ORIGINAL RESEARCH

A Survey of Patient Experience in CML: American and Canadian Perspectives

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Purpose: With treatment, chronic myeloid leukemia (CML) has a favorable prognosis, however, individuals with CML experience impairment to their quality of life (QoL). The aim of this study was to examine the perspectives and experiences of individuals with CML and to understand their challenges communicating with their CML physician.

Patients and Methods: An online survey in adults with CML (n=100) in the US and Canada assessed QoL, patient-provider relationships, treatment satisfaction, and understanding of CML and treatment goals via the MD Anderson Symptom Inventory, the Cancer Therapy Satisfaction Questionnaire and de novo survey questions. Participants were recruited via an external patient recruiter and CML Patient Groups.

Results: Many participants reported hardships due to CML and its treatment. The main impacts were on the ability to work (21%), engage in personal activities (e.g., hobbies, 28%), and to enjoy sexual relations (median=2.00, IQR=8.50). A substantial proportion (21–39%) wished to discuss additional topics with their providers (e.g., management of CML and/or its impacts). While participants reported satisfaction with therapy overall (median=85.71, IQR=17.86), they indicated low to moderate treatment satisfaction with specific components, including concerns regarding side effects (median=43.75, IQR=43.75). Participants generally had a good understanding of CML (97%) and its treatment goals (92%).

Conclusion: These findings advance our understanding of issues that need improvement to support QoL for individuals living with CML. Future work is needed to improve patient-provider relationships, address treatment-related side effects, and provide clinical information that is easier for patients to understand.

Keywords: chronic myeloid leukemia, quality of life, patient-health care provider relationship, patient experience, survey, North America

Introduction

Chronic myeloid leukemia (CML) is a rare cancer that begins in the bone marrow.[1] CML's three phases (chronic, accelerated, and blast phase) inform treatment decisions and prognosis.[2] The chronic phase, the most common phase at diagnosis, can often be adequately controlled with a tyrosine kinase inhibitor (TKI).[1] As such, most individuals with chronic phase CML can expect to have a near normal life expectancy.[3–5] Due to its slow progression and high survival rate, CML has been referred to as a "good cancer", with lower severity[6–8] compared to acute forms of leukemia. However, individuals living with CML experience impaired quality of life (QoL)[9,10] due to the disease and its treatment. For example, individuals with CML taking TKIs report lower QoL, particularly with fatigue.[11] Further, a substantial proportion (30–50%) requires multiple lines of treatment before adequate disease management,[12–16] and this may be associated with a greater burden on aspects of daily life (e.g., psychosocial, physical, financial).[17,18]

Impacts on well-being result from any cancer diagnosis, and labelling a cancer as "good" is not helpful to individuals with the diagnosis.[19,20] While presumably used to promote feelings of reassurance at diagnosis, as time progresses, patients may feel misunderstood or isolated, and could feel that their health care provider (HCP) does not take their diagnosis seriously, leading to hesitation to share concerns with HCPs.[20,21] For example, many individuals with CML report being unable to discuss anxiety or sexual problems,[22] although their sexual function has been found to be impaired compared to the US general population.[23] This is concerning given poorer sexual health could further exacerbate the impact of CML and its treatment on mental health[10] generally, and more severe depression[24] specifically.

Many individuals with CML report a lack of knowledge of CML, with only a small portion feeling prepared when making treatment decisions.[25] Similarly, many indicated a need for further resources to cope with CML.[22] Some also reported low levels of satisfaction with CML treatment.[25] Treatment satisfaction is critical, as it is associated with significantly improved QoL and less impairment of daily activities,[26] as well as strongly related to treatment adherence.[27]

This study aimed to investigate the perspectives of individuals living with CML in the United States (US) and Canada. Study objectives were to: 1) Describe patients' challenges and concerns related to their QoL, including financial (treatment-related), social, mental and physical well-being, 2) Describe patients' perceptions of their communication with their HCP(s), including whether they feel able to share their concerns/issues, and 3) Describe patients' understanding and perceptions of their treatment, related to how well they understand their diagnosis and the long-term treatment goals, what is most important to them about their treatment, and the sources of information consulted.

Materials and Methods
Sample
The study recruited US and Canadian participants with CML by an external patient recruiter (Global Perspectives) and patient advocate groups (PAGs) [most participants were recruited from CML Busters (US) and The Canadian CML Network)], with n=100 targeted as a feasible sample size for this population given the rare nature of the disease. Global Perspectives independently undertook all screening procedures. To be eligible, participants had to be 18 years of age or older, US or Canadian residents, able to understand English or French, diagnosed with CML, able to provide evidence of diagnosis (e.g., photo of CML prescription, physician letter, or health care portal confirming diagnosis) and answer screening questions. Participants were excluded if they had a mental disability or significant mental illness that, in the screener's opinion, would preclude their ability to complete the study. The study protocol and materials were reviewed and approved by Salus Independent Review Board (IRB) in the US and by Veritas IRB in Canada.

