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Research Article

Chronic Myeloid Leukaemia: A Qualitative Study of Patient and Practitioner Experiences of Managing Treatment

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Background. Following the dramatic impact of tyrosine kinase inhibitor (TKI) drugs on chronic myeloid leukaemia (CML) survival, research interest has grown into the long-term impact of treatment, identifying difficulties with medication adherence and ongoing side effects. Qualitative studies suggest the disease has a significant physical and psychological impact on patients, and medication management may be complex. However, only one study worldwide has examined healthcare practitioner (HCP) experiences of managing CML treatment and very little UK qualitative research exists exploring the patient experience. **Purpose.** Our qualitative study aimed to investigate both patient and HCP experiences of managing CML treatment in the UK. **Methods.** Patients and HCPs were purposively sampled from within the Haematological Malignancy Research Network (HMRN), a UK population-based patient cohort. Qualitative interviews were carried out with seventeen patients and thirteen HCPs, and data were analysed using thematic analysis. **Results.** Four themes were developed from interview analysis: “Importance of optimal clinical management,” “Multiple adherence strategies,” “Inconsistent management of adherence,” and “Controlling side effects is complex.” HCPs tended to focus on sometimes complex, clinical decision-making. Patients described various strategies to support adherence and manage side effects, some of which HCPs seemed to be less aware of. Several patients did not discuss non-adherence or side effects with their HCP, who tended to avoid direct enquiry regarding adherence and could be uncertain about adherence advice, whilst relying on medical strategies to manage side effects. **Conclusions.** Despite HCPs focusing on the medical management of CML treatment, patients may opt to use self-management techniques to control adherence and side effects and can be reluctant to discuss related difficulties. Increased clinic time and clear adherence advice guidance may support such discussion, in addition to adjusting the context of follow-up care through the introduction of shared care with GP services.

1. Introduction

Once potentially fatal, the rare blood cancer chronic myeloid leukaemia (CML) now has an estimated five-year survival close to that of the UK general population [1], which is largely due to the introduction of tyrosine kinase inhibitors (TKIs) which were first developed early in the 21st century [2, 3]. Controlling but not curing the disease, TKIs are taken orally once or twice daily, with the treatment response being regularly monitored in haematology outpatient clinics. TKIs that are approved by

the National Institute for Health and Clinical Excellence (NICE), the public body determining cost-effectiveness of medical treatments in England [4], are provided to patients free of charge via National Health Service (NHS) funding, the UK's publicly funded healthcare system, which also provides hospital inpatient/outpatient care free at the point of delivery [5, 6].

As the median age of CML diagnosis is 59 years [7] and TKI treatment is generally required long-term to ensure ongoing response, patients may live years or decades with this malignancy along with treatment side effects; these are

characteristics that are shared with a growing number of chronic cancer survivors [8–11].

Although recent clinical trials indicate that it may be safe for some patients to stop taking TKIs, most continue on the treatment long-term and can be defined as survivors who are “living with” their cancer [12]. In this context, cancers such as CML may be perceived as longstanding chronic illnesses [9, 13], which could indicate that a model of self-management may be appropriate [12]. This is important, because adhering to treatment and addressing side effects can be a “lifetime task” in the self-management of chronic illness [14, 15], so it is likely to be relevant for patients with CML. Much research exists examining predictors of medication adherence in CML, a term the World Health Organisation refers to as “the extent to which a person’s behaviour—taking medication, following a diet, and/or executing a lifestyle change, corresponds with agreed recommendations from a healthcare provider” [16]. As expected, adherence to prescribed TKI treatment schedules significantly impacts the treatment response [17–20], which is monitored by measuring “the level of copies of the faulty BCR-ABL gene in the blood,” and is considered a strong survival predictor [3]. However, while estimates of adherence vary (often due to the complexity of measuring this behaviour), it has been found to be as low as 51% [21]. Poorer adherence in CML can relate to worse quality of life and has been associated with increased symptom burden [22] and adverse drug reactions [23]. Furthermore, the extent to which TKIs can be missed before outcomes are affected is unclear, with Marin et al. [19] estimating this to be three doses per month, while Noens et al. [24] suggest the limit is actually “unknown.”

It is well-documented that TKIs may be associated with side effects that result in patients having a substantial symptom burden [25–28], including fatigue, muscle pain, and depression, and as the treatment is long-term, even minor symptoms can significantly impact patients over time [29, 30]. Furthermore, side effects may be underestimated by HCPs, who typically monitor these themselves, using clinician assessed numeric scales designed for use in acute oncology [3, 31–33]. CML and its treatment can also impact daily tasks and emotional state; fatigue may impede the ability to work [34] and patients can live with anxieties over their future [33].

