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Living with chronic lymphocytic leukaemia: patient perspectives from a global online cross-sectional survey on care pathways and impacts on quality of life

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Background: Chronic Lymphocytic Leukaemia (CLL) is a slow-progressing condition often managed through active monitoring ("watch and wait") strategies, which can lead to uncertainty for patients about prognosis, symptom management, and immunity-related risks. We studied the diagnostic and active monitoring pathway experiences of patients with CLL, and the impact of immunity-related knowledge on their quality of life (QoL).
Methods: We analysed data from 846 patients with CLL who responded to the cross-sectional 2023 Global Leukaemia Experience Survey, which included the Haematological Malignancy Specific Patient-reported Outcome (HM-PRO) instrument. Higher HM-PRO scores represent worse QoL. We used descriptive statistics and Kruskal-Wallis tests to quantify the impact on QoL.
Results: Most respondents (69%, 582/841) reported experiencing symptoms before diagnosis, although the majority (89%, 509/571) did not recognise these as signs of leukaemia. A large proportion (84%, 701/831) were placed on active monitoring, amongst whom 25% (172/689) reported being "*very concerned/worried*" about this approach. Fewer than half felt fully confident recognising signs of progression. QoL did not differ significantly by current active monitoring status but was associated with immunity-related knowledge: respondents unaware of their immunity status had worse QoL (median HM-PRO Part A "*No*": 13 vs "*Yes*": 11). Respondents who had not spoken to a healthcare professional about immunisation strategies reported higher HM-PRO Part-A scores ("*No*": 13 vs "*Yes, completely*": 10).
Conclusion: Our study highlights key challenges faced by individuals with CLL, including lack of symptom awareness, lack of association of those symptoms with cancer, inadequate understanding of active monitoring, and the impact of immunity-related education on QoL. Addressing these challenges through coordinated efforts amongst clinicians, advocacy groups, and policymakers may

contribute to improved disease management and QoL for individuals living with CLL. Future research could seek to account for potential confounders to enhance the robustness of conclusions and build on these global findings by examining country-level differences.

KEYWORDS

cross-sectional studies, quality of life, leukaemia, lympocytic, chronic, CLL, B-Cell, patient outcome assessment, HM-PRO

1 Introduction

Chronic Lymphocytic Leukaemia (CLL) is a condition characterised by its often-slow progression and complex treatment decisions (1, 2). Pathways to diagnosis are varied and can be lengthy (3, 4), and people may not attribute symptoms to leukaemia (5). Good communication between clinicians and patients is needed for effective treatment decisions, and there are reservations about how well this occurs for people with CLL (6–10). It has been reported that around half of patients with CLL are not engaged in discussions with their clinicians around new treatment options (8). Furthermore, disparity exists where people with lower level education are least likely to be involved in shared decision making (8). Empowering people through clear communication and shared decision-making is fundamental to improving their overall experience, quality of life (QoL), and treatment outcomes (8).

A distinctive aspect of CLL management is the use of an 'active monitoring' strategy (also known as 'active surveillance, or 'watch and wait; we use the term active monitoring hereafter) where active treatment is deferred until symptoms worsen or disease progression occurs (11, 12). Active monitoring places a responsibility on patients to manage their health, including recognising symptoms associated with disease progression. Active monitoring is medically justified (1, 13), but it may lead to uncertainty in patients if they do not understand their prognosis, how to identify and manage their symptoms, how to monitor their CLL progression, or why active treatment is not initiated immediately (6, 7, 14–17).

People with CLL are vulnerable to infections due to compromised immune systems (2, 18, 19). Understanding how people perceive and manage this risk, and how it impacts their QoL, is vital to informing support mechanisms (20, 21). Perceived vulnerability has been shown to be strongly associated with poorer QoL and greater psychological distress (22). Moreover, people who view their illness as severe may adopt restrictive behaviours, such as social isolation, which can impair emotional wellbeing (23).

