over the past week.

You may also wish to score the concerns you have ticked from 1 to 10.

1 2 3 4 5 6 7 8 9 10

WE ARE MACMILLAN. CANCER SUPPORT

DH Department of Health

NHS
NHS Improvement

Appendix J: Participant debrief information

School of Medicine
University of Nottingham
Medical School
Division of Psychiatry and
Applied Psychology
Nottingham
NG7 2UH

Version: 3.0
Date: 02.12.2021

Participant Debrief Sheet

Title of Study: Exploring the psychosocial needs of adults with haematology cancer under watch and wait.

Name of Researcher(s): Katie Russell

Contact Details of the Researcher(s) are given at the end.

Thank you for taking the time to contribute to this research. Hearing about your experiences of having cancer and being on the watch and wait pathway is important to us and it will help further our understanding of adjustment and coping. The aim of this research was to understand what support is needed for people whilst under watch and wait, whether this support is available.

Questions and withdrawing

If you have any further questions about the study, please feel free to ask the researcher or their supervisor at any time via the contact details at the end of this page.

If you wish to withdraw your data, **you have one week to do so.** Please contact the researcher or supervisor. Please note you are able to withdraw part or all of your interview.

Further help and support

If you have any ethical concerns regarding the current research, your treatment as a participant or your involvement in the study please feel free to contact research@nottingham.ac.uk or PALSandComplaints@nottshc.nhs.uk.

If you have been affected by any issues raised by taking part in this study the following organisations may be able to provide help and advice:

- MacMillan Cancer Support: 0808 808 00 00
- Blood Cancer UK: 0808 2080 888
- Lymphoma Action: 0808 808 5555
- Myeloma UK: 0800 980 3332

With best wishes,
Katie Russell
Trainee Clinical Psychologist

Further information and contact details:
Katie Russell (Trainee Clinical Psychologist)
msxkr13@exmail.nottingham.ac.uk

Supervised by:
Dr Anna Tickle (DClinPsy Academic Tutor)
lwaat@exmail.nottingham.ac.uk

Trent Doctorate in Clinical Psychology (DClinPsy)
Division of Psychiatry and Applied Psychology
University of Nottingham
YANG Fujia Building, B Floor
Jubilee Campus
Wollaton Road
Nottingham
NG8 1BB

Appendix K: Recruitment poster

Final Version 1.0

28.12.2021

Are you living under the watch and wait pathway?

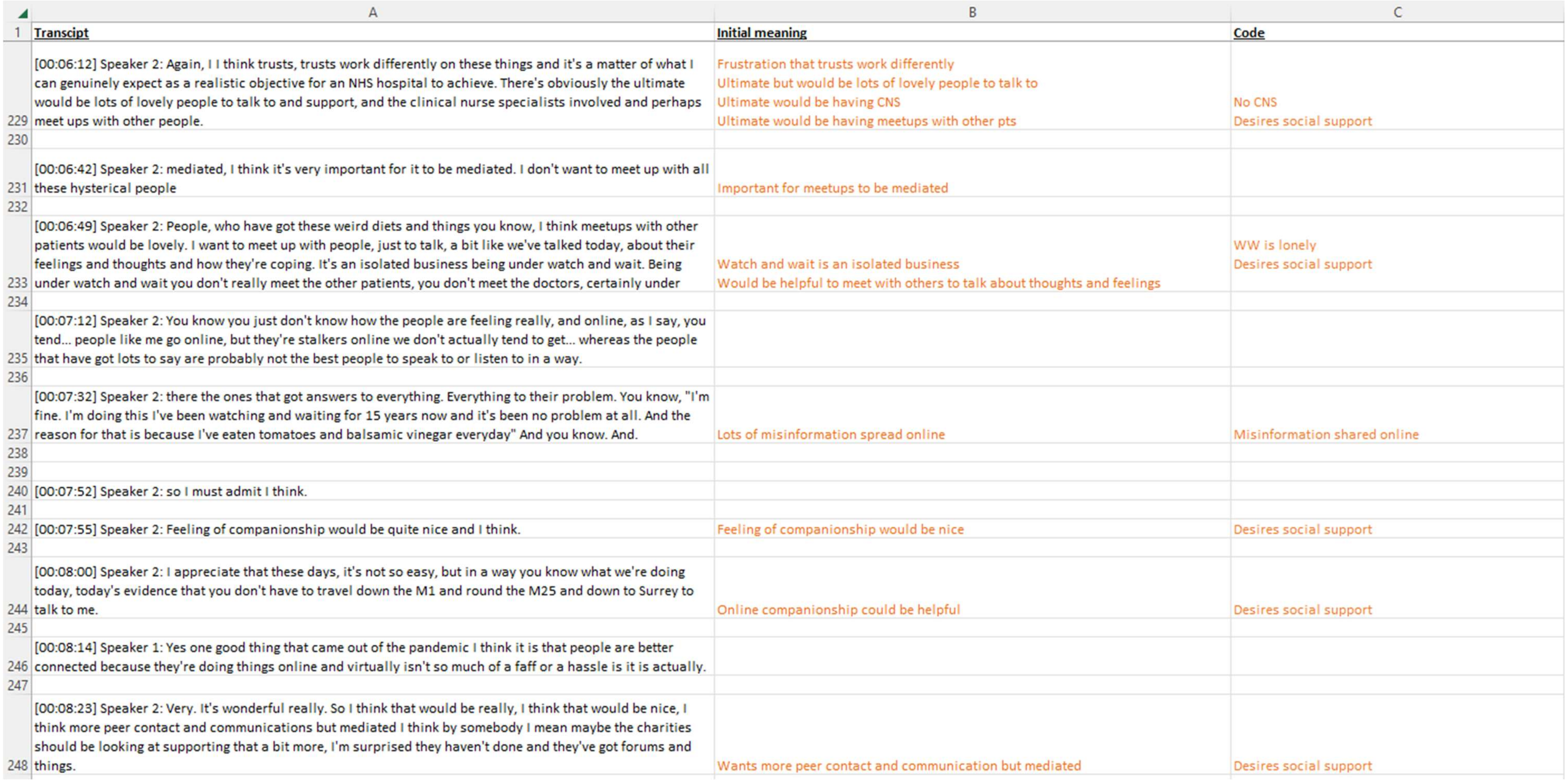
I am a Trainee Clinical Psychologist at the University of Nottingham, and I would like to interview you to understand more about the specific experiences of living on the watch and wait pathway alongside a diagnosis of haematology cancer. I hope this will build a better understanding of what people under this pathway may need, to help health and psychological services provide effective support.

If you would like to take part, or are interested in learning more about this research, please get in touch via email katie.russell@nottingham.ac.uk

Thank you.

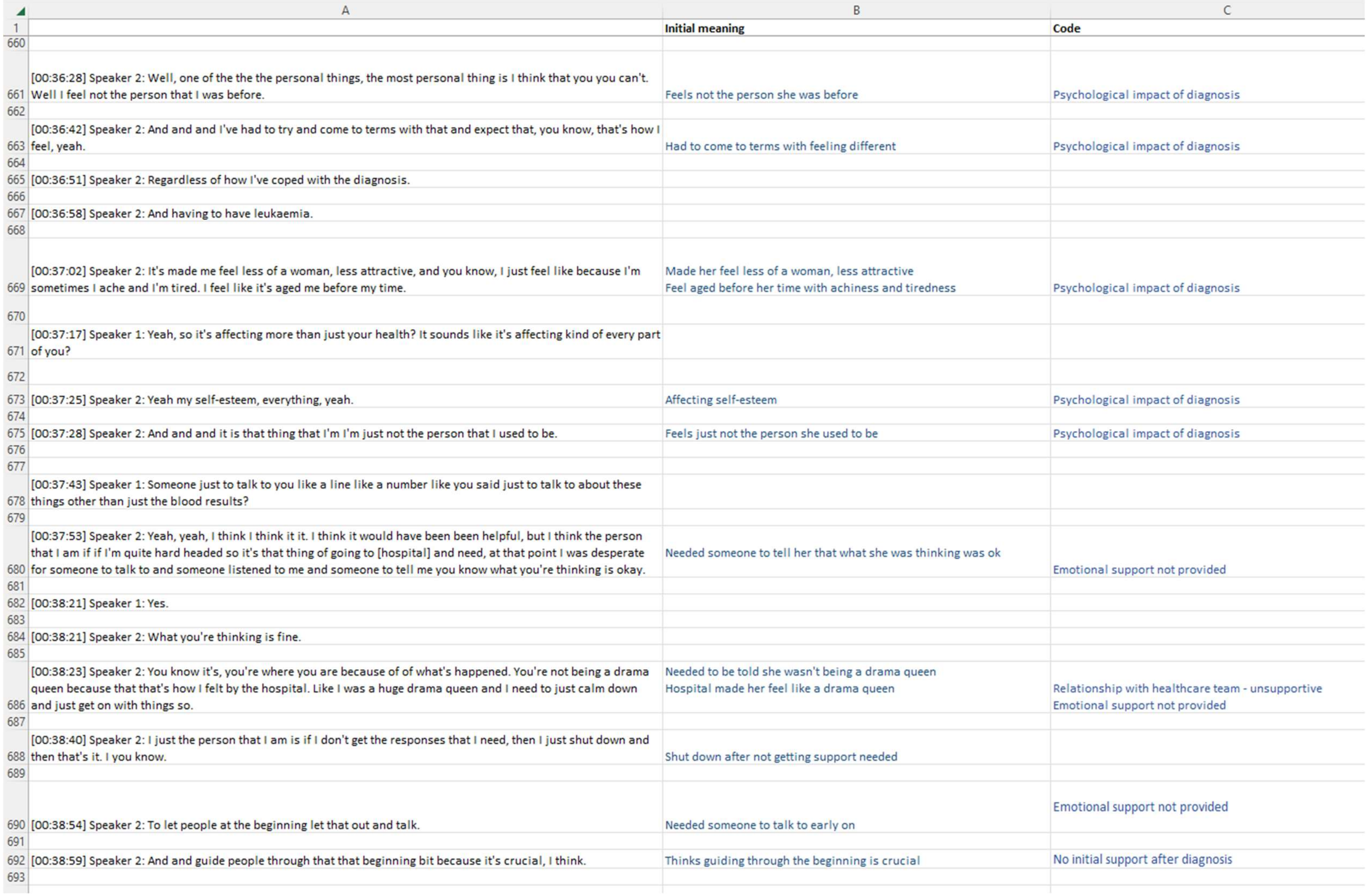
Appendix L: Excerpt from inductively coded transcript

An excerpt from Frank's first interview, where Frank is 'Speaker 2'.



