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Research Article

Qualitative Insights into the Factors Impacting Information Sharing in People with Chronic Haematological Malignancies

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Background. There are many different haematological malignancy subtypes. Most follow chronic pathways that are uncertain and unpredictable, which may lead to feelings of anxiety and distress. The provision of information can ameliorate such difficulties, but patients are known to have unmet needs in this regard. The aim of this study is to explore experiences of information sharing among patients with chronic blood cancers and the factors impacting this process. *Methods*. The study is set within a UK cohort of blood cancer patients, where care is provided across 14 hospitals according to national clinical guidelines. Purposive sampling was used to identify expert participants (based on experience), and in-depth qualitative interviews were conducted with 35 patients, 10 with a relative present. The study was intended to inform practice and utilised qualitative description, with thematic content analysis and systematic data coding. *Results*. Experiences of information sharing varied. Most patients described this positively, but not all. Several barriers and facilitators were identified, which are discussed within five themes: (1) shock affects ability to process information, (2) the importance of time to facilitate information exchange, (3) personal relationships have an impact on meeting information needs, (4) HCP interpersonal skills are central to good information sharing, and (5) communication skills and terminology. *Conclusions*. Patients with chronic blood cancers prefer to engage in information sharing when they are not in a state of shock, and when they have adequate time to process material that is effectively and sensitively delivered, by HCPs they know and trust.

1. Background

Haematological malignancies encompass leukaemias, lymphomas, and myeloma, and in economically developed countries are the fifth most common group of cancers [1]. Also known as blood cancers, these complex conditions include more than 100 different subtypes and have diverse treatments and outcomes [2, 3]: some are aggressive and can be cured, while most (60%) are indolent and incurable [4]. The latter are increasingly perceived as chronic conditions [5, 6] and often follow remitting/relapsing pathways.

Chronic blood cancers tend to be initially managed on "Watch and Wait" (W&W), which involves an ongoing process of hospital-based "monitoring" (including biomedical and physical checks), followed by treatment if the cancer progresses, then further observation. The initial monitoring phase may continue for months, years, or the remainder of the patient's life, with treatment never required. Alternatively, single or multiple treatments may be delivered at progression to regain remission, reduce symptom burden, and prolong life. Importantly, while some patients feel reassured that their malignancy is chronic rather than acute, others struggle with knowing that they have an incurable cancer and face an uncertain future [7–9]. This often leads to psychosocial difficulties, whether on or off treatment [10, 11], which may cause more distress than any physical symptoms from the cancer itself [12, 13]. This unpredictability, alongside lack of treatment at diagnosis and an awareness that relapse signifies

advancement on the disease trajectory, can lead to feelings of anxiety, turmoil, panic, isolation, and of being on an "emotional rollercoaster" [11, 14, 15].

As is likely for most people with cancer, patients with haematological malignancies are reported to rate the provision of up-to-date information that they can understand as an important aspect of their care [16]. Accordingly, patients whose needs are satisfied in this respect tend to report better quality of life and lower levels of depression and anxiety than those with outstanding requirements [17, 18]. Key information blood cancer survivors require pertains to treatment, side-effects, disease recurrence, and survival [19]. However, such material is said to be sparse, with contrasting findings, meaning this group of patients may receive less, or poorer, information compared to those with other cancers [20]. Further evidence also suggests that blood cancer patients have unmet information needs or were dissatisfied with the material provided and that preferences for information, as well as their understanding of it, were infrequently checked [11, 18, 21–25].