Procedures
Eligible individuals completed the online survey via the platform, Qualtrics. Participants completed an informed consent form before being allowed to continue to the survey. Participants were encouraged to complete the survey in one sitting, but if they had to take a break, they were required to complete the survey within 12 hours of starting due to the survey recall period. Participants received $100 USD/CAD remuneration for survey completion.

Survey Measures
MD Anderson Symptom Inventory- CML Module (MDASI-CML)
The MDASI-CML[28–30] is a 26-item instrument assessing severity of CML-related symptoms over the past 24 hours and their impact on functioning. The instrument assesses signs and symptoms, physical functioning, psychological functioning, and social functioning (including employment and housework).

Cancer Therapy Satisfaction Questionnaire (CTSQ)
The CTSQ[31,32] is a 16-item validated instrument assessing satisfaction with and preferences for cancer treatment over the past four weeks or overall. The instrument comprises three domains: Expectations of Therapy (ET; 5 items), Feelings about Side Effects (FSE; 4 items) and Satisfaction with Therapy (SWT; 7 items).

Respondents answer on a 5-point scale, with response options varying by item. Scores are calculated by domain according to published guidelines,[32] ranging from 0–100, with higher scores indicating greater satisfaction. Respondents

can skip items on the CTSQ; however, a minimum of 3, 4 and 5 completed items in, respectively, ET, FSE and SWT domains, are needed to calculate a domain score.

De Novo Survey Items

The survey included several de novo items to collect sociodemographic and medical history and measure views on QoL, HCP relationships, resource usage, and treatment issues. Questions were developed following a targeted literature review and insights from qualitative interviews with four experts. These were clinicians with extensive experience treating CML (co-authors CH and EA) and PAG leaders, one of each in both the US and Canada (co-author LM, and JC as acknowledged). The de novo survey items were reviewed in two additional cognitive interviews with PAG leaders prior to finalization to determine suitability regarding wording, relevance, response options, and instructions.

De novo survey items were translated from English to French by Pfizer Canada, using an accredited translation service.

Analysis

Statistical analysis was conducted using SAS (Version 9.4, SAS Institute, Inc., Cary, NC, USA), and included descriptive statistics, post-hoc exploratory analyses, and sensitivity analyses. Continuous variables were presented as mean, standard deviation (SD), median and interquartile range (IQR). Categorical variables were presented as frequencies (n) and percentages (%). Post-hoc exploratory analyses were conducted to assess differences between the two countries and by time since diagnosis, for variables that could be impacted by the country context.

A programming error led to seven of the de novo survey QoL items not being visible to the participants completing the survey on mobile phones (n=46; missing items as indicated in Supplementary Table 1). Sensitivity analyses compared sociodemographic and medical characteristics for participants unable to complete these items versus those who did. One additional de novo survey item "What type of Health Care Provider is the main provider who you see for CML care?" was not visible to Canadian participants.

Results

Background Characteristics

One hundred participants completed the survey between October 2021 and February 2022 [n=67, US and n=33, Canada (Table 1)]. The largest proportion of participants were aged 45–64 (46%), with 81% identifying as female and 75% married or living with a partner. Most participants identified as white (82%) and had college/university education (62%). A third (35%) of respondents worked full-time, and 22% were temporarily or permanently unable to work due to sickness or disability (although not necessarily caused by CML). Household income was distributed across response categories for both countries, with half of respondents reporting an income of at least $60,000 USD/CAD.

Most respondents showed symptoms at diagnosis (71%, Table 2). At survey completion, participants indicated that CML was in chronic phase (91%) and stable (87%). As shown in Supplementary Table 2, 57% visited their CML HCP every 3–4 months with one-way trips taking an hour or less for 83% of participants. Medical visits lasting 10–19 minutes were most common (39%), and 14% indicated that their consultation time was insufficient. Cross-country comparisons showed that Canadian participants spent significantly less time with their oncologists at each visit compared to US participants, with 60% of US participants spending 20 minutes or more compared to only 21% of Canadian participants (p=0.0016, Supplementary Table 2). Of those providing data, more than half of US participants consulted a general hematologist/oncologist for CML care (60%), followed by a CML specialist (39%, Supplementary Table 3; data not available for Canadian participants).

Sensitivity analyses compared participants who viewed the complete survey (n= 54) versus the survey with missing items due to completing on mobile phone (n=46; 31 in US and 15 in Canada) to examine differences in sociodemographic characteristics. The only significant difference was for household income in the US sample (p<0.01), where participants with missing items had higher proportions of both the highest and lowest income categories, compared to the middle categories (Supplementary Table 4A–C).