There is documented global variation in CLL care, with international guidelines noting differences in access to diagnostic tools such as genomic testing and supportive management resources across countries (1). Evidence shows substantial regional disparities in treatment access, including unequal availability and funding of modern therapies, which directly affects patient experience and outcomes (24).

These factors, combined with uncertainty around treatment timing and infection risk, highlight the importance of understanding patient experiences to uncover potential unmet needs.

1.1 Aim and objectives

This study sought to establish a global-level understanding of the above-mentioned patients' experiences rather than focusing on country-specific variations. While national contexts influence healthcare delivery, the challenges of active monitoring, infection risk, and shared decision-making cross borders. Given the variability in diagnostic pathways, treatment access, and supportive care provision for CLL, a global perspective will help to determine common themes and unmet needs that clinicians and advocacy networks can address collectively, ensuring that recommendations and support mechanisms are relevant across diverse healthcare systems. By prioritising global insights at this stage, we intend to inform strategies that benefit all patients, regardless of geography.

In this study, our overall objective was to investigate information and communication experiences throughout CLL diagnostic and active monitoring pathways. Our study questions were:

1. What is the experience of individuals with CLL regarding diagnostic and active monitoring pathways?
2. Do people who are aware of their immunity status, and risk of infection, experience lower QoL than people who are unaware?

2 Methods

2.1 Ethical approval

The Global Leukaemia Experience Survey (GLES) was conducted anonymously, online, and without any intervention, thus no significant ethical concerns were identified. People were informed about the study's objectives, the voluntary nature of involvement, and how responses would be used. People who did not agree with these terms did not proceed with the survey. Data handling adhered to the Market Research Society Code of Conduct, ISO 20252 and 27001 standards, and the UK General Data Protection Regulation (2018).

2.2 Survey method

This study used data from an international, cross-sectional online survey and patients were recruited through a convenience sample. Prior to involvement, respondents were provided with details regarding the survey's purpose, its voluntary nature, and the intended use of the collected data.

2.2.1 Questionnaire development

2.2.1.1 Survey design and content

The GLES was the result of substantial revision from previous iterations to enhance its scope and relevance. It comprised multiple sections, including demographic information, diagnosis, active monitoring (for respondents with CLL only), treatment experiences, testing and monitoring practices, access to information and support, QoL, and perspectives on potential new treatment therapies. To improve the accuracy of responses, the survey employed routed questions, ensuring respondents were only presented with items relevant to their specific circumstances and diagnosis. To refine the questionnaire, patient representatives, caregivers, and advocacy organisations provided feedback during the development process. This iterative approach resulted in a final patient questionnaire with 100 questions. For further survey design details and full patient questionnaire refer to Supplementary File 1.

This study uses a subset of GLES data pertaining to patients with CLL.

2.2.1.2 Quality of life assessment

To assess the emotional and physical burden associated with the disease, the GLES incorporated the established Haematological Malignancy Patient-Reported Outcome (HM-PRO) measure, a patient-reported outcome measure designed specifically for haematological malignancies (25–27).

The HM-PRO consists of two sections: Part-A evaluates the broader impact of the disease on physical, emotional, and social wellbeing, whilst Part-B examines disease-specific symptoms and treatment adverse events. We focus on Part-A, which comprises 24 items, generating a total score from 0 to 48; higher total scores indicate greater adverse impact on QoL (27). We have this focus as we consider it to be more amenable to modification by the independent variables in question.

2.2.2 Data collection and recruitment

Respondents to the GLES were self-selecting. In an effort to mitigate bias, the survey was advertised and recruited widely through the commissioning partnership of global leukaemia advocacy networks: CLL Advocates Network (CLLAN); the Acute Leukaemia Advocates Network (ALAN); and the Chronic Myeloid Leukaemia Advocates Network (CMLAN). The survey link was disseminated via multiple channels, including email, online forums, social media, newsletters, and direct outreach to network members. Data collection was conducted using an online survey platform (Qualtrics) and remained open from 19 August 2023 to 05 January 2024 (inclusive). Nonetheless, this convenience sample may maintain bias. There was no quota on study sample size.