The consequences of unmet information needs are clearly evidenced via reports of poor diagnostic understanding [11, 26], dissatisfaction with information about treatment and survivorship [24, 27, 28], and patient-oncologist discordance regarding cure and prognostic estimates, with patients demonstrating much greater optimism [29]. Furthermore, patients are known to prefer information to be delivered by doctors [20, 30], yet those with chronic blood cancers who start (and may remain) on observation often have less contact with their clinical team than those receiving treatment [25], thereby limiting opportunities for information-sharing [13]. Finally, much existing research includes patients with indolent and aggressive subtypes simultaneously, meaning that the needs that are specific to each group may be overlooked. In the case of chronic diagnoses, which may be associated with multiple complex treatment options, clear understanding is particularly important for informed decision-making [31] and appropriate psychological and/or supportive care interventions [32]. The present study aims to generate evidence about the information sharing experiences of patients with chronic blood cancers, including chronic lymphocytic leukaemia (CLL), follicular lymphoma (FL), marginal zone lymphoma (MZL), and myeloma, focusing on the factors that influence this process.

2. Methods

Methods are described in accordance with the Consolidated Criteria for Reporting Qualitative Research (COREQ) [33], with further explanation given in prior papers [13, 34].

2.1. Background Infrastructure. The study is set within the Haematological Malignancy Research Network (https://www.HMRN.org), which was initiated in 2004 to generate evidence to inform clinicians, researchers, and patients. Details of HMRN's configuration, methods, and ethical approvals are published elsewhere [4, 35]. Briefly, covering a catchment population of 4 million people with a similar socio-demographic profile to the UK as a whole, care within HMRN is provided across the haematology departments of 14 hospitals, all of which adhere to national treatment guidelines. Blood cancer patients enter the cohort at diagnosis (2,400 each year) and have clinical data collected from their medical records. With respect to patient and public involvement (PPI), patients co-developed this study and were co-applicants within the funding process; they were also members of the steering committee and commented on our paperwork and findings. Ethical approval was secured via London, City and East Research Ethics Committee (REC:16/LO/0740).

2.2. Identification of Interviewees and Sampling Strategy. Participants who had agreed to further contact via the HMRN consenting processes were invited to take part. The sampling strategy was purposive, aiming to identify "information-rich" sources who could provide data that were relevant to the study [36], and a preliminary frame was developed to manage this process. Initial criteria included a diagnosis of CLL, FL, MZL or myeloma, and proximity to the median diagnostic age for each subtype. Later variation was introduced by sex and time since diagnosis so that experiences at diagnosis, observation, progression, and treatment could be captured. Interviews continued until data saturation was reached [37].

2.3. Consent and Interview. After checking with NHS teams that patients were well enough to participate, selected individuals were sent an information sheet and asked to contact the study team if they wanted to take part. Respondents were informed that they could invite a relative/friend to join the interview if they wished. Interviews were conducted from February to October 2019, at a time and place chosen by the patient (mostly their home). Participants were assured of confidentiality and data security, and informed written consent was obtained (verbal from relatives). Interviews were conducted by an experienced researcher (DM), lasted 60–90 minutes and were digitally audio-recorded. Patients were asked to tell their story in their own words from diagnosis, with a topic guide used to cover areas of interest (Online Resource 1). Recordings were transcribed, checked, corrected, and anonymised by the interviewer.

2.4. Analysis. Data analysis was conducted by two members of the team (DM, DH), who drew on qualitative description, a minimally theorized method that is particularly relevant to practitioners and policy makers [38]. Interpretation involved thematic content analysis [39], which began with familiarization and engagement with the data by analytical, critical reading, rereading, and annotation of the transcripts, while attempting to interpret the accounts. This was followed by an iterative process of generating meaningful codes. Next, we searched for and grouped similar codes into themes, which were reviewed within a thematic map, before being defined and named. Verbatim quotations are presented

through the results section, enabling participants to "speak for themselves" about their experiences, with the themes providing insights into "what is going on" [39].

3. Results

Interviews took place with 35 patients (19 male, 16 female), 10 alongside relatives (3 male, 7 female), who contributed to varying extents. Participant characteristics are shown in Online Resource 2. Twelve had myeloma, ten CLL, eight FL, and five MZL; seven started and remained on W&W, with the remainder having experienced at least one line of treatment. Patients were aged 40–80 years at diagnosis, and 54–86 at interview. Barriers and facilitators were explored within five identified themes: (1) shock affects ability to process information; (2) the importance of time to facilitate information exchange; (3) personal relationships have an impact on meeting information needs; (4) HCP interpersonal skills are central to good information sharing, and (5) communication skills and terminology. Each theme is described below with quotations linked to participant numbers (P1 = patient; P1R = P1's relative). Although many people described positive experiences, this was not universal, as is depicted in the *Case Study* running through this section.

