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Chronic myeloid leukaemia: A qualitative interview study exploring disease impact from patient and practitioner perspectives

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ABSTRACT

Purpose: Improvements in chronic myeloid leukaemia treatment mean it is now relevant to examine the experiences of living with this cancer over a lifetime. This qualitative study aimed to investigate the impact of chronic myeloid leukaemia, from patient and healthcare practitioner perspectives.

Methods: The research was set within the UK's Haematological Malignancy Research Network; a population-based cohort of patients newly diagnosed with blood cancer, treated at one of fourteen hospitals. Purposive sampling led to interviews with seventeen patients and thirteen health care practitioners. Data were analysed using thematic analysis.

Results: Two analytical themes, "Significant impact of disease and treatment" and "Mediators of the impact of disease and treatment", and six sub-themes, were derived from patient interviews and supported with data from practitioners. Chronic myeloid leukaemia was described by patients as having significant widespread impact, which could be mediated by their knowledge, social support, and the quality of healthcare systems. Practitioners reflected patient accounts, but could underestimate the impact of this cancer. They generally viewed chronic myeloid leukaemia as less complex, severe and impactful than acute blood cancers; a message that reassured patients at diagnosis, but could later unintentionally contribute to difficulties discussing side effects and struggles to cope.

Conclusion: Chronic myeloid leukaemia may significantly impact individuals, particularly as it is experienced over the lifetime. Greater understanding and discussion of the breadth and extent to which patients are affected, including potential mediators, could enhance clinical care.

1. Introduction

Chronic myeloid leukaemia (CML) is a rare haematological malignancy (blood cancer) with an annual UK incidence of 1.1 per 100,000 population (HMRN, 2022). The introduction of targeted tyrosine kinase inhibitors (TKIs) in the early 21st century had a remarkable impact on survival, transforming this once rapidly fatal cancer into a chronic malignancy (Baccarani and Pane, 2014; Clark, 2020). Orally administered at least once daily at home, with simultaneous specialist hospital monitoring, UK TKI treatment is available free of charge, and five-year survival is estimated at 89.1% (HMRN, 2022). These major treatment advances mean research is now beginning to explore the long term experiences of patients living with CML, including disease- and treatment-related symptoms, the impact these may have on quality of life (QOL), and medication adherence (Noens et al., 2009; Efficace et al., 2011; Williams et al., 2013).

Existing research reports that CML and TKI treatment can significantly impact employment (Efficace et al., 2013; Zulbaran-Rojas et al., 2018) and increase the risk of depression (Buzaglo et al., 2017). Poorer QOL than the general population has also been identified, and has been associated with reduced medication adherence (Noens et al., 2009; Phillips et al., 2013). One of the drawbacks of existing research is that

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TKI side-effects have commonly been assessed by healthcare practitioners (HCPs) rather than patients themselves, using generic tools such as the National Cancer Institute Common Terminology Criteria for Adverse Events (CTCAE) (National Cancer Institute, 2017), despite the availability of CML-specific questionnaires (Williams et al., 2013; Efficace et al., 2014a). Whilst such tools can usefully identify toxicities, they are less effective at measuring symptoms such as pain, for which self-reporting may be more accurate (Baccarani et al., 2014). Furthermore, side-effects considered minor by HCPs during assessment, may be perceived as significant by patients (Guérin et al., 2014; Efficace and Cannella, 2016), particularly when experienced over prolonged time-periods.