To ensure broader accessibility, the survey was available in 14 language variations: Chinese (simplified), Czech, Danish, Dutch, English (UK), English (US), French, German, Hebrew, Italian, Korean, Portuguese (Brazilian), Russian, and Spanish. Eligible study respondents included patients and caregivers aged 18 years and older who were either diagnosed with leukaemia or supporting someone with the condition. In this study, we restrict our analyses to patient respondents only.

Contribution was voluntary, with no financial or material incentives provided. The study respondents had the flexibility to submit incomplete surveys if they chose not to answer all questions. Additionally, no restrictions were placed on the number of responses per IP address, recognising that multiple individuals within the same household may wish to respond to the survey.

Because the survey was openly disseminated through global advocacy channels, the number of individuals reached cannot be determined; therefore, a response rate cannot be calculated.

2.3 Analytical methods

We downloaded data from Qualtrics and limited the data set to respondents who were patients with CLL.

To explore Study Question 1, we used descriptive statistics (frequencies and percentages) for questions pertaining to diagnostic pathway and active monitoring for respondents with CLL (Supplementary File 2). Not all people responded to all questions; we report the frequencies of people providing a response.

For Study Question 2, we conducted inferential statistics, setting the dependent variable as the HM-PRO Part-A score and set the independent variables as questions regarding knowledge of immunity status and receipt of related information, and a derived variable marking their active monitoring status (only asked of CLL respondents, Supplementary File 2). The derived variable had the levels "*Never on active monitoring*", "*Not on active monitoring now*", "*On active monitoring now*", and "*status unknown*".

We used Kruskal-Wallis tests to examine differences in the dependent variables across groups defined by the independent variable. We applied a Bonferroni correction to mitigate multiple testing of the same outcome, with an adjusted test threshold based on the number of tests (28). This adjustment allows an assessment of "adjusted significance", with a reduced likelihood of a Type 1 error arising due to Family Wise Error Rate. We include eta-squared (η^2) as a measure of effect size (29), indicating how much variance in the dependent variable is explained by differences between the groups for the independent variable. We conducted the analyses using the freeware Python 3.09, via Spyder 5.5.1. For each analytical test, we included only respondents who provided complete data for relevant variables (i.e., complete cases, row-wise for each variable-pair in turn). For each test, we excluded responses considered uninformative, such as "*don't know*", "*cannot remember*, " or "*status unknown*".

3 Results

3.1 Socio-demographics characteristics of the study respondents

The 2023 GLES received 2,260 patient responses across all leukaemia types, of which 37% (846/2260) were respondents with CLL. We present the demographics of respondents who are patients with CLL (Table 1).

With a range of 27 to 92, the median age was 66.0 (interquartile range, IQR 59.2-72.0); there was a sizable majority of respondents (84%, 709/846) aged 56 years or more. The sex split of respondents was slightly more female (54%, 454/846). Six-tenths of respondents (61%, 514/846) were from four countries (UK, USA, Canada, and Israel). Three-in-four respondents (72%, 610/846) were living as a couple. Over half of respondents (56%, 476/846) were retired. Six-tenths of respondents (62%, 528/846) described themselves as receiving an "*average income*" for their country. Over half of respondents (56%, 475/846) had a university qualification. Three-tenths of respondents (29%, 246/846) had been diagnosed between 2020 to 2023 (i.e. the last three years at time of survey).

3.2 HM-PRO Part-A scores of the study participants

One-third of respondents (33%, 282/846) had a HM-PRO Part-A score from 0 to 8, 37% (311/846) had a score from 9 to 18, 16% (135/846) had a score from 19 to 28. One-in-twenty (5% 43/846) had a score from 29 to 48. One-in-ten respondents (9%, 75/846) were unable to be scored. The overall median of HM-PRO Part-A scores was 11 (IQR 6.0-17.5); the attained score range was 0-43.