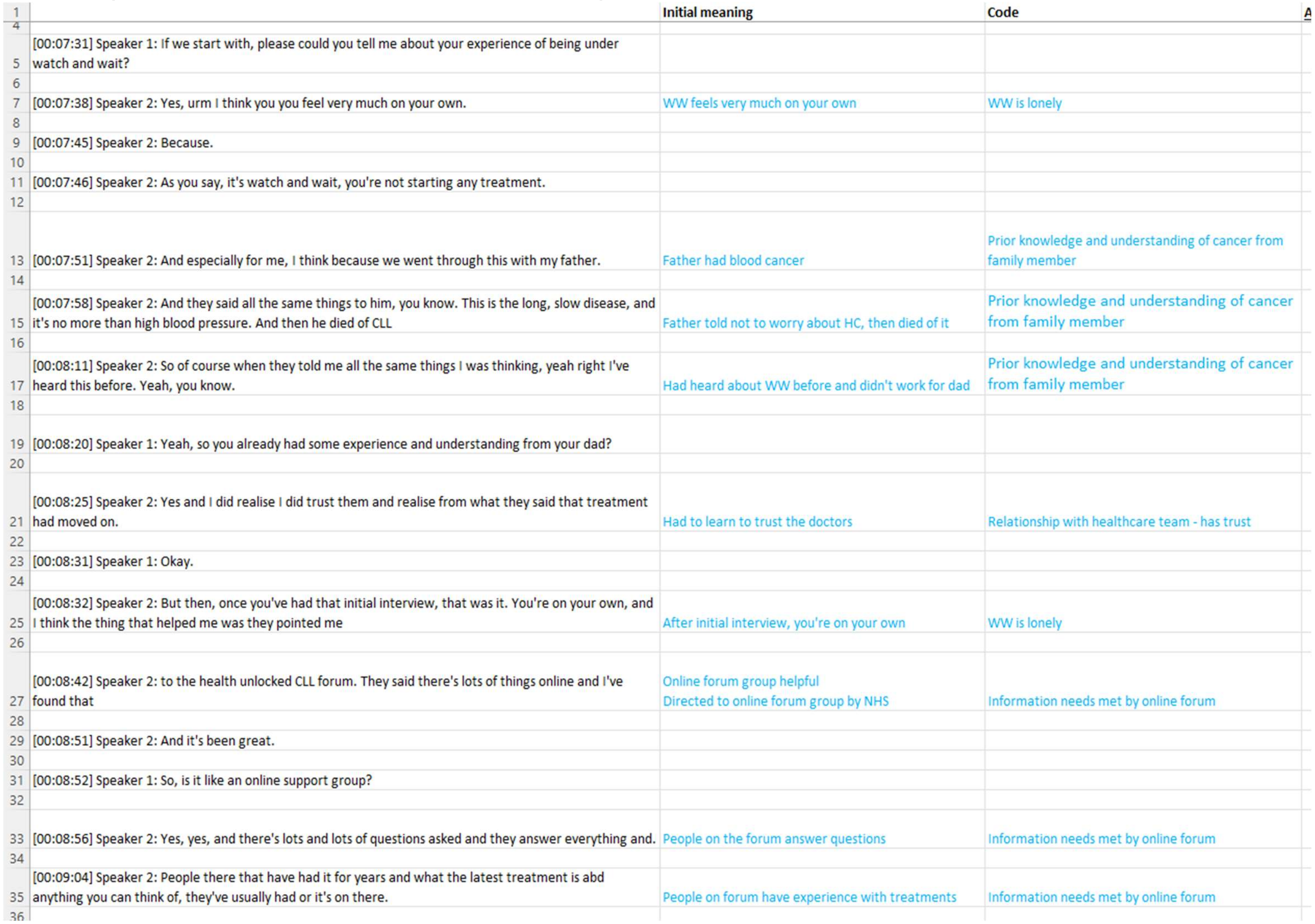
	A	B	C
1	**Transcipt**	**Initial meaning**	**Code**
229	[00:06:12] Speaker 2: Again, I I think trusts, trusts work differently on these things and it's a matter of what I can genuinely expect as a realistic objective for an NHS hospital to achieve. There's obviously the ultimate would be lots of lovely people to talk to and support, and the clinical nurse specialists involved and perhaps meet ups with other people.	Frustration that trusts work differently Ultimate but would be lots of lovely people to talk to Ultimate would be having CNS Ultimate would be having meetups with other pts	No CNS Desires social support
230			
231	[00:06:42] Speaker 2: mediated, I think it's very important for it to be mediated. I don't want to meet up with all these hysterical people	Important for meetups to be mediated	
232			
233	[00:06:49] Speaker 2: People, who have got these weird diets and things you know, I think meetups with other patients would be lovely. I want to meet up with people, just to talk, a bit like we've talked today, about their feelings and thoughts and how they're coping. It's an isolated business being under watch and wait. Being under watch and wait you don't really meet the other patients, you don't meet the doctors, certainly under	Watch and wait is an isolated business Would be helpful to meet with others to talk about thoughts and feelings	WW is lonely Desires social support
234			
235	[00:07:12] Speaker 2: You know you just don't know how the people are feeling really, and online, as I say, you tend... people like me go online, but they're stalkers online we don't actually tend to get... whereas the people that have got lots to say are probably not the best people to speak to or listen to in a way.		
236			
237	[00:07:32] Speaker 2: there the ones that got answers to everything. Everything to their problem. You know, "I'm fine. I'm doing this I've been watching and waiting for 15 years now and it's been no problem at all. And the reason for that is because I've eaten tomatoes and balsamic vinegar everyday" And you know. And.	Lots of misinformation spread online	Misinformation shared online
238			
239			
240	[00:07:52] Speaker 2: so I must admit I think.		
241			
242	[00:07:55] Speaker 2: Feeling of companionship would be quite nice and I think.	Feeling of companionship would be nice	Desires social support
243			
244	[00:08:00] Speaker 2: I appreciate that these days, it's not so easy, but in a way you know what we're doing today, today's evidence that you don't have to travel down the M1 and round the M25 and down to Surrey to talk to me.	Online companionship could be helpful	Desires social support
245			
246	[00:08:14] Speaker 1: Yes one good thing that came out of the pandemic I think it is that people are better connected because they're doing things online and virtually isn't so much of a faff or a hassle is it is actually.		
247			
248	[00:08:23] Speaker 2: Very. It's wonderful really. So I think that would be really, I think that would be nice, I think more peer contact and communications but mediated I think by somebody I mean maybe the charities should be looking at supporting that a bit more, I'm surprised they haven't done and they've got forums and things.	Wants more peer contact and communication but mediated	Desires social support

An excerpt from Marta's first interview, where Marta is 'Speaker 2'.