Qualitative studies have largely focused on patient experiences of treatment and adherence, and suggest these are complex and evolving, with numerous physical and psychological symptoms effecting daily life; complicated patient decisions regarding treatment, influenced by social context; and concern over the non-disclosure of side-effects and non-adherence (Eliasson et al., 2011; Guilhot et al., 2013; Chen et al., 2014; Wu et al., 2015; Graffigna et al., 2017; Lim et al., 2017; Mortensen and Mourek, 2017; Tan et al., 2017; Bolarinwa et al., 2018; Boons et al., 2018). Only one study has examined HCP views (Wu et al., 2015), describing perceptions of CML as a “low level” cancer compared to acute blood cancers, and suggesting this may deter patients from discussing their concerns. Our study aimed to address these deficits by examining the experiences and impact of living with, and managing CML, from both patient and HCP perspectives. Whist this paper concentrates on the impact of CML, a further paper will explore CML management by patients and HCPs, including medication adherence.

2. Methods

Methods are described in accordance with the Standards for Reporting Qualitative Research (SRQR) (O’Brien et al., 2014).

2.1. Research design

A qualitative study was conducted, using in-depth semi-structured interviews with CML patients and HCPs providing care.

2.2. Participant setting, sample and recruitment

The research was set within the UK’s Haematological Malignancy Research Network (HMRN); a population-based cohort, including all patients newly diagnosed with blood cancer in its catchment (Smith et al., 2018; Roman et al., 2022). The present study includes people with CML who had consented (via HMRN) to take part in future research, had chronic phase CML diagnosed ≥ two months pre-interview, and were aged ≥18 years. Patients meeting these criteria were purposively sampled, based on age, gender and hospital type, to reflect the total HMRN CML population. Strategic sampling followed, in an attempt to identify interviewees who had experienced challenges managing their CML; facilitated by clinical nurse specialists (CNSs).

HCP inclusion criteria included working within haematology at one of HMRN’s 14 hospitals, as a consultant, junior doctor or CNS. HCPs were purposively sampled based on having experience of CML, then asked to suggest other practitioners who could provide detailed information (snowball sampling: Ritchie, 2003). Although a grounded theory approach was not utilised, “saturation”, when no new codes could be added to the analysis (Guest et al., 2006), informed the end of data collection, thus the sample size.

Ethical approval was obtained from Leeds West NHS Ethics Committee (REC 16/YH/0016). Patients were posted an information pack and invited to take part (once), and HCPs were contacted by email (up to two reminders). Before the interview, participants were invited to ask questions, and offered reassurances about confidentiality, anonymity and the chance to withdraw. Participants were then asked to provide their written consent to take part in the study, which included agreeing to the interview being recorded and transcribed, and for interview data to be used anonymously. Study information included informing participants that research findings will be published in scientific journals. All interview data was anonymised in a way that participants cannot be identified, interviewees being assigned a unique ID, which was subsequently used to refer to them.

2.3. Data collection

A prior narrative literature review (Hewison, 2021) and qualitative synthesis (Hewison et al., 2020) were used to develop the interview schedules, alongside consultations with research and clinical colleagues, and patients (see Supplementary materials 1 and 2). Questions were open-ended and the initial schedule was revised on learning more about participants’ preferences for sequencing accounts, and from reflecting on the data. Interviews were conducted 2016–2019 in patients’ homes, HCPs’ work-places, or university offices. They were carried out by AH who was younger than several participants and, at the time, a PhD student. AH provided a thorough description of the study and HMRN research team in order to assure participants of study quality.

All interviews were digitally recorded onto an encrypted device, transcribed, checked and amended; including the removal of all identifiable data. Patients were interviewed first, to facilitate an understanding of living with CML, prior to data collection from HCPs.

2.4. Data analysis

Thematic analysis was used to analyse the data (AH), and involved six stages (Braun and Clarke, 2006, 2013). Initially, transcripts were read and re-read to gain familiarity with the dataset. Codes were then generated using complete coding of all text relevant to the study aims. A coding frame was subsequently developed, via an iterative process, with codes compared and their meaning and overlap checked, and sub codes organised under code headings. The final coding frame was reviewed by a second researcher (DM) alongside several transcripts, and discussed until consensus was reached. After hand-coding, transcripts were uploaded to NVivo 11 & 12 Pro (QSR International Pty Ltd., 2015), to facilitate the management and retrieval of all text applied to specific codes/sub codes.