3.3 Study question 1. What is the experience of individuals with CLL regarding diagnostic and active monitoring pathways?

We provide high-level descriptive statistics in this section (more detailed visualisations are available in Supplementary File 3). Because responding to all questions was not mandatory, the number of respondents to each question varies throughout the results. Due to this, the denominator of follow up questions may not match the numerator of the preceding question. For instance, whilst 846 people responded overall, five people did not respond to the question on symptoms experienced before diagnosis. Although 582 respondents reported symptoms, not all answered the follow-up question on awareness symptoms could be signs of leukaemia.

Most respondents (69%, 582/841) reported experiencing symptoms before diagnosis, yet 89% (509/571) were unaware that these could be leukaemia symptoms. The most frequently reported symptoms included fatigue (40%, 340/841), swollen lymph nodes (27%, 223/841), and fever/night sweats (19%, 161/841; Figure 1).

Most respondents (71%, 592/843) had their leukaemia detected by a blood test or health check. One in five respondents (20%, 117/577) waited over a year before seeking healthcare advice after first noticing symptoms, while nearly half (49%, 280/577) spoke to a

TABLE 1 Socio-demographics of the study participants. Note respondents may not have answered every question.

Variable	Category	n	Percentage
Age group	26 to 35	3	0%
	36 to 45	24	3%
	46 to 55	110	13%
	56 to 65	270	32%
	66 to 75	316	37%
	76 and over	123	15%
Sex	Female	454	54%
	Male	357	42%
	Prefer not to say	20	2%
	Prefer to self-describe	15	2%
Country	United Kingdom	272	32%
	United States of America	105	12%
	Canada	69	8%
	Israel	68	8%
	Denmark	52	6%
	Netherlands	50	6%
	Italy	35	4%
	Brazil	32	4%
	China	29	3%
	Ireland	27	3%
	Czechia (Czech Republic)	24	3%
	All other countries	82	10%
	unknown	1	0%
Living situation	Living as a couple	610	72%
	Living alone	143	17%
	Living with adult family (non-dependent)	47	6%
	Living as a lone adult with dependent children	11	1%
	Living with another dependent (non-child)	3	0%
	Living with non-family e.g. friends, house mates	3	0%
	Other	19	2%
	Prefer not to say	9	1%
	unknown	1	0%
Employment status	Retired	476	56%
	Employed	255	30%
	Unemployed	50	6%
	Other (e.g. student, stay at home parent, other)	31	4%
	Prefer not to say	10	1%
	unknown	24	3%
Income (self-assessed)	Low income	119	14%

(Continued)

TABLE 1 Continued

Variable	Category	n	Percentage
	Average income	528	62%
	High income	145	17%
	Don't know	7	1%
	Prefer not to say	41	5%
	unknown	6	1%
Highest qualification	No formal qualifications	37	4%
	High school qualifications or diploma	187	22%
	University – Bachelors or Undergraduate degree	272	32%
	University – Masters, PhD or MD	203	24%
	Career/technical/ vocational qualifications	99	12%
	Prefer not to say	21	2%
	unknown	27	3%
Year of diagnosis	Prior to 2008	88	10%
	2008 to 2010	77	9%
	2011 to 2013	95	11%
	2014 to 2016	123	15%
	2017 to 2019	198	23%
	2020 to 2023	246	29%
	unknown	19	2%

Healthcare Professional (HCP) within 3 months. Further, 46% (266/577) stated that they saw a HCP about their symptoms one or two times before they were diagnosed and 67% (555/830) were diagnosed within 3 months of first talking to a HCP. Less than half of respondents (43%, 359/828) reported that their diagnosis was explained in a way they could completely understand.

