Improving chronic myeloid leukemia management and quality of life: patient and physician survey on unmet needs from the CML SUN survey

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Supplementary Appendix

Supplementary Methods

Qualitative interviews

In the qualitative phase, 60-minute in-depth qualitative interviews were conducted with 21 adult patients who had been treated with ≥1 prior TKI and 24 physicians treating patients with CML in France, Germany, Japan, and the US to identify the appropriate topics for the quantitative surveys.

Quantitative surveys

Quantitative surveys took approximately 40 minutes for patients and approximately 30 minutes for physicians to complete. Questions for both patients and physicians were related to CML diagnosis, treatment, impact on daily life, treatment switching, and shared decision-making. In addition, physicians were asked about disease monitoring.

Analysis

Reported results were derived from survey questions asked as follows:

Information sharing at diagnosis and treatment switching. Patients were asked to select the 5 most important areas of information that they wanted to receive at diagnosis/switch out of 17 options and then ranked in order of importance from 1 to 5, with 1 being the most important. Physicians were asked to select any information they provided to patients at diagnosis/switch (no ranking) out of 16 options.

Treatment goals. Patients were asked to rank their 3 most important goals, and physicians were asked to select any goals.

Shared treatment decision-making. Physicians were asked on a scale from 1 to 7, where 1 means "strongly disagree" and 7 means "strongly agree" to indicate how much they agreed with the following statement: “CML patients' input to a treatment decision is welcomed, but ultimately, I am the decision-maker.” Patients were asked how treatments were described by and agreed upon with their physicians. Physicians were asked how many TKI options they offered and to what extent their patients were involved in treatment decisions.

Burden of disease. Patient perceptions of how CML treatment affects their life were assessed by asking them how much they agreed with certain statements related to treatment impact.

Side effects. Patients were asked to recall conversations with their doctor about side effects, including who initiated the conversations and how the doctor reacted when informed about side effects.

Adherence. Patients were asked to choose reasons for missed doses from a list of 15 options. Physicians were asked what they thought were the reasons for their patients missing doses of their TKI medication from a list of 11 options.

A. Supplemental Tables

Supplemental Table S1. Eligibility criteria

Patient inclusion criteria[a]
≥18 years of age and diagnosed with CML-CP
Not currently employed by a market research company, advertising agency, or a pharmaceutical/biotechnology company
Received 1 to 3 prior TKIs and currently receiving their second, third, or fourth TKI
Physician inclusion criteria[b]
Transplant specialist or hematologist and/or oncologist in practice for 3 to 35 years and personally responsible for treatment decisions for patients with CML-CP
Not currently employed by a market research company, advertising agency, or a pharmaceutical/biotechnology company
Spent ≥50% of their time caring for patients
Switched patients’ treatment from their second to third TKI

CML-CP, chronic myeloid leukemia in chronic phase; TKI, tyrosine kinase inhibitor.

[a] Patients were recruited via open internet invitation through patient databases, physician and nurse referrals, and patient advocacy groups. [b] Physicians were recruited via open internet invitation through online physician panels.

Supplemental Table S2. Countries of physician and patient origin

Country	Patient sample/proportion of total, n (%)	Physician sample/proportion of total, n (%)
Australia	20 (6)	13 (7)
Brazil	42 (12)	15 (8)
Canada	10 (3)	15 (8)
France	15 (4)	20 (10)
Germany	37 (10)	20 (10)
Italy	25 (7)	20 (10)
Japan	34 (9)	15 (8)
South Korea	40 (11)	10 (5)
Spain	24 (7)	20 (10)
UK	44 (12)	20 (10)
US	70 (19)	30 (15)
Total	**361/100**[a]	**198/100**[b]

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[a] A total of 3,671 patients clicked on the survey link; 3,310 screened out/did not qualify, while 361 qualified and completed the survey. An additional 626 patients expressed interest in joining the survey but were unable to participate because the respective quotas were already reached.

[b] A total of 327 physicians clicked on the survey link; 129 screened out/did not qualify, while 198 qualified and completed the survey. An additional 111 physicians expressed interest in joining the survey but were unable to participate because the respective quotas were already reached.

