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Patient perspectives of 'Watch and Wait' for chronic haematological cancers: Findings from a qualitative study

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ABSTRACT

Purpose: Chronic blood cancers are incurable, and characterised by unpredictable, remitting-relapsing pathways. Management often involves periods of observation prior to treatment (if required), and post-treatment, in an approach known as 'Watch and Wait'. This study aimed to explore patient experiences of 'Watch and Wait'.

Methods: In-depth interviews with 35 patients (10 accompanied by relatives) with chronic lymphocytic leukaemia, follicular lymphoma, marginal zone lymphoma or myeloma. Data were analysed using descriptive qualitative techniques.

Results: Patient views of Watch and Wait ranged along a continuum, from immediate acceptance, to concern about treatment deferral. Significant ongoing anxiety and distress were described by some, due to the uncertain pathways associated with Watch and Wait. Infrequent contact with clinical staff was said to exacerbate this, as there was limited opportunity to ask questions and seek reassurance. Patients indicated that the impact of their malignancy could be underestimated by clinicians; possibly due to them comparing chronic and acute subtypes. Most patients lacked knowledge of blood cancers. Support from clinicians was considered greater among treated patients, possibly due to increased contact, and many drew on relatives for aid. Most patients were satisfied with their time-allocation with haematology staff, although experiences could be improved by greater access to clinical nurse specialists, counselling services, and community-based facilities.

Conclusion: Experiences varied. Anxiety about unpredictable futures could be more distressing than any physical symptoms and have a greater impact on quality of life. Ongoing assessment could facilitate identification of difficulties, and is particularly important among individuals without supportive networks.

1. Introduction

Haematological malignancies (blood cancers) comprise over 100 heterogenous subtypes, with varying clinical trajectories (Swerdlow et al., 2017). Combined, these are the fifth most common cancer grouping in economically developed regions of the world (Office for National Statistics, 2017; Islami et al., 2021). Whilst some are aggressive and potentially curable with intensive chemotherapy, around 60% are incurable and follow a chronic remitting-relapsing pathway. Accounting for three-quarters of the total, the most common chronic haematological cancers (CHCs) (and the focus of the present report), are chronic lymphocytic leukaemia (CLL), follicular lymphoma (FL), marginal zone lymphoma (MZL), and myeloma. The 5-year relative survival of patients with these cancers is 86% (CLL), 88% (FL), 80% (MZL) and 48% (myeloma) (https://hmrn.org/statistics/survival); the comparatively poor survival of the latter reflecting increased likelihood of disease progression compared to the other subtypes.

Patients with CHCs are often initially observed, either continuously, or until progression, when treatment is given to regain remission or improve quality of life (QoL) (Ardeshna et al., 2014; Gentile et al., 2015; NICE, 2016; Perrone et al., 2016; Yuda et al., 2016; Goldschmidt et al., 2019; Hallek, 2019; Sindel et al., 2019; Bolli et al., 2021; Dreyling et al., 2021; Muchtar et al., 2021). CHCs may be managed in this way for many years, with periods of observation interspersed with treatment(s), as required; some then needing stem cell transplantation (SCT). This approach is variously termed 'Watch and Wait' (W&W), monitoring,

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observation or active surveillance, by patients and clinical staff, and entails haematology check-ups, typically several times a year, and more regularly during treatment.

Immediate treatment may not improve outcomes for some CHCs (Yuda et al., 2016; Steinmetz et al., 2020; Dimopoulos et al., 2021; Muchtar et al., 2021), and an advantage of observation is that the potentially harmful side-effects of chemotherapy are deferred or avoided altogether, which is particularly beneficial in patients with comorbidities. It is, however, contrary to treatment-delay avoidance policies seen for cancer (NHS England, 2019), and may be incongruent with lay-expectations (Levin et al., 2007). It can also give rise to difficulties, as patients have relatively infrequent contact with clinicians, whilst knowing their cancer is incurable, and may affect their survival Evans et al., 2012; Muchtar et al., 2021; Howell et al., 2022; McCaughan et al., 2022).

Living with a CHC is known to negatively impact QoL (Allart-Vorelli et al., 2015; Holtzer-Goor et al., 2015; Parsons et al., 2019; Goswami et al., 2019, 2020; Waweru et al., 2020), and further in-depth evidence is required about such issues, in order to underpin changes to clinical practice for the benefit of patients and families. Constituting one strand of a broader programme of work designed to enhance knowledge of CHCs (Howell et al., 2022; McCaughan et al., 2022), the present study explores the experiences and views of patients on W&W, which herein refers to any part of the pathway characterised by ongoing or intermittent periods of observation (i.e. before and between treatment(s)).

2. Methods

A qualitative study was conducted, with semi-structured in-depth interviews. Methods are reported in accordance with Consolidated Criteria for Reporting Qualitative Research (COREQ) criteria (Tong et al., 2007).