Most respondents (84%, 701/831) were placed on active monitoring, with 67% (457/679) indicating they were currently under that strategy. Six-tenths of respondents (59%, 407/690) completely understood why they were placed on active monitoring. Respondents were asked how they felt when they were first placed on active monitoring, and one-in-four (25%, 172/689) selected "*I was very concerned/worried about it*". Fewer than half (47%, 313/667) selected "*Yes, definitely*" when asked if they were involved as much as they wanted to be in decisions about being placed on active monitoring.

As regards to symptoms, 38% (173/453) of patients currently on active monitoring reported that they did not experience any pain or other symptoms. However, where pain or symptoms were present, 52% (145/280) self-managed, 22% (62/280) received help from their hospital doctor, and 21% (59/280) received help from their GP or family doctor. Less than half (45%, 309/689) felt "*definitely confident*" in their ability to recognise signs and symptoms of CLL progression.

Almost one quarter of respondents (24%, 182/770) reported receiving no information or support at diagnosis, whilst 76% (588/770) received or were directed to resources. This was most likely to be "*written information/booklets/leaflets*" (44%, 336/770); "*direction to leukaemia charities/associations/organizations*" (34%, 263/770); and "*information on side effects and risks of treatment*" (31%, 239/770).

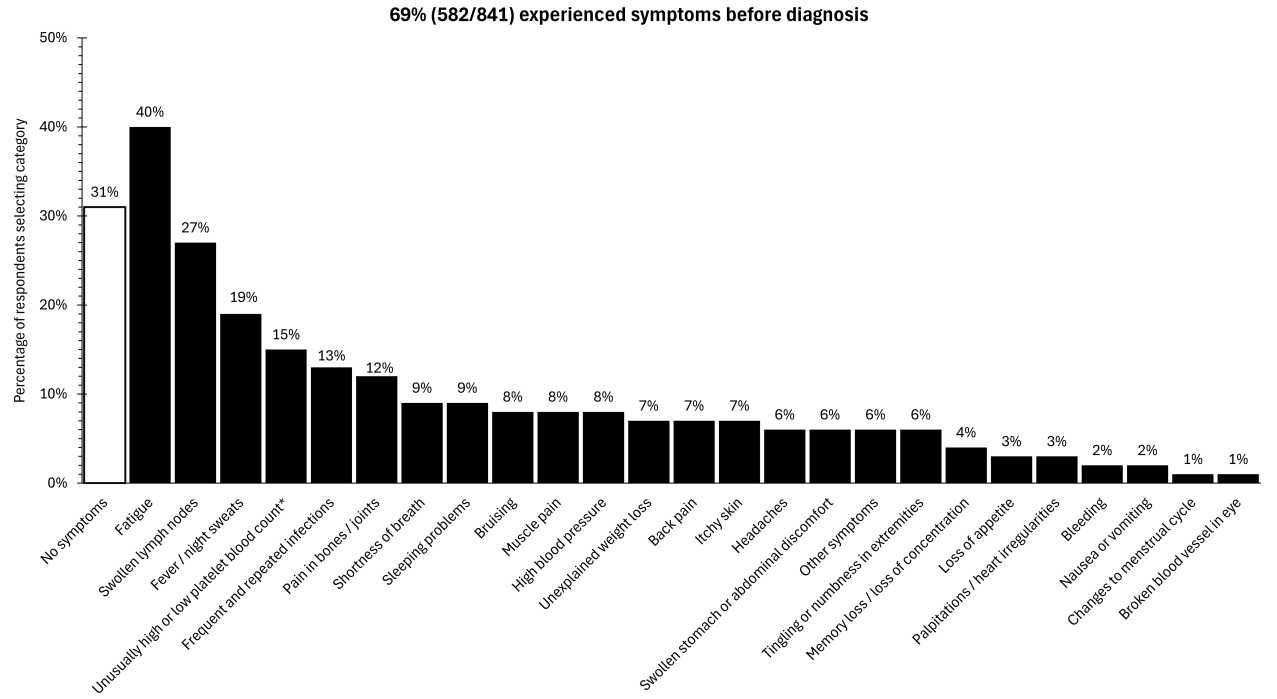

FIGURE 1
Symptoms experienced by people with CLL before diagnosis of the condition. Respondents could select multiple symptoms. The "*No symptoms*" option was set as mutually exclusive to the selection of other categories. *Red or white blood cells.