Supplemental Table S3. Physician and patient demographics

Patients	**n=361**	
Female, %	56	
Age, median (range), years	45 (19-82)	
Time from diagnosis of CML, median (range), years	5 (1-33)	
Type of insurance coverage, %		
Public insurance only	33	
Public insurance plus private supplementary insurance	27	
Other[a]	18	
Private insurance only	17	
Public assistance program[b]	5	
Currently receiving treatment by line at the time of the survey, %		
Second TKI	66	
Third TKI	24	
Fourth TKI or later	9	
TKI treatment, %	**Current**	**Past**
Dasatinib	26	36
Nilotinib	16	24
Imatinib	16	45
Generic imatinib	12	17
Bosutinib	10	13
Ponatinib	7	9
Generic dasatinib	6	8
Asciminib	6	4
Radotinib	NR	18

Physicians	**n=198**
Hematologists, %	41
Hematologist-oncologists, %	59
Time in practice, median (range), years	18 (3-31)
Practice setting, %	
University teaching hospital	59
Community or general hospital	17
Cancer center	15
Office-based (solo or group practice)	8
General hospital	1
Time spent on patient care, median (range), %	90 (50-100)
Patients treated for hematologic cancers over last 12 months, median (range), n	230 (15-3200)
Patients with CML-CP seen in last 12 months, median (range), n	35 (10-600)

Patients with CML-CP seen in last 12 months by practice setting, mean (SD), n	
University teaching hospital (n=117)	62 (80)
Community or general hospital (n=34)	84 (135)
Cancer center (n=30)	72 (84)
Office-based (solo or group practice) (n=16)	38 (36)
General hospital (n=1)	15 (0)
Patients with CML on each line of treatment seen in the last 12 months, median (range), %	
First TKI	50 (10-95)
Second TKI	27 (10-95)
Third TKI	20 (0-90)
Fourth TKI or later	9 (0-90)

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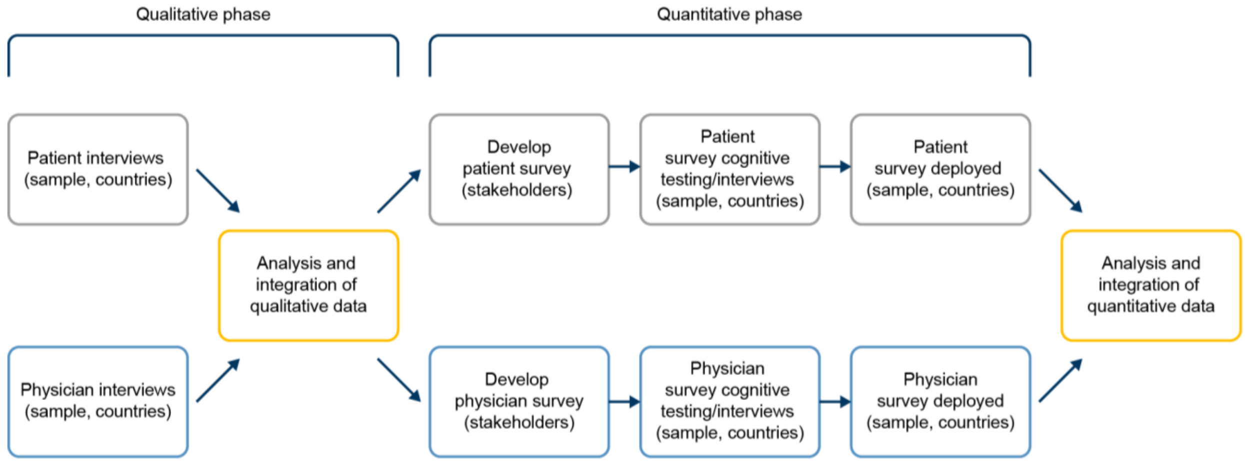
CML, chronic myeloid leukemia; CML-CP, chronic myeloid leukemia in chronic phase; NR, not reported; SD, standard deviation; TKI, tyrosine kinase inhibitor.

[a] Other includes employer-provided, private self-paid, health insurance exchange, military, private insurance plus Medicare, National Health Insurance, and none. [b] Public assistance program includes Medicare, Medicaid, disability, and social security insurance.