The study was set within the UK's Haematological Malignancy Research Network (HMRN: www.hmrn.org), a unique collaboration between NHS clinicians, patients and family members, and researchers (Smith et al., 2010; Roman et al., 2022). Briefly, set within a population of ~4 million, HMRN comprises a cohort of newly diagnosed patients with blood cancers, whose data are interrogated for research purposes, with the aim of improving clinical practice.

2.1. Sample

In qualitative research, sampling aims to acquire information that is useful for understanding the complexity, depth, variation, or context surrounding a phenomenon (Gentles et al., 2015; Malterud et al., 2016). Our objective was to capture a broad range of experiences amongst patients with CLL, FL, myeloma and MZL, identified from within HMRN. Sampling was purposive (Palinkas et al., 2015), aiming to recruit males and females across the diagnostic age range, with variation in time since diagnosis and time-points on the clinical pathway, to capture varied perspectives. Patients were asked to invite a relative/friend to attend the interview, if they wished.

2.2. Data collection and processing

Thirty-five patients took part and were interviewed February–October 2019, mostly in their homes. Interviews ranged from 45 to 90 minutes and followed a topic guide (Supplementary Material 1.0), which allowed patients to 'tell their own story' from diagnosis and was modified over time to include new lines of inquiry, including perspectives of W&W. Recruitment continued until thematic saturation was reached, and data were sufficiently 'rich' to answer the research questions (Malterud et al., 2016; Saunders et al., 2018; Braun and Clarke, 2022, p28). Interviews were digitally recorded, transcribed, checked for accuracy and anonymised, prior to analysis.

2.3. Ethical considerations

Approval already existed for HMRN (Leeds West, REC: 04/Q1205/69), and additional permission was granted for the present study (London, City and East, REC: 16/LO/0740). Patients were approached after checking NHS hospital data to ensure they were able to participate. Informed, written consent was obtained, to take part and to use anonymised quotations in publications. Participants were told they could pause/discontinue the interview if they felt upset; and could withdraw from the study at any point, prior to inclusion of their data in the analysis. Consent forms, recordings and transcripts were stored in accordance with University of York policy, General Data Protection Regulations (GDPR) and the Data Protection Act (2018), which provide the framework for processing personal data across the UK.

2.4. Data analysis

Analysis involved qualitative description, based on thematic content analysis (Sandelowski, 2000), was undertaken by two researchers, and is depicted in Fig. 1 and Table 1. Transcripts were read for familiarisation, and summarised through dynamic engagement with the dataset, while staying close to participants' accounts (Sandelowski, 2000). Initial codes (units of meaning) were identified, then expanded and modified through a reflexive and interactive process of 'interrogating' the data, in the search for common patterns (themes). Analysis was primarily inductive: we drew on the data to generate meaning, aiming to transform the 'raw' data into a new and coherent depiction of the phenomena under scrutiny (Thorne, 2000; Sandelowski, 2010).

3. Results

Nineteen of the 35 patients were male and 10 were accompanied by relatives, who contributed to varying extents. Ages ranged from 40 to 80 years at diagnosis, and 54 to 86 at interview; most lived with family members, with only three living alone; and ten had CLL, eight FL, twelve myeloma, and five MZL. Patients had experienced different pathways, determined by their diagnosis and pattern of progression: seven began and stayed on W&W; the remainder receiving treatment at least once, with six of these having multiple lines of chemotherapy prior to SCT (see Supplementary Material 2.0). Five themes were identified: 1. Impact of CHC diagnosis; 2. Views of W&W; 3. Living with uncertainty during W&W; 4. Key support; and 5. Views and experiences of service provision. Each was accompanied by various sub-themes (Fig. 2). These are described below with quotations, linked to the Patients' ID (P is Patient; R is Relative [thus R,P6 is the Relative of Patient 6]).

3.1. Theme 1: Impact of CHC diagnosis

3.1.1. Shock and surprise

As expected, and in common with other cancers and serious conditions, patients had a profound response to their diagnosis, which impacted their ability to process information: *'I was in a state of shock … it just knocks you sideways … totally out of the blue … it just re-wrote my life'* (P2). In the context of CHCs, this was exacerbated on learning cure was impossible: *'the doctor just said, you've got this cancer and it's not curable … I didn't hear much after that … I was absolutely gutted'* (P25). It was also enhanced because most interviewees had no, or little, prior knowledge of haematological malignancies, or the difference between chronic and acute subtypes: *'you don't realise how many cancers there are … I've never heard of this one [myeloma]'* (P16).

Some patients had symptoms that they said they '*half-expected*' were caused by malignancy (such as neck, breast or groin *'lumps'*), but were surprised to find they had CHC: *'it was in the breast cancer clinic that I was diagnosed with this lymphoma, which was a bit of a shock. I wasn't shocked that there was a problem, but [the diagnosis] was unexpected'* (P15); *'I was referred to an ENT doctor … because I had a lump on my neck so I got the*

Fig. 1. Steps involved in data analysis.