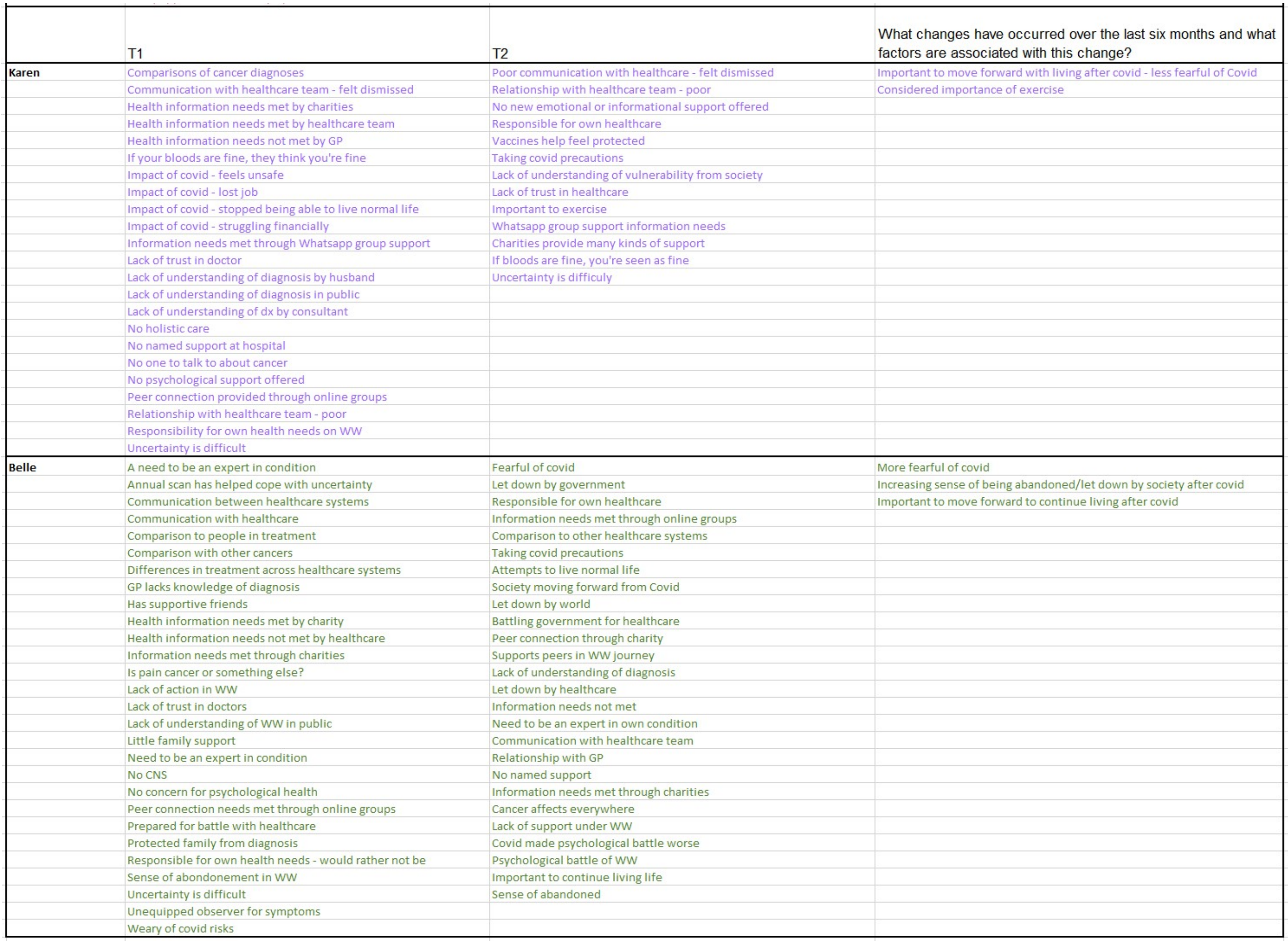
	A	B	C
1		**Initial meaning**	**Code**
660			
661	[00:36:28] Speaker 2: Well, one of the the the personal things, the most personal thing is I think that you you can't. Well I feel not the person that I was before.	Feels not the person she was before	Psychological impact of diagnosis
662			
663	[00:36:42] Speaker 2: And and and I've had to try and come to terms with that and expect that, you know, that's how I feel, yeah.	Had to come to terms with feeling different	Psychological impact of diagnosis
664			
665	[00:36:51] Speaker 2: Regardless of how I've coped with the diagnosis.		
666			
667	[00:36:58] Speaker 2: And having to have leukaemia.		
668			
669	[00:37:02] Speaker 2: It's made me feel less of a woman, less attractive, and you know, I just feel like because I'm sometimes I ache and I'm tired. I feel like it's aged me before my time.	Made her feel less of a woman, less attractive Feel aged before her time with achiness and tiredness	Psychological impact of diagnosis
670			
671	[00:37:17] Speaker 1: Yeah, so it's affecting more than just your health? It sounds like it's affecting kind of every part of you?		
672			
673	[00:37:25] Speaker 2: Yeah my self-esteem, everything, yeah.	Affecting self-esteem	Psychological impact of diagnosis
674			
675	[00:37:28] Speaker 2: And and and it is that thing that I'm I'm just not the person that I used to be.	Feels just not the person she used to be	Psychological impact of diagnosis
676			
677			
678	[00:37:43] Speaker 1: Someone just to talk to you like a line like a number like you said just to talk to about these things other than just the blood results?		
679			
680	[00:37:53] Speaker 2: Yeah, yeah, I think I think it it. I think it would have been been helpful, but I think the person that I am if if I'm quite hard headed so it's that thing of going to [hospital] and need, at that point I was desperate for someone to talk to and someone listened to me and someone to tell me you know what you're thinking is okay.	Needed someone to tell her that what she was thinking was ok	Emotional support not provided
681			
682	[00:38:21] Speaker 1: Yes.		
683			
684	[00:38:21] Speaker 2: What you're thinking is fine.		
685			
686	[00:38:23] Speaker 2: You know it's, you're where you are because of of what's happened. You're not being a drama queen because that that's how I felt by the hospital. Like I was a huge drama queen and I need to just calm down and just get on with things so.	Needed to be told she wasn't being a drama queen Hospital made her feel like a drama queen	Relationship with healthcare team - unsupportive Emotional support not provided
687			
688	[00:38:40] Speaker 2: I just the person that I am is if I don't get the responses that I need, then I just shut down and then that's it. I you know.	Shut down after not getting support needed	
689			
690	[00:38:54] Speaker 2: To let people at the beginning let that out and talk.	Needed someone to talk to early on	Emotional support not provided
691			
692	[00:38:59] Speaker 2: And and guide people through that that beginning bit because it's crucial, I think.	Thinks guiding through the beginning is crucial	No initial support after diagnosis
693			

An excerpt from Ann's interview, where Ann is 'Speaker 2'.



	Initial meaning	Code
[00:07:31] Speaker 1: If we start with, please could you tell me about your experience of being under watch and wait?		
[00:07:38] Speaker 2: Yes, urm I think you you feel very much on your own.	WW feels very much on your own	WW is lonely
[00:07:45] Speaker 2: Because.		
[00:07:46] Speaker 2: As you say, it's watch and wait, you're not starting any treatment.		
[00:07:51] Speaker 2: And especially for me, I think because we went through this with my father.	Father had blood cancer	Prior knowledge and understanding of cancer from family member
[00:07:58] Speaker 2: And they said all the same things to him, you know. This is the long, slow disease, and it's no more than high blood pressure. And then he died of CLL	Father told not to worry about HC, then died of it	Prior knowledge and understanding of cancer from family member
[00:08:11] Speaker 2: So of course when they told me all the same things I was thinking, yeah right I've heard this before. Yeah, you know.	Had heard about WW before and didn't work for dad	Prior knowledge and understanding of cancer from family member
[00:08:20] Speaker 1: Yeah, so you already had some experience and understanding from your dad?		
[00:08:25] Speaker 2: Yes and I did realise I did trust them and realise from what they said that treatment had moved on.	Had to learn to trust the doctors	Relationship with healthcare team - has trust
[00:08:31] Speaker 1: Okay.		
[00:08:32] Speaker 2: But then, once you've had that initial interview, that was it. You're on your own, and I think the thing that helped me was they pointed me	After initial interview, you're on your own	WW is lonely
[00:08:42] Speaker 2: to the health unlocked CLL forum. They said there's lots of things online and I've found that	Online forum group helpful Directed to online forum group by NHS	Information needs met by online forum
[00:08:51] Speaker 2: And it's been great.		
[00:08:52] Speaker 1: So, is it like an online support group?		
[00:08:56] Speaker 2: Yes, yes, and there's lots and lots of questions asked and they answer everything and.	People on the forum answer questions	Information needs met by online forum
[00:09:04] Speaker 2: People there that have had it for years and what the latest treatment is abd anything you can think of, they've usually had or it's on there.	People on forum have experience with treatments	Information needs met by online forum

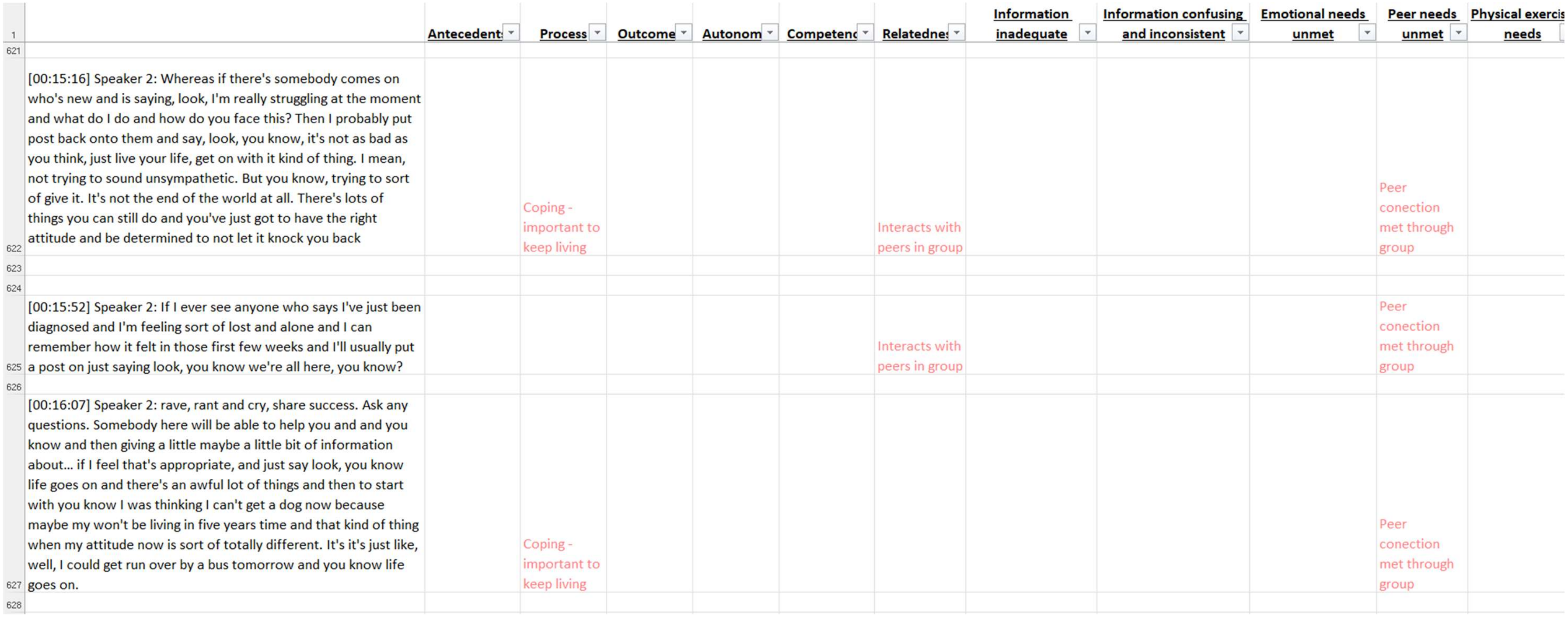
Appendix M: Excerpt from the POLA analysis



