

Research Article

Exploring the Psychosocial Needs of Adults with Haematological Cancer under Watch-and-Wait: A Qualitative Study

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Received 21 June 2023; Revised 31 August 2023; Accepted 15 October 2023; Published 30 October 2023

Academic Editor: Liren Qian

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Objective. 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. **Methods.** A longitudinal design using semistructured 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 semistructured 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. **Results.** 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 how Oncology and Haematology services can holistically support individuals with indolent cancers to live well alongside their diagnosis.

1. Introduction

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) [1]. 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 [2]. In these cases, individuals are placed under “watch-and-wait” (W&W), a pathway whereby patients see their team at set intervals for monitoring. They will only receive treatment if/when the disease progresses to a stage where treatment is found to be

most effective [3]. The prolonged nature of IHCs has led to them being considered by some as “chronic cancers” [4].

In the literature, various models of chronic illness exist [5]. However, despite them fitting diagnostically, most models have excluded cancer diagnoses from consideration [4]. One model that considers cancer and may be useful in identifying unmet needs in such a population is the Psychosocial Adaptation to Chronic Illness and Disability (PACID) model [6, 7]. The PACID model comprises three components: antecedents (medical and contextual factors prior to diagnosis); processes (psychological reactions, coping, and appraisals); and outcomes (assessment of functioning and quality of life following illness onset). 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.

Research suggests a particularly high prevalence of psychological distress in individuals with HC, compared to the wider cancer population [8]. 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 [9]. Critically, these differences were reported as barriers to accessing further care, as participants reported they did not align with being a “cancer patient” [9]. In addition to physical differences, those with HC have also 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 [10].

Those with IHC face the additional challenge of not receiving immediate treatment, which often contradicts expectations of having cancer [11]. Results from a large survey study recently reported that 41% of individuals with IHC did not understand W&W and 53% expressed concerns about it [12]. In addition, 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 [13]. A recent study by Damen et al. [14] is exceptional in exploring the needs in people with IHC. Their quantitative findings indicated individuals with IHC 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 needs described significantly higher levels of anxiety and depression than those with low or no unmet needs.

The W&W pathway is not unique to individuals with HC and is commonly used for people with prostate cancer (PCa) [15]. 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 needs [16]. Whilst these findings may generalise to individuals with HC to some degree, there are several key differences to consider, including the potential impact of gender [17], PCa as a contained solid tumour, and patient involvement in treatment decisions. Unlike PCa, W&W for HC is determined by the stage of disease, and therefore, people with HC have little choice in when they receive treatment [2]. The reduced involvement is an important difference when considered in the context of Self-Determination Theory (SDT) [18], which posits humans need to feel autonomous, competent, and socially connected for psychological wellbeing.

Despite the high prevalence of psychological distress found in people with IHC, the 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 [19]. Therefore, the present study aimed to explore the subjective identification of the 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 [20]. Given the present research took place during the evolving COVID-19 pandemic, 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 the following:

- (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?
- (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?

2. Methods

Ethical approval was granted on 8th March 2022 by the NHS Research Ethics Committee and the Health Research Authority and the South Central–Oxford A Research Ethics Committee (reference: 22/SC/0044).

2.1. Study Design. Due to the limited understanding of individuals’ experiences of being under W&W, a qualitative design was deemed appropriate. A “critical realist” epistemological stance was taken by the researchers. This stance recognises that a social reality exists but that individuals only access this reality through the lens of their own experiences and perceptions [21]. Data were collected through individual semistructured interviews conducted at two time points, six months apart.

2.2. 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 advertisement on Facebook groups, using self-select sampling. Interested eligible individuals were provided with study documents. The study recruited 15 participants. Participants’ self-reported cancer diagnoses and treatment pathways were not formally verified.

2.3. Data Collection. All participants provided written consent prior to being interviewed. At the beginning of each interview, assurances of confidentiality and its limits were given. All interviews were conducted by the main researcher (KR), who had undertaken doctoral-level training in qualitative research. All interviews were recorded and took place remotely, either via video call ($n=9$ at T1, $n=7$ at T2) or telephone call ($n=6$ at T1, $n=5$ at T2), depending on participant preference. Participants were asked to complete the Hospital Anxiety and Depression Scale (HADS) [22] at both time points to give an indication of the psychological distress in the sample. To contextualise the data collected, demographic information was also gathered during the first interview.

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. The second interview (T2) followed a similar schedule, but with a focus on the previous six months. Interviews at T1 ranged from 35 minutes to 60 minutes ($n=15$). Both interview schedules are available to view in the supplementary files (available here). 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. Data were transcribed using the University of Nottingham's Automatic Transcription Service (GDPR compliant) and the main researcher (KR) checked the accuracy of each transcription against the original audio recording. 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.

2.4. Data Analysis. Thematic analysis (TA) following a reflexive guide [23] 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 were coded separately. A pattern-oriented longitudinal analysis (POLA) was then applied to the data [24], allowing for both within and between participant comparisons to be made across time points. Finally, a deductive codebook approach was also taken to consider how the 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 [18], PACID model [7], and needs identified in individuals with PCa under W&W [16].

Qualitative trustworthiness guidance [25] 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 (KR) 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 supported through discussions of coding and code grouping amongst the research team.

3. Results

3.1. 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. Table 1 details the demographic information of each participant, and Table 2 shows the average responses to the HADS [22] at each time point.

3.2. 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 sub-themes. 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 [26, 27]. Therefore, the present paper focuses on the two more novel themes.

3.2.1. Understanding the Impossible: Having Cancer That Does Not Require Treatment

(1) *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.

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
s (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).

“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 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).