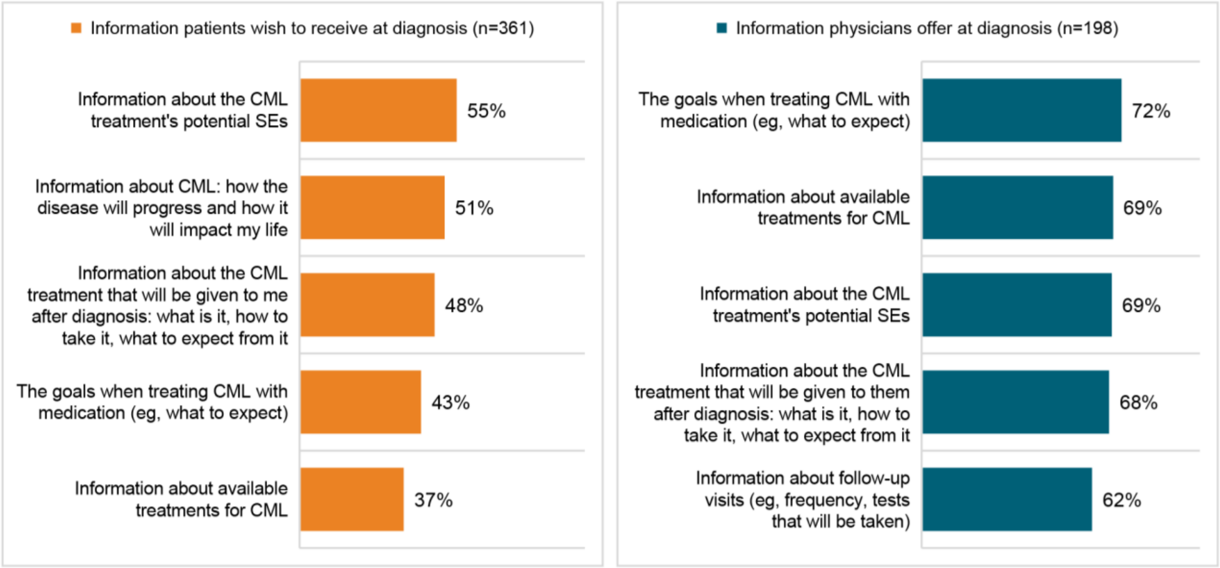
B. Supplemental Figures

Figure S1. CML SUN study design. A mixed methods research with exploratory sequential design. After each phase, qualitative then quantitative, results from both patients and physicians were analyzed and integrated.



CML SUN, Chronic Myeloid Leukemia Survey on Unmet Needs.

Figure S2. Top 5 most important areas of information patients want to receive vs what physicians give at diagnosis. Top 5 areas of information related to CML-CP that patients want to receive at diagnosis ranked in order of preference compared with what physicians actually provide, as assessed by proportions of patients and physicians.



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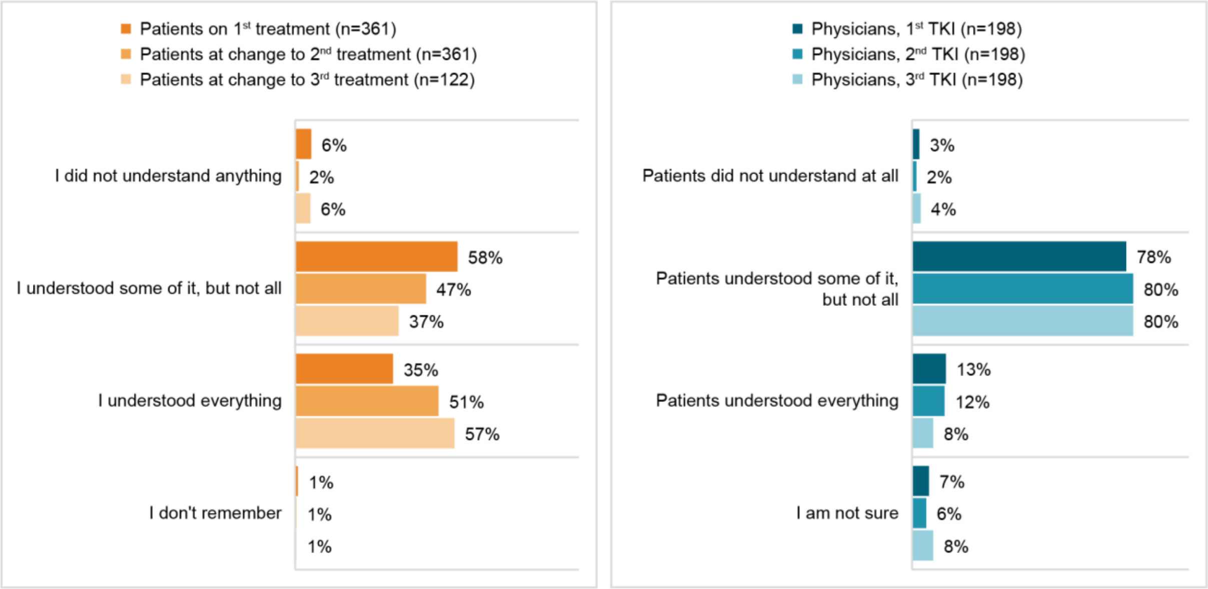
CML, chronic myeloid leukemia; CML-CP chronic myeloid leukemia in chronic phase; SE, side effect.