	T1	T2	What changes have occurred over the last six months and what factors are associated with this change?
Karen	Comparisons of cancer diagnoses	Poor communication with healthcare - felt dismissed	Important to move forward with living after covid - less fearful of Covid
	Communication with healthcare team - felt dismissed	Relationship with healthcare team - poor	Considered importance of exercise
	Health information needs met by charities	No new emotional or informational support offered	
	Health information needs met by healthcare team	Responsible for own healthcare	
	Health information needs not met by GP	Vaccines help feel protected	
	If your bloods are fine, they think you're fine	Taking covid precautions	
	Impact of covid - feels unsafe	Lack of understanding of vulnerability from society	
	Impact of covid - lost job	Lack of trust in healthcare	
	Impact of covid - stopped being able to live normal life	Important to exercise	
	Impact of covid - struggling financially	Whatsapp group support information needs	
	Information needs met through Whatsapp group support	Charities provide many kinds of support	
	Lack of trust in doctor	If bloods are fine, you're seen as fine	
	Lack of understanding of diagnosis by husband	Uncertainty is difficuly	
	Lack of understanding of diagnosis in public		
	Lack of understanding of dx by consultant		
	No holistic care		
	No named support at hospital		
	No one to talk to about cancer		
	No psychological support offered		
	Peer connection provided through online groups		
	Relationship with healthcare team - poor		
	Responsibility for own health needs on WW		
	Uncertainty is difficult		
Belle	A need to be an expert in condition	Fearful of covid	More fearful of covid
	Annual scan has helped cope with uncertainty	Let down by government	Increasing sense of being abandoned/let down by society after covid
	Communication between healthcare systems	Responsible for own healthcare	Important to move forward to continue living after covid
	Communication with healthcare	Information needs met through online groups	
	Comparison to people in treatment	Comparison to other healthcare systems	
	Comparison with other cancers	Taking covid precautions	
	Differences in treatment across healthcare systems	Attempts to live normal life	
	GP lacks knowledge of diagnosis	Society moving forward from Covid	
	Has supportive friends	Let down by world	
	Health information needs met by charity	Battling government for healthcare	
	Health information needs not met by healthcare	Peer connection through charity	
	Information needs met through charities	Supports peers in WW journey	
	Is pain cancer or something else?	Lack of understanding of diagnosis	
	Lack of action in WW	Let down by healthcare	
	Lack of trust in doctors	Information needs not met	
	Lack of understanding of WW in public	Need to be an expert in own condition	
	Little family support	Communication with healthcare team	
	Need to be an expert in condition	Relationship with GP	
	No CNS	No named support	
	No concern for psychological health	Information needs met through charities	
	Peer connection needs met through online groups	Cancer affects everywhere	
	Prepared for battle with healthcare	Lack of support under WW	
	Protected family from diagnosis	Covid made psychological battle worse	
	Responsible for own health needs - would rather not be	Psychological battle of WW	
	Sense of abondonement in WW	Important to continue living life	
	Uncertainty is difficult	Sense of abandoned	
	Unequipped observer for symptoms		
	Weary of covid risks		

Appendix N: Excerpt from deductively coded transcript

An excerpt from Olivia's second interview, where Olivia is 'Speaker 2'



1		Antecedent	Process	Outcome	Autonom	Competenc	Relatedne	Information inadequate	Information confusing and inconsistent	Emotional needs unmet	Peer needs unmet	Physical exercis needs
621												
622	[00:15:16] Speaker 2: Whereas if there's somebody comes on who's new and is saying, look, I'm really struggling at the moment and what do I do and how do you face this? Then I probably put post back onto them and say, look, you know, it's not as bad as you think, just live your life, get on with it kind of thing. I mean, not trying to sound unsympathetic. But you know, trying to sort of give it. It's not the end of the world at all. There's lots of things you can still do and you've just got to have the right attitude and be determined to not let it knock you back		Coping - important to keep living				Interacts with peers in group				Peer conection met through group	
623												
624												
625	[00:15:52] Speaker 2: If I ever see anyone who says I've just been diagnosed and I'm feeling sort of lost and alone and I can remember how it felt in those first few weeks and I'll usually put a post on just saying look, you know we're all here, you know?						Interacts with peers in group				Peer conection met through group	
626												
627	[00:16:07] Speaker 2: rave, rant and cry, share success. Ask any questions. Somebody here will be able to help you and and you know and then giving a little maybe a little bit of information about... if I feel that's appropriate, and just say look, you know life goes on and there's an awful lot of things and then to start with you know I was thinking I can't get a dog now because maybe my won't be living in five years time and that kind of thing when my attitude now is sort of totally different. It's it's just like, well, I could get run over by a bus tomorrow and you know life goes on.		Coping - important to keep living								Peer conection met through group	
628												

Appendix O: Excerpts from reflexive diary

Delia – T1 – row 272

> *“If there's anything you could put in your paper about junior doctors. I think they're getting their trained too quickly. Now they have no idea. I don't think... I think they should be sitting in listening”*

This is raising an ethical difficulty for me as I know I can’t just put everything that comes up in the write-up, but her experiences with junior doctors seem to be central to her poor experiences of healthcare. What unmet needs is this representing? Lack of trust in junior doctors?

Noel – T1 – row 1175

> *“All the doctors here are whatever race they are, but you can't find an English doctor. That concerns me. I phoned up for an appointment with the Doctor the other day. Now they say to phone up at 8:00 o'clock in the morning. So I rang at 8:00 o'clock in the morning. Then I was 39th in the queue”*

I found this interview the most challenging so far. Some of the difficulties Noel spoke about, such as difficulty getting a GP appointment, I have experienced myself and I know how frustrating it is. However, in this bit and others, he seems to attach the meaning that this was related to his doctors not being English. He didn’t give any reason for making this link and so this made me consider that this link was perhaps associated to his own beliefs and views of the world, and I found this very uncomfortable. I found it difficult to continue navigating the interview around this and I have reflected on this again whilst I coding this part of the interview.

Frank – T2 – row 561

> *“You know, you see these guys on video. Well, not just men. Women as well, saying how wonderful they are now. Their light chains right down and it's not a problem at all. So, yeah, I think I do. I do feel a little bit. Are we doing the right thing here? But there's nothing I can do about it”*

Frank spoke a lot about the protocols and treatments available in other countries, and how in e.g., America he may well have received treatment by now. This reinforced my understanding of how needs will likely be quite dependent on the individual’s local healthcare system, but also how peer support might be impacted if Facebook groups are global. From the last bit of this quote and the tone of the interview, I was getting a sense that Frank has almost resigned to being powerless in this situation. I think this is relating to autonomy – a lack of it.

Ian – T2 – row 854

> *“We now live in a time where it really feels like society has kind of written us off, like we’re an acceptable loss. It almost feels like they want us to die because we are expensive. I mean, my drug costs thousands each month, you know, and so if I die, they don’t have to pay that anymore and they won't have to pay for any expensive treatments in the future”*

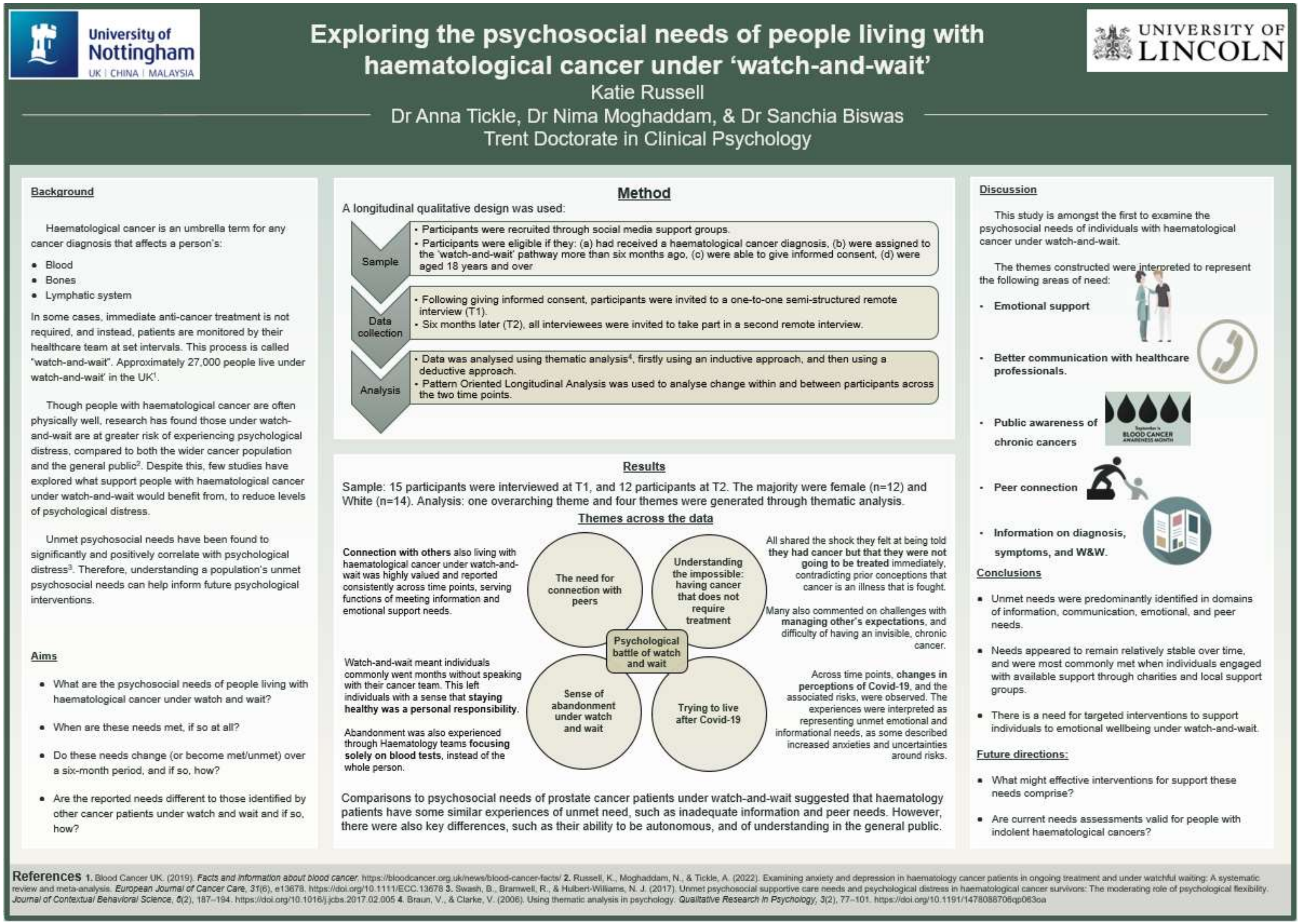
I think the fact that Ian is an ex-NHS doctor himself makes these opinions even more powerful. I wonder if having worked in the NHS almost makes these needs to feel cared for even more prominent? The fact that he has an understanding of the NHS and the people who work in it makes me very sad that he still feels this way. I wondered whether there was something here about how a person’s relationship with their healthcare team/the healthcare system may impact their processing and making sense of their treatment and diagnosis, but there doesn’t seem to be a domain for considering the patient’s relationship with their healthcare team in the PACID.