3.1. Shock Affects Ability to Process Information. Interviewees talked about their experiences of receiving information at key points, often when they were feeling particularly emotional (e.g., diagnosis, progression, and treatment) and experiencing shock, which could be overwhelming. Unsurprisingly, this was said to create a barrier to processing information and impede the ability to "*take information in*" (P16), with P21R noting "*you're just sat there going [nodding] and then you come out*, "*Oh, what was all that about?*." In relation to their diagnosis, patients said, "*I just shut down. . .I couldn't process it. . .the nurse explained everything, but it didn't go in*" (P8); "*my brain was just not computing it*" (P13). When explaining this response, P2 said that it was due to hearing the words "*cancer (and) chemotherapy*," while P13 said that it was particularly connected to the term "*leukaemia*."

Shock was also said to impact on the ability to request information and formulate questions, with P17 not asking anything at diagnosis, as she was "*taking in information*", and P16 saying, "*your brain is working on so many different levels*," including worrying if the cancer was life-threatening and how this would impact future finances. P4 reported being "*in no state to ask questions*," and P8 stated that she "*didn't know what to ask*." Others said that it was only later that information was absorbed, with P13 saying that it was the next day that "*things started to kind of slot into place and (then) your brain works overtime*." P18 described HCPs who seemed to be "*pushing (information) at you*," while P6R would have preferred time to let the diagnosis "*sink in*" and discuss it with others, before returning to clinic with questions. These issues are clearly demonstrated in *Case Study—Part 1*.

3.1.1. Case Study—Part 1: Shock as a Barrier to Information Processing. *"I think (clinical staff) did say at the time, have you any questions about (diagnosis)? But because it had hit us out of the blue, we hadn't prepared any questions, you know, we were sat there 5 minutes. . .I don't think we even spoke, really, did we? You're more or less going in, seeing what they've got to say and then coming out and it is only on the way home you think, oh, should we have said summit [sic]? Should we have asked summit [sic]? I think maybe if they'd just sort of explained it all and said go. . .sit with (nurse), have a pot of tea in the canteen and (nurse will) explain it best, (then) another appointment, either same day or day after or. . .But they didn't and by the time. . .it sunk in, we were driving home weren't we? You know, we thought "What's happened. . .?" It is as if your brain switched off for half an hour or summit [sic] and then we were just sat in the car going home, and (thinking) "What the hell just happened there. . .?" It just wasn't. . .it were [sic] probably explained perfectly to us, but our naivety, (we) needed it explaining in very, very easy terms. . ."* (P32, P32R)

Some patients said they had blocked information at diagnosis as a way of coping, in what P2 called a "*head in the sand*" approach, where he "*didn't want to know*" but preferred to "*let (HCPs) get on with it*." P33 described being given a lot of "*paperwork*" but not being able to understand or take it in: "*I was like, so emotional that I thought, I can't read any of this stuff, you know*."

3.2. The Importance of Time to Facilitate Information Exchange. Time was considered an important factor in relation to understanding the unusual nature of chronic blood cancers, and this impacted on the ability of patients and relatives to share and retain information, as well as ask questions. Many patients said their clinicians made every effort to provide adequate time for meaningful appointments: "*Time was never a problem*" (P16); "*I never feel rushed during consultations*" (P11); "*Time pressure? Oh no, never thought that ever. . .they always say, is there anything else you want to know? They don't rush you. . .they're not trying to get you out*' (P31). Similarly, P28 said his consultant gave him "*all the time in the world*," and the opportunity to ask further questions, and P12 said, "*there's no shortage of time if you want to ask a question*." Sufficient time was said to facilitate information sharing as it enabled HCPs to check patients had understood the material discussed, with P27 reporting how his consultant "*always asks if there's any questions*," while P11's doctor was said to ask: "*. . .do you understand. . .is there anything you are uncertain about. . .let's go through it. . .point you in the right direction. . .*"