The initial search for themes involved identifying similarities in the essence of meaning in the coded text rather than literal meaning (Braun and Clarke, 2006, 2013). Visual mapping codes (by physically moving them around) facilitated combining those with similar meanings. Themes were reviewed by re-reading original transcripts to check meaning and ensure salient features of the data were captured in the themes. Defining and naming themes occurred in a way that explained a feature of the coding that had relevance to the research question, and attended to both the scope and depth of the data (Braun and Clarke, 2006; Morse, 2015). Once themes were finalised they were looked at by an HMRN patient with CML who provided feedback in support of their credibility.

3. Findings

Data saturation was reached at thirty interviews with seventeen patients and thirteen HCPs. Patients broadly represented the HMRN CML population in terms of sex (8 females, 9 males), age at diagnosis (median 55 years) and hospital attended (53% local hospital, 47% cancer centre: Table 1). HCPs represented HMRN hospital type, however were intentionally weighted towards CML or myeloid practitioners; 38% worked in cancer centres and 62% had at least ten years’ experience (Table 2).

Table 1
Patients characteristics.

Study ID	Hospital	Age at diagnosis	Gender	Year of diagnosis
PA02*	CC[1]	61–70	M	2005–2010
PA04	LH[2]	61–70	F	2005–2010
PA06	CC	51–60	F	2005–2010
PA07	LH	51–60	M	2011–2015
PA11	CC	61–70	M	2016+
PA15	LH	51–60	M	2011–2015
PA19	LH	61–70	M	2016+
PA20	LH	51–60	F	2016+
PA21	LH	51–60	F	2011–2015
PA24	CC	≤50	M	2005–2010
PA25	CC	51–60	F	2011–2015
PA26	CC	61–70	F	Pre-2004
PA27	CC	Not known	M	Pre-2004
PA28	LH	71–80	M	2011–2015
PA29	LH	Not known	F	Pre-2004
PA30	LH	≤50	F	2005–2010
PA32	LH	≤50	M	2011–2015

*Missing IDs represent invited patients who did not participate.
[1] CC - Cancer centre.
[2] LH - Local hospital.

Table 2
Health Care Practitioners occupational details.

Study ID	Role	Years in role	Hospital type	Specialism	Clinic type
PR01*	CNS[3]	10 years +	CC[1]	Myeloid ± CML	Specialist CML
PR02	Consultant	10 years +	CC	Myeloid ± CML	Specialist CML
PR03	CNS	10 years +	CC	Myeloid ± CML	Specialist CML
PR04	CNS	10 years +	LH[2]	Myeloid ± CML	General haematology
PR05	CNS	10 years +	LH	Myeloid ± CML	Specialist/ general haematology
PR06	Consultant	10 years +	LH	Generalist	General haematology
PR08	CNS	1–5 years	LH	Myeloid ± CML	Specialist CML
PR10	Consultant	10 years +	LH	Myeloid ± CML	General haematology
PR11	Consultant	1–5 years	LH	Myeloid ± CML	General haematology
PR14	CNS	10 years +	CC	Myeloid ± CML	Specialist CML
PR15	Consultant	1–5 years	LH	Generalist	General haematology
PR19	CNS	10 years +	LH	Generalist	General haematology
PR20	Consultant	1–5 years	CC	Myeloid ± CML	Specialist CML

*Missing IDs represent invited HCPs who did not participate [1] CC - Cancer centre. [2] LH - Local hospital, [3] CNS - Clinical Nurse Specialist.

3.1. *Analytical themes*

Rich descriptions from patients facilitated the generation of two themes: "Significant impact of disease and treatment" and "Mediators of the impact of disease and treatment", each with multiple sub-themes (Fig. 1). Findings are based on patient accounts, with further insights provided from within the HCP data. Quotations are attributed to individuals: PA = patients; PR=HCPs.