Table 1
Theme development (illustrated for Theme 3: Living with uncertainty during W&W).

Activity	Examples/notes
1. Text from transcripts where patients describe uncertainty and the feelings this leads to during W&W	*'how long might I have?'; 'there isn't an answer'; 'it's horrendous'; 'it's stressful'; 'you're anxious'; 'it's incurable'; 'I know it's going to come back'*
2. Text coded 'in-vivo'	Codes are derived from the data itself, rather than the researcher, so authentically represent participants.
3. Group/merge similar codes	Quotations identified as relating to a broader category (e.g. 'prognostic uncertainty')
4. Codes brought together under a unifying theme	Generation of theme (Theme 3) 'Living with uncertainty during W&W'

result [FL diagnosis], so it was a bit shocking' (P17). A routine blood test, as part of a general health check, can identify several CHCs, which enhanced surprise: *' … it was a shock when he started talking about cancer because that hadn't even entered my head … I thought I was going for [doctor] to do a random [sic] blood test and say, "everything is alright"'* (P4).

Patients found it hard to understand how symptoms such as nerve or back pain, or a 'lump', could be linked to blood cancer: *'I had a very small lump in one of my breasts … they took a [lymph node] biopsy … they called me back the following week and just said, you have CLL. I didn't understand it at all … it's in the blood … '* (P13). They were also unsure about treatment approaches: *'you think, well you can't take my blood out and put some new blood in'* (P4).

A minority of interviewees reported a seeming lack of awareness or understanding among some HCPs about the impact of their diagnosis. Some described brusque interactions, leaving them feeling uninformed and unsupported: *'I don't feel the nurse explained it to me, [to] somebody who's never been involved in cancer'* (P4); *'it was just like [nurse] was ticking boxes, sort of being all jolly … it wasn't making me feel any better'* (P35); *'this particular [doctor] is abrupt really, [and] just said 'Oh, yeah you've got lymphoma' … and then this nurse gave me a book and said … 'it's nothing that will affect you anytime soon' … and I bet we were out of there in 5 minutes '* (P32).

3.1.2. Communication with clinicians

Communication of the unusual nature of CHCs was recollected by most interviewees, with many saying this had occurred in an empathetic and optimistic manner, which they appreciated and had impacted positively on their views: *'[HCPs] were quite upbeat about it … they said, we can treat it'* (P31); *'[HCPs] were quite careful not to overload you with too much [information] and it was very sensitively done … obviously, they don't know you at the beginning … they were quite positive about potential outcome … that kind of positivity was really, really helpful'* (P18). P15 (FL) commented that *'[HCPs] were very positive about treatment … I was told I was stage 4 … and there's no cure, but there is treatment and that treatment has very good results'*, adding that it was helpful to be told: *'you've got a*

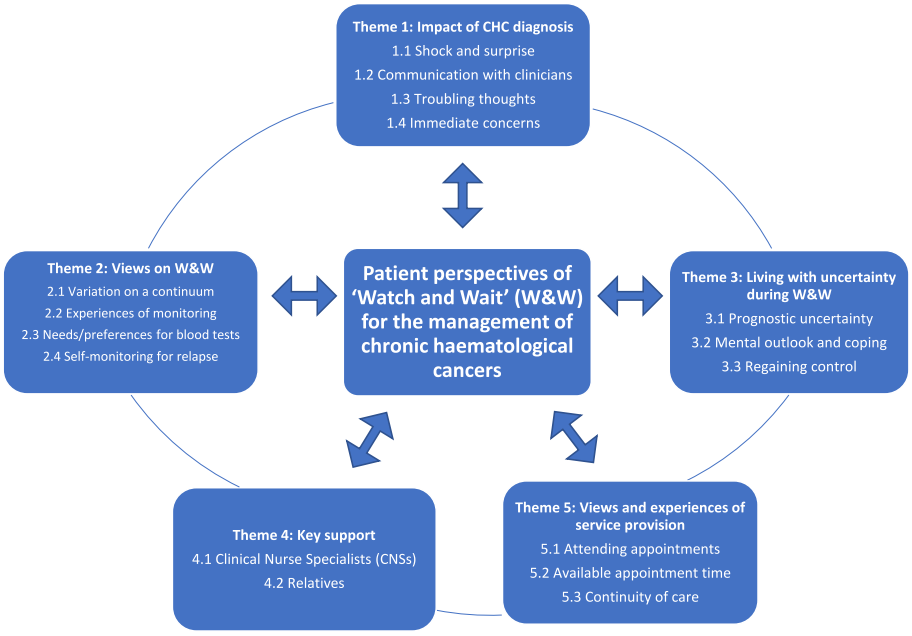

Fig. 2. Patient perspectives on 'Watch and Wait'.

chronic disease, you've got to treat it as a chronic illness, like diabetes … you manage it, you live with it, and you can live with it.'