In terms of qualitative research, a recent thematic synthesis (including studies up to 2018) noted the marked impact CML and TKIs can have on patients, who were found to experience both physical and psychological changes to their wellbeing due to cancer/treatment [25]. Regarding current limitations, the only UK research [35] pre-dates important treatment developments (i.e., introduction of second- and third-generation TKIs); and just one study, set in Australia, has investigated HCP experiences [36] which focussed on HCP’s difficulties in estimating patient adherence. Triangulation of HCP perspectives with those of patients may enable deeper understanding of phenomena relating to the CML experience [37]. The current qualitative study, therefore, aims to investigate UK patient and HCP experiences of managing TKI treatment, including

adherence and side effects, in order to provide new insights that could be used to improve clinical care.

2. Methods

2.1. Research Design and Setting. Methods are described according to Standards for Reporting Qualitative Research (SRQR) (supplementary material 1). The study was set within the UK’s Haematological Malignancy Research Network [7, 38], a population-based patient cohort initiated in 2004 with NHS clinicians across fourteen hospitals. HMRN aims to generate research and improve clinical practice [7]; it includes and collects data on all patients living in the study area who are newly diagnosed with any type of blood cancer and has ethical approval (REC 04/01205/69) and Section 251 support under the NHS Act (2006) (PIAG 1-05 (h)/2007).

2.2. Participant Sample and Recruitment. The patient sampling frame comprised those aged ≥ 18 years who had agreed they could be contacted for research purposes and had been diagnosed with chronic stage CML at least 2 months prior to interview. Patients were purposively sampled (based on age, gender, and hospital type) to reflect the HMRN CML population; after which, clinical nurse specialists (CNSs) in the study area identified patients with more complex experiences for inclusion. Some patients of the latter group were not part of the HMRN cohort because, for example, their diagnosis was before 2004 or they were diagnosed outside of the HMRN area. CNSs obtained their informed consent to provide contact details and receive a study invite from the researcher. For HCPs, clinical staff known to provide care for patients with CML were sampled from Network hospitals and then asked to recommend a colleague with similar experience (snowball sampling). Sample size was estimated prior to data collection, as required for NHS REC approval, and was approximated to be 15–20 patients and 15–20 HCPs. This followed consultation with experienced researchers on the anticipated number of interviews that might be required to reach data saturation, defined as the point where no new codes could be added to the data analysis [39]. It was further supported by the concept of ensuring adequate information power [40], our sample requiring a larger participant number due to certain study features such as the broad study aim and lack of pre-existing theoretical framework. Our intention was to re-evaluate this estimate once data collection and analysis were underway.

2.3. Data Collection and Analysis. Following ethical approval (Leeds West NHS Committee: REC 16/YH/0016), in-depth interviews were conducted with patients and HCPs between 2016 and 2019. Written informed consent to take part in the study was obtained from all participants, which included assurance regarding data confidentiality. Patients were interviewed first, with their insights used to finalise the topic guide for HCPs, and initiate discussions. The interview schedules (supplementary material 2) were developed through discussion with HMRN senior researchers, a CML

specialist CNS, who also participated in an interview, and two CML patients from a support group, neither of whom took part in interviews. Development of the schedules was also guided by existing literature reviews [25, 41]. Interviews were carried out in a place of the participants choosing; all patients were interviewed at home, and all but one HCP were interviewed in their workplace, and one was interviewed at the University of York. Interviews with patients and HCPs were semi-structured, combining questions on the schedule with probing questions to fully explore their responses, and lasted, on average, 49 minutes for patients and 30 minutes for HCPs. Interviews were conducted by AH, a PhD student at the time of interview, who was familiar with HMRN through her work as a study nurse collecting patient data for the cohort study. AH had not carried out qualitative interviews prior to this study; however, she had gained valuable communication skills during several years working as a clinical nurse in the NHS; additionally, she was supported by senior research colleagues and academic supervisors. Participants were given a unique study number; and interviews were recorded, transcribed verbatim, checked, and anonymised.

Data were assessed using inductive thematic analysis, following the six stages described by Braun and Clarke [37, 42]. This approach aims to identify patterns and meanings in the data to create themes and is a common, flexible, pragmatic approach that is suited to the research aims. The first step was familiarisation with the transcripts by reading/re-reading interviews. This was followed by complete hand-coding of the data and development of a coding frame, which was then iteratively defined and refined. A second researcher independently coded 10% of transcripts to enhance dependability, with discrepancies discussed until consensus.

