

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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Abstract

For patients with chronic myeloid leukemia in chronic phase (CML-CP), disease management, treatment experiences, and decisions around switching therapies due to resistance or intolerance can have significant impacts on their lives. Experiences and perspectives regarding the roles of patients and treating physicians in shared decision-making are poorly understood. The CML Survey on Unmet Needs (CML SUN), the largest CML survey to date, was initiated to gather insights from patients with CML-CP and physicians on disease management, including treatment goals, decision-making, satisfaction, tolerability, and the impact of CML on daily life. The survey was deployed in 11 countries with 361 patient and 198 physician participants and comprised separate questionnaires for each group. Results indicated that nearly three-quarters of physicians saw themselves as the ultimate initial treatment decision-makers; only a quarter of patients reported that these decisions were discussed and decided together with their physician. Nearly half of physicians reported making treatment decisions across all lines of therapy with little to no input from the patient. Disparities between patient and physician opinions were observed regarding treatment goals, especially the balance between efficacy and tolerability. The CML SUN highlights the need for improvements in communication about treatment options and the importance of shared treatment decision-making to unify treatment goals.

Introduction

Survival among patients diagnosed with chronic myeloid leukemia in chronic phase (CML-CP) has markedly improved with the use of tyrosine kinase inhibitors (TKI) such that most patients now have a life expectancy close to that of the general population.¹⁻³ Approximately a quarter of patients with CML-CP with prolonged molecular remission are able to successfully discontinue TKI treatment.⁴ However, the majority of patients will require lifelong treatment, which may have a substantial impact on their quality of life (QOL).¹⁻³ Patients report an impact on sleep, memory, mental state, mood, work, general activities, and sexual relations.⁵ When choosing a new therapy, overall patient health, presence of specific comorbidities, treatment goals, and prior ther-

apies (for patients receiving their second or later TKI) are important considerations for both disease control and QOL. Therefore, an optimized patient-physician relationship built on good communication and shared decision-making is an essential part of every patient's journey.⁵ Despite the fact that TKI have been the cornerstone of CML treatment for more than 20 years, starting with the approval of imatinib in 2001 in the USA, there remains a critical gap in understanding the real-world experiences of patients and physicians.⁶ While clinical milestones and molecular response rates are widely studied, the nuances of patient-physician communication, treatment satisfaction, and shared decision-making are often overlooked. These aspects, however, play a fundamental role in adherence, QOL, and long-term treatment success. In recent years,

some studies have sought to gather insights on patient experience and treatment goals.^{5,7} A 2020 synthesis of qualitative studies reported that CML patients receiving a TKI experience significant treatment-related side effects and alterations to their mental and physical wellness.⁷ In addition, this study noted that patients may not have received sufficient information about their disease and may feel unprepared to participate in treatment decisions.⁷ Another study reported low levels of treatment satisfaction, specifically around eliminating CML, preventing its recurrence, and returning to a normal life, which is particularly important given the relationship between satisfaction, QOL, and treatment adherence.⁵ These earlier studies, although valuable, were limited by their inclusion of only a few countries and their focus primarily on the patients' perspective without a comparison with that of the treating physicians.^{5,7} With the increasing prevalence of CML, there is a need for more data on both patient and physician perspectives of the respective priorities in CML management to enable a unified understanding of factors impacting adherence, QOL, and optimal disease outcomes. To address these knowledge gaps, the Chronic Myeloid Leukemia Survey on Unmet Needs (CML SUN) was conducted.

Methods

The CML SUN used a mixed-methods research approach with an exploratory sequential design in which a qualitative phase was followed by a quantitative phase. Data analysis and integration of patient and physician responses were conducted after each phase (*Online Supplementary Figure S1*). An external steering committee composed of physicians and advocates of patients with CML provided guidance throughout the research and input into the fieldwork material. Findings from the qualitative phase have been previously reported in abstract form⁸ and the results from the quantitative phase are reported here.

Qualitative interviews and quantitative surveys

Qualitative interviews were conducted using semi-structured discussion guides developed from an assessment of patient-focused literature in CML as well as the collective insights of patients with CML, patient advocates, and treating physicians involved in the research.⁸

In the quantitative phase, the results of the qualitative interviews were used to inform topics and questions for the quantitative online surveys. Further details on the qualitative and quantitative assessments are described in the *Online Supplementary Methods*.

Cognitive testing

Cognitive testing was performed to minimize ambiguity and ensure that respondents understood the survey questions and response options, recalled the information being

asked, did not miss any important questions or response options, and did not become overwhelmed. A sample of target respondents completed cognitive testing via video conferencing with screen-sharing prior to deployment of the online surveys. Target respondents were six patients and three physicians in the USA, Canada, and the UK who met the inclusion criteria for survey participation (*Online Supplementary Table S1*). Results of cognitive interviews were analyzed by the research team, and the feedback was used to adapt the survey content. The revised surveys were shared with the steering committee before survey implementation.

Recruitment

The target population for CML SUN were patients with CML-CP and physicians who treated patients with CML. Eligibility criteria are described in *Online Supplementary Table S1*. Patients were recruited through patient databases, physician and nurse referrals, and patient advocacy groups. Physicians were recruited via online physician panels. In appreciation for their time, patients and physicians were offered compensation in line with fair market value, including options to donate to an international patient organization or decline compensation.

Analysis

For analysis of the qualitative and quantitative data, transcripts and descriptive statistics were used, respectively. Continuous variables were summarized using means and medians. Reported results were derived from the survey questions described in the *Online Supplementary Methods*.

Ethics

Answers from both patients and physicians were anonymized to ensure confidentiality and avoid bias during data collection and analysis. The surveys conducted were reviewed by a central Institutional Review Board (IRB). Two exemptions (one for the qualitative phase and one for the quantitative phase) were granted by Pearl IRB. Eligible respondents gave electronic informed consent prior to participation. CML SUN was conducted in accordance with the Declaration of Helsinki and all standards of Good Clinical Practice (GCP), as well as US-healthcare personal data protection law (HIPAA, Health Insurance Portability and Accountability Act), and European laws and regulations (GDPR, General Data Protection Regulation).