Figure S3. Patients' understanding of information about treatment. Different levels of patient understanding of treatment information as reported by patients and physicians and assessed by proportions of patients and physicians by sequence of TKIs



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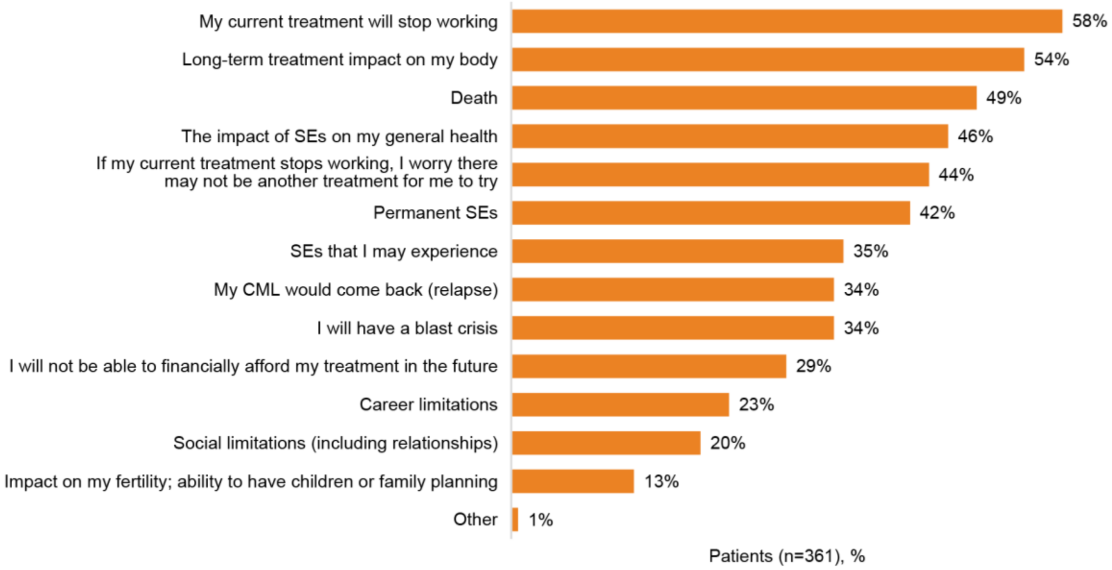
TKI, tyrosine kinase inhibitor.

Figure S4. Patients' fears about CML-CP. Proportions of patients with CML-CP who fear how their disease may impact them.