3.2. *Theme 1: significant impact of disease and treatment*

3.2.1. *Sub-theme a: widespread side-effects*

Most patients described wide-ranging side-effects, most commonly gastrointestinal complications, fatigue, and muscular pain and cramps, which they attributed to taking TKIs; but also respiratory, skin and hair, and cardiovascular effects; and less frequently, prolonged infections, dizziness, tinnitus, allergy, mood change and blurred vision:

> *"It's once a day and I have it at breakfast time and I sandwich it within my breakfast. I can be sick after it if I don't … if I just take the tablet I would definitely be sick, it really irritates my stomach."* (PA04)

> *"I go to the gym a couple of, 3 times a week depending on how tired I feel afterwards. I'm not so bad when I'm there. I feel as though I've got the energy to do it but it's the aftermath. It's the next day, I'm really fatigued."* (PA21)

> *"When I get the cramps in my legs and my arms … that can be bad."* (PA15)

Several patients discussed living with side-effects alongside symptoms from co-morbidities, which could be hard to distinguish, and according to several HCPs may augment difficulties. Co-morbidities could also limit treatment choices or require TKI modification:

> *"I have other medical problems, which you don't know whether it's the leukaemia or the diabetes or anything else what's going off."* (PA19)

Several HCPs reported that TKIs were usually well tolerated, but many discussed side-effects, which reflected some of the problems patients commonly reported:

> *"The biggest thing these guys complain of is tiredness and tiredness is a nightmare, you've just had a bad nights' sleep but it's more than that in these guys."* (PR20)

Only one HCP referred to muscle pain/cramps and there were no reports of respiratory issues, although these are both known side effects to TKIs.

3.2.2. *Sub-theme b: impact on daily life*

Daily life was impacted in many ways, at diagnosis and over time, with the most frequently reported effects being psychological, patients describing changes to their mood; some saying they felt "*upset*", "*less positive*" and like they were "*losing control*":

> *"It's putting me down. I used to be more positive, really, really positive but yet I'm more down."* (PA29)

Several patients still worked, and just under half of these described needing to reduce or stop this due to fatigue, shortness of breath and feeling generally unwell. While some expressed being "*less stressed*" and more "*in control*" as a result, others found change difficult to instigate, as they were reluctant to disclose symptoms or pessimistic about finding and sustaining suitable hours or roles:

> *"I had a battle working in the NHS … it was within my first year, I had a battle with my employer [laughs]. I only worked part-time … 20 hours, but that was a struggle because I did it over 4 days. Now with the fatigue I couldn't, you know."* (PA25)

Several HCPs corroborated patient accounts regarding fatigue, although others believed a normal working life should be possible:

> *"Most [patients] hold down jobs and whatever and are fine."* (PR05)

Some patients indicated physical or mobility issues due to generally "slowing down", which impacted activities such as attending hospital appointments. Patients also referred to many other activities they felt were affected by their CML, including holidays and travel, sport, socialising, dining out and household jobs:

> *"… it's a bit awkward if you're going out for a meal with other people because I've got to sort of eat round about 8 o'clock … you know that you can't eat anything 2 hours before and 2 hours after [taking medication]."* (PA07)