A minority, however, described a clear lack of time, which they perceived as a barrier to information exchange. P4, for example, reported not having a chance to discuss treatment with a nurse, and P23 described wanting "*more information from the specialists*" but not having the opportunity to meet with a nurse because they were "*so busy, just so busy*." While some said there was only enough time at the initial appointment to receive "*basic information*" (P6R), others corroborated this saying they needed to search for detailed information online themselves (P12).

Participants appeared acutely aware of time pressures in busy clinics, with P34 saying "*I know (doctors have) a limited amount of time (and) when I sit there in the clinic waiting. . . and it is a big wait and I sometimes think, well I want to make this pretty quick because I don't want to take up loads of their time*." Even when consultants did not rush them, patients were aware of time, with P13 saying "*I'm always mindful of other patients waiting*." More specifically, with regard to asking questions, P32 said "*I should have asked that question, but they (doctors) were that far behind time, you know, that comes into it then. . ..*" Conversely, regarding requests for information, P28 said that HCPs always took time to answer questions, no matter how busy the clinic, so he never felt "*Oh, I won't ask that question because there's a load of people waiting*."

3.3. Personal Relationships Have an Impact on Meeting Information Needs. Given the potentially prolonged nature of chronic blood cancers, patients often described attending hospital and seeing the clinical team over extended periods of time. As a result, they talked in detail about their relationships with HCPs and how these could deter or facilitate information exchange. Many described their doctors and nurses positively, using phrases such as "*understanding*," "*gentle and sensitive*," "*brilliant and lovely*," or "*very approachable*." They were often complimentary about how HCPs had spoken to them and their relatives at various timepoints on the pathway: "*the first thing (doctor) said was* "*we are going to be able to help you*" *and that was a big reassurance. . .we're not just a commodity*" (P17); "*warm, pleasant, smiling, we have a laugh. . .you come away. . .feeling elated rather than "phew"*" (P10). They also demonstrated feelings of affection, with P33 saying she "*loves (her consultant) to pieces*": "*I'd hug him and stuff. . . he's lovely*."

Such good quality trusting relationships were said to facilitate information sharing, with P25 explaining that "*to open up to someone, you've got to know them*" and P28 also saying "*you have to get to know the consultant before you can have a decent conversation*." In comparison, others were concerned that their doctors did not know them, with P33 saying "*understudies or whatever you call them, they didn't know enough, about me*", and with respect to communicating bad news, P2 said "*they have no idea who I am and they're trying to tell me things. . .I want somebody who can tell me because I know and trust them*."

The trust required for effective information exchange was considered harder to establish with HCPs who were considered "*dismissive*" or "*gruffer or more dogmatic*." One relative, for example, described a poor relationship with a doctor who was considered "*stand-offish*" (P27R). However, not everyone considered the absence of easy rapport a barrier to information sharing. P7, for example, described his doctor as "*aloof*," yet technically "*brilliant*," and someone who "*gives you the facts*," which he preferred above all else.

Patients described relationships with their HCPs as developing over time, alongside improved communication. P18, for example, noted that clinical staff intentionally tried to avoid overwhelming him with material initially, but that more was shared as they got to know each other better. Similarly, P26 described being "*daunted*" by her consultant's manner at first, as he appeared "*detached*" and "*a little bit severe*," but considering him "*a different person*" as she got to know him, which caused her to think that clinicians may have to "*adopt a persona*" in order to give bad news. Strong relationships did not always develop, however, as was the case with P25, who went on to say that "*(doctors) could treat you a little more like a person. . .(with) a life outside hospital. . .a human being with feelings. . ..*"

Continuity of care from known HCPs was considered vital for developing the trust with particular individuals that was needed to facilitate information exchange. P8, for example, communicated a desire to see "*their*" doctor, P30 knew the name of "*his*" nurse, and P29 was "*very happy*" knowing that she could ring her "*dedicated haematology nurse*," who would provide "*brilliant information*." Conversely, lack of continuity ("*it is just that busy. . .you just see who's available*," P32) was said to impede information sharing, with P25 describing how she sees a different doctor each time and feels like "*just a number*."