Transcripts were uploaded onto NVivo 11 and 12 Pro [43] to support storage and retrieval of coded data. Themes were generated semantically rather than applying literal definitions [37, 42], which involved physically manipulating printed codes to identify similarities and differences. Themes were re-examined alongside each full transcript to ensure they reflected entire interviews and encompassed coherent meaning. Theme names were developed to capture a feature of the aims and to echo the range and depth of the data [42, 44]. Finally, a patient with CML from the Network, who was not a study participant, reviewed findings for authenticity, thereby supporting credibility.

3. Results

3.1. Participant Characteristics. Data saturation occurred at 30 interviews, with 17 patients and 13 HCPs, following an appraisal of sample size during data collection/analysis and agreement being reached by the team that at this point no new codes or themes were identified. Patients reflected the wider HMRN CML population (median diagnostic age 55 years; 8 female, 9 male; 53% managed at a local hospital, 47% at a cancer centre) (Table 1, supplementary material 3). HCPs originated from 13 hospitals (no response from one) and reflected hospital type (62% local, 38% cancer centre),

TABLE 1: Patient characteristics.

| Study ID | Hospital | Age at diagnosis ³ (years) | 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. ¹CC-cancer centre. ²LH-local hospital. ³Age at diagnosis and year of diagnosis grouped to ensure anonymity.

and were intentionally selected on the basis of working closely with CML patients, with 62% having more than 10 years' experience in their role (Table 2, supplementary material 3).

4. Themes

Four themes and six sub-themes were derived from the analysis, which describe patient and HCP experiences of CML management (Figure 1). The first central theme is "Importance of optimal clinical management," which indicates HCP focus on consistent treatment decisions and that the success of this treatment was valued by patients. This is impacted by a further three overlapping patient/HCP related themes: "Multiple adherence strategies," "Inconsistent management of non-adherence" and "Controlling side effects is complex." Themes/sub-themes are described below, with verbatim quotes from patients (PA) and HCPs (PR).

4.1. Theme 1: The Importance of Optimal Clinical Management.

Theme 1 reflects HCP focus on the clinical management of CML treatment, where much of their interview data were concentrated, and this was supported by the value patients also placed on successful therapy. Despite variations in CML follow-up care, most practitioners agreed on the main influences on clinical decision-making, an aspect of their role where they felt a clear sense of responsibility. Theme one is placed as the central theme to show that successful treatment is vital to survival outcomes; however, other contextual factors can impact this success, such as a patient's choice of strategy to support medication adherence.

4.1.1. Subtheme a: Care Settings Vary across Hospitals but Clinical Decisions Are Consistent. Type of outpatient follow-up varied, with 9 of the 13 hospitals offering CML

TABLE 2: HCP characteristics.

| Study ID | Role | Years in role | Hospital type | Specialism | Clinic type |
|----------|------------|---------------|-----------------|----------------------------|------------------------------------|
| PR01* | CNS1 | 10 years+ | CC ² | Myeloid ⁴ ± 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 ³ | Myeloid ± CML | General haematology |
| PR05 | CNS | 10 years+ | LH | Myeloid ± CML | Specialist CML/general haematology |
| PR06 | Consultant | 10 years+ | LH | Generalist ⁵ | 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. ¹CNS-clinical nurse specialist. ²CC-cancer centre; ³LH-local hospital, ⁴Myeloid-manages patients with myeloid malignancies, including CML, and/or a specific interest in caring for CML patients, ⁵Generalist-manages patients with a range of haematological malignancies and disorders.