Results

A total of 361 patients with CML-CP and 198 physicians in 11 countries participated in the online survey from November 2022 to March 2023 (*Online Supplementary Table S2*). Patients had a median age of 45 years (range, 19–82 years), most (66%) were on their second TKI, and 56% were female

(*Online Supplementary Table S3*). Patients reported public insurance only (33%) or public insurance plus private supplementary insurance (27%), with 17% of patients reporting private insurance coverage only (*Online Supplementary Table S3*). Physicians had been in practice a median of 18 years (range, 3–31 years) and spent a median of 90% of their time caring for patients. Most physician respondents (59%) practiced at university teaching hospitals, 17% practiced at community or general hospitals, 15% practiced at dedicated cancer centers, 8% were in solo or group practice, and 1% practiced in a general hospital. Half of their patients were currently receiving their first TKI, while the other half were receiving their second or later TKI (*Online Supplementary Table S3*).

Information sharing at diagnosis

The top three areas of information patients wanted to receive at diagnosis were: (i) potential side effects of treatment; (ii) how the disease would progress and impact their life; and (iii) the CML treatment that would be given to them, what it would be, how it should be taken, and what to expect from it (*Online Supplementary Figure S2*). Approximately 70% of physicians reported providing information on these topics but only about half of patients reported receiving all the information they needed, and a third wished they had received more information at diagnosis.

Information sharing at switching treatment

Patients switching treatments similarly wanted information about potential side effects and how to manage them, as well as how to understand test results, available treatment options, and how to contact their care team. However, only about 60% of physicians reported offering information on management of potential side effects and reasons for treatment switching. Only half of physicians reported providing information specifically about what to do if patients experienced intolerable side effects and only 36% provided a way to contact the care team if the patient had any questions. Approximately a third reported providing information on other treatment options in case the second treatment was not successful and only 29% reported providing patients with information on how to understand their test results.

Treatment goals

Although patients and physicians were generally aligned on the importance of having manageable side effects and maintaining or improving QOL, physicians ranked achievement of major molecular response and deep molecular response higher than patients, regardless of the number of prior TKI the patients had received (Figure 1).

Shared treatment decision-making

Patients reported that they wanted to receive information about treatment options at diagnosis and if a treatment

switch was needed (*Online Supplementary Figure S2*), but approximately 40% reported receiving information about only one TKI from their physician regardless of number of prior TKI. Furthermore, only about 25% of patients felt that treatment decisions were discussed and decided on together with their physicians (Figure 2).

Most physicians thought that patients should be more involved in treatment decisions and reported that their patients have an active role in determining their treatment; most (74%) saw themselves as the ultimate decision-maker (Figure 3). Approximately half reported making treatment decisions with little to no input from the patient (Figure 2). Regardless of number of prior TKI, more than half of physicians reported presenting only one treatment option, mostly to avoid overwhelming patients and/or because they felt that the patients may not understand all the details and thus could not make an informed decision (Figure 4). Physicians perceived that less than a quarter of patients understood information they were given; in contrast, most patients report understanding all the information they received (*Online Supplementary Figure S3*).

Burden of disease: patient perspective

While most patients were satisfied with current treatments (Figure 3), many reported that the diagnosis and treatment caused worry and stress, and made them physically and emotionally fatigued, thus limiting their personal and social lives and adversely affecting their QOL (Figure 5). Some patients expressed dissatisfaction with the impact of side effects on their finances and occupational, social, and educational lives (Figure 6). The top patient fears were that their treatment would stop working, have a long-term impact on their body, or produce side effects (*Online Supplementary Figure S4*).

Treatment switching

When asked who initiated discussions of treatment change, patients and physicians agreed that physicians usually initiated the discussion (*Online Supplementary Figure S5*). Lack of efficacy and intolerance were reported by both groups as the most common reasons for treatment switching (*Online Supplementary Figure S6*). The most important factors for patients when considering a treatment change were to have a normal life expectancy and maintain or improve QOL, while achieving molecular response, helping long-term survival, and having manageable side effects were the most important factors for physicians. Treatment logistics were among the least important factors for both patients and physicians (*Online Supplementary Figures S7 and S8*).

Side effects

When asked who initiated the discussions around side effects, up to one in five patients reported that they noticed side effects but did not tell their doctor unless specifically asked (*Online Supplementary Figure S9*). Patients were al-