Exploratory country-level visualisations (Supplementary File 4) are included to illustrate the distribution of HM-PRO Part-A scores across countries. These plots show overlapping score ranges with some variation (lowest median 7, highest 18) but are not intended for inferential comparison because the non-probabilistic, advocacy-based sampling, resulting in uneven country distributions.

3.4 Study question 2. Do people who are aware of their immunity status, and risk of infection, experience lower quality of life than people who are unaware?

QoL scores did not differ significantly by active monitoring status (p=0.176, η^2=0.005). Median HM-PRO Part-A scores (Table 2) were similar across groups: 12 for "*Never on active monitoring*", 12 for "*Not on active monitoring now*", and 11 for "*On active monitoring now*". Higher HM-PRO Part-A scores reflect greater impact and thus poorer QoL, so these results suggest minimal difference in QoL related to active monitoring status.

Awareness of immunity was associated with a statistically significant difference in QoL scores (p=0.010, η^2=0.010). Respondents unaware of their immunity status reported higher median HM-PRO Part-A scores (median 13) compared to those who were aware (median 11).

Receiving clear information on how to avoid infection was linked to modestly better QoL scores (p=0.008, η^2=0.024). Median HM-PRO Part-A scores were 10 for "*Yes, completely*", 12 for "*Yes, to some extent*", and 11 for "*No*".

Discussion of vaccination protocols with a HCP was associated with significantly lower QoL impact scores (p < 0.001, η^2=0.045): respondents who stated they had "*Yes, completely*" spoken with a HCP about the protocols had the lowest scores (median score 10), while respondents who stated "*No*" or "*Yes, to some extent*" had higher scores (median 13 for each).

4 Discussion

Our analysis of people with CLL in the 2023 GLES data revealed significant gaps in symptom awareness and association of those symptoms with CLL, understanding of active monitoring, understanding of immunity status and prophylactic measures. Our findings highlight opportunities to improve patient-centred education, clinician communication, and advocacy efforts to support patient experiences and outcomes. Our results align with previous literature reporting low symptom awareness among people with CLL (4, 5). This further supports calls for enhanced public awareness campaigns including for primary care providers (30–32). Additionally, we corroborate prior findings that active monitoring is a source of concern (6, 13). Our survey did not include structured items on the reasons for concern, which is an area for future refinement.

Our findings indicate that clear communication is associated with modest improvements in QoL, with small effect sizes, particularly regarding awareness of their compromised immunity. Respondents who received partial or incomplete information reported poorer QoL compared to those who received complete information.

TABLE 2 HM-PRO Part-A score by active monitoring status and knowledge about immunity.

Dependent variable: HM-PRO Part-A independent variable:	n	HM-PRO Part-A score Median (IQR)	H-statistic	p	Significance using Bonferroni adjusted threshold	η^2
Active monitoring status	**725**	**11 (IQR 5-17)**	**3.470**	**0.176**	**Not Significant**	**0.005**
Never on active monitoring	92	12 (IQR 5 - 21)				
Not on active monitoring now	194	12 (IQR 7 – 18)				
On active monitoring now	439	11 (IQR 5 - 17)				
Q72 Do you know your immunity status?	**676**	**11 (IQR 6-18)**	**6.716**	**0.010**	**Significant**	**0.010**
No	267	13 (IQR 7 - 19)				
Yes	409	11 (IQR 5 - 17)				
Q73 (ROUTED Q72 = Yes) Were you given clear information about what steps you can take to stay healthy and avoid infections?	**407**	**11 (IQR 5-17)**	**9.763**	**0.008**	**Significant**	**0.024**
No	51	11 (IQR 6 - 28)				
Yes, to some extent	169	12 (IQR 6 - 19)				
Yes, completely	187	10 (IQR 5 - 15)				
Q74 Has a health professional spoken to you about the protocols for CLL immunisations / vaccinations, including which you should receive and which you should avoid?	**759**	**11 (IQR 6-18)**	**33.810**	**<0.001**	**Significant**	**0.045**
No	209	13 (IQR 6 - 19)				
Yes, to some extent	249	13 (IQR 8 - 20)				
Yes, completely	301	10 (IQR 5 - 15)				