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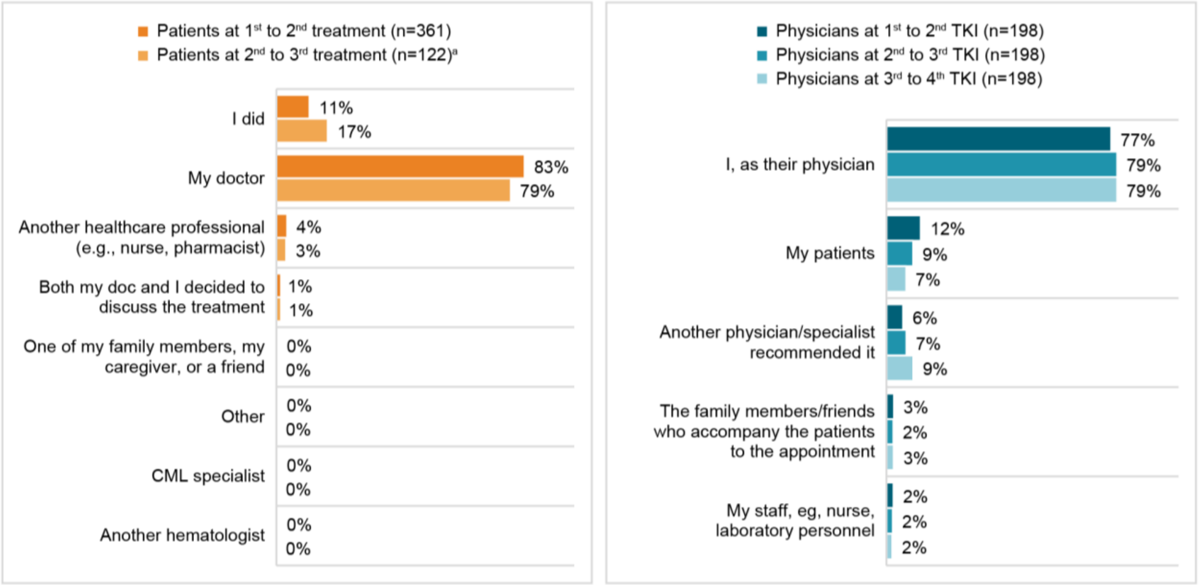
CML, chronic myeloid leukemia; CML-CP, chronic myeloid leukemia in chronic phase; SE, side effect.

Figure S5. Initiation of the discussion on treatment change. Who specifically initiated the discussion on treatment change as reported by patients and physicians, assessed by proportions of patients and physicians by sequence of TKIs.



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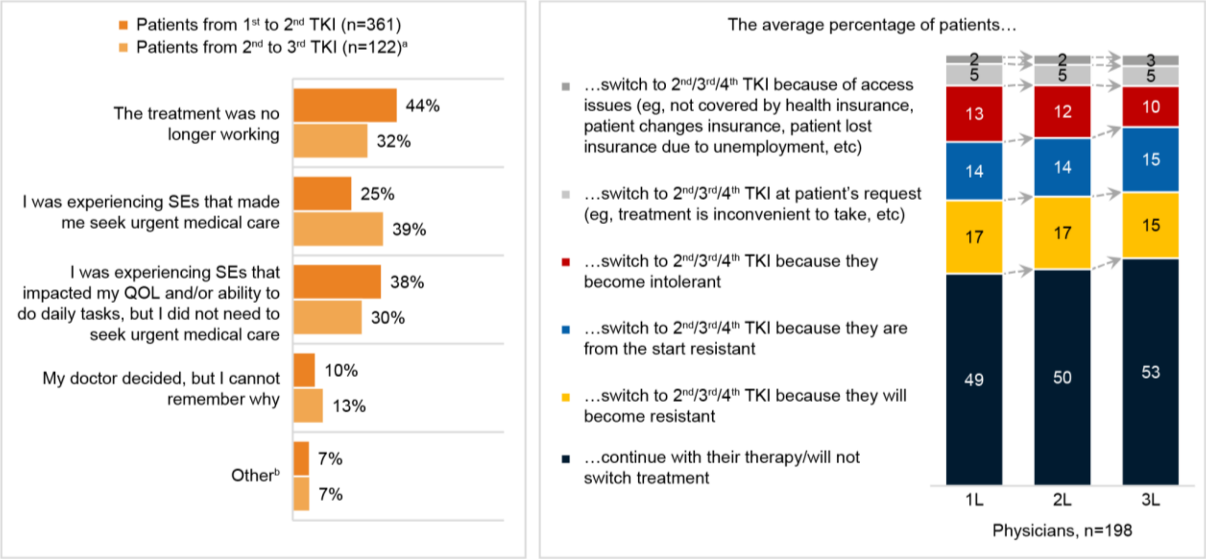
CML, chronic myeloid leukemia; TKI, tyrosine kinase inhibitor.

[a] Included only patients on their third and fourth TKI.

Figure S6. Reasons for switching treatment. Reasons for switching treatment for CML-CP as reported by patients by sequence of TKIs and physicians, assessed by proportions of patients.