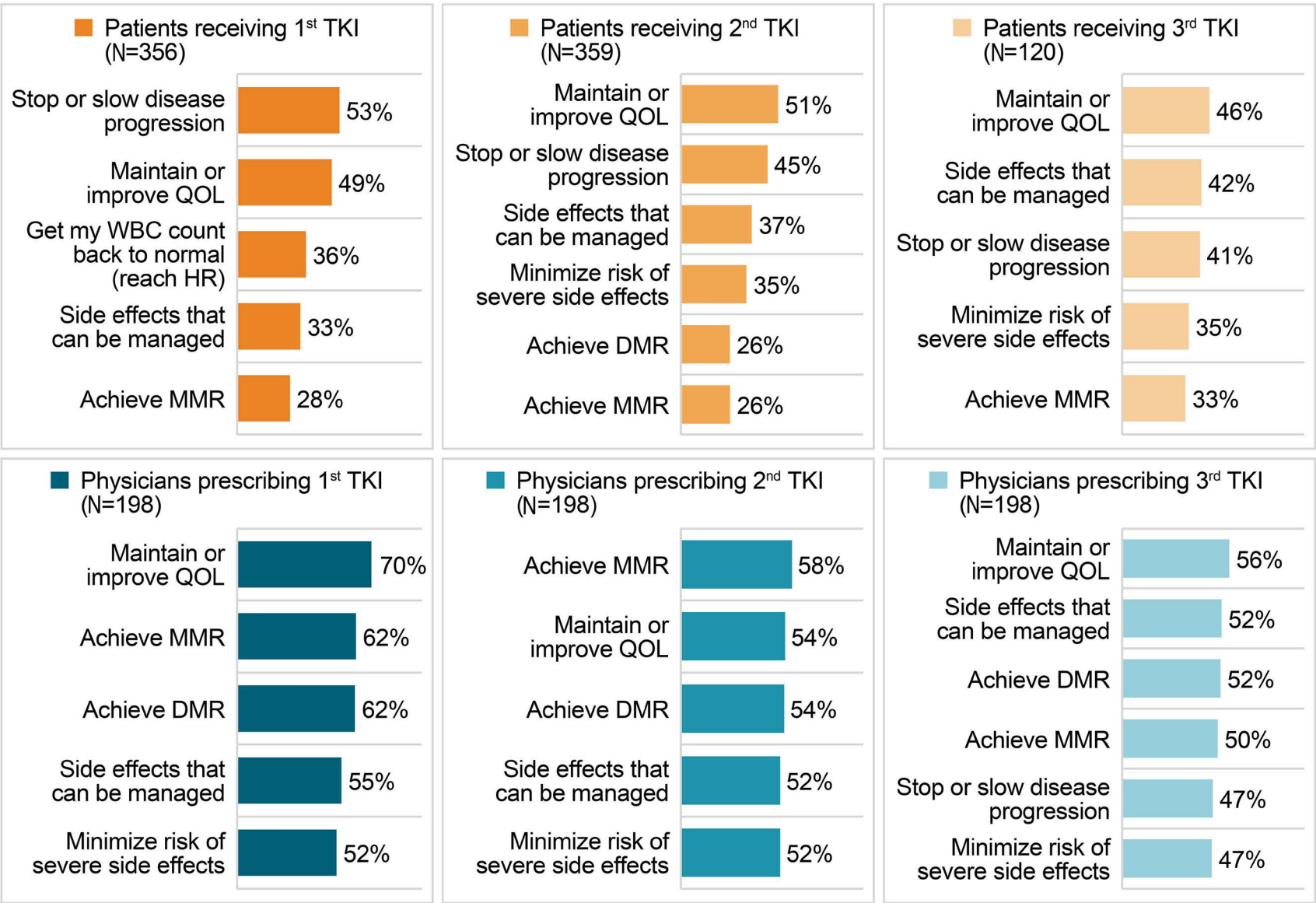


Figure 1. Top five treatment goals by number of tyrosine kinase inhibitors. Top treatment goals of patients and physicians by number of tyrosine kinase inhibitors (TKI). Patients ranked their three most important treatment goals by number of prior TKI; physicians selected any goals that they had by number of prior TKI. Lang F, et al. Presented at the European Hematology Association 2023 Hybrid Congress. Poster 668. Reprinted with permission from the author. QOL: quality of life; WBC: white blood cell; HR: hematologic response; MMR: major molecular response; DMR: deep molecular response.

so asked what their doctor did when they informed them of side effects (Figure 7). Notably, less than half reported feeling empathy from their physician and only a third of patients reported being given medication to manage side effects. About 20% of patients reported that their physician did not think that their side effects were serious and expected them to continue their current therapy.

Adherence

Both patients and physicians reported forgetfulness and side effects as the primary reasons for missed doses (*Online Supplementary Figure S10*).

Digital healthcare solutions for managing chronic myeloid leukemia

Patients ranked the most helpful digital tools to assist with managing CML as digital solutions to aid their diet, exercise, and well-being (73%), save important information between clinical visits (73%), get in touch with other patients with CML (72%), track and help manage symp-

toms and side effects (72%), and remind them of medical appointments/tests (71%) (*Online Supplementary Figure S11*). Patients ranked the least helpful digital tools as those which remind them when to take medication (19%), look up the drugs that are used to treat CML (15%), look up information about clinical trials (13%), remind them of medical appointments/tests (13%), and remote consultation with healthcare professionals, supporting communication and information sharing (12%) (*Online Supplementary Figure S11*).

Discussion

This study underscores the need to re-evaluate how treatment success is defined – not solely through molecular response, but also through patient-centered measures such as QOL, treatment burden, and informed decision-making. The disconnect between physician and patient priorities has profound implications for treatment adherence and long-term outcomes, highlighting areas that could inform