Table 1 Socio-Demographic Characteristics of Overall Sample

Variable, n (%)[a,b]	Country		Total (N=100)
	US (N=67)	Canada (N=33)	
Age			
18–34	5 (7.5%)	2 (6.1%)	7 (7.0%)
35–44	17 (25.4%)	8 (24.2%)	25 (25.0%)
45–64	30 (44.8%)	16 (48.5%)	46 (46.0%)
65–74	10 (14.9%)	4 (12.1%)	14 (14.0%)
75 or older	5 (7.5%)	3 (9.1%)	8 (8.0%)
Gender			
Female	54 (80.6%)	27 (81.8%)	81 (81.0%)
Marital status			
Single	11 (16.4%)	3 (9.1%)	14 (14.0%)
Married or living with a partner	48 (71.6%)	27 (81.8%)	75 (75.0%)
Divorced/separated	6 (9.0%)	2 (6.1%)	8 (8.0%)
Widowed	1 (1.5%)	1 (3.0%)	2 (2.0%)
I prefer not to answer	1 (1.5%)	0 (0.0%)	1 (1.0%)
Working status*			
Working full-time	28 (41.8%)	7 (21.2%)	35 (35.0%)
Working part-time	8 (11.9%)	7 (21.2%)	15 (15.0%)
Self-employed	4 (6.0%)	1 (3.0%)	5 (5.0%)
Retired	15 (22.4%)	7 (21.2%)	22 (22.0%)
Temporarily unable to work due to sickness or injury	4 (6.0%)	6 (18.2%)	10 (10.0%)
Permanently unable to work due to sickness or disability	6 (9.0%)	6 (18.2%)	12 (12.0%)
Other**	6 (9.0%)	2 (6.1%)	8 (8.0%)
Race*			
American Indian or Alaska Native	1 (1.5%)	n/a	1 (1.0%)
Asian[†]	3 (4.5%)	4 (12.1%)	7 (7.0%)
Black or African American****	5 (7.5%)	0 (0.0%)	5 (5.0%)
White	54 (80.6%)	28 (84.8%)	82 (82.0%)
Hispanic or Latino	4 (6.0%)	2 (6.1%)	6 (6.0%)
Other*****	1 (1.5%)	1 (3.0%)	2 (2.0%)
I prefer not to answer	1 (1.5%)	0 (0.0%)	1 (1.0%)

(*Continued*)

Table 1 (Continued).

Variable, n (%)[a,b]	Country		Total (N=100)
	US (N=67)	**Canada (N=33)**	
Highest level of education / degree			
Completed high school, General Educational Development (GED) or equivalent (secondary school)	3 (4.5%)	6 (18.2%)	9 (9.0%)
Some college or university	20 (29.9%)	2 (6.1%)	22 (22.0%)
Associate degree	7 (10.4%)	n/a	7 (7.0%)
Bachelor's degree/college diploma	20 (29.9%)	19 (57.6%)	39 (39.0%)
Post-graduate degree (e.g., Master's, PhD, MD, JD)	17 (25.4%)	6 (18.2%)	23 (23.0%)
Yearly household income before tax (USD/CAD)			
Less than $30,000	6 (9.0%)	1 (3.0%)	7 (7.0%)
$30,000-$59,999	14 (20.9%)	8 (24.2%)	22 (22.0%)
$60,000-$89,999	15 (22.4%)	3 (9.1%)	18 (18.0%)
$90,000-$119,999	11 (16.4%)	4 (12.1%)	15 (15.0%)
$120,000 or more	16 (23.9%)	9 (27.3%)	25 (25.0%)
I prefer not to answer	5 (7.5%)	8 (24.2%)	13 (13.0%)

Notes: [a]Prefer not to answer data included in calculation of percentages. [b]Response options that were not selected by any of the participants have not been included in this table (ie "Indigenous", "Native Hawaiian or Other Pacific Islander", "Southeast Asian", "Less than high school", "I prefer not to answer", "Other"). *For this question, participants were allowed to choose more than one answer. **"Other" includes participants who selected "Student", "Looking after home or family", "Unemployed – seeking work" and "Other". ***For this question, participants were allowed to choose more than one answer. ****The term "Black" was used for the Canadian survey. *****"Other" explicitly included "Mixed Race" for the Canadian survey. [†]In the Canadian survey, Asian included "East Asian", "South Asian", and "West Asian/Arab".

Table 2 Medical Background Characteristics of Overall Sample

Variable[a,b]	Total (N=100)
When were you diagnosed with CML?	
Less than 6 months ago	3 (3.0%)
6 months to 1 year ago	8 (8.0%)
More than 1 year to 2 years ago	12 (12.0%)
More than 2 years to 5 years ago	29 (29.0%)
More than 5 years to 10 years ago	22 (22.0%)
More than 10 years ago	25 (25.0%)
I prefer not to answer	1 (1.0%)
Did you have any symptoms when you were diagnosed?	
Yes	71 (71.0%)
No	29 (29.0%)

(Continued)

Table 2 (Continued).

Variable[a,b]	Total (N=100)
What phase was the CML at your diagnosis?	
Chronic phase	91 (91.0%)
Accelerated phase	5 (5.0%)
Blast phase	1 (1.0%)
I do not know	3 (3.0%)
What phase of CML did your doctor say you are in now?	
Chronic phase	93 (93.0%)
Accelerated phase	1 (1.0%)
Blast phase	1 (1.0%)
I do not know	3 (3.0%)
I prefer not to answer	2 (2.0%)
Do you consider the CML currently stable?	
Yes	87 (87.0%)
No	7 (7.0%)
I do not know	6 (6.0%)

Notes: [a]Prefer not to answer' data not included in calculation of percentages. [b]Response options that were not selected by any of the participants have not been included in this table (ie "I do not recall", "I prefer not to answer").