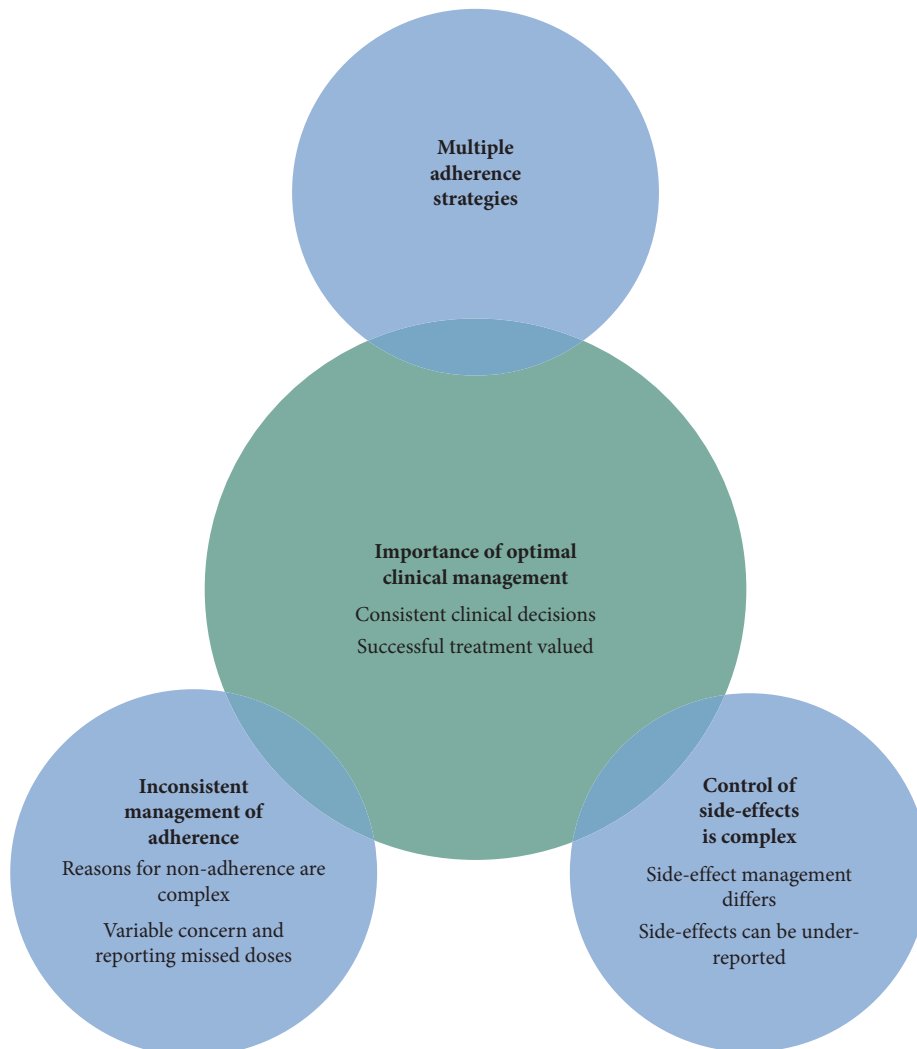


FIGURE 1: CML management and potentially impacting factors.

appointments in haematology consultant-led clinics, alongside patients with other blood cancers. This was seen as a practical solution by some HCPs in smaller hospitals with few CML patients:

“...in a little DGH [District General Hospital] where it’s a minority of patients, it’s a rare disease, so we couldn’t, practicality [sic] we couldn’t have a CML specific clinic here.” (PR10)

CML-specific clinics were held at the two large cancer centres and two local hospitals, the latter suggesting minimal patients did not always preclude dedicated clinics. As well as being consultant led, clinics could be managed by CNSs (face-to-face or telephone), or specifically for teenagers and young adults. Variation also existed in HCP roles; some being generalist and managing all types of blood cancer, while several had a specialist role or interest in myeloid malignancies and/or CML, which could result in them establishing dedicated clinics. Further diversity was seen according to the characteristics of each hospital’s catchment (i.e., the age and comorbidities of the resident population); the extent to which HCPs were required to manage hospitalised haematology patients, which differed markedly.

In contrast to differences in the organisation of care, there was consistency in HCP reports of their approach to clinical decision-making. Clinical guidelines appeared central to this, with several HCPs referring to European Leukaemia Network (ELN) Guidance [3, 38]. Many also found decision-support via communication with colleagues, often at multi-disciplinary team (MDT) meetings or from the regional CML lead-consultant:

“I rarely make a very complex decision, particularly if it’s something like a transplant decision, without at least sounding out somebody else which is quite nice to be able to do that.” (PR02)

“We all decide together. Collective responsibility. The more brains the better.” (PR05)

4.1.2. Subtheme b: Successful Treatment Is Valued. A key issue to HCPs was the importance of good clinical decision-making in the medical management of CML, with significant issues including TKI choice, disease response, drug toxicity/tolerance, and de-escalation and stopping of TKIs. Some HCPs also described the complexity of managing TKIs alongside other co-morbidities:

“Older patients are more challenging in that they don’t tolerate the medicines very well. ... because they’re having side-effects or they’ve got the co-morbidities that mean choosing therapies or the number of therapeutic options are reduced.” (PR20)