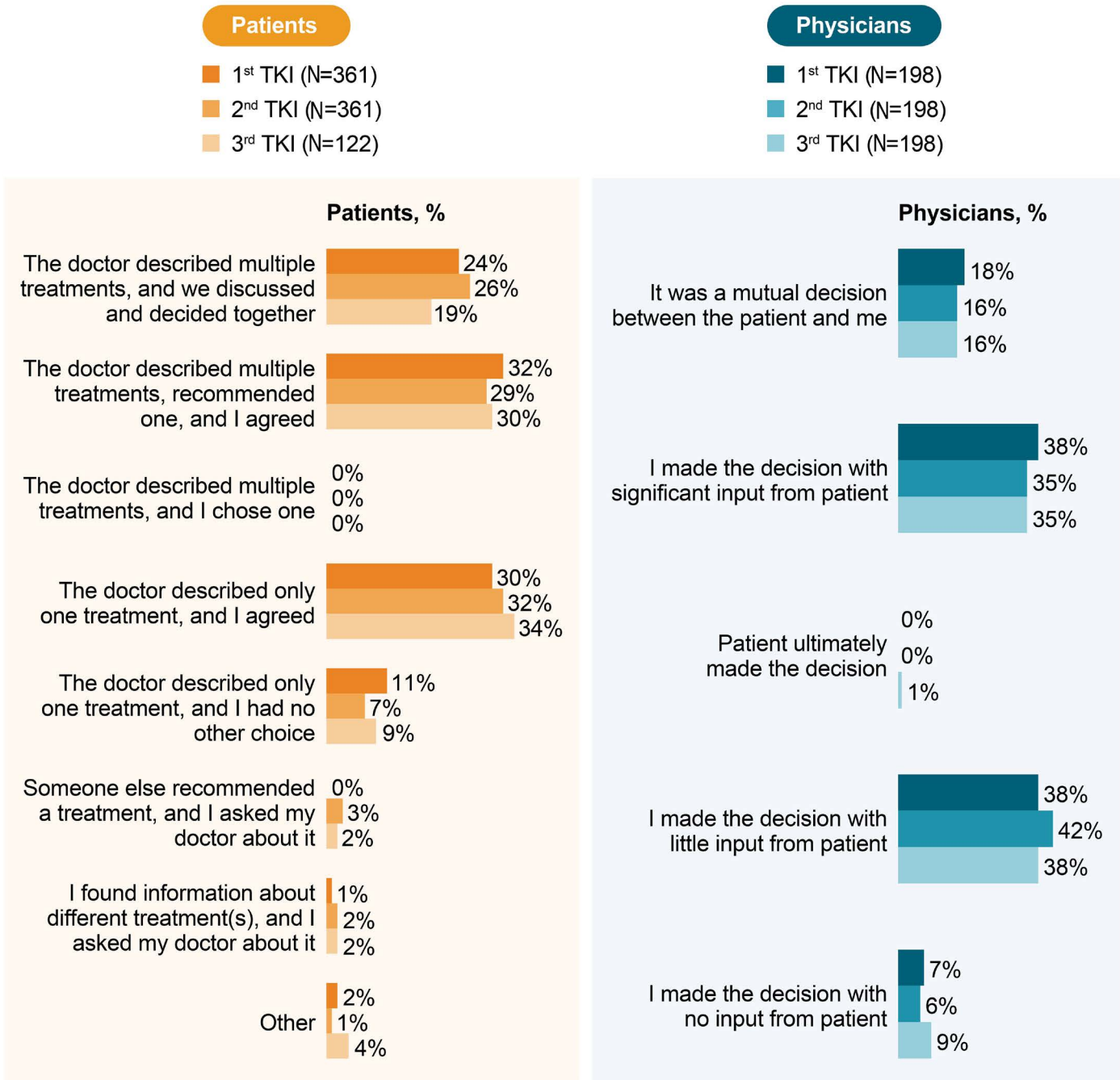


Figure 2. Patient and physician input on treatment selection. Roles in treatment decision-making as assessed by proportion of patients and physicians by number of tyrosine kinase inhibitors. Lang F, et al. Presented at the European Hematology Association 2023 Hybrid Congress. Poster 668. Reprinted with permission from the author. TKI: tyrosine kinase inhibitor.

future improvements in clinical practice and patient care. While the results underscore some disparities in prioritization and communication, they also reveal opportunities to enhance shared decision-making and align treatment goals more effectively. As the medical community continues to advance CML treatment options, optimizing patient-physician communication and ensuring alignment in treatment expectations are equally critical.

One key finding was the perception by patients of their physician’s recognition of side effects and their impact on QOL. Approximately one in five patients did not tell their doctor about side effects unless specifically asked. Less than half felt their doctor showed empathy and asked sufficient questions about side effects. This is consistent with other studies indicating that physicians tend to underestimate the symptoms experienced by patients.⁹ Unlike safety, which is based on the physician’s judgment,¹⁰ tolerability reflects the extent to which adverse events affect the ability or

desire of patients to adhere to therapy.¹¹ Noting that side effects were a main factor influencing adherence, a failure of communication may lead to suboptimal treatment outcomes. Hence, this study suggests that an environment in which the patient feels comfortable in discussing treatment and their doctor routinely initiates such discussion and takes their concerns seriously is not always the case but should be the aim in all such interactions. This communication deficiency could be addressed by pharmacy teams, teaching and involvement of advanced practitioners, and defined roles for nursing in the follow-up process, which have been shown to foster greater identification of QOL changes and low-grade side effects among varied patient populations.¹²⁻¹⁴

Patients placed more emphasis on stopping/slowing disease progression and physicians placed greater emphasis on achievement of molecular responses. Similarly, achieving normal life expectancy was the predominant factor for