Objective 1: Quality of Life

The median and IQR MDASI-CML Severity Subscale Score (2.40, 3.33) indicated mild symptoms (including treatment side-effects) on average, yet a range of severity levels were reported (min=0.05, max=7.30). Almost half of participants (46%) answered 8 or higher to at least one symptom. The median and IQR for the three most severe symptoms were fatigue/tiredness (5.00, 5.00), disturbed sleep (3.50, 6.00), and memory problems (4.00, 4.50). The median and IQR Interference Subscale Score of the sample (2.92, 4.67) indicated mild interference with QoL overall with a range of interference levels reported (min=0.00, max=10.00). The median and IQR for the three most impacted domains were work (including around the house; 4.00, 6.00), general activities (4.00, 7.00), and mood (3.00, 6.00) (Table 3). One third (33%) of participants answered 8 or higher to at least one interference.

Of those providing data, participants overall reported low levels of anxiety about having CML (median=2.50, IQR=5.00), although a range of anxiety levels was found (Supplementary Table 1). Similarly, interference with activities was low overall, but the median and IQR for the three most severe items were interest in sexual relations (3.00, 9.00), ability to enjoy sexual relations (2.00, 8.50), and ability to concentrate (3.00, 5.00). Over two thirds reported that their employer knew about their diagnosis (69%) and all respondents shared their diagnosis with family. Family and friends generally understood their condition (78%). Participants reported an impact on specific daily activities (e.g., travel, work for pay), with the most impacted areas relating to ability to engage in personal interests (28%), travelling (21%), or working as many hours as desired (21%). No statistically significant differences in QoL by country or time since diagnosis were found (Supplementary Tables 1 and 5). Additional data are provided in Supplementary Figures 1–26.

Table 3 MDASI-CML Scores (n=100)

Variable	Mean (SD) [Min-Max]	Median (IQR) [Q1-Q3]
MDASI-CML Severity Subscale Score	**2.70 (1.94) [0.05–7.30]**	**2.40 (3.33) [0.98–4.30]**
Your pain at its WORST?	2.78 (3.09) [0.00–10.00]	2.00 (5.00) [0.00–5.00]
Your fatigue (tiredness) at its WORST?	4.68 (2.99) [0.00–10.00]	5.00 (5.00) [2.00–7.00]
Your nausea at its WORST?	2.00 (2.65) [0.00–9.00]	0.50 (4.00) [0.00–4.00]
Your disturbed sleep at its WORST?	4.18 (3.17) [0.00–10.00]	3.50 (6.00) [1.00–7.00]
Your feelings of being distressed (upset) at its WORST?	3.08 (3.00) [0.00–10.00]	3.00 (5.00) [0.00–5.00]
Your shortness of breath at its WORST?	1.87 (2.58) [0.00–9.00]	0.00 (3.00) [0.00–3.00]
Your problem with remembering things at its WORST?	4.01 (2.88) [0.00–10.00]	4.00 (4.50) [1.50–6.00]
Your problem with lack of appetite at its WORST?	1.98 (2.69) [0.00–9.00]	0.00 (4.00) [0.00–4.00]
Your feeling drowsy (sleepy) at its WORST?	3.73 (3.13) [0.00–10.00]	3.00 (6.00) [1.00–7.00]
Your having a dry mouth at its WORST?	2.28 (2.77) [0.00–10.00]	1.00 (4.00) [0.00–4.00]
Your feeling sad at its WORST?	2.91 (2.97) [0.00–10.00]	2.00 (5.00) [0.00–5.00]
Your vomiting at its WORST?	0.53 (1.31) [0.00–6.00]	0.00 (0.00) [0.00–0.00]
Your numbness or tingling at its WORST?	2.26 (2.49) [0.00–9.00]	1.00 (4.00) [0.00–4.00]
Your diarrhea at its WORST?	2.08 (2.89) [0.00–10.00]	0.00 (3.00) [0.00–3.00]
Your swelling of your hands, legs, feet, abdomen, or around your eyes at its WORST?	2.54 (2.83) [0.00–10.00]	2.00 (4.00) [0.00–4.00]
Your rash or skin change at its WORST?	2.43 (2.64) [0.00–10.00]	2.00 (5.00) [0.00–5.00]
Your muscle soreness or cramping at its WORST?	3.54 (3.10) [0.00–10.00]	3.00 (6.00) [0.00–6.00]
Your bruising easily or bleeding at its WORST?	1.97 (2.69) [0.00–10.00]	1.00 (3.00) [0.00–3.00]
Your feeling of malaise (not feeling well) at its WORST?	3.01 (2.93) [0.00–10.00]	2.00 (5.00) [0.00–5.00]
Your headache at its WORST?	2.20 (3.11) [0.00–10.00]	0.00 (4.00) [0.00–4.00]
MDASI-CML Interference Subscale Score	**3.33 (2.77) [0.00–10.00]**	**2.92 (4.67) [0.67–5.33]**
General Activity?	3.87 (3.19) [0.00–10.00]	4.00 (7.00) [0.00–7.00]
Mood?	3.41 (3.10) [0.00–10.00]	3.00 (6.00) [0.00–6.00]
Work (including work around the house)?	4.05 (3.36) [0.00–10.00]	4.00 (6.00) [1.00–7.00]
Relations with other people?	2.55 (2.82) [0.00–10.00]	1.00 (5.00) [0.00–5.00]
Walking?	2.88 (3.18) [0.00–10.00]	2.00 (6.00) [0.00–6.00]
Enjoyment of life?	3.19 (2.98) [0.00–10.00]	2.00 (5.50) [0.00–5.50]