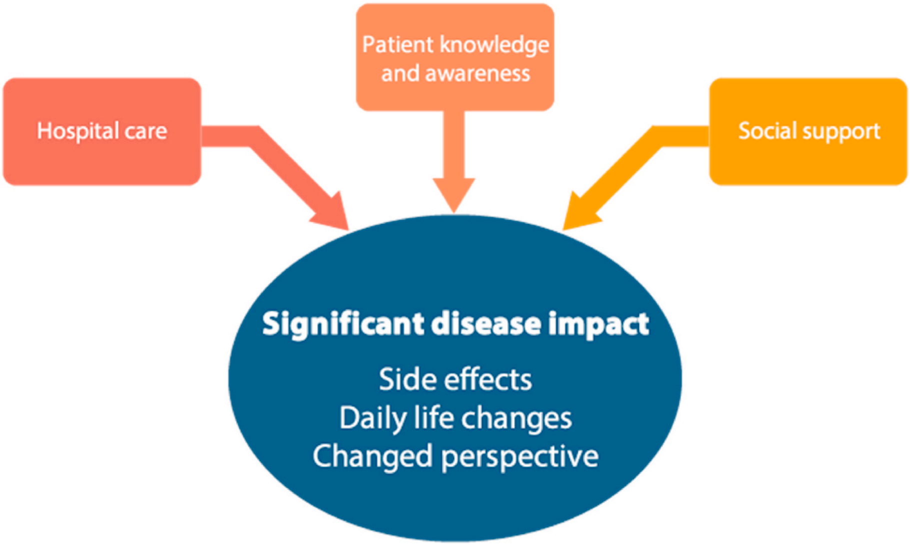

Fig. 1. Significant impact of disease and its mediators.

Daily life could also be affected by co-morbidities, which could have more impact than the CML itself:

> *"My stroke limits me more than my leukaemia. I can cope with that easily."* (PA26)

HCPs reported that travel insurance caused particular difficulties, but their reports did not reflect the number and range of other impacts on daily life described by patients.

3.2.3. Sub-theme c: changed perspective on life

Most patients noted how CML had changed their perspective on life, reporting mixed emotions, frequently beginning with shock at an often unexpected diagnosis. Many HCPs mirrored these accounts, acknowledging the diagnosis as a "*challenge*", a "*burden*", and "*life-changing*", with such feelings often enhanced in younger people:

> *"Certainly, to begin with, you're going to be, you have a chronic illness and you're going to be taking the drugs for a long period of time is a real burden for some … particularly younger people who didn't see this coming."* (PR02)

Following diagnosis, most patients described accepting their cancer and returning to usual activities. Rather than passive, this seemed an active process, occurring after learning more about CML and its prognosis, and evidence of a positive response to TKIs, and for some, overriding concerns about co-morbidities:

> *"I got introduced to the nurses and they gave me some information and I started reading up on it and I'm thinking, oh it's not as bad as what – it's probably one of the best cancers to get if you're going to get it. So I was positive then and thinking right I can cope with this."* (PA15)

Several patients felt their positive personality and will to keep active enabled them to accept and cope with their diagnosis. Some expressed a renewed appreciation for life, and felt lucky, or grateful for their treatment:

> *"But we just live for us [sic] holidays now, and it's made me appreciate life a lot more, you know.*" (PA07)

Conversely, despite presenting a positive perspective, several of the same patients also expressed negative emotions, including fear of cancer progression and general health anxiety:

> *"I do get a little bit worked up before I go [to hospital], I think because I forget about it the rest of the time and it's always just on your mind that it could, you know, it might not be as good as it was last time."* (PA20)

When asked what advice they would give a friend receiving the same diagnosis, patients said they would urge them not to worry and to keep active, however, phrases such as: "*don't give up*" (PA28), "*don't let it get you down"* (PA15) and *"accept what your life is now … you have to"* (PA25) suggests they struggled to maintain this positivity.

HCPs showed some agreement, believing many patients had a positive attitude to living with CML, which some felt could support medication adherence and coping:

> *"[TKIs have] transformed their life … It's enabled them to live really. Yeah they feel quite positive about things."* (PR03)

Whilst many HCPs noted the psychological impact of CML diagnosis, there was little description of the active process and struggle patients described to accept their diagnosis and remain positive. This may be because HCPs compared CML to the more acute subtypes, receiving intensive chemotherapy within their wider caseload:

> *"When you compare it with acute myeloid leukaemias or dysplastic syndrome then obviously CML patients have much more, better prognosis, it's basically now chronic benign condition …"* (PR11)