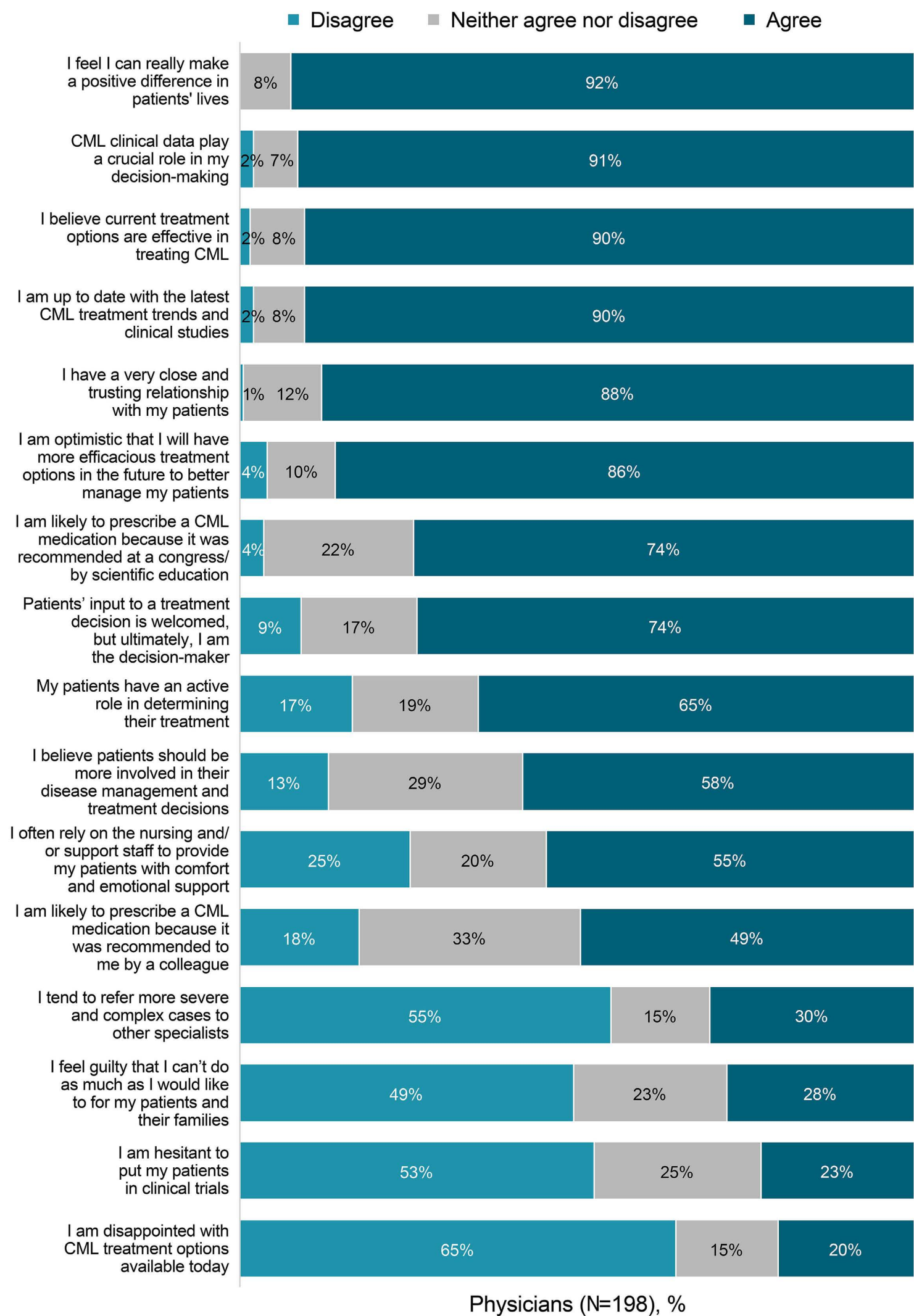


Figure 3. Physicians’ perspectives regarding different management of chronic phase chronic myeloid leukemia. Physicians ranked items on a scale of 1 to 7, where 1 means strongly disagree and 7 means strongly agree (disagree, 1-3; neither agree nor disagree, 4; agree, 5-7). Lang F, et al. Presented at the European Hematology Association 2023 Hybrid Congress. Poster 668. Reprinted with permission from the author. CML: chronic myeloid leukemia.

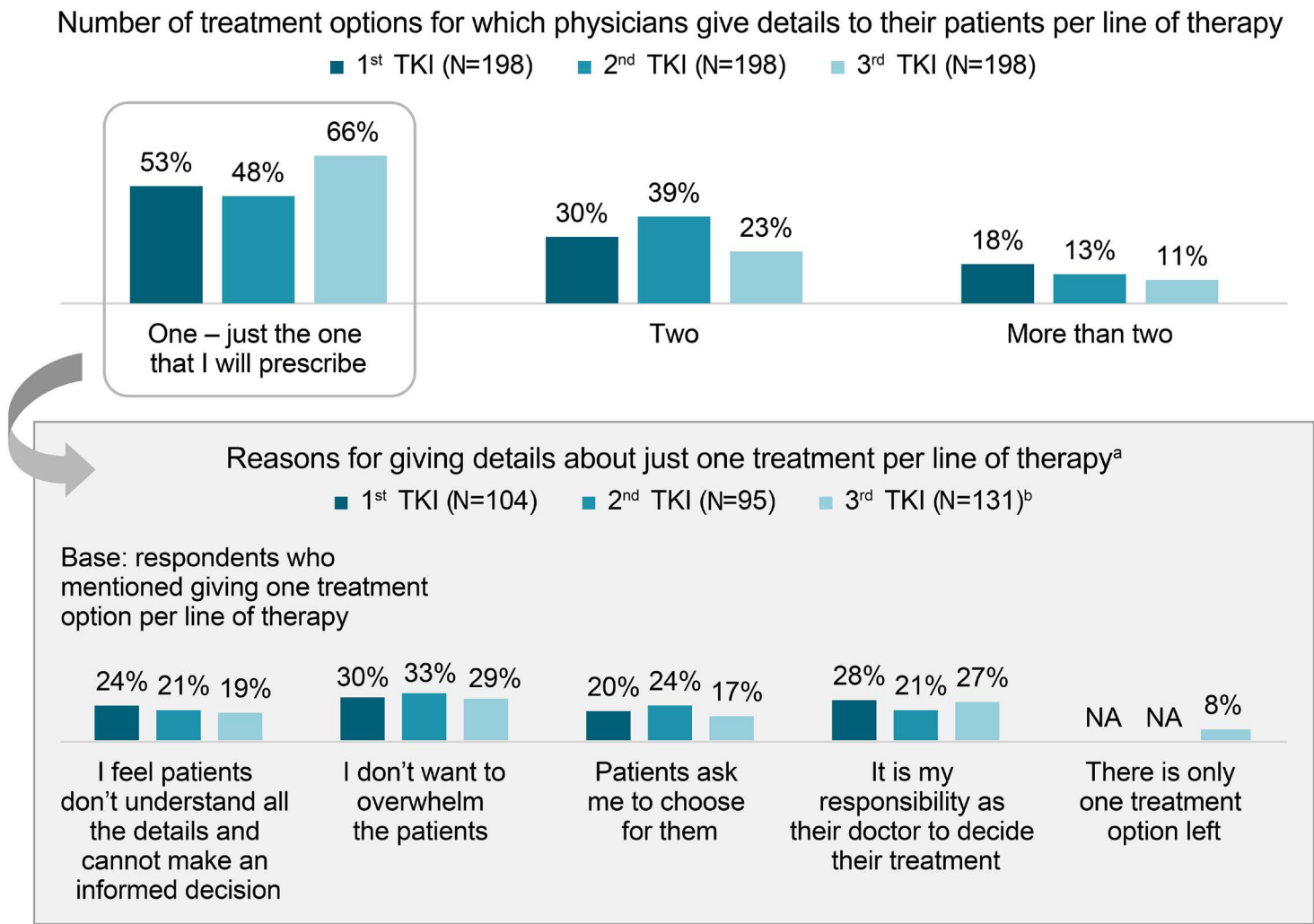


Figure 4. Number of treatment options presented to patients by physicians. The number of treatment options for which physicians give details and the reasons for giving details about just one treatment, as assessed by the proportion of physicians by number of tyrosine kinase inhibitors (TKI). ^aLess than 5% of respondents chose the responses regardless of number of TKI: other (reason not listed as an option) provided just the details of the treatments available for a given number of TKI, and provided just the details of the treatments available as per the guidelines/protocols. ^bBase: respondents who mentioned giving one treatment option per number of TKI. Lang F, et al. Presented at the European Hematology Association 2023 Hybrid Congress. Poster 668. Reprinted with permission from the author. NA: no answer.