Objective 2: HCP and Resources

Participants provided mixed responses regarding the nature and extent of involvement in decision-making for CML management (Table 4). Most participants (93%) regularly discussed with their HCP how they were feeling and their CML symptoms. One fifth (22%) of participants (and 42% of male responders) indicated there is at least one side effect that they do not currently discuss

Table 4 HCP Relationship

Variable[a,b]	Total (N=100)
When deciding how to manage CML, which of the following best describes how your healthcare provider discussed your treatment options with you?	
I suggested a specific treatment to my healthcare provider	4 (4.0%)
My healthcare provider presented several options for treatment and discussed each one with me, ultimately letting me decide	10 (10.0%)
I felt like my healthcare provider and I made a plan for my treatment as a team	28 (28.0%)
My healthcare provider discussed treatment options with me and then provided a recommendation	32 (32.0%)
My healthcare provider told me what treatment I should take without much discussion	26 (26.0%)
Regular discussions with HCP: Symptoms and side effects	
How I am feeling in general	
Yes, sometimes	93 (93.0%)
No, but I would like to	6 (6.0%)
Not, but I do not want to	1 (1.0%)
CML symptoms and whether they have changed since my last visit	
Yes, sometimes	93 (93.0%)
No, but I would like to	7 (7.0%)
If I have fatigue that I consider a CML treatment side effect	
Yes, sometimes	76 (76.0%)
No, but I would like to	12 (12.0%)
Not, but I do not want to	11 (11.0%)
Choose not to respond	1 (1.0%)
If I have diarrhea and/or nausea that I consider a CML treatment side effect	
Yes, sometimes	68 (68.0%)
No, but I would like to	9 (9.0%)
Not, but I do not want to	21 (21.0%)
Choose not to respond	2 (2.0%)
Any other side effects from CML treatment	
Yes, sometimes	83 (83.0%)
No, but I would like to	14 (14.0%)
Not, but I do not want to	3 (3.0%)
Regular discussions with HCP: Everyday impacts	
The effect of CML on my daily activities	
Yes, sometimes	66 (66.0%)
No, but I would like to	21 (21.0%)

(*Continued*)

Table 4 (Continued).

Variable[a,b]	Total (N=100)
Not, but I do not want to	12 (12.0%)
Choose not to respond	1 (1.0%)
The effect of CML on my emotions	
Yes, sometimes	44 (44.0%)
No, but I would like to	33 (33.0%)
Not, but I do not want to	22 (22.0%)
Choose not to respond	1 (1.0%)
The effect of CML on my relationships with others	
Yes, sometimes	27 (27.0%)
No, but I would like to	28 (28.0%)
Not, but I do not want to	43 (43.0%)
Choose not to respond	2 (2.0%)
The effect of CML on work/school	
Yes, sometimes	36 (36.0%)
No, but I would like to	32 (32.0%)
Not, but I do not want to	28 (28.0%)
Choose not to respond	4 (4.0%)
Regular discussions with HCP: Management topics	
Ways I can better manage CML	
Yes, sometimes	51 (51.0%)
No, but I would like to	35 (35.0%)
Not, but I do not want to	14 (14.0%)
Resources I can access to help me with CML	
Yes, sometimes	41 (41.0%)
No, but I would like to	39 (39.0%)
Not, but I do not want to	19 (19.0%)
Choose not to respond	1 (1.0%)
Other treatment options for CML	
Yes, sometimes	58 (58.0%)
No, but I would like to	25 (25.0%)
Not, but I do not want to	17 (17.0%)

(*Continued*)

Table 4 (Continued).

Variable[a,b]	Total (N=100)
Potentially stopping treatment or lowering medication dosage	
Yes, sometimes	67 (67.0%)
No, but I would like to	20 (20.0%)
Not, but I do not want to	13 (13.0%)
HCP relationship	
Listens to any concerns about any treatment side effects	
No, not at all	0 (0.0%)
Somewhat	20 (20.0%)
Mostly	25 (25.0%)
Very much	55 (55.0%)
Listens to your concerns about any impacts of CML on your daily life and activities	
No, not at all	7 (7.0%)
Somewhat	28 (28.0%)
Mostly	24 (24.0%)
Very much	38 (38.0%)
Does not apply	3 (3.0%)
Explains your disease and treatment options in a way that is easy to understand	
No, not at all	2 (2.0%)
Somewhat	16 (16.0%)
Mostly	20 (20.0%)
Very much	62 (62.0%)
Manages your side effects to your satisfaction	
No, not at all	9 (9.0%)
Somewhat	26 (26.0%)
Mostly	32 (32.0%)
Very much	32 (32.0%)
Does not apply	1 (1.0%)
Gives you a chance to ask questions	
No, not at all	1 (1.0%)
Somewhat	16 (16.0%)
Mostly	16 (16.0%)
Very much	67 (67.0%)

(*Continued*)

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Table 4 (Continued).