Appendix P: Checklist for good reflexive TA (Clarke & Braun, 2022)

Process	No.	Criteria	Researcher response
Transcription	1	Data has been transcribed to an appropriate level of detail; all transcripts have been checked against the original recordings for ‘accuracy’.	Yes – all transcripts were transcribed verbatim using an automated transcript service. Each transcription was concurrently listened to, read, and corrected, to ensure accuracy.
Coding and theme development	2	Each data item has been given thorough and repeated attention in the coding process.	Yes – all data was coded using an iterative process of coding and recoding each transcript.
	3	The coding process has been thorough, inclusive, and comprehensive; themes have not been developed from a few vivid examples (an anecdotal approach).	Yes – themes were constructed following coding the entire dataset and following a process of moving back and forth between code labelling and theme generation.
	4	All relevant extracts for each theme have been collated.	Yes – collated onto a Microsoft Word document.
	5	Candidate themes have been checked against coded data and back to the original dataset.	Yes – candidate themes were checked against the coded data, the original dataset, and were discussed in the research team.
	6	Themes are internally coherent, consistent, and distinctive; each theme contains well-defined central organising concept; any subthemes share the central organising concept of the theme	Yes – themes were checked for internal coherence and distinctiveness with the research team. Subthemes were carefully constructed to ensure they were centred around the theme.
Analysis and interpretation	7	Data have been *analysed* – interpreted, made sense of – rather than just summarised, described, or paraphrased.	Yes – evidenced in the write-up.

	8	Analysis and data match each other – the extracts evidence the analytic claims.	Yes – evidenced in the write-up.
	9	Analysis tells a convincing and well-organised story about the data and topic; analysis addresses the research question.	Yes – evidenced in the write-up. The analysis produced an understanding of what unmet needs individuals have, the factors that influence them becoming met/unmet, and the extent to which the needs map onto those reported in other watch-and-wait populations.
	10	An appropriate balance between analytic narrative and data extracts is provided.	Yes – a ratio of 50:50 was used, as recommended by Clarke and Braun (2022).
Overall	11	Enough time has been allocated to complete all phases of the analysis adequately, without rushing a phase, or giving it a once-over-lightly (including returning to earlier phases or redoing the analysis if need be).	Yes – extensive time was taken over each stage of analysis, with KR conferring with the research team between each stage to discuss the process and progress.
Written report	12	The specific approach to thematic analysis, and the particulars of the approach, including theoretical positions and assumptions, are clearly explicit.	Yes – evidenced in the write-up.
	13	There is a good fit between what was claimed, and what was done – i.e., the described method and reported analysis are consistent.	Yes – evidenced in the write-up.
	14	The language and concepts used in the report are consistent with the ontological and epistemological positions of the analysis.	Yes – evidenced in the write-up.
	15	The researcher is positioned as *active* in the research process, themes do not just ‘emerge’.	Yes – themes were described as “constructed” and “generated” by the researcher.

Poster



Exploring the psychosocial needs of people living with haematological cancer under 'watch-and-wait'

Katie Russell
Dr Anna Tickle, Dr Nima Moghaddam, & Dr Sanchia Biswas
Trent Doctorate in Clinical Psychology

Background

Haematological cancer is an umbrella term for any cancer diagnosis that affects a person's:

- Blood
- Bones
- Lymphatic system

In some cases, immediate anti-cancer treatment is not required, and instead, patients are monitored by their healthcare team at set intervals. This process is called "watch-and-wait". Approximately 27,000 people live under watch-and-wait' in the UK[1].

Though people with haematological cancer are often physically well, research has found those under watch-and-wait are at greater risk of experiencing psychological distress, compared to both the wider cancer population and the general public[2]. Despite this, few studies have explored what support people with haematological cancer under watch-and-wait would benefit from, to reduce levels of psychological distress.

Unmet psychosocial needs have been found to significantly and positively correlate with psychological distress[3]. Therefore, understanding a population's unmet psychosocial needs can help inform future psychological interventions.

Aims

- What are the psychosocial needs of people living with haematological cancer under watch and wait?
- When are these needs met, if so at all?
- Do these needs change (or become met/unmet) over a six-month period, and if so, how?
- Are the reported needs different to those identified by other cancer patients under watch and wait and if so, how?

Method

A longitudinal qualitative design was used:

Sample
- Participants were recruited through social media support groups.
- Participants were eligible if they: (a) had received a haematological cancer diagnosis, (b) were assigned to the 'watch-and-wait' pathway more than six months ago, (c) were able to give informed consent, (d) were aged 18 years and over

Data collection
- Following giving informed consent, participants were invited to a one-to-one semi-structured remote interview (T1).
- Six months later (T2), all interviewees were invited to take part in a second remote interview.

Analysis
- Data was analysed using thematic analysis[4], firstly using an inductive approach, and then using a deductive approach.
- Pattern Oriented Longitudinal Analysis was used to analyse change within and between participants across the two time points.

Results

Sample: 15 participants were interviewed at T1, and 12 participants at T2. The majority were female (n=12) and White (n=14). Analysis: one overarching theme and four themes were generated through thematic analysis.

Themes across the data

Psychological battle of watch and wait

The need for connection with peers

Understanding the impossible: having cancer that does not require treatment

Sense of abandonment under watch and wait

Trying to live after Covid-19

Connection with others also living with haematological cancer under watch-and-wait was highly valued and reported consistently across time points, serving functions of meeting information and emotional support needs.

All shared the shock they felt at being told **they had cancer but that they were not going to be treated** immediately, contradicting prior conceptions that cancer is an illness that is fought.

Many also commented on challenges with **managing other's expectations**, and difficulty of having an invisible, chronic cancer.

Watch-and-wait meant individuals commonly went months without speaking with their cancer team. This left individuals with a sense that **staying healthy was a personal responsibility**.

Abandonment was also experienced through Haematology teams **focusing solely on blood tests**, instead of the whole person.

Across time points, **changes in perceptions of Covid-19**, and the associated risks, were observed. The experiences were interpreted as representing unmet emotional and informational needs, as some described increased anxieties and uncertainties around risks.

Comparisons to psychosocial needs of prostate cancer patients under watch-and-wait suggested that haematology patients have some similar experiences of unmet need, such as inadequate information and peer needs. However, there were also key differences, such as their ability to be autonomous, and of understanding in the general public.

Discussion

This study is amongst the first to examine the psychosocial needs of individuals with haematological cancer under watch-and-wait.

The themes constructed were interpreted to represent the following areas of need:

- **Emotional support**
- **Better communication with healthcare professionals.**
- **Public awareness of chronic cancers**
- **Peer connection**
- **Information on diagnosis, symptoms, and W&W.**

Conclusions

- Unmet needs were predominantly identified in domains of information, communication, emotional, and peer needs.
- Needs appeared to remain relatively stable over time, and were most commonly met when individuals engaged with available support through charities and local support groups.
- There is a need for targeted interventions to support individuals to emotional wellbeing under watch-and-wait.

Future directions:

- What might effective interventions for support these needs comprise?
- Are current needs assessments valid for people with indolent haematological cancers?

References **1.** Blood Cancer UK. (2019). *Facts and information about blood cancer.* https://bloodcancer.org.uk/news/blood-cancer-facts/ **2.** Russell, K., Moghaddam, N., & Tickle, A. (2022). Examining anxiety and depression in haematology cancer patients in ongoing treatment and under watchful waiting: A systematic review and meta-analysis. *European Journal of Cancer Care, 31*(6), e13678. https://doi.org/10.1111/ECC.13678 **3.** Swash, B., Bramwell, R., & Hulbert-Williams, N. J. (2017). Unmet psychosocial supportive care needs and psychological distress in haematological cancer survivors: The moderating role of psychological flexibility. *Journal of Contextual Behavioral Science, 6*(2), 187–194. https://doi.org/10.1016/j.jcbs.2017.02.005 **4.** Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77–101. https://doi.org/10.1191/1478088706qp063oa

Small-Scale Research Project

An evaluation of trauma-informed care training delivered to staff in Older Adult Mental Health Services.

Abstract

Objective

By older adulthood, the majority of individuals will have experienced at least one traumatic event. Trauma-informed care (TIC) is proposed to improve effectivity of healthcare provision and to reduce likelihood of services causing retraumatisation. The present evaluation aimed to assess the effectiveness of staff training in TIC in Older Adult services.

Methods

TIC training was delivered to five Older Adult Community Mental Health Teams in the same UK organisation. Questionnaires were administered before and after training: a psychometrically robust measure, the ARTIC-10, was used to assess TIC-related attitudes, and a service-developed scale was used to measure changes in TIC competence. Qualitative data regarding the impact of training was gathered one month after training through a free-text questionnaire.

Results

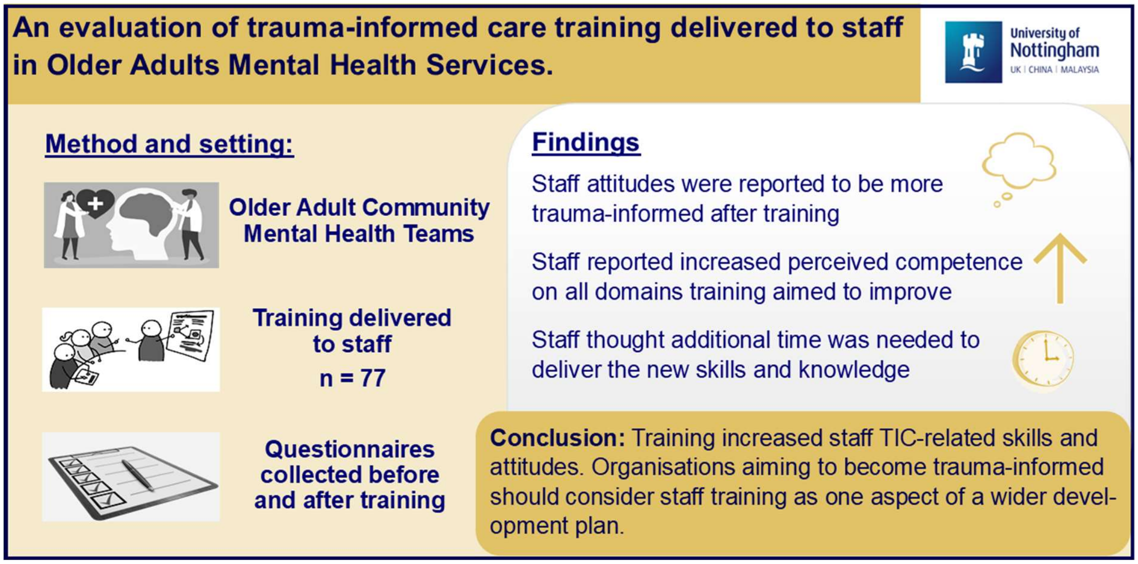
Linear mixed effects modelling on pre and post data revealed that staff training significantly increased competencies across all measured TIC domains. Overall, staff attitudes were also significantly more trauma-informed after training. Qualitatively, staff identified time as the only additional resource required to deliver the skills and knowledge gained from training.