patients when considering a treatment switch, whereas for physicians it was molecular response. However, this may not represent misalignment of treatment goals in all instances, as physicians may view molecular response as a surrogate marker for reduced risk of disease progression. While these perspectives suggest a shared overarching goal, patient education around the importance of molecular response milestones¹⁵ can be improved and may lead to better adherence and foster a stronger alignment between clinical objectives and patient understanding. The findings also highlight gaps in the information exchange at critical points in the treatment journey. About 70% of physicians reported providing information on topics ranked by patients as most important to receive at diagnosis. However, despite physicians' reported efforts to provide key information, many patients indicated unmet informational needs, particularly regarding treatment options, side effect management, and strategies for handling treatment transitions. Addressing these gaps could improve patient empowerment and satisfaction. Tailoring informational resources to individual preferences and different literacy levels and integrating tools such as visual aids or decision

support systems may help bridge this gap and improve patient engagement. Indeed, the CML SUN found that a digital tool to track medical appointments and tests was ranked as helpful or very helpful by 71% of patients – placing it in the top five tools – yet 13% rated it not very helpful or not at all helpful, placing it simultaneously among the bottom five. This variability highlights that a one-size-fits-all approach may fall short in meeting patients' diverse informational needs. Another key insight is the disparity in perceptions of treatment decision-making. Most physicians agreed with the statement that while patient input is valued, the responsibility of the final decision ultimately lies with physicians. However, patients expressed a desire for more involvement in these decisions. This disconnect may stem from physicians underestimating patients' capacity to understand treatment details even though more than half of patients surveyed reported understanding all the information they received. While the level of understanding may depend on both the complexity of the information provided and the way it is presented, physician perception of a lack of patient understanding might be a limiting factor in involving

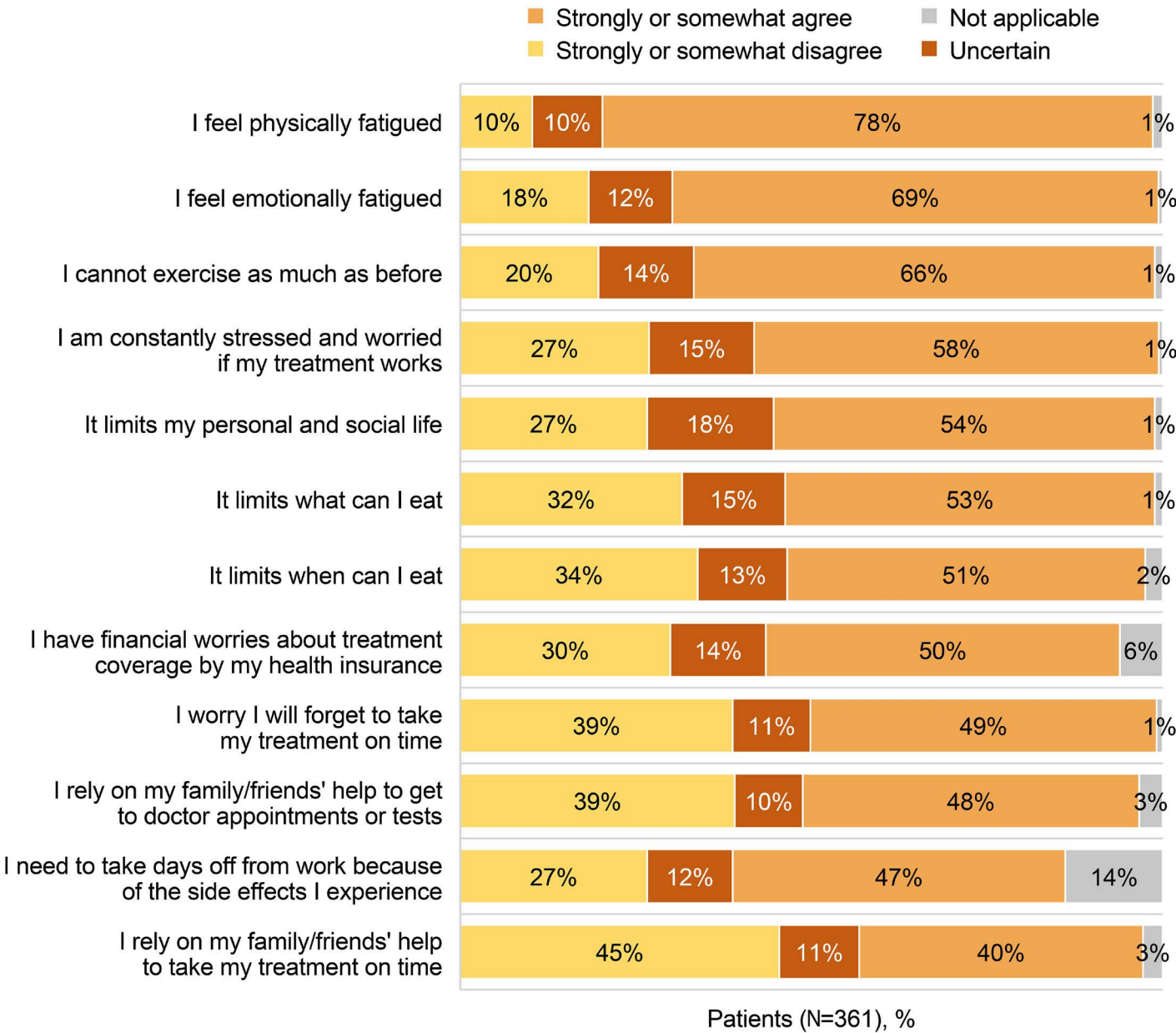


Figure 5. Patients’ perceptions of how treatment of chronic phase chronic myeloid leukemia affects their lives. Patients were asked how much they agreed with statements around how their current tyrosine kinase inhibitor treatment impacted their lives and answered from the following choices: strongly or somewhat agree, strongly or somewhat disagree, uncertain, or not applicable. Lang F, et al. Presented at the European Hematology Association 2023 Hybrid Congress. Poster 668. Reprinted with permission from the author.