Variable[a,b]	Total (N=100)
Seems to understand what goals are important to you	
No, not at all	12 (12.0%)
Somewhat	18 (18.0%)
Mostly	25 (25.0%)
Very much	43 (43.0%)
Does not apply	2 (2.0%)
Seems to answer your questions honestly	
No, not at all	2 (2.0%)
Somewhat	10 (10.0%)
Mostly	14 (14.0%)
Very much	74 (74.0%)
Develops a treatment plan to which you agree	
No, not at all	4 (4.0%)
Somewhat	12 (12.0%)
Mostly	22 (22.0%)
Very much	62 (62.0%)
Compares CML to other types of cancer	
No, not at all	66 (66.0%)
Somewhat	23 (23.0%)
Mostly	3 (3.0%)
Very much	7 (7.0%)
Does not apply	1 (1.0%)
In addition to your main health care provider, do you have other health care providers for CML?	
Yes, and they are more informative and/or supportive than my main health care provider	17 (17.0%)
Yes, and they are as informative and/or supportive as my main health care provider	28 (28.0%)
Yes, and they are less informative and/or supportive as my main heath care provider	12 (12.0%)
No	42 (42.0%)
Choose not to respond	1 (1.0%)

Notes: [a]Prefer not to answer'/'Choose not to respond' data included in calculation of percentages. [b]Response options that were not selected by any of the participants have not been included in this table (ie "Not, but I do not want to", "Does not apply", "Choose not to respond/I prefer not to answer", "Other").

with their oncologist but would like to (9% for diarrhea, 12% for fatigue and 14% for any other side effect). Two-thirds (65%) indicated there was at least one everyday impact (e.g., daily activities) or management topic (e.g., treatment options) that they do not discuss with their CML HCP but would like to (21–39% across everyday impacts and management topics). Twenty percent or more of participants reported that their oncologist only somewhat or does not manage their side effects satisfactorily (35%),

listen to their concerns about CML-related impacts on daily life and activities (35%), understand goals that were important to them (30%), or listen to concerns about treatment side-effects (20%). A third of respondents (33%) indicated that their CML HCP compared CML to other types of cancer. When asked about receiving CML care from additional HCPs other than their primary CML provider (e.g., other physicians), 17% of respondents (and 37% of male respondents) indicated that they had other HCPs who were more helpful than their primary CML HCP (Supplementary Table 6). These responses were consistent across countries (p=0.373).

A large majority of participants (88%) stated that they did at least somewhat understand their test results, treatment milestones (89%), CML (97%), or treatment goals (92%) (Supplementary Table 7). Most participants wanted more information about CML (76%), particularly the long-term impacts of treatment (71%). Most participants (70%) indicated that they would like more resources to help them cope with CML, including access to counselors/therapists that understand CML (45%). Of the 11 listed resource types, the most helpful resources used were other patients (52%), support/advocacy groups (45%), and medical websites (45%). Despite their usefulness, some patients stated they were not connected to support/advocacy groups (26%) or other patients (20%). Seventy-seven percent of participants felt supported by their partner in managing CML, but 19% reported their partner did not have the information needed to support them.

Objective 3: Treatment Issues

There was moderate satisfaction regarding treatment expectations (median=60.00, IQR=30.00; Table 5 and Supplementary Tables 8–11). The lowest satisfaction was regarding getting rid of the cancer (median=2.00, IQR=3.00), preventing the cancer from coming back (median=3.00, IQR=2.00), and helping return to a normal life (median=3.00, IQR=2.00)). There were some concerns over side effects (median=43.75, IQR=43.75). Participants were satisfied with their cancer therapy overall, yet the score range indicates that some were dissatisfied (SWT median=85.71, IQR=17.86).

Table 5 Treatment Satisfaction (n=100)

Variable[a,b]	Mean (SD) [Min-Max]	Median (IQR) [Q1-Q3]
CTSQ Expectations of Therapy (ET) Dimension Score	57.99 (22.97) [10.00–100.00]	60.00 (30.00) [45.00–75.00]
Feelings about Side Effects (FSE) Dimension Score	47.98 (26.23) [0.00–100.00]	43.75 (43.75) [25.00–68.75]
Satisfaction with Therapy (SWT) Score	82.32 (13.80) [35.71–100.00]	85.71 (17.86) [75.00–92.86]
Medication Issues		
What are the reasons that have caused you to miss a dose of your prescription (TKI) medication for CML in the past?* + n (%)		
I forgot to take it	55 (55.0%)	–
I ran out of medication	14 (14.0%)	–
I was not able to afford my medication	4 (4.0%)	–
I wanted to avoid side effects	21 (21.0%)	–
I did not have my medication with me at the time of my dose	24 (24.0%)	–
Insurance did not approve my medication in time	7 (7.0%)	–
The pharmacy did not ship my medication in time	10 (10.0%)	–
The doctor's office did not respond to the request for refill, leading to a delay in getting my medication	2 (2.0%)	–
I was sick	26 (26.0%)	–

(*Continued*)

Table 5 (Continued).