A sense of clinical responsibility was identified in HCP accounts of concerns about managing patients with poor TKI experiences, including severe side effects or extreme

non-adherence, meaning further interventions (e.g., stem cell transplant) were required, or they died. PR14 reflected on a patient who had died and the relationship built with this individual’s family:

“He was very challenging, but I do have a real soft spot for him still and I still speak to his mum even now. She rings me a couple of times a year but he was just a troubled soul unfortunately.” (PR14)

Understandably, treatment success was equally important to patients, many of whom reported a good response at interview, which they implied could promote disease acceptance and the resumption of daily activities:

Well I’ve got me head round it now. I think the thing is as long as you keep taking your medication, I think things are going to be fine and dandy, you know.” (PA07)

However, several patients had experienced past treatment failure due to poor response or side effects:

“I was getting diarrhoea and sickness, nausea all the time, headaches with it. So, when I got back in touch with [consultant] down at [hospital] he put me on an easier dosage not as strong. ...I’m fine now. It’s great.” (PA07)

In addition to successful TKI decisions, patients and HCPs noted the impact of treatment side effects and managing adherence which could impact on treatment success, as encapsulated in the following three themes.

4.2. Theme 2: Multiple Adherence Strategies. Theme 2 describes measures patients put in place to support optimal medication adherence, practitioner level of awareness about these practices and their differing approach to promoting medication adherence.

All patients discussed adherence support strategies, which often included memory prompts linked to daily routines, commonly mealtimes; the timing of which also acted to prevent side effects or comply with pharmacy instructions:

“I always remember that one because I have it with my dinner at night. You’ve to have it before you go to bed, an hour before at least but they advise you to take it with food.” (PA11)

Patients described other methods to promote adherence, including family support, or use of an alarm or device, such as a pill box. In contrast, HCPs did not appear aware of the full range of strategies patients used; their accounts instead concentrating on advice at diagnosis about the importance of adherence:

“...just to make sure that they actually understand what they’re taking, and why they’re taking it and that.” (PR19)

Interestingly, patients did not explicitly describe such advice from HCPs at diagnosis; yet some suggested an implicit understanding when noting their perspective on the chronicity of their CML:

“...think it’s like having, I presume it’s like having diabetes. If you know you’ve got to have it every day, you do it don’t you.” (PA04)

4.3. Theme 3: Inconsistent Management of Non-Adherence.

Theme 3 demonstrates the value of gaining both patient and practitioner perspectives in capturing the range of reasons for, and management of, non-adherence. It also suggested some inconsistency in understanding why non-adherence occurs and how patients and practitioners deal with the issue.

4.3.1. Subtheme a: Reasons for Non-Adherence Are Complex.

Although none of the patients reported missing their medication more than 3 days per month (the clinical cut-off described by Marin et al. [19]) most said they had missed their TKI at some point in the past month or year. Missing was often due to forgetfulness, which was frequently caused by changes in normal routine, but also illness or polypharmacy:

“I’ve got a camper van and we go away at the weekends, take the grandkids, they’ll have probably been late tea and I’ve forgot my tablet.” (PA15)

Forgetfulness was recognised as a potential cause of inadvertent non-adherence by some HCPs, who provided further social context, suggesting socioeconomic issues (e.g., financial/housing problems) could also cause an impact:

“My understanding would be that if [a] patient has a difficult social background, and lots of other issues and problems in their life then obviously, it’s my feeling or the way how I see it, they are more likely to forget the medication.” (PR11)

Some HCPs conjectured that lower educational level could lead to poorer disease understanding, and that mental health difficulties and learning disability could impair adherence. They also noted a reason for unintentional non-adherence not being reported by patients; namely, a lack of organisational and self-management skills, for example, patients not planning prescriptions ahead:

“...they don’t think it’s important till they get down to their last few tablets, even though we put it on the paperwork in bright red letters, “let us know when you get down to a month’s supply”. (PR03)

Intentional non-adherence was rarely reported by patients and mainly occurred following HCP advice, for example, withholding TKIs due to post-surgical complications; or as an individual choice to avoid side effects:

“When my son got married and I were going for a meal, we stayed in a hotel and we had a meal and I thought I really want a glass of wine, you know, when you’re... mother of the groom, and I thought do I really have to take that [TKI]?” (PA29)

HCPs suggested intentional non-adherence may be more common than patients reported, providing many examples to support this assertion. One reason identified in this study is an active patient decision to avoid taking their TKIs because they did not want, or like to take them; perhaps feeling they did not need it, did not want to follow instructions, or struggled to accept or take responsibility for managing their cancer:

“No problem, I don’t have a problem,” you know, “I don’t have that problem.” So, putting your head in the sand sort of like not wanting to own up to the fact that you’ve got a condition.” (PR01)

4.3.2. Subtheme b: Variable Concern and Reporting of Missed Doses.

Several patients believed that not taking an occasional TKI was acceptable, which was one of the reasons for not discussing non-adherence with HCPs. Around half of those who had missed medication said they had not reported it as they felt well, their response had not been impacted, it occurred too infrequently to be important, or they did not want to bother HCPs:

“Very rarely does that happen but if for any reason it does, I leave it that day. I don’t think one day within a month is going to make any difference.” (PA04)

“...it’s really on me, for me to manage it. [Consultant] doesn’t need me whinging on about it (laughs).” (PA32)

There was some awareness amongst HCPs that patients may not report non-adherence, yet their perceived reasons for patient non-reporting did not always reflect those provided by the patients themselves. HCPs suggested under-reporting could be due to patients’ views of their cancer as non-serious, their young age, or them forgetting to disclose this information. A few described this in stronger terms, reporting patients “lying” (PR01) to them:

A small number of HCPs routinely enquired about adherence during appointments, but more frequently such discussions were triggered by raised BCR-ABL levels, an abnormal full blood count, or a build-up of prescriptions:

“They’re all different counts aren’t they but if there is a change then depending on the change, I’ll speak to the patient straight away, try and work out if they’ve stopped taking their tablets and we’ll repeat the PCR [blood test to check disease response].” (PR03)

The reliability of BCR-ABL as an adherence indicator was questioned by some HCPs, as a good response could occur despite some non-adherence, or a poor response could

manifest due to disease mutation rather than poor adherence. Patient-instigated discussions about non-adherence suggest standardised advice was lacking from HCPs, with some providing general guidance: “it is not a good idea” (PA06); whilst others were more specific:

“I’ll say “I’ve missed a tablet what do I do?” [HCP] said “well don’t take two just take another one the following day””. (PA15)

This reflected inconsistency in HCP’s accounts about the significance of missed doses, with some expressing uncertainty or believing an occasional missed dose was not concerning:

“...if they occasionally forget the drug, what impact does that actually have? I don’t think anybody really knows.” (PR10)

“I try and persuade them to take tablets ninety percent of the time, so they can miss one weekend a month.” (PR20)

HCPs described their approach to discussing non-adherence with patients, saying supportive discussions should involve honesty from all parties, while also exploring reasons for non-adherence, persevering with the issue, and offering reassurance:

“It’s finding out the why’s, seeing what’s fixable, putting it into context and sometimes just very much trying to get their take on things.” (PR02)

A more challenging, direct style was also described, which involved “telling” patients about the consequences of non-adherence, showing them their BCR-ABL response graph, questioning their accounts of adherence, and using stronger language:

“I say: “Do you want to die? Don’t be so stupid, just take your tablets, it’s only 1 or 2 a day. Stop it. Just go and do it.”” (PR05)

4.4. Theme 4: Controlling Side Effects Is Complex. Theme 4 demonstrates the differing focus of patients and HCPs in terms of managing side effects and captures both patient and practitioner perspectives on the reasons behind a lack of discussion around side effects.

4.4.1. Subtheme a: Side Effect Management Differs. A number of patients discussed measures taken to manage TKI side effects, and particularly muscle cramps, gastrointestinal problems, and fatigue. Interestingly, muscle cramps were rarely mentioned by HCPs. Measures taken to manage side effects included over-the-counter medications, muscle stretching, or learning to live with the problem:

“Well you stand up and do a few stretches but it just gets a bit awkward sometimes when you’re in the pub or something like that.” (PA15)

In contrast, several HCPs concentrated on the medical management of side effects, including switching to a different TKI, dose reduction, or prescribing supportive medication:

“If there is any sort of jiggling around with prescriptions and things, I go to the consultants or I’m a prescriber and I can prescribe supportive meds, especially for loose stools and things.” (PR04)

Some HCPs described providing patients with information at diagnosis about side effects, including medical and nonmedical measures, such as taking tablets with food to avoid nausea:

“I try and go over the fact that you will get some side-effects and you will have some toxicity and this is what we do to manage it, so that they’re armed really.” (PR14)

4.4.2. Subtheme b: Side Effects Can Be Under-Reported. While some patients concurred with HCP accounts of discussions about side effects, others said they were reluctant to talk to HCPs, as they did not want to take any more medication (which might be prescribed), felt they could cope independently, or perceived the HCP as too busy or unwilling to listen to their concerns:

“I cope with a bit of cramp that I get because I just think there’s no point in putting even more drugs in my system you know.” (PA21)

“I do say stuff over the phone but I often think it just falls on deaf ears and just think, yeah that’s par for the course really and that’s it.” (PA24)

Many HCPs seemed aware that patients could be reluctant to discuss side effects, as well as other more general issues, and agreed this may be due to limited clinic time. HCPs also felt patients believed their problems were too “low-level” to be discussed, which perhaps reflects the reassurance many HCPs provided at diagnosis; that CML is less acute than other blood cancers:

“If they’re ticking along okay, albeit having those low-level side-effects, they never pick up the phone and ring us. We never actively seek them out, because they think they’re okay.” (PR01)

5. Discussion

5.1. Summary of Findings. Interviewing patients and HCPs facilitated identification of two unique findings about the reasons for non-adherence, namely, an unintentional lack of organisation, and deliberately choosing not to take medication. Strategies used to promote adherence were also located, which for patients were often based on self-management; whereas HCPs were typically concerned with, and felt responsible for, successful clinical management, which tended to rely on medically-based changes/

interventions. Under-reporting of non-adherence and side effects is a major concern for both patients and HCPs and could lead to further, potentially unnecessary treatment interventions and poorer outcomes. Equally worrying was a lack of knowledge about the medical significance of missing TKIs, and the advice patients were given in this regard. Finally, we found marked variation in the organisation of CML services, but consistent, well-supported decision-making, which was crucial to HCPs.

5.2. Comparison to Other Literature. Wherever comparable, our findings largely align with existing literature. The variations in follow-up we identified, for example, reflect cancer services across England [45]. Others have also noted the development of dedicated outpatient and nurse-led telephone clinics for patients with cancer, which attempt to better meet the needs of a growing number of survivors via a cost-effective alternative to consultant-led follow-up [46]. Importantly, a recent systematic review found little difference in health-related quality of life, anxiety, and depression for oncology patients followed up by nurse- or consultant-led clinics; although the impact on survival was unclear [47].

Use of European Leukaemia Network (ELN) treatment guidance [3] was common amongst the HCPs we interviewed. Some studies have, however, questioned the “real world” applicability of such guidance, for example in the areas where HCPs fail to comply with ELN and National Comprehensive Cancer Network guidelines [48], and raised concerns about suboptimal monitoring, inadequate cardiovascular risk assessment and multiple TKI switches [49, 50]. Regarding treatment decisions, a lack of trials comparing second-line TKI drugs to each other, along with their differing side effect profiles, means the decision can be complex and based on individual patients’ risk and tolerability [3, 51]. This may be linked to the sense of responsibility we found among HCPs regarding treatment decisions, and the value placed on support from colleagues and MDTs. However, although MDTs are considered “gold standard” for decision-making in oncology [52], several factors (not mentioned in our study) could diminish their effectiveness, including time-pressure, poor attendance, and leadership issues [53, 54].

Use of a range of adherence strategies (often memory aids) by CML patients has been noted in other qualitative research [35, 36, 55–59]. Our findings closely mirror the most common reasons patients intentionally missed medication, to avoid side effects or following medical advice [55, 56, 60, 61]. Advice from HCPs about the risks of non-adherence could be inconsistent, possibly reflecting their own uncertainty about the significance of missed medication. Perhaps related to this HCP uncertainty, was a lack of concern and reporting of occasional non-adherence among patients, as observed by other authors [35, 36, 56, 60, 61]. Although research indicates that three missed TKI doses per month could affect disease response [19], clear advice about this risk is lacking in national and international guidance. We highlighted the issue of HCP reliance on BCR-ABL blood results as an indicator of non-adherence, which mirrors findings from Boons et al. [56] and Eliasson et al.

[35] and suggests that using good BCR-ABL results to reassure patients that their CML is well-controlled, in the presence of occasional non-adherence, could inadvertently imply that missing TKI medication is safe. Such actions could risk failure of treatment, lead to unnecessary TKI switches, impact patients’ QOL, and have cost implications for the NHS [24, 62]. Standard advice may be of value in such scenarios, although HCPs would need to apply this sensitively to individual patients, considering contextual factors such as co-morbidities, personality, and social circumstances, which HCPs in our study clearly understood.

Self-management of TKI side effects is reported in our findings and other qualitative work [35, 36, 58], and contrasts with the focus among HCPs on treatment changes and interventions (e.g., additional supportive medications), which were not always wanted by patients and prevented some from discussing their side effects. Difficulty in communicating side effects to HCPs was also reported by others and found to lead to the under-reporting of side effects [35, 36, 56, 58, 61].