Such underestimation of the impact of CML could also be due to insufficient clinic time for exploratory discussions with patients:

> *"If you have a busy clinic with lots of patients, lots of them take longer than 15 minutes, other diseases which are more complex have more complex chemotherapy … If you then have a stable CML patient in between … it's not uncommon to then kind of use this to make up time."* (PR10)

3.3. Theme 2: mediators of the impact of disease and treatment

3.3.1. Sub-theme a: knowledge and awareness

Patient knowledge and awareness varied between and within individuals, and over time. Even where knowledge existed, for example around disease response, patients understood this in different ways; some referring to specific terms, such as *"BCR-ABL level"*, "*MMR"* and "*log-reduction"*, whilst others based this on blood results or talked about their results graph:

> *"… the last time I went … I'd just got into the green [on graph] so that's what they were aiming for.*" (PA07)

Poor understanding of side-effects was evident in some patients, who were unsure whether their symptoms were caused by the TKI, or who believed they had received insufficient information:

> *"Never had the energy and to be fair, I've never really spoke to anybody else who has the same symptoms or (is) on the same medication to find out what other effects people have. So I wouldn't know whether it's part of it or what really."* (PA24)

This contrasts with HCP accounts, several of which report providing advice about side-effects at diagnosis, and supportive discussions:

> *"I think in trying to encourage people to stay on therapy who do have side-effects it's trying to help them see the positives and the reasoning behind it all and why the side-effects are happening … knowledge is helpful* isn't it?" (PR02)

Major misunderstandings were infrequent, although concerning:

> *"They say Pennsylvania strain what I've got, which I don't know what that is … I suppose it's one type of leukaemia … if I've got this faulty gene, will it be passed down in any way?"* (PA28)

Several HCPs reported information needs declining over time, alongside a growing preference for psychosocial support, with some accepting that anxiety may be an ongoing struggle:

> *"There's always the anxiety every time they come to clinic about their blood results."* (PR4)

3.3.2. Sub-theme b: social support

All patients talked about the role of family, friends, employers and others in providing social support, which was considered important. This included help with daily tasks, having someone to share emotions, and advocacy:

> *"There was [Haematologist] and [CNS] … they were just lovely, they went through everything. There was [sic] obviously some bits I hadn't taken in but [son] obviously had and [son] asked more questions than me."* (PA20)

Patients used words such as "*close*", "*looking after*", "*coping*" and "*keeping in touch*" when referring to their support network, suggesting their appreciation for the "personal" aspects of care. However, such support could become complex; for example post-bereavement or among patients who had caring responsibilities themselves, highlighting the lifelong nature of CML, lived within a dynamic context:

> "*… my daughter, he's her third (child) and … she had to be hospitalised twice. So grandma had to step in and take over."* (PA25)

Few HCPs discussed the role of family and friends, despite several considering the impact of patients' social contexts on their experience, such as the relationship between socioeconomic status and co-morbidity.

3.3.3. Sub-theme c: hospital care

Aspects of hospital care, described in the context of the HCP's role and healthcare quality, could be beneficial (reassurance and explanations); or negative (missing results that delayed treatment decisions). Patients largely described their overall care positively, although were more ambivalent about specific aspects of it. Many spoke positively about the nature of hospital staff and several described good, trusting relationships, including the ability to talk about their feelings, which instilled reassurance, particularly at diagnosis:

> "*There's not much [HCP] doesn't know … and if you have any worries you can get in touch and she puts it right … she's very good. You can't ask for anything else."* (PA11)

> *"We do encourage [patients] to lead as normal life as possible."* (PR04)

Almost a third of HCPs likened CML to chronic illness, compared to two patients:

> *"I tell patients, this is like hypertension now, we can control it very well and if we control it well, there's nothing much to worry about.*" (PR15)