Variable[a,b]	Mean (SD) [Min-Max]	Median (IQR) [Q1-Q3]
I was advised by a health care provider to miss a dose or doses	18 (18.0%)	–
I did not feel I needed it	0 (0.0%)	–
I did not want to be reminded of CML	7 (7.0%)	–
Other	4 (4.0%)	–
I have never missed a dose of my medication for CML	19 (19.0%)	–
My medication fits in with my daily life* n (%)		
Strongly disagree	5 (5.0%)	–
Disagree	9 (9.0%)	–
Agree	42 (42.0%)	–
Strongly agree	44 (44.0%)	–
Have you ever reduced or missed a dose of your medication for CML due to the cost?* n (%)		
Yes	8 (8.0%)	–
No	91 (91.0%)	–
I prefer not to answer	1 (1.0%)	–
Have you ever stopped taking your medication for CML on a long-term (regular, ongoing) basis for a reason OTHER THAN attempting treatment-free remission (TFR)?* n (%)		
Yes	22 (22.0%)	–
No	78 (78.0%)	–

Notes: [a]Participants were allowed to not answer any item in this instrument. [b]Response options that were not selected by any of the participants have not been included in this table (ie "Not applicable", "I prefer not to answer"). *Between-country analyses were conducted and there was no significant difference except for time spent during each visit. Please refer to Supplementary Tables 1, 2, 6 and 10. +Participants were allowed to choose multiple responses. Reproduced with permission from Pfizer. Copyright © Pfizer Inc.

Almost 80% of the sample reported missing a dose of medication, with reasons of: forgetting (55%), not having their medication with them (34%), and being sick (26%; Supplementary Table 9). Nine percent reduced or missed a dose due to medication cost, while 22% stopped treatment on a long-term basis (defined as "regular, ongoing") for reasons other than to attempt treatment-free remission (TFR). Among those who did stop for other reasons, side effects (77%) and HCP advice (64%) were the main reasons. Thirty-four percent of participants who stopped treatment did not discuss stopping with their HCP ahead of time. Of those who did discuss with their HCP, 61% thought their HCP was accepting of their decision.

There were no statistically significant differences by country regarding issues that make it difficult to take medication as instructed (Supplementary Tables 10 and 11).

Discussion

The present study sought to understand the impact of CML on QoL, relationships with HCPs, and knowledge and understanding of the disease for those living with CML in the US and Canada. A range of symptom and impact severity from CML or its treatment was reported, indicating that some participants are experiencing severe symptoms and interference in daily life. Participants reported the most bothersome symptoms being fatigue/tiredness, disturbed sleep, and memory problems, along with a range of distress levels, consistent with previous studies.[10,24] While participants generally reported low levels of interference in daily life, a range of severity was reported, indicating that some participants experience severe interference in their daily lives, with the most impact on work (including housework),

general activities, and mood. Interference was also reported for interest and ability to enjoy sexual relations, an understudied finding noted in the literature.[11,22,33]

Employment was another area where participants reported interference, with some reporting not being able to work as many hours as desired. Canadian participants reported an impact on ability to work for pay. Previous research found wide variation in employment rates among cancer survivors (41–84%), with symptom burden being the primary reason.[34,35]

Relationships with HCPs were an area where participants reported unmet needs. While some participants reported being able to share negative experiences with their HCPs, a substantial portion did not but would like to, consistent with prior research.[22] Further, a third did not agree that their HCP listened to concerns and managed side effects adequately, while some (20 to 39%) would like to further discuss management topics. It is possible that these perceptions of HCPs' receptiveness to concerns and ability to manage side effects contributed to participants not sharing negative experiences with their HCPs. At the same time, a smaller proportion reported not wanting to discuss these topics, which may be reflective of a desire to not burden their provider, or a concern that it will not be helpful to bring them up. Future work should address how HCPs can make those with CML feel that their experiences are relevant, and they are listened to, regardless of high survival rates. Furthermore, individuals with CML may be reluctant to volunteer some clinically relevant information, such as diarrhea and/or nausea. HCPs should make sure to raise these issues during clinic visits to ensure they are not overlooked. Future research should examine the characteristics of individuals with CML who are dissatisfied with their treatment and HCPs.

One-third of participants who stopped treatment did not discuss this with their HCP beforehand, consistent with prior research.[36] This further indicates discomfort in discussing important issues with their HCP. A synthesis of qualitative studies[37] found that patients made decisions about treatment adherence for a variety of reasons, including communication issues and misunderstandings regarding TKI treatment.