(2) *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 anticancer 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 the resulting internalised stigma were understood to lead to individuals having unmet emotional and relational needs.

3.2.2. Sense of Abandonment under Watch-and-Wait

(1) *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 professional opinions, and a sense of needing to be “prepared to battle” to have their physical health, emotional, and informational needs met.

(2) *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 and T2; Bridget, T2; Lisa, T1; Delia, T1 and 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 the physical and emotional needs of patients.

3.2.3. *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 and T2; Lisa, T1; Ann; T1; Ian, T1 and T2; Marta, T1), suggesting that contact with others under W&W is fundamental for supporting social and emotional needs in individuals with HC.

“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).

3.2.4. 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 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.

3.3. Deductive Analysis. 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 [16], unmet emotional needs were frequently reported, with participants desiring support to manage the psychological burden of living with cancer without requiring treatment. Similarly, many commented on receiving inadequate information. This relates to understanding their diagnosis, W&W, and receiving results from blood tests and scans. In contrast, only a minority shared that they found the 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 [18] 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 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. The 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 [7].

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 is helpfully considered in the first domain “antecedents” of the PACID model [7]. 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 [7] 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.

4. 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 [18]. 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. The deductive analysis demonstrated: (1) three out of five key unmet needs identified in the PCa literature [16] were identified in the present HC sample; (2) SDT [18] was applicable to understanding individuals' reported needs; and (3) IHCs may be understood as "chronic illnesses," as highlighted by the applicability of the PACID model [7]. These findings contribute to the early literature on the needs and experiences of people living with HC under W&W and advance knowledge of where to target psychosocial interventions to support the wellbeing of this population.

4.1. 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; a finding in line with previous research [28]. 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 [29]. This need was considered as "competence," as identified in the basic needs of SDT [16]. 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 [30]. In the wider health literature, increased health competence through intervention was associated with increased quality of life [31]. In line with these findings, individuals in the present sample who engaged with blood cancer charities, and particularly webinars, more commonly reported that their information needs were met.

Managing others' expectations of what a cancer diagnosis means (i.e., having treatment/looking "ill") was experienced as burdensome, and individuals expressed a desire for greater awareness in the general public. It is possible that increasing patients' competence would also 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 the 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. 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 a 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 [32]. Such an experience was not reported by the sample, and therefore, this holds implications for how healthcare teams could adapt their communication to meet individuals' needs in the future.

4.2. Emotional Needs. Across the sample, increased psychological distress and limited access to psychological support were described, findings in line with previous research [14, 16]. It is also notable that participants made very limited reference to the role of family members and friends in providing support, likely reflecting the limitations of informal support provided (with the exception of peer support). 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) [1]. Older adults' mental health is suggested to be particularly at risk of being overlooked, with depressive symptoms being normalised and consequently not treated [33]. When coupled with the understanding that older adults are less likely to seek emotional support themselves due to barriers such as fearing stigma [34], it becomes clear that it is imperative for Haematology teams to follow routine procedures for assessing psychological wellbeing [35] and signposting to support as necessary. In addition, recent findings suggest that cancer care staff feel inadequately trained to support patients' psychological wellbeing [36]. Future research could explore the impact of brief psychological interventions training for Haematology staff on patients' emotional support needs.

4.3. Peer Needs. The benefits of peer connection and formal peer support have been well documented across psycho-oncology [37] and chronic health literature [38]. Further, peer connection features as fundamental in theories of human need, as demonstrated by the inclusion of "relatedness" in SDT [18] and "belonging" in Maslow's hierarchy of needs [39]. 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 that 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. Knowledge in this area would be advanced further through research specifically exploring the barriers and facilitators to effective peer support in the IHC population.

4.4. Implications, Limitations, and Future Research.

Whilst it is not an aim of small-sample research to produce generalisable findings [24], 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 [28]. In addition, the longitudinal nature of the research allowed for exploration of how needs change over time. 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 [18] to explain motivation and health behaviour in people with chronic health conditions [40]. 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 [7] was explored. Whilst this model focuses on psychosocial adaptation 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. This also holds 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. 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 [41].

Aside from diagnoses, the study recruited a relatively homogenous sample. Firstly, the recruited sample was predominantly women, despite IHCs being more commonly diagnosed in men [42]. This is particularly pertinent given that men with HC have been found to report significantly fewer unmet needs compared to women [43]. Similarly, the

sample was relatively young compared to the average age of those diagnosed with an IHC, and this may also hold implications for biases in the types and frequency of needs reported here. Secondly, 14 out of 15 participants identified as White British. Whilst research indicates people from White backgrounds are at the highest risk of developing HC [44], racial discrimination has been found to have a significant negative impact on individuals' health outcomes [45]. 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, the 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 [47], rather than people with HCs. Given the findings that people with IHC may have some 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.

5. Conclusions

People living with IHC described several domains of need such as 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), and further research is needed to develop these. In the meantime, healthcare services could support patients' psychological wellbeing by ensuring effective communication, consistently, and routinely offering information, and signposting to available support. The present findings provide insight into the underreported 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 [18] and the PACID model [7] [46].

Data Availability

The transcription data used to support the findings of this study are available from the corresponding author upon request.

Disclosure

The study was registered on the Open Science Forum at <https://osf.io/fgdpe>.

Conflicts of Interest

The authors declare that there are no conflicts of interest.

Acknowledgments

This research was funded as part of the Trent Doctorate in Clinical Psychology (DClinPsy) Programme by NHS Health Education England. The study was funded by the Health Education England as part of a Doctorate in Clinical Psychology. Open access funding is enabled and organized by JISC.

Supplementary Materials

Please find the interview schedules used at each time point available under supplementary files. (*Supplementary Materials*)

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