Several patients said they had appreciated receiving clear information from HCPs. However, whilst some were satisfied with explanations about side-effects, others perceived HCPs as too busy or disinterested to note their symptoms; they were also worried how HCPs may react:

> *"… she's always busy and that, and you sort of feel, you get to the point and I got to the point when you think I've had [CML] that long [HCPs] really don't want to know."* (PA29)

When discussing hospital systems, several patients highlighted efficiency, particularly regarding the diagnostic process, receipt of test results, and clinic functioning:

> *"… they sent me straightaway to the hospital. I was dealt with amazingly, the treatment I had was absolutely superb. Within the week I was diagnosed and then it went from there."* (PA04)

Some HCPs offered more detail about measures to ensure clinic efficiency, such as arranging prior blood tests and informing pharmacy of medication requirements, and many emphasised the quality of the regional specialist laboratory.

> *"HMDS [regional specialist laboratory] who produce a nice integrated report with a graphical picture for me to say, this is where their BCR-ABL ratio is compared with previously and actually showing that to patients is really, really useful."* (PR20)

A number of patients were managed via nurse-led telephone clinics, and while one patient felt it easier to express himself face-to face, most preferred this remote contact, as lengthy waiting times were avoided:

> *"You know, you're sitting there for maybe an hour and a half and it's boring. It's nice when you go in to see the doctor but I'm fed up by then."* (PA26)

A medication home delivery service was sometimes available and seen positively by clinical staff, and some patients.

Conversely, some patients found clinics to be inefficient and delayed, with lost results and letters. Several found hospital parking expensive, unpredictable or busy, with one patient attending alone as her husband was unable to park (PA29). Many reported pharmacy issues, meaning medication could run out early and extra trips to hospital were required. Such difficulties were reported less frequently by HCPs:

> "*Most of the time they don't have enough (medication) … and, half the time they end up owing you some so you have to go back."* (PA21)

4. Discussion

Unique findings were generated from this, the first UK study to explore experiences of living with CML from patient and HCP perspectives, via in-depth interviews. We found that CML may markedly impact individuals, particularly as it is experienced over dynamic, life-long time-periods. Frequent and widespread side-effects were reported, as well as changed daily activities; and despite an optimistic outlook, anxieties could persist, although patients were generally positive about their care. HCPs demonstrated awareness of the impact of CML, but could perceive it as a minor cancer compared to acute subtypes, thereby potentially underestimating some of the difficulties patients faced. Although unsurprising when compared to their overall caseload, such perceptions could mean patients were reluctant to disclose problems. Reduced clinic-time and HCP reassurances about the future may have reinforced this. New evidence on three aspects that could mediate the impact of CML were identified: patient knowledge and awareness; social support; and hospital care.

Corroborating our findings, others report muscle cramps/pain, fatigue and gastro-intestinal issues as common (Efficace et al., 2012, 2014b; Williams et al., 2013) and also a mismatch in HCP and patient accounts, with patients considering TKI side-effects greater and more impactful on QOL and the ability to work than HCPs (Efficace et al., 2104 b; Jiang et al., 2018) Shock at diagnosis and ongoing anxiety has also been described (Chen et al., 2014; Graffigna et al., 2017; Mortensen and Mourek, 2017), alongside HCP awareness of this (Efficace et al., 2012). Ongoing distress and uncertainty about the future has been found amongst people with certain indolent blood cancers (Howell et al., 2022). The patient's struggle to accept their CML diagnosis and maintain positivity has been reported (Eliasson et al., 2011; Guilhot et al., 2013; Graffigna et al., 2017), but may be an issue that HCPs are less aware of.

Considering mediators to CML, others have observed a lack of patient knowledge about TKI side-effects (Chen et al., 2014; Lim et al., 2017; Boons et al., 2018), along with the desire for more input to manage such issues (Zaleta et al., 2017). Poor communication of information about side-effects is reported in a review of blood cancer studies (LeBlanc et al., 2019), as well as limited disease knowledge (Howell et al., 2022), which is echoed in the wider cancer literature (Harrison et al., 2009; Moghaddam et al., 2016). Our study also suggested patients may understand information in different ways using differing language, which LeBlanc et al. (2019) also highlighted, suggesting information was not routinely "tailored" to individuals with blood cancer.