3.4. HCP Interpersonal Skills Are Central to Good Information Sharing. In the context of prolonged, often complex future trajectories, the HCPs' attitude and ability to establish rapport was considered important, with P27 saying that he was reassured that he immediately "*gelled*" with his haematologist and was disappointed if he saw someone else, and P21R noting "*we love (consultant). . .a totally approachable guy. . .very laid back. . ..*" Other preferred attributes were "*friendliness, interest in people, a sympathetic attitude. . .* (P29), "*not all hoity-toity*" (P25), and having "*a positive attitude*" (P10). Similarly, P18 described feeling "*on the same wavelength*" as his haematologist, who "*talked as if having a chat*," which made him feel comfortable. In addition, patients said "*compassion*" (P10) was important; that it was crucial to appreciate the emotional impact that living with a chronic cancer "*24/7*" (P10, P6) may have; and that "*Plenty of empathy. . . makes a difference*." Empathy was not always perceived, however, with P4 describing the CNS present at her diagnosis as lacking this quality, highlighting that staff should bear in mind that "*it is (CNSs) job every day. . . but for each (newly diagnosed patient) it is something new*."

Another highly appreciated attribute was the ability to respond to humour during conversations, with P25 saying "*a bit of humour goes a long way*"; P34 noting that a trait valued in his haematologist was that ". . .*he was funny. . .*" and P25R liking that their doctor ". . .*can take a joke, (and is) witty*." A confident approach to imparting information was also

appreciated, with P25 describing one haematologist as "*embarrassed*" to provide "difficult" information which made the patient feel awkward: "*it was very hard for her, and I didn't really want it to be hard for her, so I just tried to be quite cheerful and say, "oh no, no tell me, that's alright*." This was compared to a current doctor, who "*didn't mind giving me information. . .enjoyed talking all the ins and outs of it and telling me all about it. He was quite nerdy which I quite liked (laughs). . .any question I asked he just told me instantly*."

Having the ability to talk to people as equals and adapt information to individual needs and preferences (e.g., for certain treatment types) was considered important. P33, for example, noted how her doctor never made her feel like "*just a number. . .*" saying: "*he explains things, even though he's very knowledgeable and the main man, and high (up). . .he never makes you feel inferior. I feel like I could ask him. . .can you explain that?*" P34 said a trait he appreciated in his consultant was their ability to "*talk to you like you're a person and not just a patient*." This doctor had also individualised their approach by directing the patient in an information leaflet, saying "*Oh, yeah, you don't need to read this; (but do) read this bit*." Responding to preferences for specific information, P24 described how his doctor shared the NHS computer screen, so they could view and discuss his blood results together.

Listening skills were also highly valued, with P29 describing HCPs: *"giving time for people to actually speak. . .to think about things before they ask (further) questions. . .listening is at the top of the list."* Similarly, P27 described how his consultant asks him a question then waits for reply, which made him *"feel you can tell him what you want to tell him."* This ability was sometimes appreciated over other attributes, with P18, for example, describing his consultant as *"not a natural communicator,"* but nonetheless, *"a good listener (who) is absolutely fine to communicate with (and) gives you space and time. . .."* Nonverbal skills were also considered important, with the demeanour of HCPs also noted by patients: *"if I can see nurse smiling. . . everything will be fine"* (P13).

Other important factors included adequate HCP preparation for consultations, as such behaviour made patients feel like their doctors knew them as individuals, were aware of their prior experiences (e.g., tests and treatments), the impact of these, and patient preferences. Dislike was expressed for HCPs who overfocused on computer equipment during consultations, with P28, for example, describing how their doctor looked at the screen throughout his initial consultation while talking to him, checking the "*numbers*" (e.g. age, bone marrow result), whereas he wanted the doctor to be "*alert to who I am*."