Patients appreciated hearing from HCPs that their cancer was likely to be *'slow growing'* (P4), and they may *'actually die with it, not because of it'* (P7). Such expressions were considered indicative of hope. For example, P20 reported feeling reassured when the nurse told him *'[CLL] can be a progressive disease, but nothing might happen during your lifetime, in other words, you might live with it as long as you live',* and by his haematologist's remark that *'we can look after you, we can treat this.'* However, in a few instances, patients were not reassured about the likely chronic nature of their cancer, particularly if they recalled someone with the same cancer, who had died: *'a few people that I've got to know, within 7 weeks of their transplant, they've passed away'* (P33).

Additionally, a few patients *'struggled'* to accept that, unlike other cancers, their haematological malignancy could not be cured through surgical or other interventions, and that they would have to adapt to living with it: *'[I thought] they would just cut it out because it was in the stomach … I struggled a bit with the fact that they couldn't actually get rid of it. I can only ever go into remission … '* (P5, MZL).

3.1.3. Troubling thoughts

CHC diagnosis frequently overturned patients' perceptions about their health, invoking helplessness and emotional volatility: *'the terrible thing is you feel like your body is out of control … and you can't do anything about it'* (P3); *'you're fully fit and then for no reason that seems apparent, you've got cancer, and it's in every bone in your body and you start wondering, how did that happen?'* (P16, myeloma).

Some patients (particularly those with myeloma) described troubling thoughts concerning their own mortality: *'I thought, I'm not going to get to see my grandchild … '* (P23); *'I woke up in the middle of the night and I had a massive, massive panic attack … I'm going, you're going to be alright … no, you're dying, you're dying … it was absolutely horrendous'* (P33); *'you could wake up … and think all sorts. You'd think about death'* (P14).

3.1.4. Immediate concerns

More specific concerns varied by interviewee characteristics. Younger patients, for example, worried about continuing working; not only for financial reasons, but because work was important to their sense of identity and stability in the face of an uncertain future: ' … *am I going to be able to work anymore … have I got to retire?'* (P16); *'if I hadn't been able to [work], well, you then go down all the alternative routes … allowances and assistance'* (P11); *'I was made to finish work … that was horrendous because it was the only thing for me that was stable in my life'* (P33).

Patients living alone (P4, P5, P8) worried how they would cope without the practical and emotional support a partner might provide with respect to living and coping with future uncertainty, whilst not wishing to become burdensome to others: *'I was in panic mode really … that is the best way to explain it … how am I going to cope? I'm living on my own … I don't like to be beholden or a burden on anybody'* (P8).

3.2. Theme 2: Views of W&W

3.2.1. Variation on a continuum

Perceptions of W&W ranged along a continuum; some readily accepted W&W as a standard approach for managing their cancer, based on what they had been told or read: *'It felt like the norm … everything that I'd read was … you'll be on Watch and Wait for 10, 15, 20 years, so it was just like, you're going to have to get used to this'* (P13).

Others questioned non-treatment, perceiving this as counterintuitive, with P1 saying that *'it's as if you've got to become ill'* before treatment can start; and P6's relative saying: *'We were just told that you're going on Watch and Wait and there was no sort of real reasoning … because one naturally thinks, well, cancer, let's get busy, start treatment and get moving … '*.

Participants receptive towards W&W sometimes expressed a desire to *'stay off chemo as long as possible'* (P5) due to concerns about toxicity, and hoped they might be *'one of the lucky ones'* who *'never need treatment'* (P17). Acceptance appeared greater when HCPs took time to explain the rationale for W&W: *'the situation was discussed and [haematologist] said "We'll stick you on Watch and Wait. I don't think I need to treat you at this present time", [haematologist] was quite definite …, and that gave me a bit of confidence. So, there was no dubiety about whether I should be treated or not'* (P12).

3.2.2. Experiences of monitoring

Mostly experienced as reassuring, patients reported that the main focus of hospital appointments was blood monitoring and symptom checking: *'[Doctor] said … you're now on our books, and we will monitor you … every two months I had a check-up, under the arms, round the groin, stomach, back, neck … all the areas where lymphomas are likely to come''*

(P10); *'it's very good that they are monitoring everything and checking everything … I feel reassured'* (P23).

Pre-appointment anxiety was common, however, linked to fear of progression/relapse: *'the night before you go [for appointment] you're gonna not sleep … you're on Watch and Wait and that's all there is to it … '* (P13); *'It's just stressful … your whole life just revolves around these [blood count] numbers, this number going up'* (P35).

3.2.3. Needs and preferences regarding blood tests

Knowledge and understanding of the significance of blood results varied widely, with many saying they were satisfied just to hear their results were *'okay'*: *'I know they need to do bloods because that's how you tell if something's not right'* (P34); *'I think, well if they say "that's okay", and "it's within okay parameters", that's fine … they know what they are doing'* (P26). Others said they would have preferred further explanation: *'[blood results] give the various levels of haemoglobin or paraprotein … what would be quite useful would be to have more information about what these figures mean'* (P12).