Patient views of HCPs being reluctant to listen to their difficulties echo clinician concerns about the lack of time for such discussions. Perceptions of CML as a “low-level” disease (compared to other blood cancers) could reflect reassurance from HCPs about prognosis, as is common with other chronic blood cancers [63]. While this message may be appreciated, such “downward comparison” [36] may deter patients from raising concerns about side effects and adherence, due to their interpretation of “low-level” as an indication that self-management may be possible. Ensuring discussions at diagnosis include an understanding that CML was, until recently, a life-threatening disease, may help adjust such perceptions.

5.3. Implications for Policy and Practice. Patient’s difficulties discussing side effects and non-adherence with HCPs may be improved via changes to follow-up care. Initially, although requiring extra resources, increased clinic time may facilitate further HCP initiated enquiry about difficulties, which would be increasingly beneficial if supported by clearer national guidance on adherence. Second, the rising prevalence of patients living with CML and other cancers means traditional NHS hospital-based follow-up is becoming increasingly unsustainable [64, 65]. Furthermore, hospitals may be less able to manage the ongoing psychosocial and emotional needs known to be associated with chronic blood cancers [63], meaning alternative options may be required [66–69]. In this context, shared care (between primary and secondary settings) offers an alternative strategy that could relieve pressure on services and enable adaptation to a chronic trajectory, by placing patient management directly within their day-to-day home-life. Moreover, it may prevent “downward comparison” [36] to acutely ill patients seen in the hospital setting. UK policy [12, 70] recommends that primary care and cancer survivorship become further integrated, as this may bring greater patient satisfaction than standard care [71]. However, evidence to support shared care is limited [72, 73], with interventions described as complex and lacking effective physical, psychological and

economic outcomes [71]. Furthermore, there are barriers to implementation, which include undefined professional responsibilities, limited HCP time and differing attitudes [74–76]. Finally, use of patient-reported outcome measures (PROMs) may help the recognition of issues related to side effects and non-adherence, and trigger mutual discussion in clinic follow-up. Two PROMs which have been developed specifically for CML patients are the MDASI-CML [30] and EORTC QLQ-CML24 [77].

5.4. Strengths and Limitations. This study offers rich, detailed insights into experiences of living with, and managing, CML. Credibility was supported by including both patients and HCPs (the first UK study to do this), and checking findings with a CML patient. Dependability was strengthened by a second researcher checking analytical codes; rigour was enhanced by providing a detailed description of the methodology and findings, and using a systematic, iterative approach to the analysis (see [41] for further details). HCP characteristics, and types of clinic/follow-up care will undoubtedly vary across the UK (and beyond), but it is likely that our findings are broadly representative of current practice and experiences; and purposive/snowball sampling of this group led to meaningful insights. Although strategic sampling was used to identify patients with complex experiences, such as those choosing not to take their TKIs, this was not wholly successful, as patients demonstrating these characteristics were reluctant to participate in research; thus, the sample may not reflect behaviour across the CML population. This underscores the value of including HCPs as a means of accessing information about such hard-to-reach groups, which would otherwise have been missed.

6. Conclusions

This in-depth study provides an update about experiences of living with, and managing, CML; it also furthers understanding of adherence, the types and reasons for non-adherence, and strategies used to ensure TKIs are taken. Unique behaviours were identified, as well as contextual issues that may impact behaviour. While patients often chose to self-manage, and may not disclose their difficulties, clinical staff typically opted for medical interventions and had limited time for discussion. Additional clinic time and clearer guidance on adherence could improve experiences, as could shared care (between primary and secondary settings) and the use of PROMs; but as with all changes, this is dependent on resource availability.

Data Availability

The data collected from participants in this study are not accessible to readers on ethical grounds, as doing so would compromise the confidentiality we assured to patients and healthcare professionals when they consented to participate. Examples of analytical codes, themes, and associated quotes are available from the corresponding author on reasonable request.

Conflicts of Interest

The authors declare that there are no conflicts of interest regarding the publication of this article.

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Supplementary Materials

Supplementary 1. Supplementary material 1: SRQR reporting guidelines checklist. Supplementary 2. Supplementary material 2: Patient interview schedule: living with chronic myeloid leukaemia and Practitioner interview schedule: managing CML. Supplementary 3. Supplementary material 3: Table 1: Patient characteristics and Table 2: HCP characteristics. (*Supplementary Materials*)

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