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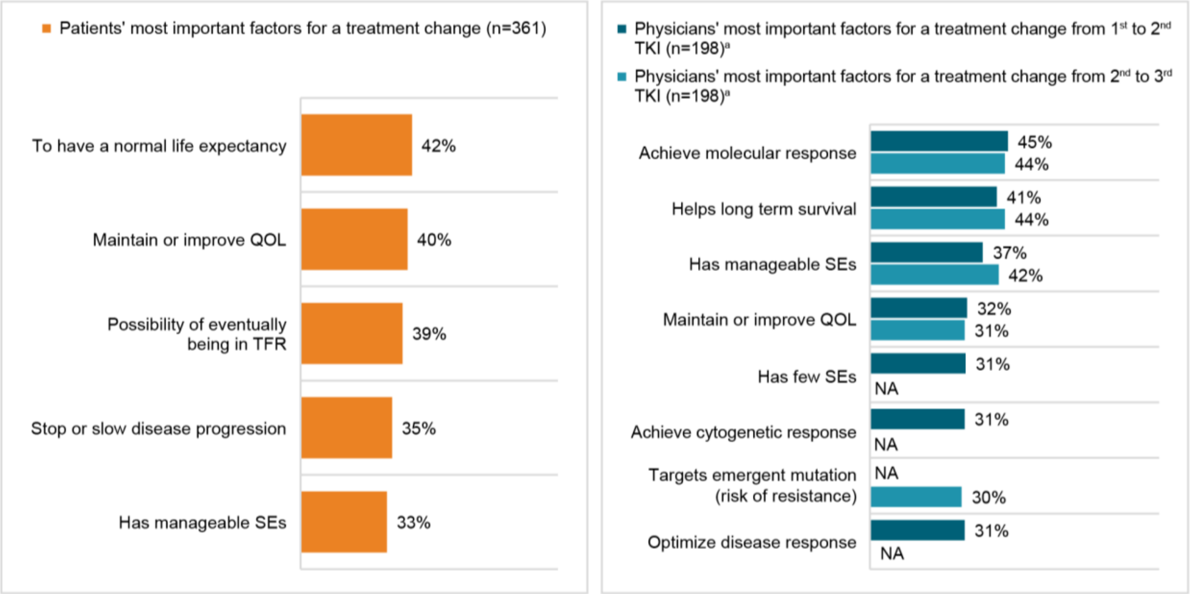
CML-CP, chronic myeloid leukemia in chronic phase; QOL, quality of life; SE, side effect; TKI, tyrosine kinase inhibitor.

[a] Included only patients on their third and fourth TKI. [b] "Other" is a sum of responses to: other, recommended by the doctor, better availability/accessibility, for faster onset of action, increased frequency of administration, poor adherence to treatment, restriction on meal time, based on the guidelines/protocol, I participated in the clinical trial, I wanted to conceive/get pregnant, new treatment option, comorbidities, received funding for the treatment, none, don't know, and refused/no answer.

Figure S7. Top 5 most important factors for patients and physicians when considering a treatment change. Five most important factors to physicians when considering a treatment change, by sequence of TKIs, compared with the 5 most important factors to patients when considering a treatment change, assessed by proportions of physicians and patients.