patients in decision-making and may create a new communication gap or widen an existing one. Each patient has a different level of motivation and comprehension when it comes to disease awareness and treatment decisions, and physicians must take this into account during patient interactions as well. For example, some patients come to their physician with preconceived notions based on their own research, which may influence the treatment decision. Thus, there is a need for balanced and inclusive discussions to address the gap between patient expectations and professional medical advice, and for tailored patient education and support to ensure that patients feel heard and involved in informed decision-making. Results from this study support the findings of prior patient-focused research, including the negative impact of treatment on QOL and adherence, and a need for better patient-physician communication and understanding of patient-specific goals.^{5,7} Previous surveys generally included smaller samples, primarily captured patients’ views, and

were focused on individual countries or a small number of countries. The CML SUN study expands on these findings, including not only more patients from more countries but also bringing the physicians’ perspectives to provide a more holistic view.^{5,7} Limitations of this study include the potential for recall and selection bias. Some responses may have been affected by limited recall and/or influenced by more recent experiences, such as first-line insights and motivations for treatment selection at diagnosis. Although we aimed for as diverse patient recruitment channels as possible via physicians/nurses, patient organizations, and online patient panels, the voluntary nature of the surveys may have resulted in self-selection bias, possibly leading to a higher level of both patient involvement and motivation in the study population. Patients who volunteered to participate were likely to have greater health literacy and be more active in the management of their CML than the general population of patients with CML. Physicians, in contrast, may have been alluding

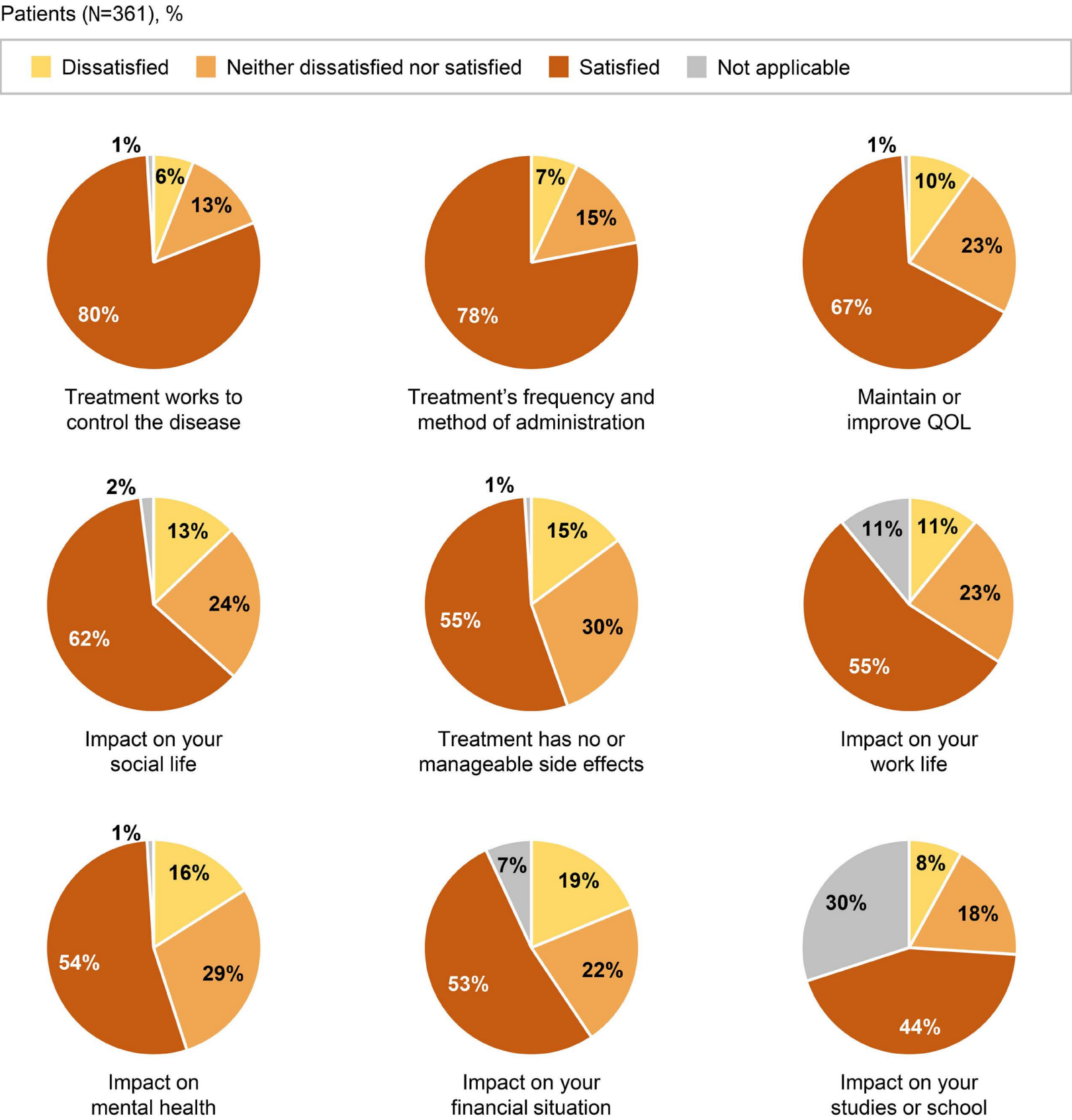


Figure 6. Patients' satisfaction with their current treatment. Patients ranked items on a scale of 1 to 10, where 0 to 3 is dissatisfied, 4 to 6 is neither dissatisfied nor satisfied, and 7 to 10 is satisfied. Lang F, et al. Presented at the European Hematology Association 2023 Hybrid Congress. Poster 668. Reprinted with permission from the author. QOL: quality of life.

to a more diverse patient population when reflecting about their experience and thoughts. Indeed, practice setting (e.g., university teaching hospital vs. community cancer center) and volume of patients with CML treated may also influence physicians' perspectives and impact findings. Additionally, the surveys were conducted independently among two distinct groups – patients and physicians – rather than pairing the responses of individual patients with their treating physicians, which may limit the depth of potential conclusions. Furthermore, stratification by geographic area

(including regional restrictions and regulatory differences), communication culture and expectations, and healthcare systems may reveal region-specific trends and shed light on how such factors influence patient-physician dynamics. This is particularly relevant when considering disparities in treatment access and physician expertise driven by the factors outlined above. In conclusion, this study underscores the critical role of effective communication and shared decision-making in CML management. Specifically, there is a perceived need by