A minority reported keeping records and graphs of their results, which they interpreted alongside their own 'research', using this to initiate discussion with haematologists: *'my white blood cells were 75 … when I got this blood test back my white blood cells were 175 and it just seemed in a few months, it was just a massive leap and I just needed clarification for that'* (P13); *'so those [results] that I get [from portal] are really good … I can point out to them, to the consultant … I can sort of say, well so, what's this about, sodium … you know, why's that gone up?'* (P28).

Detailed understanding of blood results could lead to concern, if anticipated actions did not follow. P6's relative, for example, who had read widely about CLL, said *'[we] can't understand why nothing is sort of being done and each time she goes for a visit to the consultant, the readings have gone up, the lymphocytes have increased and she is wondering when we are going to reverse the process, when is something going to happen'*.

3.2.4. Self-monitoring for relapse

Regarding signs and symptoms of progression, most interviewees said HCPs had informed them what to check for, and felt confident about identifying and reporting these: *'I got a big lump came up … virtually overnight, like a cyst … almost to golf ball size and immediately you obviously think it's something to do with the lymphoma … so I rang up … and they said, just come in, we'll see you'* (P17).

Others feared missing signs however, and/or worried that any change could relate to their blood cancer: *'it's up to me to say, I've got a lump, I can feel a lump … but you could have lumps you can't feel'* (P15). P4 commented that *'I didn't know how it was going to flare up … apparently it could flare up in different ways for different people … when I've got an ache or pain … when you've got cancer, you straightaway think, oh, it's the cancer'*.

Responsibility for detecting signs of progression was sometimes perceived as burdensome and could generate distress: *'it feels like it's all on to me and so now I'm almost paranoid about everything'* (P35); *'I was scared stiff … when I was in the shower I could feel lumps down the side of my body and I could feel them in my groin, and behind my ears and it was suddenly becoming more real … when I was feeling the lumps, I knew I was getting myself more upset'* (P13).

3.3. Theme 3: Living with uncertainty during W&W

3.3.1. Prognostic uncertainty

This was a predominant concern during W&W, as patients realised clinicians could not definitively answer their questions: *'How long might I have? What is going to happen? How soon will it become active? You want that information but unfortunately everybody is individual and there aren't any answers really and we [patient and wife] know now, from experience, that you've just got to wait and see what happens really, which is why it's Watch and Wait really … with hindsight you know there isn't an answer'* (P7).

Treated patients being monitored during remission referred to relapse as an ever-present threat *'mine [myeloma] is not curable … so I know it's going to come back … '* (P16). Fear of recurrence could erode quality of life between appointments: *'it's just on me [sic] mind all the time'* (P25); *'I hate dwelling on all this … it does my head in'* (P35). It also compounded anxiety before check-ups: *'it's horrendous … you're anxious before you go in … God, it's stressful'* (P35). These people sometimes sought, or were referred to, counselling: *'I felt I was on the brink of this big black pit and I was going to fall in and I couldn't see any way of coming back out of it, and I started crying so [doctor] called the clinical nurse and she referred me to counselling'* (P25).

3.3.2. Mental outlook and coping

A positive mental outlook, exemplified in the phrase *'getting on with life'*, and not worrying ahead of disease progression, were prevalent countermeasures for coping in untreated patients: *'A lot of people call it 'watch and worry', but I don't 'watch and worry' at all … I get on with my life, I do think of myself as a very, very positive person'* (P1); *'I know something quite likely will happen further down the line, but I don't particularly want to be worrying about it until it happens'* (P17).

With respect to not letting the CHC dominate, P5 stated: *'I don't want to be absorbed into cancer … I don't want it to represent me';* and P3 said: *'I didn't want CLL to rule my life … I wanted to just forget about it at times, but you can never totally, it's always at the back of your mind, but not let it rule my life'* (P3). A philosophical or fatalistic stance could also be helpful: *'just seize the day, you know, carpe diem'* (P29); *'they say it [myeloma] will get worse … how it will affect me, I haven't a clue … If it comes, it comes. I can't do 'owt [sic] about it … '* (P30).

3.3.3. Regaining control

Promoting general health and psychological well-being was described as empowering, enabling individuals to regain control following diagnosis. Strategies often included outdoor hobbies and exercise, and healthy eating: *'something that works for you … I'm a keen gardener … I recommend it to people who have psychological issues or health issues'* (P24); *'I always try to be fit … I've always had a dog to take out … I've got an allotment … we don't hardly eat any red meat … '* (P31); *'my running … '* (P3); *'I'd rather be out with my dog [than dwelling on diagnosis], that makes me feel better'* (P35). Others took dietary supplements, or accessed alternative and/or complementary therapies: *'I'm just looking at … a multivitamin … something extra, so I've got a good immune system'* (P23); *'the massages, I found very therapeutic'* (P25).