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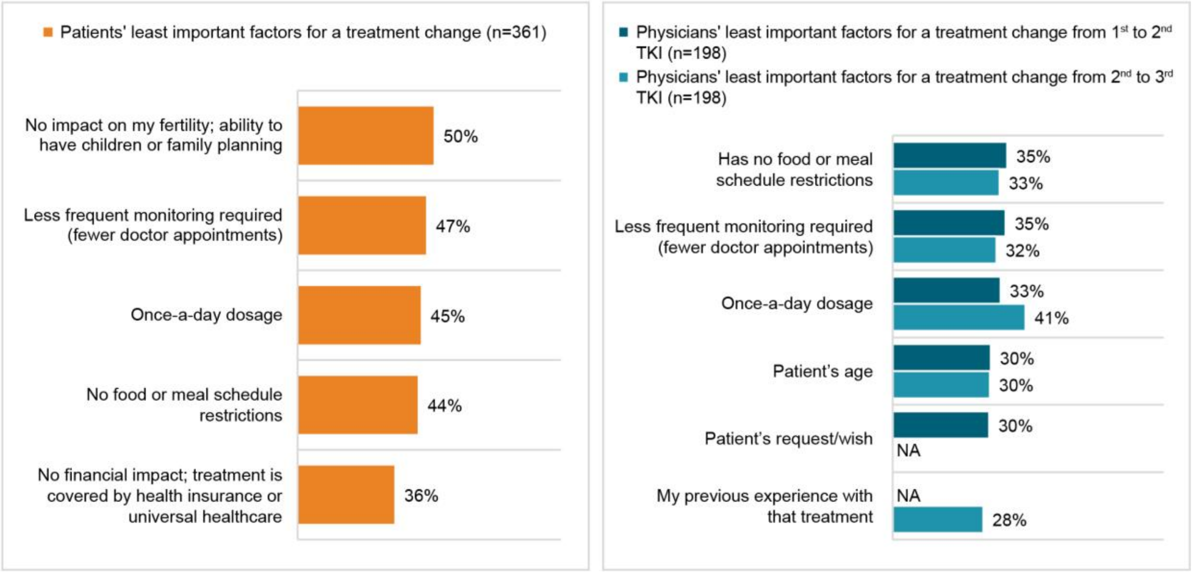
NA, no answer; QOL, quality of life; SE, side effect; TFR, treatment-free remission; TKI, tyrosine kinase inhibitor.

[a] Besides enabling patients to live longer.

Figure S8. Top 5 least important factors for patients and physicians when considering a treatment change. Five least important factors to physicians when considering a treatment change, by sequence of TKIs, compared with the 5 least important factors to patients when considering a treatment change, assessed by proportions of physicians and patients.



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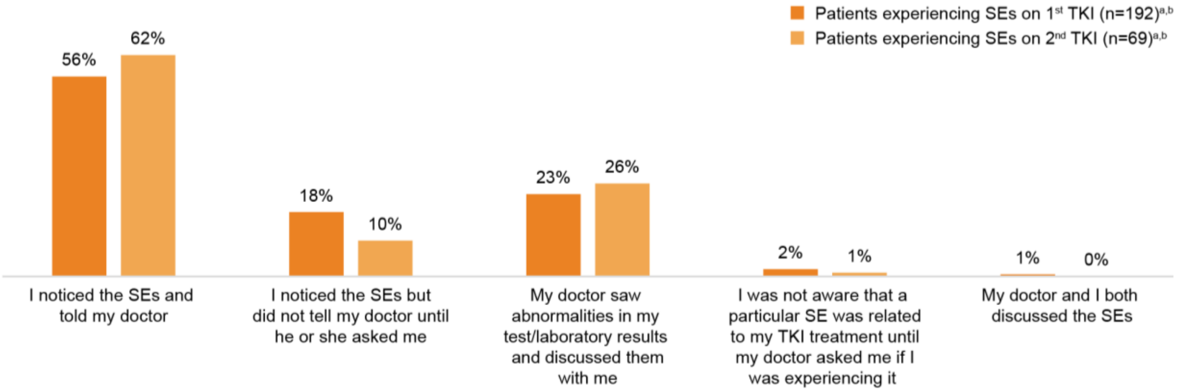
NA, no answer; TKI, tyrosine kinase inhibitor.

Figure S9. Roles in initiating side effect discussions. Different ways that discussions around side effects were initiated as assessed by proportions of patients on first and second TKI therapy.