Kruskal Wallis test. The number (n) and median and interquartile range (IQR) of each group, the H statistic and associated p-value, and the eta-squared (h^2) as a measure of effect size. Statistical significance was assessed against a Bonferroni adjusted threshold, which divides the test threshold by the number of tests (adjusted threshold = 0.05 / 4 = 0.0125).

A large proportion of respondents were unaware that their symptoms could be indicative of leukaemia. Educational initiatives targeting the public and healthcare professionals could enhance early recognition and expedite referrals to haematologists. We note that several reported symptoms (such as bleeding, sleep problems, joint pains, itchy skin, palpitations and headaches) are not specific to CLL and may reflect comorbidities or misattribution; these responses should therefore be interpreted with caution. Once a diagnosis is made, our findings show that individuals with CLL need to receive clearer explanations regarding their condition.

Reinforcing previous findings, many respondents expressed uncertainty about the active monitoring strategy and reported insufficient support in managing symptoms during this phase (6, 14, 15). Given that nearly half of study respondents lacked full comprehension of active monitoring, clearer educational resources should be provided, emphasising disease progression indicators and symptom self-tracking strategies. Further to this, all HCP's involved in treatment and care provision should assess patient health literacy and understanding of educational resources to ensure the educational intervention has had the intended impact.

Our analyses found that active monitoring status did not significantly impact QoL, as measured by the HM-PRO Part-A. These findings suggest that active monitoring status alone may not have a substantial impact on QoL. In contrast, we found that knowledge of one's compromised immunity status was significantly associated with QoL, suggesting that uncertainty and lack of information may contribute to psychological distress. We found that the degree of information provision matters: respondents who received complete information reported better QoL scores. To address the QoL impacts, clinicians need to assess and ensure that traditional communication and education tools are understood by patients and supplement this with additional support as required.

Providing accessible, patient-centred resources may improve understanding and support informed decision-making regarding treatment options and management strategies. Clear guidance on infection prevention was associated with better QoL scores, whereas lack of guidance correlated with poorer outcomes. Literature calls for a focus to treat the patient, and not the disease (33).

Given the increased risk of infections in people with CLL due to disease-related and treatment-related immunosuppression, patient education on immunity management is essential. Clinicians should ensure that people with CLL receive tailored guidance on vaccination protocols, infection prevention, and when to seek medical assistance for potential infections. The key message is our findings highlight opportunities for enhanced information provision to people with CLL throughout the diagnostic and active monitoring pathways. When people with CLL receive clear explanations and information about their immunity status and infection prevention strategies, they report better QoL.

4.1 Strengths and limitations

Utilising data from a global survey offers several advantages: (i) the breadth of data collected across multiple countries provides a global perspective; however, pooling results limits interpretation within specific jurisdictions and reduces applicability to local healthcare contexts; (ii) the use of an online platform facilitated accessibility for many respondents; however, it may have limited participation among underserved populations with restricted internet access or digital literacy; (iii) secondary analyses reduce respondent burden by minimising the proliferation of multiple questionnaires.