3.4. Theme 4: Key support

3.4.1. Clinical nurse specialists (CNSs)

Almost all interviewees reported receiving details of their CNS at diagnosis. For many, however, contact only occurred during clinic appointments, typically 3–6 monthly, but sometimes as much as 6–12 months apart, meaning patients could wait lengthy periods before they could ask questions: *'if I had any questions, I had to wait* 3 months *to get an answer'* (P4). Several interviewees revealed occasionally wanting to contact their CNS for advice or support, but not doing so, in case their concerns appeared inappropriate, or trivial, or because they thought the nurses would be busy with acutely ill patients, meaning their needs remained unmet: *'[CNS is] more if I need advice about medication, not necessarily a psychological [aspect]'* (P5); *I didn't feel I could be ringing [CNS] every day … obviously, she's got lots of other things to do and lots of other people to deal with … I don't feel I can ring at any time … you think, oh, that's a bit petty … '* (P4).

Several patients on long-term W&W reported scant or no further contact after diagnosis: *'this specialist nurse … I did meet her but I never saw her again and never had any communication with her … that's probably understandable, because mine was a "Watch and Wait'* (P2). Contrastingly, participants treated from diagnosis often developed a good rapport with CNSs, who became an on-going source of support: *'[CNSs said] if you*

need anything, to talk about it, emotional or practical, you know, if you get a side-effect or something like that, let us know, straightaway, and they gave two numbers, for out of hours … at that point I felt kind of pretty well looked after' (P28, myeloma).

Patients needing treatment following a period of W&W described feeling shock again, and alarm if rapidly initiated, with little time for adjustment. A few said they had felt unsupported by clinicians, including CNSs, at this juncture: *'I knew chemo was what I'd have to have, but when [doctor] told me, that shocked me and I was so upset and scared … I only had a fortnight's notice … I could have really done with someone at the hospital to talk to'* (P4).

3.4.2. Relatives

Relatives supported patients during W&W by seeking information (sometimes extensively) and attending appointments, often involving a substantial time commitment: *'we always go together … my wife's been with me every step'* (P31). They also promoted understanding and information recall: *'[wife] is my backbone really because she can remember things … what [doctor] just said to you … it's good to have two heads there I think'* (P22); and participated in consultations, including deliberating treatment options: *'if things start to change and we're talking about treatment … [wife] wants to be in on the discussions'* (P11).

Emotional support from a partner seemed especially important during remission: *'you need somebody with you, and somebody that understands what you are going through … obviously it is ideal … if you've got a decent partner and they can take the strain off you'* (P16, myeloma); *'[partner] does care for me kind of emotionally and things and when I've been flat on my back with fatigue … she certainly has been caring … the worry is done by the carers'* (P28, myeloma).

Relatives with work commitments could not always attend appointments, and some patients preferred to go alone, to spare family members inconvenience and/or anxiety: *'I've been going for years and I think my wife would just worry herself silly … for her it is probably more stress inducing than for me to be honest'* (P3). Sometimes, patients described 'shielding' relatives from their CHC: '*I think they don't want to know … it's too frightening … one of my sons, he was really struggling with his anxiety … '* (P33), which could result in negative feelings being suppressed.

3.5. Theme 5: Views and experiences of service provision

3.5.1. Attending appointments

Waiting times for clinic appointments were considered lengthy, though most patients accepted this as inevitable, due to service pressures: *'it's a hectically busy clinic … it's just unbelievably busy'* (R, P7). Having blood tests during the clinic visit was said to increase waiting times: *'I've always gone to the hospital and they do the blood test and then I wait there because they analyse the results, and then I see the consultant … sometimes you're there a long time'* (P26). By comparison, prior local collection (at a GP surgery or other facility) offered convenience, reduced waiting, and meant the results were more likely to be available: '*the community blood test box … I go to clinic every* 4 months *… so when I get an appointment I get the blood specimen packets … and I have to go and get my bloods done before I see the haematologist so they have the results through in time for my appointment'* (P23).

P26 (myeloma, on 3-monthly W&W), was the only interviewee to mention telephone monitoring, saying they preferred this approach: *'what they've decided now is, have the blood test done, and then a couple of weeks later at a pre-arranged time, the consultant will call. He said, if there is any problem we can have you back in, but if it's just to tell you that nothing has changed, it's pointless you sitting there for 2–3 hours'*.

Patients were highly sensitive to changes to their monitoring, which they regarded as mirroring their CHC status; longer intervals were viewed positively as stability, and shorter intervals negatively as progression and the growing need for treatment. Unexplained delay, or sudden cancellation, could provoke anxiety: *'I went for my appointment in February and the doctor said, I'll see you in three months and I haven't heard a thing … it's now the end of July and I haven't heard … I know I'm alright, but I'm not the doctor … '* (P25).