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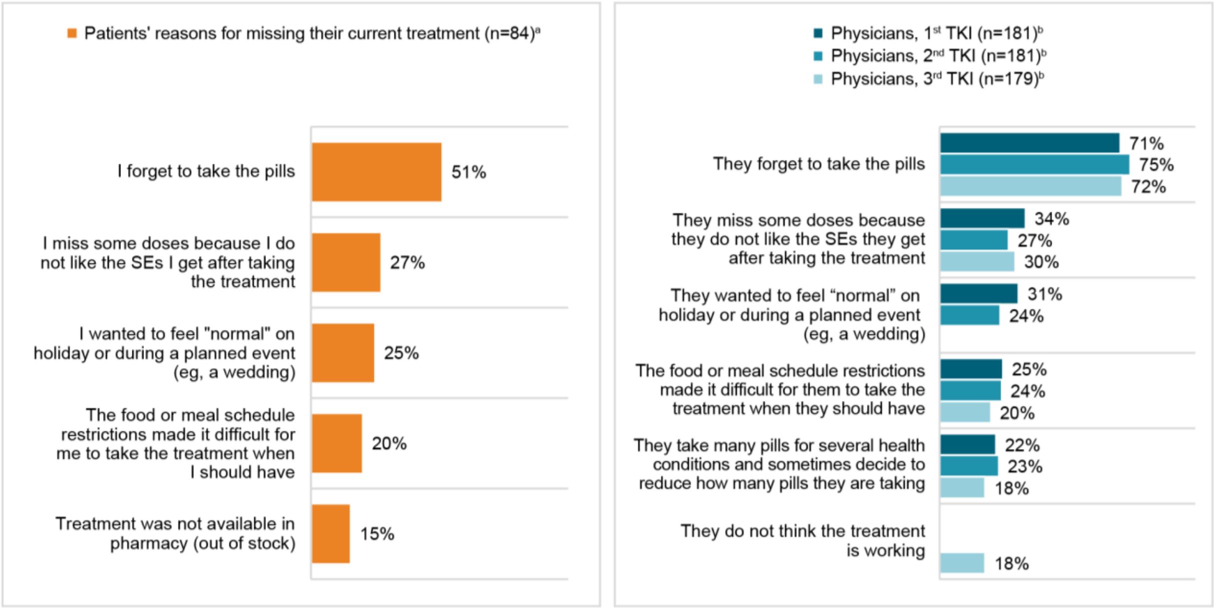
SE, side effect; TKI, tyrosine kinase inhibitor.

[a] Included patients who responded that they switched treatment because of side effects. [b] No patients selected “other”.

Figure S10. Top 5 reasons for missed doses. Top 5 reasons for missed doses from the physician perspective, as assessed by the proportion of physicians by number of TKIs and from the patient perspective, as assessed by the proportion of patients.



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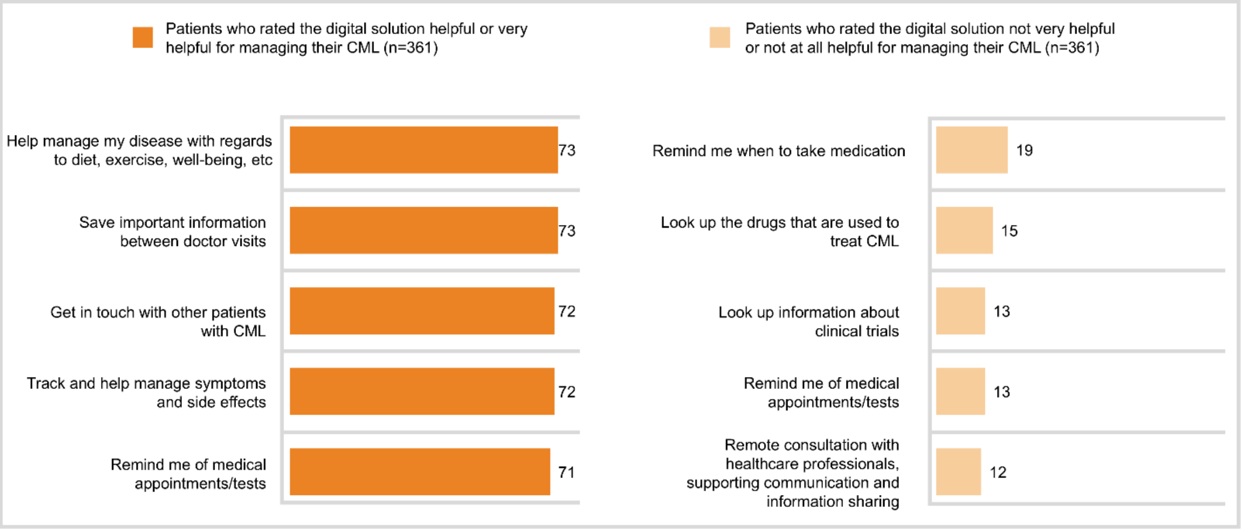
SE, side effect; TKI, tyrosine kinase inhibitor.

[a] Included patients who reported being nonadherent ≥1 time. [b] Included physicians who thought patients may be nonadherent.

Figure S11. Top 5 and bottom 5 digital healthcare solutions for managing CML (patient perspective).



CML, chronic myeloid leukemia.