However, limitations must be acknowledged: (i) self-reported data are subject to recall bias when completing a survey for the first time; (ii) convenience sampling may not fully capture the experiences of underserved populations. The sample was skewed toward respondents from the UK and USA, with a predominance of English-language responses; (iii) variations in healthcare access and cultural perceptions of illness across regions may influence responses; (iv) the absence of clinical verification of CLL status means responses rely on self-reported diagnosis and disease status. Thus, the generalisability of these findings may not apply to people who are less health literate, are digitally excluded, or have lower educational attainment than the respondents. Our sample differed from typical CLL epidemiology: the median age was 66 years, slightly younger than the commonly reported diagnostic median of ~70 years (2), and the proportion of male respondents (42%) was lower than the usual male predominance observed in CLL (34). In our sample, educational attainment was high, with 56% reporting university-level education, household-income data indicated a relatively advantaged socioeconomic profile. These demographic differences may increase health literacy and engagement with care; therefore, generalisability is greatest for digitally engaged, well-resourced patients.

We did not conduct country-level analyses because the non-probabilistic, advocacy-based recruitment was expected to, and did, produce uneven country sample sizes. Given these constraints, global aggregation was the most appropriate approach for addressing our aim of characterising overarching patient-reported experiences. An exploratory country-level plot is included in the Supplement for transparency but are not suitable for comparative interpretation. The large proportion of responses from Western countries may limit generalisability to other regions, future studies specifically designed and powered for country-level comparisons would therefore be valuable.

The statistical analyses, employing Kruskal-Wallis tests with Bonferroni corrections, enabled the exploration of relationships whilst mitigating the risk of incorrectly detecting an effect that does not exist (incorrectly rejecting a true null hypothesis, a Type I error). However, they do not establish causation nor account for potential confounders, thereby limiting the ability to draw definitive conclusions regarding the impact of specific factors on patient-reported outcomes.

5 Conclusion

Our study highlights key challenges faced by individuals with CLL, including lack of symptom awareness, lack of association of those symptoms with cancer, inadequate understanding of active monitoring, and the impact of immunity-related education on QoL.

Whilst the global survey approach provides valuable insights, findings should be interpreted considering its methodological limitations. Future research could seek to account for potential confounders to enhance the robustness of conclusions and build on these global findings by examining country-level differences in healthcare infrastructure, cultural attitudes, and access to infection prevention resources. This will enable tailored interventions that respect local contexts whilst maintaining consistency with global best practice.

Looking ahead, targeted educational initiatives, improved patient-clinician communication, and a stronger emphasis on shared decision-making could enhance patient experiences and outcomes in CLL care. Addressing these gaps through coordinated efforts amongst clinicians, advocacy groups, and policymakers may ultimately contribute to improved disease management and QoL for individuals living with CLL.

Data availability statement

The original contributions presented in the study are included in the article/Supplementary Material. Further inquiries can be directed to the corresponding author.

Ethics statement

Ethical approval was not required for the studies involving humans because The Global Leukaemia Experience Survey (GLES) was conducted anonymously, online, and without any intervention, thus no significant ethical concerns were identified. People were informed about the study's objectives, the voluntary nature of involvement, and how responses would be used. People who did not agree with these terms did not proceed with the survey. Data handling adhered to the Market Research Society Code of Conduct, ISO 20252 and 27001 standards, and the UK General Data Protection Regulation (2018). The studies were conducted in accordance with the local legislation and institutional requirements. The participants provided their written informed consent to participate in this study.

Author contributions

KH: Conceptualisation, Funding acquisition, Validation, Supervision, Writing – review & editing. AP: Methodology, Software, Writing – review & editing, Writing – original draft, Formal analysis, Visualisation, Data curation. SG: Resources, Investigation, Project administration, Writing – review & editing, Visualisation, Data curation, Methodology, Writing – original draft. JR: Funding acquisition, Writing – review & editing, Conceptualisation. NY: Funding acquisition, Conceptualisation, Writing – review & editing. SS: Conceptualisation, Supervision, Writing – review & editing.

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Conflict of interest

The author(s) declared that this work was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Generative AI statement

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Supplementary material

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/frhem.2026.1794624/full#supplementary-material

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