3.5.2. Available appointment time

Clinicians' time was regarded as a valuable commodity shared amongst many patients, with most commenting that HCPs endeavoured to match time to need, whilst ensuring information exchange and relationship-building could occur: *'the patients coming in and are on Watch and Wait and don't need any treatment, [nurses] are maybe going to kind of look after them and then free up the doctors, so they can see the patients that maybe need a little bit of extra time'* (P13); *'I've seen [doctor] every month now for nearly 3 years and I've never felt that I've had to leave that clinic appointment for the next patient … you can ask them anything'* (P19). There was also recognition that adequate time might mean longer waits: *'[doctor] is terrible for having queues … she doesn't just shoo you out, she spends time with people'* (P15). In some instances, patients described appointments as perfunctory, deterring them from raising concerns: *'the doctor will say, okay, all good, nothing in your blood, great. Any questions, any problems? No. Okay, see you in* 3 months*. Short, sharp and sweet'* (P16).

3.5.3. Continuity of care

Patients indicated that seeing the same clinicians, particularly doctors, was important for relationship-building: *'I've never seen anybody else, [consultant], she's lovely, she's super'* (P12); although they accepted that continuity could not be guaranteed. Those with long intervals between appointments recalled feeling detached from the haematology service, as they did not know, and were not known by, the team: *'it was like a conveyor belt … I was almost just a number … I used to go and get my blood tests and see the doctor and they'd check me over … and say, 'you're okay'. I used to get different doctors and you just felt … part of a process, whereas with my homeopath … we talk about my symptoms, how I'm feeling'* (P2).

4. Discussion

4.1. Summary of principal findings

Views of W&W ranged along a continuum: some being reassured that their cancer was indolent and did not require immediate treatment, while others found this particularly distressing, especially if they considered treatment deferral counterintuitive. We found that *'dwelling on'* the cancer and on the uncertainty and unpredictability of W&W resulted in increased anxiety, which could be more problematic than any physical symptoms. Difficulties were enhanced in patients who felt responsible for monitoring their symptoms but struggled to do this, and some were particularly anxious prior to appointments, fearing progression. Distress appeared to be greater in patients with myeloma, where disease progression and a shortened life-span was almost inevitable; although such feelings were also influenced by personal characteristics, coping mechanisms and frequency of HCP contact. Various strategies were used to manage difficulties, including undertaking activities to improve well-being, and seeking input from relatives and friends; with perceptions of support from CNSs being better for those receiving treatment. We noted intense shock at CHC diagnosis, limited understanding of blood cancers, and perceptions that some HCPs underestimated the impact of the diagnosis. Most interviewees appreciated their time-allocation with haematologists and continuity of care; less satisfactory were hospital-based blood tests, and delayed clinic times.

4.2. Findings in the context of other research

That living with W&W is experienced along a continuum is portrayed in two other studies, with Woyach (2019) describing treatment-naïve

patients with CLL reporting low anxiety, and '*getting on with [normal] life*', hoping they might never need treatment; while Hauksdottir et al. (2017) note ongoing difficulties in myeloma patients due to the ever-intrusive threat of relapse. Furthermore, W&W is said to negatively impact psychosocial and physical health and QoL (Schanafelt et al., 2007; Ansell, 2014; Rittenmeyer et al., 2016; Damen et al., 2022); with Rubins et al. (2022) describing myeloma patients as 'in limbo' between wellness and illness, while struggling with persistent uncertainty and pre-appointment apprehension. More broadly, Bury (1982) notes how the sudden intrusion of chronic illness ("biographical disruption"), can disturb everyday life-structures, overturn plans, and require a rethink of biography and the concept of self. In this context, reports of low mood and depression (prominent among our interviewees) may have been a corollary of an impoverished sense of self and loss of control over 'normal' life, and/or linked to specific personality traits. Interestingly, Mishel and Braden (1988) suggest an individual's ability to cope with uncertainty could allow them to remain hopeful and decrease anxiety, or could lead to increased anxiety and poorer mood.

Under-recognition of the impact of CHCs by HCPs may be due to clinical staff viewing the needs of patients in terms of disease aggressiveness and treatment needs; comparing patients with CHCs to those with more acute cancer sub-types that require intensive chemotherapy. The impact of this has been reported by others. Pemberton-Whitely and Martin (2019), for example, note less likelihood of UK CLL patients on W&W receiving information about support, compared to those on treatment; and Goswami et al. (2020) found '*not a single patient mentioned [being] offered any psychosocial screening.*' Furthermore, around a third of patients on W&W report unmet needs (Damen et al., 2022); with suggested interventions including routine screening for difficulties and access to psychological services.