Conclusion

Training was found to be effective in increasing TIC-related skills and attitudes. Organisations aiming to become trauma-informed should consider staff training as one aspect of a wider development plan.

Key words: older adults, trauma-informed care, retraumatisation, staff training, evaluation.

Graphical abstract



An evaluation of trauma-informed care training delivered to staff in Older Adults Mental Health Services.

Method and setting:

Older Adult Community Mental Health Teams

Training delivered to staff
n = 77

Questionnaires collected before and after training

Findings

Staff attitudes were reported to be more trauma-informed after training

Staff reported increased perceived competence on all domains training aimed to improve

Staff thought additional time was needed to deliver the new skills and knowledge

Conclusion: Training increased staff TIC-related skills and attitudes. Organisations aiming to become trauma-informed should consider staff training as one aspect of a wider development plan.

Introduction

Research supporting the link between experiencing trauma and subsequent difficulties in mental health has grown considerably in recent years (Garfin et al., 2018). Longitudinal research has found that those who have disclosed trauma are two times more likely to report symptoms of depression and anxiety, three times more likely to experience psychosis, and eight times more likely to attempt suicide (Lewis et al., 2019). Understanding of what constitutes trauma has also developed, with definitions broadly incorporating the objective and subjective perceptions of single events (e.g., car accident), ongoing events (e.g., childhood abuse), and societal experiences (e.g., racism, poverty) (Sweeney et al., 2016).

It is estimated that up to 90% of the older adulthood population (aged 65 years and above) have experienced at least one traumatic event during their lifetime (Kuwert et al., 2013). Those who are now older adults (OAs) lived through or experienced life following World War II; a time associated with huge loss, forced displacement, and persistent fear (Strauss & Schmidt, 2009). Further, there was the significant impact on marginalised populations, such as Jewish people, targeted in the Holocaust. Studies examining the impact of exposure to WWII in childhood report greater subsequent psychological distress in older adulthood (Waugh et al., 2007), greater reporting of somatoform symptoms, and increased prevalence of post-traumatic stress disorder (PTSD) (Freitag et al., 2013). Another example of societal trauma affecting those now entering OA services is the “Windrush scandal”; a case of institutional racism that resulted in thousands of individuals being denied their rights to live and work in the UK (Williams, 2020). Most recently, the Covid-19 pandemic presented further psychological challenges for OAs. Media reports became rife with ageism, with articles widely implying OAs were vulnerable and burdensome to society (D’cruz & Banerjee, 2020).

Research examining OAs’ understanding of the significance of psychological trauma found OAs were more likely to regard adversity as ‘just part of life’ and less likely to seek support or disclose experiences (Hiskey & McPherson, 2013). This may in part be due to PTSD not being officially recognised in diagnostic systems until the 1980s (American Psychiatric Association, 1980). Consequently, the impact of trauma in OAs can be mislabelled as being part of the “typical” aging process (e.g., losing a partner) or misunderstood as a seemingly irrelevant distant past event (e.g., being evacuated) (Kusmaul & Anderson, 2018). Such oversights can reduce clinician understanding and could lead to clinicians underestimating the relevance of past traumas to current presentations.

Services that do not inherently consider the impact of trauma are at risk of causing retraumatisation (Sweeney et al., 2016): a process whereby something in the present triggers re-experiencing of a past trauma. Retraumatisation in healthcare has been found to occur when individuals feel a lack of autonomy and power, for example, in situations such as medical prescribing (Sweeney & Taggart, 2018). More recent research has found retraumatisation can also occur when trauma-uninformed services conceptualise societal trauma, such as experiences of racism, as an individual’s responsibility or pathology, as opposed to a wider community issue (Grossman et al., 2021). The increased understanding around the risks of mental health services causing retraumatisation has led to emphasis being placed on the importance of services providing trauma-informed care (TIC) (Grossman et al., 2021). Despite increased attention, definitions of TIC remain broad and vary across the literature. NHS Education for Scotland (NES) (2017), who are arguably pioneers for organisation-wide TIC delivery in the UK, define TIC as being underpinned by abilities to:

1. Understand how frequently trauma and adversity are experienced.
2. Understand the many ways trauma can affect people.
3. Appropriately respond to accounts of trauma and support recovery.
4. Avoid retraumatisation through providing safety, offering choice, and encouraging collaboration and empowerment with all service users and staff members.
5. Understand that building relationships are of central importance.

This definition can be operationalised through trauma-informed services functioning on the assumption that people accessing support *may* have experienced trauma, and therefore, delivering care through approaches that engender safety, trust, and use methods that reduce likelihood of retraumatisation (Sweeney et al., 2016). It is important to note that this definition of TIC does not assume that *all* service users have experienced trauma, or that traumatic experiences are the cause of *all* distress. Instead, it implies that trauma-informed services should provide all service users with accessible, high quality healthcare (Sweeney & Taggart, 2018).

TIC Staff training

One concrete and measurable approach to implementing TIC is through staff training; a method that has been found to increase routine enquiry into trauma histories, empower service users, and improve therapeutic relationships (Oral et al., 2015). A recent examination of encouraging provision of TIC through training staff in primary care settings found staff reported increased conversations around trauma, its impacts, and how their service models could be adapted to be more trauma-informed (Levine et al., 2020). Participants further noted the importance of interprofessional training to facilitate these conversations, as opposed to specialised training for frontline clinicians only. Only increasing frontline staff's TIC knowledge and skill has been found to have limited success in establishing change at the organisational level (Lovell et al., 2022). Instead, offering training to staff across an organisation, from both clinical and non-clinical disciplines, has been identified as a key ingredient in creating system-wide change (Menschner & Maul, 2016).

Despite the evidence suggesting its benefits, documents recommending staff training in TIC are vague (Sweeney & Taggart, 2018). Further, research exploring TIC in OA services is scarce. The lack of practical guidance has resulted in services developing their own TIC training packages, and consequently, the quality and effectiveness of such training has been found to vary. A review of 23 studies evaluating TIC staff training in organisations globally found great variability in training design and methodology and consequently, effectiveness (Purtle, 2018). Across studies, the duration of TIC training ranged from an hour to multiple days, and evaluation methodologies varied (single and multiple group pre-/post-test, and randomised controlled trials). A second challenge identified in evaluating TIC training pertains to the lack of a gold standard measure of TIC attitudes, knowledge, and skills (Thirkle et al., 2021). This has resulted in studies reporting outcomes based on a variety of measures, making comparisons across training designs difficult and questioning the reliability of the reported findings (Purtle, 2018).

Across the literature, there are similarities reported in the components covered by TIC training, including: definitions of trauma, psychological and physiological impacts of trauma, risks around retraumatisation of clients, and skills in discussing trauma (Purtle, 2018). Despite this, variability in effectiveness has remained. Arguably, there is a need to continue evaluating the effectiveness of training at the service level, particularly in underrepresented providers such as OA services, and publishing details on training design, content, and findings, to improve understanding of how organisations can develop effective TIC training.

The local context

TIC staff training was developed in response to the organisation’s goal of adopting a trauma-informed culture by 2022, an aim in line with wider national policies stating that Community Mental Health Teams (CMHTs) should become trauma-informed services (NHS England, 2019). Consequently, Clinical Psychologists working in the organisation developed tailored TIC workshops for all staff working across Adult and OA CMHTs. The facilitators requested an evaluation of the training to inform the development of the programme, with the hope of expanding the delivery across the organisation. Due to previously discussed cohort effects, it was deemed important to complete evaluation of training in Adult and OA teams independently. Therefore, the present review has focused on training delivered to five OA teams.

Aims:

The study aimed to evaluate the TIC staff training workshops by:

1. Examining whether TIC training changed staff attitudes surrounding trauma and trauma-informed care.
2. Measuring the extent to which staff improved in TIC-related competencies, as agreed upon by the facilitators.
3. Exploring whether, and if so, how, the training influenced staff clinical practice in the month following the training.

Method

The evaluation was approved and supported by the organisation, and best practice guidelines were followed throughout: staff were informed of the evaluation and its aims, to ensure informed consent, and participants were clearly advised that participation was anonymous and voluntary (NIHR, 2017). Formal ethical approval was not sought as the evaluation was undertaken as part of planned organisational development. Principles of RE-AIM were followed when designing the evaluation (Glasgow et al., 2019).

Participants

Training was delivered in five OA CMHTs operating across a Midlands NHS Trust. Voluntary participation in training was open to all staff working in the organisation and comprised staff members from across disciplines: Nursing, Psychology, Support Work, Managerial, Occupational Therapy, Administration, and Psychiatry. The training was delivered five times, once to each team, between November 2021 and May 2022. The total number of participants who attended the training was 77.

Measures

Participants were asked to complete the Human Services version of the Attitudes Related to Trauma-Informed Care short form (ARTIC-10) (Baker et al., 2016) before and after training. The ARTIC-10 contains ten questions aimed at measuring staff attitudes across different TIC-related domains (please see Table 3 notes). The ARTIC-10 was deemed most suitable following a review of the available psychometrically evaluated tools measuring TIC (Thirkle et al., 2021). The ARTIC-10 has demonstrated acceptable internal consistency (Cronbach's $\alpha = 0.82$) and strong test-retest reliability at three months ($r = 0.82$) (Baker et al., 2016).

A second questionnaire was developed by the training facilitators to measure perceived confidence on competencies the training was designed to address. Before and after training, participants were asked to rate their knowledge and skill level on each competency via an 11-point Likert scale (whereby a rating of zero inferred no knowledge and skill, and ten inferred well-developed knowledge and skill).

Finally, a follow-up questionnaire was sent one month after training completion to capture the extent to which staff had begun implementing the training in clinical practice. The questionnaire comprised three questions exploring the uptake of skills and knowledge, resources required/any barriers, and staff perceptions of effectiveness in clinical practice. A free-text box accompanied each question to allow staff to answer in as much detail as they wished.