One-third of participants reported that their HCPs compare CML to other types of cancers. It is difficult to determine the impact of this comparison on participants, since questions about the impact were not directly asked, however, based on prior research,[20,21] it is possible that participants either perceived this comparison as minimizing their experience (and causing reluctance to share negative experiences), or as reassuring that their prognosis was favorable. Qualitative interviews could be an appropriate way to learn more about the reasons for reluctance to discuss certain issues with HCPs as well as to understand the impacts of such comparisons on QoL.

Between-country comparisons in HCP visit characteristics found Canadian participants spent less time with HCPs at each visit, which is not surprising given their public healthcare system. However, satisfaction with the amount of time spent with their HCP was similar. While the reasons are unknown, it is possible that participants in these countries had different expectations, or that Canadian HCPs are more efficient with the available time.

Participants had a good understanding of CML, its clinical characteristics and treatment. Nonetheless, there are areas needing improvement in treatment planning and participants' understanding. Around one-fourth of participants reported not being included in treatment decision-making. A few participants reported not knowing their diagnosis or if the CML was stable and desired resources in easy-to-understand language. While such information may be provided by HCPs, this may not translate into patients' understanding, consistent with past studies.[1] However, despite these gaps, all participants reported needing their medication and around a quarter reported having access to all of the information they need.

Treatment satisfaction was also a concern. Low to moderate treatment satisfaction was reported in many areas, including side effects. Participants were mixed as to whether treatment limited their daily activities and in the difficulty of treatment compared to expectations. Despite these issues, more than three-quarters of participants were satisfied with their therapy overall. However, increased HCP focus on addressing side effects could improve QoL for those living with CML. Between-country comparisons found no significant differences regarding treatment issues.

Study limitations include sample bias related to the use of PAGs to recruit a large proportion of participants, as these are typically more engaged and well-informed individuals. A large proportion of US participants were treated by CML specialists, were from a higher socioeconomic background and have more formal education than the general CML population. Therefore, these results may not be necessarily representative of the general CML population. However, educational backgrounds in the sample were similar to other CML studies,[24,38] while incomes were slightly higher.[39] Another limitation is the composition of the sample. While CML is more common in males,[40] 81% of participants were

female, possibly due to the use of PAGs for recruitment. It is possible that females are more likely to join PAGs, or may reflect differences in ways females engage with their health, as males are less likely to seek help from health professionals.[41–43] Age and race of the sample were similar to other CML studies.[1,24,44] While missing data is a limitation, few differences were found between participants with complete and missing data.

Conclusion

This study contributes to the literature by utilizing validated measures and de novo survey items to assess QoL and treatment experiences in individuals living with CML, and by examination of the experiences of individuals living with CML in the US and Canada. In conclusion, these findings highlight areas of unmet need for those living with CML and provide important suggestions for improvements, including QoL challenges, relationships with their physician and treatment understanding and satisfaction. Addressing these issues could help ensure the highest QoL for these individuals.

Abbreviations

CML, Chronic Myeloid Leukemia; CTSQ, Cancer Therapy Satisfaction Questionnaire; EF, Expectations of Therapy; FSE, Feelings about Side Effects; HCP, Health Care Provider; IQ, Interquartile Range; IRB, Independent Review Board; MDASI-CML; MD Anderson Symptom Inventory- CML Module; PAGs, Patient Advocate Groups; QoL, Quality of Life; SD, Standard Deviation; SWT, Satisfaction with Therapy; TFS, Treatment-Free Remission; TKI, Tyrosine Kinase Inhibitor; US, United States.

Data Sharing Statement

The dataset generated and/or analyzed during the current study is available as Supplementary Materials.

Ethics Approval

The study was conducted in accordance with the Declaration of Helsinki. The study protocol and materials were reviewed and approved by Salus Independent Review Board (IRB) in the US (protocol 9002-0779, approved October 1, 2021) and by Veritas IRB in Canada (approved October 6, 2021).

Consent to Participate

Participants completed an online informed consent form prior to taking part in the study.

Consent to Publish

Participants provided consent to publish the combined responses of all participants in reports or other scientific publications, which does not include identifying information.

Author Contributions

All authors made a significant contribution to the work reported, whether that is in the conception, study design, execution, acquisition of data, analysis and interpretation, or in all these areas; took part in drafting, revising or critically reviewing the article; gave final approval of the version to be published; have agreed on the journal to which the article has been submitted; and agree to be accountable for all aspects of the work.

Disclosure

EHG, TSML, JV, and SD are employees of Pfizer Inc. RB, HFB, ADP, and VB, employees of ICON, received consultancy fees from Pfizer. KEF and CH received consultancy fees from Pfizer. CH also reports grants from Novartis, outside the submitted work. KEF also reports consultancy fees from Inhibikase and grant to her institution from Novartis, outside the submitted work. EA receives research support and consultancy fees from Novartis and Takeda, and consultancy fees from BMS, Abbvie and Pfizer. The remaining authors report no conflicts of interest in this work.

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