In this group of patients, in which acute difficulties could arise rapidly, on a background of long-term monitoring, accessibility was also said to be important, and CNSs were considered particularly strong in this regard. Open access to these HCPs was considered important, particularly in potential emergency situations, such as post-treatment sepsis. In this context, P28 said that he had been given a card with "*clear instructions*" and found it reassuring to know if he could use this "*straightaway*," including out of hours. P31 also commented that he had learned most about his diagnosis from his CNS, who was accessible and "*so good*" at providing information.

3.5. Communication Skills and Terminology. HCPs were often considered to have strong communication skills. P16, for example, noted receiving "*enough*" material, provided in a way he could understand. Information exchange was said to be "*well-handled*" (P11) by others and "*very clear*" (P12). Clarity was important, with P27R saying that her husband's consultant was "*very, very good at explaining. . .in those early days of everything happening*." P17 said they did not need to ask questions as "*the consultant had given such a good explanation,*" and P24 reported how his doctors were "*very good in terms of information*" and that it was "*hard to fault them*." P34 said "*It is nice if they can talk to you a bit and give you as much information as possible really. But I find most of the doctors and nurses are pretty good in that regard*." Also appreciated was an ability to "*explain rather than "waffle"; give you all the facts so you can go away and think about them. . .*" (P10).

Such skills varied, however, and others contrasted the communication styles of their various doctors, with P35 explaining how she asked the first: ""*Have I got a lot to face?*" *And (was told)* "*Yes*" *[taps table to mimic haematologist] just sort of [bang, bang] like that. Whereas I think some of the other doctors might have been a lot more positive. . .because even now, my last appointment you get ones who are sort of saying, look there's plenty of treatments and they try and make you feel better about it. . .I suppose he thought that was his job, to tell me the facts. Whereas it is too much. . .quite brutal really, I realise now, because there were other ones that have not been like that. . .if I'd had a different doctor, it wouldn't have been quite as (bad). . .*."

Other accounts of poor communication were also reported. P2, for example, noted: "*I felt there was very little listening and all telling*"; P25 described inadequate explanation (just given "*books*"); P7 reported only being given the "*basic facts*"; and P21R saying the family's questions had not been answered, that information had been "*vague, meaningless*," and that the diagnosis had not been fully explained. Further evidence is presented based on P32 in *Case Study—Part 2*.

3.5.1. Case Study—Part 2: Perceptions of Poor Traits and Skills at Diagnosis. "*. . .rubbish really. . .they were a bit vague. . . they called us in. . .and (CNS) was just sort of flittering around in the background, and then this particular (doctor) (who) was abrupt really. . .just said, "Oh yeah you've got lymphoma and it is such and such," and then (CNS) just gave me a book, a big book. . .and said, "Ah, really it is nothing that will affect you anytime soon" and. . .gave me a sheet of paper, and I bet we were out in 5 minutes. It were [sic] just so clinical how she explained it, there was no compassion". . . From that day I've never looked at that book. It is upstairs. They just marked a page and said that's what you've got. . .she just put sheet of paper. . . "(look at) that page. . ." and just, away you go.*" (P32 described being "speechless" at diagnosis and expecting the nurse give further explanation, which did not occur and she never received verbal information about her lymphoma).

Use of technical language was frequently said to deter information sharing, with P2 saying his haematologist: "*talks very much in the jargon. . .(and) needs to bring it down a little into plain English*." P23 said "*sometimes they come out with all these big words, and you think, actually I am not sure what that word is. . . (but) it is about you, and (so) it is important that you know what it is*"; and P4 noted "*I don't feel (HCP) explained (diagnosis) to me in lay-man terms*." P13 described being "*bombarded with clinical terms. . .*," and unclear about "*cell mutation*" and "*cell deletion*," saying "*I can't get my head around whether it is a good or bad thing for you to have this. . .TP53. . .there's another one with four letters. . . IV. . .IGHV?*," but worrying about the impact this may have on treatment options.