Training

Clinical Psychologists working across the organisation identified an outstanding need in staff knowledge and skills of working with people who have experienced trauma. Whilst the organisation had identified the goal of becoming "trauma-informed", no training was available through the organisation, and therefore, facilitators began developing a TIC programme. The training content was predominantly informed by the core TIC competencies identified in the NHS Scotland Transforming Psychological Trauma: Knowledge and Skills Framework (NES, 2017). Please see Table 1 for a detailed breakdown of the training content.

Table 1

Training programme content based on a framework by NES (2017)

	Topics covered
Session 1	
Prevalence and effects of early trauma	Definitions of trauma, prevalence, exacerbating factors, trauma in OAs, trauma and the impact on the brain and memories, impact of trauma on homeostasis, attachment trauma, complex trauma, relational indicators of trauma, impact of trauma at each life stage.
Assessment	Trauma-informed assessment, considerations for OAs and cohort differences, barriers to asking about trauma, methods of approaching assessment, self-care during assessment, therapeutic relationship factors (creating a sense of safety and trust, working collaboratively, and offering choice).
Formulation	Formulation models: making sense of the impact of early trauma using case examples.
Session 2	
Intervention	Psychoeducation on impact of trauma on the brain, recovery from trauma and post-traumatic growth, top down (cognitive-based) and bottom-up (body-based) approaches, recognising common triggers for retraumatisation, mindfulness, compassion skills, grounding skills.
Trauma and dementia	Supporting people with dementia, importance of relationships, control, and choice.
Therapeutic relationship	Importance of therapeutic relationships, building relationships, maintaining relationships, and managing resistance.
Retraumatisation within services	Examples given of when retraumatisation can occur, ruptures in relationships, managing endings, self-care, self-care recourses.

Procedure

Training was delivered by three Clinical Psychologists working in the OAs service. Due to ongoing Covid-19 restrictions, all training sessions were delivered remotely. Web links to the competency questionnaire and the ARTIC-10 were disseminated electronically before beginning and immediately following training completion. One month after the training was completed, participants were emailed the follow-up questionnaire. To ensure participant anonymity, all questionnaires were completed via the organisation's online anonymous survey platform, where results were password protected. Participants were asked to create a personal identifier to allow pre and post data to be linked. Personal identifiers would have also allowed individuals' data to be identified should anyone have wished for their responses to be removed from the study.

Analysis

Data analyses were conducted on IBM SPSS Statistics (Version 27) predictive analytics software. Linear mixed effects modelling (LMM) has been reported as a robust method for analysing repeated measures data due to its ability to handle missing information, consequently increasing power (Meteyard & Davies, 2020). Therefore, LMM was chosen as an alternative to a t-test or an Analysis of Variance. LMMs were used to measure the impact of training on changes in scores on the ARTIC and on each competency of the competency questionnaire. LMMs were built to include fixed effects of time (i.e., pre and post) and random effects of participant intercepts. Maximum Likelihood Estimations were used to obtain estimates of missing data, enabling all data from individuals to be analysed, including those who missed a time point (Enders, 2005). The Satterthwaite adjustment was used to calculate degrees of freedom. To explore the magnitude of the effect, effect sizes were computed through Cohen's d (Cohen, 1988).

Paired pre and post ARTIC scores were also subjected to individual change analysis to evaluate variations in individual's pre and post scores. The extent to which individual change was greater than expected within measurement imprecision was computed using the Reliable Change Index (RCI) (Jacobson & Truax, 1991).

Qualitative data gathered at one month follow up was evaluated through content analysis, following guidance by Elo and Kyngäs (2008).

Results

Responses to demographic information was poor, with only 45 out of 77 invited participants (58.4%) opting to complete the information. Across the five teams training was delivered to, there were no observed differences in demographic information. Table 2 details the demographic data collected.

Table 2

Demographic information

	Total (%)
Age	
16-25 years	2 (4.4)
26-35 years	10 (22.2)
36-45 years	15 (26.7)
46-55 years	16 (35.6)
56-65 years	2 (4.4)
Ethnicity	
White British	45 (100.0)
Staff group	
Nursing	34 (75.6)
Support	4 (8.9)
Psychology	3 (6.7)
Administration	1 (2.2)
Occupational therapy	3 (6.7)

Before beginning modelling, analyses of skewness and kurtosis were conducted, and it was concluded that the distribution of both ARTIC scores and individual competency scores were approximately normally distributed (Kline, 2011). For all outcome measures, histogram plots of residuals were examined and found to be normal. Therefore, linear mixed modelling was considered suitable for analyses and best practice guidance was followed (Meteyard & Davies, 2020).

Attitudes related to TIC

In total, 44 participants (57.1%) completed the ARTIC questionnaire pre and post training, with an additional 12 participants completing only the pre-training questionnaire and 2 participants completing only the post-training questionnaire. Table 3 displays descriptive statistics for responses to the ARTIC questionnaire. The overall average score increased by 7.7%, from 5.61 (SD = 0.94) to 6.15 (SD = 0.83), out of a maximum score of 7.

Results of the LMM for ARTIC scores indicated a significant effect of time ($F_{1, 101.54} = 9.42$, $p < .01$), revealing participants reported a significant improvement in their attitudes towards TIC after training, with medium effect (Cohen's $d = 0.60$). The main effect of team was not significant ($F_{4, 101.27} = 1.89$, $p = .12$), suggesting that there were no meaningful differences between the five teams in terms of their attitudes towards TIC either prior to or after training. Further, the interaction between time and team was not significant, indicating all teams showed improvements of a similar magnitude.

At the item level, participants reported significant changes on items relating to client responses to trauma and staff acceptance of complex presentations in people who have experienced trauma (items 1, 3, 4, 6 and 8). The improvements in the remaining items were not significant, suggesting no practical improvement in attitudes was gained. Observationally, least change was observed on attitudes regarding approaches to working with people who have experienced trauma, and staff burnout (items 2 and 9 respectively). Please note, exact wording of items has not been given due to copyright.

Table 3.

Descriptive statistics and comparisons of pre- and post- ARTIC scores

ARTIC	**Pre-training (n = 56) Mean (SD)**	**Post-training (n = 46) Mean (SD)**	**Pre- to post-change *p***	**Effect size *Cohen's d***
Total average	5.61 (0.94)	6.15 (0.83)	< .01*	0.60
Item 1	5.13 (2.00)	6.17 (1.42)	< .01*	0.60
Item 2	5.91 (1.79)	6.17 (1.58)	< .44	0.16
Item 3	5.54 (1.58)	6.33 (0.99)	< .01*	0.59
Item 4	5.61 (1.38)	6.20 (1.00)	< .05*	0.48
Item 5	5.59 (1.69)	6.04 (1.62)	< .17	0.27
Item 6	5.50 (1.53)	6.11 (1.42)	< .05*	0.41
Item 7	5.48 (1.60)	6.11 (1.25)	< .09	0.34
Item 8	6.13 (1.38)	6.54 (1.05)	< .05*	0.43
Item 9	5.64 (0.98)	5.63 (1.60)	< .96	0.01
Item 10	5.61 (1.50)	6.15 (1.33)	< .06	0.38

Notes: n = number of participants; SD = standard deviation, **p* values of less than 0.05 were considered significant. Items related to the following trauma-informed principles: understanding client responses to trauma (1), focusing on developing healthy relationships with clients who have experienced trauma (2), understanding clients' behaviour in the context of trauma (3), understanding the job role (4), sharing work-related stress with colleagues (5), understanding clients will have different responses on different days in the context of trauma (6), the importance of experiencing healing relationships (7), understanding client behaviour in the context of trauma (8), avoiding burnout (9), importance of recognising the impact of working with individuals who have experienced trauma on oneself (10).

At the individual-level analysis, RCI calculations indicated that 7/44 participants (15.9%), who completed both pre and post questionnaires, reported a reliable improvement in TIC attitudes, as indicated by increased scores from pre to post. No individuals reported a reliable decline in scores.

TIC-related competencies

In total, 35 participants (45.5% response rate) completed the competency scale pre and post training, with an additional 13 participants completing only pre-training data, and 18 participants completing only post-training data. Table 4 displays descriptive statistics for scores on each competency on the scale.

The LMMs showed a significant effect of time on each competency, indicating participants perceived competence increased in all seven domains after training (see Table 4). Large effect sizes were found on all changes in perceived competence, with the strongest effect on competence around managing endings with service users who have experienced trauma.

Again, no significant effect of team membership was found on any of the seven competencies, indicating that perceived TIC competency was relatively consistent across teams in the organisation. Further, the interaction between team and time was not significant, suggesting that team membership did not influence the effectiveness of the training.

Table 4.

Descriptive statistics for pre- and post- scores on the competency scale

Competency	**Pre-training (n = 48) Mean (SD)**	**Post-training (n = 53) Mean (SD)**	***F***	***p***	**Cohen's *d***
1. Prevalence of trauma	5.02 (2.11)	7.62 (1.69)	46.59	<.001*	1.37
2. The threat system	4.46 (2.42)	7.64 (1.81)	55.55	<.001*	1.94
3. Long-term effects of trauma	5.40 (2.07)	7.89 (1.63)	45.25	<.001*	1.35
4. Recognition and assessment of trauma in OAs	4.40 (1.92)	7.44 (1.85)	66.34	<.001*	1.61
5. Impact of trauma	5.19 (2.00)	7.73 (1.65)	48.69	<.001*	1.83
6. Intervening	4.23 (2.07)	7.45 (1.60)	76.94	<.001*	2.22
7. Managing endings	4.10 (1.85)	7.58 (1.37)	114.89	<.001*	2.65

Notes: n = number of participants; SD = standard deviation; **p* values of less than .05 were considered significant.

Due to the competency scale being an organisation developed questionnaire, psychometric properties were not available. Further, each perceived competency was judged on a single item and no test-retest data was available, negating the possibility of computing reliability scores. These factors meant it was not appropriate to conduct individual change analyses on each competency.

Influence of training on clinical practice

One month after training, qualitative data was provided through the free-text questionnaire by 14 participants. Content analysis revealed three factors arising from the data. Two related to changed practice following the training: the use of a trauma-informed lens and the use of practical interventions. The third related to barriers to implementing TIC: the need for additional time. See Table 5 for details.