Shock has also been noted among patients with acute blood cancers and other malignancies (LeBlanc et al., 2017; Coronado et al., 2017; Edmondson et al., 2017; Sharpley et al., 2018; Fitch, 2020; Goswami et al., 2020), with LeBlanc et al. (2019) portraying patients newly diagnosed with myeloma as overwhelmed and unable to process information. Regarding understanding treatment deferral, Cartron and Trotman (2022) suggest patients may consider this *'time lost in the fight against the disease'*, and caution HCPs against underestimating the negative impact this could have, suggesting comprehensive explanation of the rationale for W&W, with periodic reiteration. The importance of emotional support from relatives is echoed by Swash et al. (2018) and Tsatsou et al. (2020), who suggest people living alone, or with unsupportive relatives, may require increased input from HCPs and counselling.

4.3. Potential changes to clinical practice

Our study depicts the extent to which psycho-social difficulties were experienced. Increased recognition by clinicians of the impact that CHC may have on patients, even if they do not require immediate treatment, may help mitigate such negative effects. Use of an appropriate measure, such as the Survivor Unmet Needs Survey (SUNS) for haematological cancers (Hall et al., 2014) could enable HCPs to provide reassurance and timely interventions, such as counselling referrals. We noted that anxiety and distress could be exacerbated by infrequent hospital contact soon after diagnosis, and whilst on W&W; during which time patients may consider their needs too minor to raise with HCPs. Although additional clinician-patient contact time could facilitate in-depth discussion of such issues, extra resources would be required to effectively instigate this. Lifestyle changes empowered our interviewees and are recommended as a way to encourage patients to become more active in managing and coping with their diagnosis (McCorkle et al., 2011; Arts et al., 2017). Accessible social networks were valued by patients, but inaccessible to some, and exploration of such circumstances could uncover difficulties that HCPs might redress via signposting to services.

Lehmann et al. (2021) report receptiveness towards self-management of blood cancers, and some UK hospitals have introduced patient-initiated care (https://www.lymphoma-action.org.uk) for low risk disease, whereby patients arrange their own follow-up according to their symptoms. Such schemes could benefit individuals with pre-appointment anxiety (Nørgaard et al., 2018), though might disadvantage those reassured by regular monitoring. However, this should be considered cautiously since a Cochrane review showed such interventions had little or no effect on anxiety, depression and QoL compared to existing practices (Whear et al., 2020). Telemedicine, used extensively during the COVID-19 pandemic (Ahmed et al., 2020; Monaghesh and Alireza Hajizadeh, 2020), could offer an alternative follow-up (Overend et al., 2008; Dickinson et al., 2014), although more research is required to explore whether this can effectively identify needs. Primary care is another option, as a shared-care solution (Nørgaard et al., 2018), and greater use of community blood collection could offer convenience, and expedite the availability of results.

4.4. Future research

Studies investigating the support needs of relatives of patients on W&W are lacking and in-depth research in this area is merited (Quinoa-Salanova et al., 2019). Haemato-oncology is one of the most rapidly evolving fields in cancer research, and novel treatments that will undoubtedly impact on patient experiences and outcomes are constantly emerging. Clearly, such changes also need to be monitored. For example, a recent shift in CLL has seen a move away from cyclic chemo-immunotherapy, towards continuous targeted pathway inhibitors from diagnosis onwards (Walewska et al., 2022).

4.5. Strengths and Limitations

A major strength of our study is data capture from patients with various subtypes, at different time-points on their pathway. We included patients diagnosed several years before interview, as well as those more recently; and participants referred to diaries during the interview. Relatives augmented patient accounts, by contributing their own views and recollections. Data were analysed by experienced researchers, and our findings are likely to be transferable to other UK settings, and countries with similar healthcare systems.

5. Conclusion

We have provided new knowledge in an important, under-researched aspect of haematological malignancies, highlighting the impact CHC and W&W may have on patients. Participants responded in divergent ways to their diagnosis and the characteristics of their cancer. Anxiety and distress were common and more significant than physical symptoms. Monitoring such issues over time may facilitate the identification and resolution of difficulties. Community-based follow-up during W&W was favoured by some, but should be considered cautiously.

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CRediT authorship contribution statement

Dorothy McCaughan: Data curation, Formal analysis, Methodology, Writing – original draft, Writing – review & editing. **Eve Roman:** Conceptualization, Funding acquisition, Writing – review & editing. **Rebecca Sheridan:** Formal analysis, Writing – review & editing. **Ann Hewison:** Formal analysis, Writing – review & editing. **Alexandra G. Smith:** Conceptualization, Funding acquisition, Writing – review &

editing. **Russell Patmore:** Conceptualization, Funding acquisition, Writing – review & editing. **Debra A. Howell:** Conceptualization, Data curation, Formal analysis, Funding acquisition, Methodology, Project administration, Supervision, Writing – original draft, Writing – review & editing.

Declaration of competing interest

The authors declare that they have no competing interests or declarations.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.ejon.2023.102349.

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