Several patients said that they did not understand the meaning of blood results. P2, for example, was told his paraprotein "*levels were wrong. . .*," which he said "*meant nothing to me*." Similarly, P20 said "*you've no median line. . . so you don't know whether you're down near the bottom. . .or in the middle even. . .if you could just pinpoint how good or bad. . .it is just the fact you don't know where you are. . ..*" This was confirmed more generally by P13, who said "*white blood counts, red blood counts. . . it is an awful lot to take in*."

P21R stated a preference for terminology that "*doesn't try to blind you with science*." In another example, P30 described being unable to ask questions as he did not understand the terminology of his condition: "*they explain it in such technical (terms). . .it takes a bit of sinking in. . .some of them words, I can't even spell them let alone read them!*" There was, however, an appreciation of the challenges HCPs face to pitch information appropriately and "*get it over to the average person without baffling them with science. . .because the average person in the street understands certain words, but not when (HCPs) starts to go on about certain diseases and all the various pitfalls*" (P16). P23 also highlighted how difficult it is for clinicians to give enough information without "*overwhelming*" individuals. P32 and P32R depict their experience clearly in *Case Study—Part 3*.

3.5.2. Case Study—Part 3: Technical Language as a Barrier to Information Sharing. P32R *". . .the first time. . .specialist spoke to us, I thought she was talking another language. She was just coming out with all these medical terms and I thought, well I don't know, I hope (relative) does. But we both come out [sic] and said, we didn't understand hardly any of that.*

P32 All we understood was "You've got cancer," that's all we understood. . .

P32R But they just kept coming out with all these medical terms didn't they, as if we're expected to know them and we didn't have a clue, I mean as simple as we are. . .when they're telling you things. . .and they expect you to know what they're on about medically, I think that confuses you. . .big words confuse you, and they're saying these big words and you think they're ultimately bad. . .."

P32 . . .it was (later) put to us in layman terms (by another specialist) and then we sort of thought, oh great, because we had been going, and I amm not saying we were expecting the worst, but we were not expecting good news, you know. . .

P32R Yeah, it wasn't as bad as you thought. . .

P32 No, no, and once they sort of broke it all down and told us, it were [sic] a weight off our shoulders wasn't it because at the time, you know, we were panicking and stuff like that.

P32R No they hadn't (checked we understood), I mean that (doctor) who we went to see first. . . did assume that we knew something of it, and that was the first time when we went to (hospital) wasn't it. So, we didn't know anything about it."

4. Discussion

Novel in-depth evidence was identified about the barriers and facilitators to information sharing for patients with chronic blood cancers. This includes preferences to engage when not in a state of shock, and when there is adequate time to process material and ask questions; and for the sensitive and effective sharing of material by skilled, experienced HCPs who are known and trusted. Specific experiences varied and although many reports were positive, others were not. Unfortunately, some patients were never informed about the complex and unusual nature of their diagnosis in a way that they could fully understand or explain to others, as has been noted in previous work [11]. This suggests that information is not always effectively communicated to individuals. Further, haemato-oncology's rapidly changing diagnostic and treatment landscape may result in this scenario becoming increasingly common as new tests (such as those able to identify risk of progression) are introduced, meaning that HCPs will need to keep abreast of such vicissitudes if they are to effectively meet information needs.

Similar research involving patients with chronic, acute, and/or unspecified blood cancer subtypes largely aligns with our findings regarding shock, unmet information needs, and relationships with HCPs [6, 26, 40]. Also, in agreement with our results, some studies indicated that patients' information needs were largely met [18, 41], and that they found monitoring appointments and blood tests reassuring [24]. One review noted that caring, trusting relationships were integral to meeting the information needs of patients [16]. Although sufficient clinic time was said to be largely available by our participants, however, several studies reported the opposite, with only limited opportunity to talk to HCPs and check-ups that were considered superficial or cursory [11, 12, 14, 23].