Use of a trauma-informed lens

Using a trauma-informed lens means that individuals understand and acknowledge the relationship between experiencing trauma and the impact on one's mental health (Sweeney & Taggart, 2018). Encouragingly, the majority of participants reported that the training increased their thinking around trauma and their willingness to ask about trauma histories. Further, participants commonly referred to having an increased understanding of clients' behaviour in the context of possible trauma. No participant inferred that the training was unhelpful or irrelevant to their practice.

Practical interventions

Talking through how trauma can impact individuals' arousal levels, and their ability to manage these (concept of the Window of Tolerance (Siegel, 1999)) appeared to be the most helpful practical intervention taken on board by participants. Several participants commented on how this was a helpful framework for both themselves and for the individuals they were working with. Psychoeducation was also commonly referenced as a skill that was developed through TIC training, and again, some participants reported to observe this as helpful for individuals who disclosed experiences of trauma.

Additional time

No participants reported needing any additional practical resources, and over half of participants did not comment on needing additional time. However, some participants believed that additional time was needed for aspects such as delivering trauma-related psychoeducation, giving attention to the therapeutic relationship, and to reflect on work afterwards. Interestingly, one participant commented that they believed spending more time working from a trauma-informed perspective in the present could reduce the length of input over the long-term.

Table 5.

Content analysis of training impact on clinical practice

Factor	Theme
Trauma-informed lens	Increased thinking around clients' experiences of trauma (11) Understanding clients presenting behaviour in the context of previous trauma experiences (9)
Practical interventions	Use of window of tolerance with clients (6) Use of psychoeducation around impact of trauma on the brain and body (5) Increased confidence in delivering routine interventions (e.g., mindfulness, breathing) to people with disclosed histories of trauma (2) Increased focus on building therapeutic relationships (1) Increased empathy (1)
Resources	Additional time needed to deliver interventions (4) Additional time needed for assessment of history of trauma (1) Additional time needed to reflect on work after sessions (1) No resources needed (8)

Notes: number in parentheses represents the number of participants who commented on the theme

Discussion

It is estimated that the majority of OAs will have experienced some form of trauma over their lifetime, but due to reasons associated with generational differences, they are less likely to disclose them or recognise their importance (Hiskey & McPherson, 2013). The reduced likelihood of OAs sharing experiences of trauma with healthcare professionals increases the importance that OA services deliver TIC. The present evaluation found that OA staff training in TIC improved participants perceived TIC-related competence, and increased TIC-favourable attitudes.

Data from the ARTIC questionnaire indicated that prior to training, staff held attitudes that were relatively TIC-favourable, with some capacity for improvement (M = 5.6, out of a possible total score of 7.0). Participants in the present study demonstrated similar pre-training scores to healthcare professional samples reported in the literature (Champine et al., 2022 (5.8), Wagner et al., 2020 (5.8), Niimura et al., 2019 (5.1)). In the present study, an increase of 0.54 points towards TIC-favourable attitudes was observed, an amount again comparable to other training programmes using the ARTIC (Wagner et al., 2020 (0.37); (Niimura et al., 2019 (0.40)). The findings suggest that there may be a significant but limited gain to enhancing trauma-informed attitudes through training in samples where TIC favourable attitudes are already relatively established. Burge et al. (2021) discussed the importance of TIC training being supplemented with wider system and cultural change, given an individual's trauma-informed attitudes may be of limited benefit if the systems they are working in remain trauma-uninformed. Therefore, provision of training, even across the organisation, should not be equated to the organisation becoming trauma-informed. Changes such as to policy and service models will likely be necessary to support staff apply TIC attitudes and approaches to their work (Homes & Grandison, 2021).

On an individual level, analyses revealed that only 7 out of 44 participants demonstrated a reliable improvement in TIC favourable attitudes after training. Demographic information was only shared by six out of the seven participants. Amongst them, no defining characteristic was identified (i.e., participants represented different staff roles, ages, and genders), though all pre-training scores fell below the group mean. Whilst it may be the case that training was limited in its ability to create reliable change in participants' attitudes, it is also possible that the low number was due to a ceiling effect on the ARTIC. The relatively favourable pre-training TIC attitudes resulted in reduced capacity for training to create an improvement in attitudes, and this may have hindered the accuracy of the RCI analysis (McAleavey, in press).

The training programme was designed to develop staff's TIC-related competence across domains identified by NES (2017). The competency questionnaire was devised to measure change on each of the identified competencies to assess how suitable the training content was for meeting the identified TIC needs. Staff reported significant improvements in their perceived competence across all items, suggesting the training content and delivery was effective in targeting the competencies it aimed to. It would be logical to assume that staff who feel more knowledgeable in understanding, recognising, assessing, and intervening in trauma, will be more prepared to implement TIC in practice (Menschner & Maul, 2016). Research that examined the impact of training on client outcomes supports this notion, with client satisfaction increasing, and disengagement in treatment reducing (Hales et al., 2018). However, reports using objective measures of change in staff practice following TIC training are generally lacking. This is perhaps due to the relative recency of the notion of TIC and most evidence, including the present evaluation, offering preliminary results with evaluation ongoing.

One component important to TIC, covered in the training, but not captured on the competence questionnaire, is staff ability to engage in self-care and avoiding burnout. The ARTIC questionnaire revealed the least improved item related to burnout amongst staff. Burnout can result in staff feeling both physically and emotionally exhausted (Yang & Hayes, 2020), potentially impeding their ability to deliver TIC. Further, on an organisational level, burnout has been consistently linked to increased staff turnover and job dissatisfaction (Yang & Hayes, 2020). The findings from the ARTIC suggest that the self-care components of training were not sufficient to change participants perceptions of burnout. Further, research suggests that a high proportion of individuals working in human services have themselves experienced trauma (Esaki & Larkin, 2018). This bolsters the importance of organisations having an entrenched trauma-informed culture that promotes self-care, rather than simply improving surface level skills and knowledge needed for clinical work.

Both the competency questionnaire and the ARTIC-10 only measured perceived competence and attitudes, rather than observed or objectively measured competence and attitudes. There may be systemic constraints or other barriers that mean TIC developed competencies and attitudes aren't implemented in practice (Burge et al., 2021). However, feedback provided on the one-month follow-up questionnaire suggested that the training was sufficient to influence approaches to assessment, intervention, and the therapeutic relationship. Encouragingly, no participants reported difficulties in engaging OAs in conversations around trauma, an aspect that has been noted in previous research (Hiskey & McPherson, 2013). In line with other study findings (Hoysted et al., 2018), the main barrier to delivering TIC was identified as the additional time needed.

Implications, limitations, and future directions

The present evaluation met the organisation's aims of evaluating how impactful service-developed TIC training was on staff attitudes and competencies. The evaluation also holds implications regarding the wider understanding surrounding TIC implementation through staff training methods. Further, it is hoped that the provision of a detailed breakdown of the training programme will support other organisations in developing effective TIC training. However, several limiting factors are important to note. Firstly, the study was undertaken as a service development evaluation, and therefore, access to a relevant control group (such as OA CMHT services in a different organisation) was not feasible. Access to a matched control sample may have afforded deeper analysis of the impact of training on TIC competency and attitudes in OA services (Purtle, 2018).

Secondly, the evaluation solely relied on self-report measures. The study aimed to provide preliminary evidence for the effectiveness of staff training and thus used a simple pre-post design. However, future evaluation may benefit from incorporating long-term service user outcomes and experiences, and objective measures of staff implementation of TIC. Researchers should also examine other actions organisations could take to increase TIC culture, for example, through exploring aspects such as supervision or team reflective practice.

Staff engagement with the evaluation was generally low and this was reflected in a poor response rate to all questionnaires. Further, demographic information provided showed that staff who did engage were relatively homogenous in characteristics, particularly with regard to ethnicity. Whilst the organisation’s staff demographics were found to be relatively homogenous and thus the sample may be fairly representative, the sample’s high homogeneity limits the generalisability of the findings to more diverse staff populations. Reasons for the reduced response rate were not explored, but we hypothesised that the online nature of delivery may have contributed, as found in other studies using web surveys (Daikeler et al., 2020). To reduce the impact of missing data at one time point (i.e., at either pre or post training), an intention-to-treat approach was used through utilising maximum likelihood estimations (MLE). Using MLE assumes missing responses at random, and therefore does not account for any bias in characteristics of people who chose not to complete a questionnaire at one time point. This study assumed, but cannot confirm, that data was missing at random.

Finally, between the ARTIC-10 and the competency scale, only one question related specifically to working with OAs, and no competencies addressed the aspect of training on trauma and dementia. Further, no participant commented on any of the OA related components of training on the free-text questionnaire. Therefore, the study has very limited data regarding potential (if any) adaptations needed for delivering TIC in OA services. Given the generational differences between OAs and younger populations, it is important that future research further examines how to implement TIC approaches most effectively in OA services.

Recommendations

The following recommendations have been made to support continued development of a TIC culture within the organisation:

a) Given the importance of staff self-care in TIC, and the lack of impact training had on this aspect, the organisation should consider other ways to support staff to develop TIC favourable attitudes around self-care and burnout. It would be prudent to ask staff what they believe their needs are in regard to avoiding burnout to identify any areas of the service model that could be adapted to assist in this.

b) Attitudes surrounding how to approach working with individuals who have disclosed experiences of trauma were unchanged after training. The organisation should consider developing additional methods to support staff to develop trauma-informed approaches to clinical work.

c) Staff identified the only additional resource required to implement the skills from training was additional time. We recommend that the organisation considers the models the service uses and adapts these to ensure staff feel supported to spend adequate time with service users.

d) The organisation should complete further evaluation once all staff members (including non-clinical) have received training. Evaluation of patient outcomes and patient experiences would allow for deeper and more accurate analysis of the extent to which the organisation has met its goal of becoming trauma informed. Further, ongoing evaluation at the organisational level using a measure such as the TICOMETER (Bassuk et al., 2017), a brief measure to track TIC changes over time, would allow the organisation to refine its approach to implementing TIC.

Conclusion

The present evaluation found that staff training can be a valuable tool in promoting TIC favourable attitudes, and improving competencies associated with TIC, in OA staff. Designing training content to meet previously identified overarching competencies can be a successful approach to developing effective TIC training. However, questions remain around the impact of changed attitudes and increased competence on clinical practice, particularly in relation to OA services, and thus the extent to which the organisation implements TIC should continue to be evaluated.

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