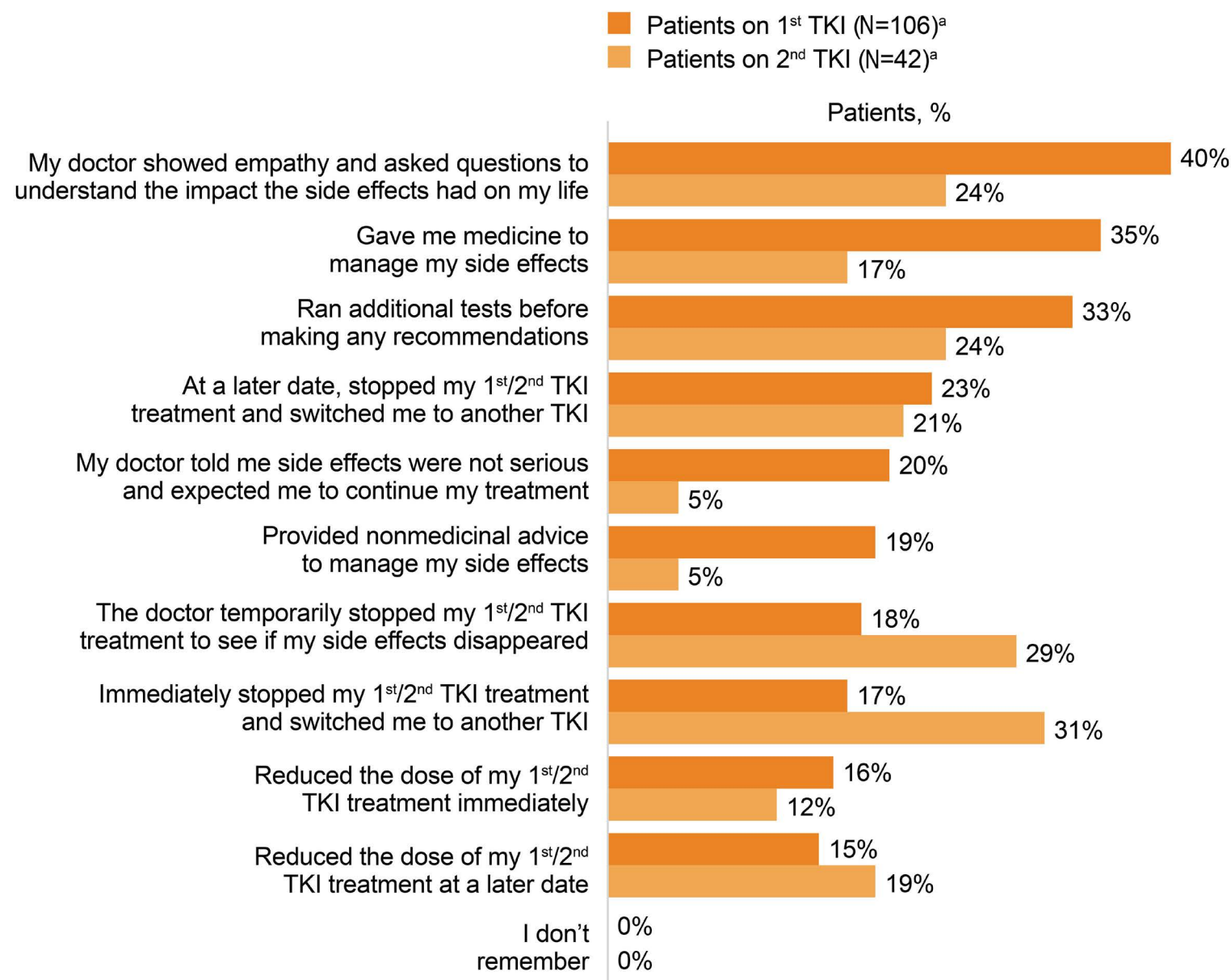


Figure 7. Response of physicians to side effects from the patient perspective. Proportion of patients with different responses from their physicians about side effects when recalling side effects on their first and second tyrosine kinase inhibitor. ^aIncludes patients who switched treatment because of side effects and reported informing their physician about their side effects. Lang F, et al. Presented at the European Hematology Association 2023 Hybrid Congress. Poster 668. Reprinted with permission from the author. TKI: tyrosine kinase inhibitor.

patients for greater involvement in treatment decisions and more empathy in dealing with both specific side effects of treatment and other effects of the CML diagnosis on their QOL and financial security. The likely outcome is that this will enhance decision-making about the most appropriate and optimal TKI at the start of therapy and at the time of treatment switch due to resistance or intolerance, while also enhancing adherence and ultimately improving outcomes. By addressing the informational and relational gaps identified, patients and physicians can collaborate more effectively to optimize treatment success. These findings emphasize the need for a patient-centered approach that balances safety and efficacy goals while fostering mutual understanding, such as a care team or specialist nurses for more thorough follow-up and patient-friendly educational material. For instance, specialist nurse programs have been shown to reduce emergency admissions and improve outcomes significantly in diverse clinical settings.^{12,13} Similarly, the use of patient-friendly educational material, including digital tools, has been associated with

improved treatment adherence, satisfaction, and clinical outcomes across multiple disease areas.^{16,17} The results of the CML SUN can also be used by healthcare institutions, patient advocacy groups, industry leaders, and other key stakeholders in CML-CP management to achieve better outcomes through shared decision-making.

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Contributions

FL, ZP-W, JC, CR, DR, LM, NT, S-HM, AG, CBor, PS, CBoq and JEC provided comprehensive and editorial assistance with this manuscript. In addition to editorial support, CC and PF provided key information related to ethical considerations and assisted with developing study methodology and data analysis. All authors critically reviewed and approved this manuscript.

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Data-sharing statement

Novartis is committed to sharing with qualified external researchers access to patient-level data and supporting clinical documents from eligible studies. These requests are reviewed and approved by an independent review panel on the basis of scientific merit. All data provided are anonymized to respect the privacy of patients who participated in the study in line with applicable laws and regulations. The criteria and process for accessing the data of this study are described on www.clinicalstudydatarequest.com.

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