Looking more broadly, our findings may resonate to some extent with aggressive, potentially curable blood cancers and unrelated cancer types, with studies of acute myeloid leukaemia noting similar difficulties as the present work, although in this context, some patients refused

information as a mechanism for managing their diagnosis, suppressing anxiety, and maintaining hope [42]. Generally, however, our findings are likely to have more in common with other long-term conditions than with cancers that can be treated and cured. This is because chronic blood cancers are typically incurable, they remit and relapse, may require continuous or intermittent treatment, and if they progress might need treatment escalation to regain and maintain response. As treatment improves and less aggressive blood cancers are increasingly being perceived as chronic [5, 6], our findings may impact beyond the scope of haematological malignancies.

The evidence generated within our study could be used to inform clinical practice. For patients with chronic blood cancers, this might include checking existing knowledge, allowing time for diagnostic information to be processed and absorbed, use of non-technical language, inviting questions, and checking understanding of any material shared. Awareness of the shock and significance a chronic blood cancer diagnosis may have on individuals is also important, not least due to the infrequency with which such patients may attend clinic and have the opportunity to raise concerns and exchange information. In this context, it is useful to consider newly diagnosed cancer patients as using information to regain control following a cancer diagnosis [43]. One study of motor neuron disease found that a 2-tier approach (initial appointment to share the diagnosis and another later for discussion) performed better than standard care [44], and a similar method could improve the experiences of patients with chronic blood cancers.

Optimal cancer care requires the provision of adequate information, which is challenging to provide, as cancer evokes strong emotional responses from patients and requires information that may be dense and complex, particularly if multiple treatment options are available [45]. Face-to-face clinician training in communication skills may facilitate this process but can be time-consuming, difficult to schedule, and expensive [46]. Although the information needs of patients with blood cancers have been increasingly explored [9, 16, 23], and are frequently considered "unmet" [47], little is known about information-sharing from the perspectives of healthcare staff. One small study in oncology found that although HCPs strive to inform patients, they may struggle to tailor information to individual needs and to deal with emotions, especially with increasing time pressures [45]. This work concluded that healthcare staff are willing to use digital training tools to improve their skills, and descriptions of prototype digital tools to engage oncologists in learning information-sharing skills have been reported [46], although more research is required.

A major strength of our study is the richness of information shared by interviewees about their experiences. The sampling frame ensured key participants were included, by diagnosis, treatment, sex, and age. Our methods were rigorous and transparent [39], and analytical processes were managed by experienced researchers, one of whom conducted the interviews. Our results are clearly described and likely to be transferable to regions and countries with similar healthcare systems and to other chronic cancers/conditions. Recruitment was, however, limited to patients who were well enough to consent to further research.

5. Conclusions

This study identifies factors affecting information sharing in patients with chronic blood cancers. Experiences varied; most interactions with HCPs were described positively, but not all. Our evidence provides a useful foundation from which to inform clinical practice and potentially reduce the anxiety and distress associated with these conditions.

Data Availability

The dataset generated and analysed during the current study is not publicly available due to the risk of participant identification and the terms and conditions regarding the release of data to third parties which underpin the study approvals. Data may be available from the corresponding author on reasonable requests.

Additional Points

Key Points. (1) The information sharing experiences of patients with chronic blood cancers varies markedly. (2) Some discussions are poor, and patients do not always sufficiently understand the unusual nature of their cancer. (3) Diagnosis often causes shock and time is needed to process information, facilitated by good relationships with HCPs, who have strong interpersonal skills.

Conflicts of Interest

The authors declare that they have no conflicts of interest.

Authors' Contributions

DH conducted conceptualisation, funding, methodology, supervision, administration, analysis, and writing (original draft, review, and editing). DM conducted data collection, analysis, investigation, and writing (original draft, review, and editing). RS conducted investigation and writing (review and editing). RP conducted conceptualisation, funding, and writing (review and editing). ER conducted conceptualisation, funding, and writing (original draft, review, and editing).

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Supplementary Materials

Online Resource 1: topic guide. Online Resource 2: characteristics of interviewees. (*Supplementary Materials*)

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