The value of social support is a unique theme for CML, although has been identified in non-Hodgkin lymphoma (Swash et al., 2018). Much existing research on social support and coping can be found in the chronic disease literature, where it is regarded as crucial (Dwarswaard et al., 2016); mirroring the need we identified for emotional and practical help, and advocacy (Whitehead et al., 2018). Research exploring hospital care in CML is scarce, however Breccia et al. (2015) found that 41% of patients wanted to discuss "discomfort, anxiety and fear of the future" with HCPs, but felt unable to do so; suggesting such concerns were not routinely raised in clinic. There is little evidence about hospital pharmacy and parking issues, however accessible and affordable parking has been identified as an unmet need among mixed cancer patients (Turner et al., 2011) and work on chronic cancer experiences identified a theme describing "clinical services", including the accessibility of appointments (Harley et al., 2012, 2019; Boele et al., 2019).

4.1. *Implications for practice and research*

Raising awareness about muscle pain/cramp, employment difficulties, the value patients placed on social support, and the challenges of discussing side-effects and struggling to maintain positivity is important. Although additional clinic time could facilitate in-depth discussion of such issues, implementation would need to be underpinned by additional resources. Use of Patient Reported Outcomes measures (PROMS), alongside HCP assessed scales, may support the identification of unmet needs, with tools specific to CML/haematological malignancies including the MDASI-CML (Williams et al., 2013), EORTC QLQ-CML24 (Efficace et al., 2014a) and SUNS (Hall et al., 2014).

Following publication of discontinuation trials, TKIs can now be safely reduced and/or stopped for some (Radich et al., 2018; Hochhaus et al., 2020; Smith et al., 2020). Research is, however, required to explore discontinuation, including fear of progression and "withdrawal syndrome" (Petrova et al., 2020). Remote medical consultations have become increasingly common in the post-COVID era, and their influence on patient-HCP relationships, including the HCP's ability to identify need, requires examination. Research comparing the experiences of CML patients to those with other chronic haematological malignancies would also be of interest. Regarding healthcare services, these should be viewed as central to patient experiences, and the patient completed CCEQ tool (Harley et al., 2012, 2019; Boele et al., 2019) could provide evidence to underpin service improvements.

4.2. *Strengths and limitations*

Our methods were robust and the interviewees provided rich, insightful information. Rigour was supported by detailed description of the thematic analysis, an iterative approach to analysis and use of quotations to support findings. Dependability of study findings was enhanced through a second researcher reviewing the coding frame and a review of analytical themes by a CML patient improved study credibility. This was further supported by the inclusion of both patients and HCPs, and is the first UK study to do this.

Included patients may not have reflected the CML patient population as a whole, despite efforts to include those with complex issues. However, included HCPs were experienced in CML which led to insightful interview data regarding patient characteristics, supporting the value of HCP perspectives on patients who may not come forward for interview. HMRN's infrastructure (Smith et al., 2018; Roman et al., 2022) facilitated access to an affiliated patient support group, whose members contributed to the interview schedule, thereby enhancing credibility. Consequently, our findings are likely to be relevant to other locations with similar populations and healthcare systems.

5. Conclusion

We have shown that CML may significantly impact individuals, particularly as it is experienced over life-long time-periods. Some impacts may be underestimated by HCPs as evidenced in other CML literature (Efficace et al., 2014b; Jiang et al., 2018). Greater understanding and discussion of the breadth and extent to which patients are affected, and potential mediators, could enhance clinical care.

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Declaration of competing interest

The authors have no interests to declare.

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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.2023.102421.

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