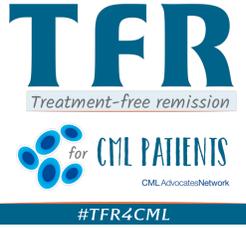




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Chronic Myeloid Leukemia Patients' Concerns during Phase I of the Treatment-Free Remission Journey:

Considerations Between Patients and Doctors in the Different CML Advocates Network Regions.

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ABSTRACT

While Treatment-Free Remission (TFR) is now an emerging treatment goal for many Chronic Myeloid Leukemia (CML) patients, much is still unknown about the experiences of those considering and undertaking TFR.

AIMS

We sought to obtain quantitative evidence of patient experience that has previously only been anecdotal along all phases of the TFR journey (Figure 1) and to identify areas of unmet needs.

METHOD

A global online survey was conducted, recruiting patients through CML patient associations.

The questionnaire was designed by an expert panel of CML patients. Once the question set was agreed, the questionnaire went through two rounds of testing by volunteers.

This exercise contributed towards refining the questionnaire into a finished version. The questionnaire was translated into eleven languages. Fieldwork lasted 20 weeks.

60% (n=606) of respondents discussed risks of stopping; 50% (n=513) discussed the requirements to be met in order to stop; 48% (n=490) discussed the benefits of stopping; 34% (n=346) discussed the timing of when to stop; 21% (n=215) discussed the drug withdrawal symptoms. 14% (n=143) did not have a discussion with their doctor. (Figure 3).

When respondents (n=1016) were asked about which topics still concerned them following their discussion with the doctor, 55% n=555 answered the recurrence of disease but just 19% n=198 answered the frequency of doing PCR tests after stopping. (Figure 4).

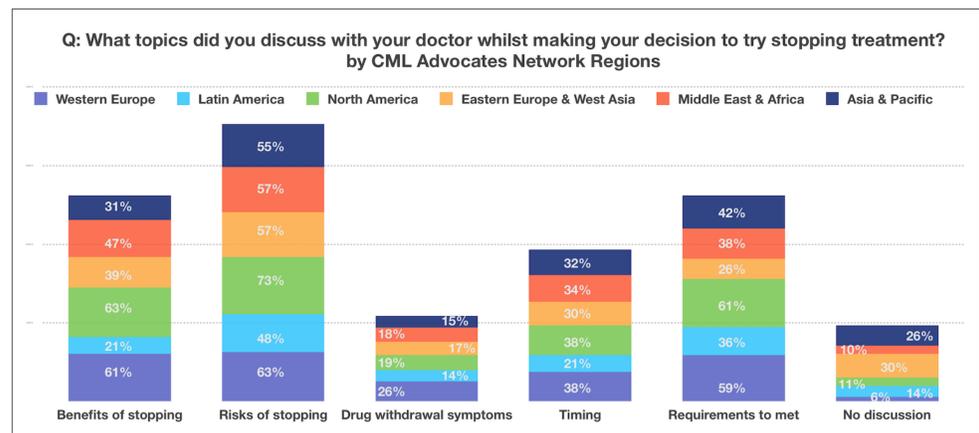


Figure 3

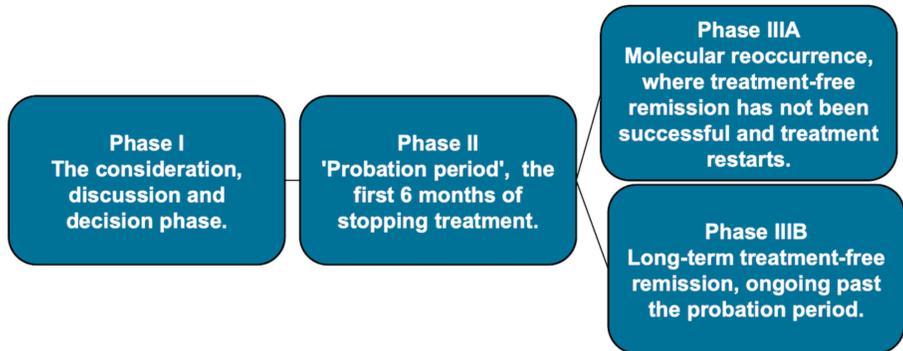


Figure 1

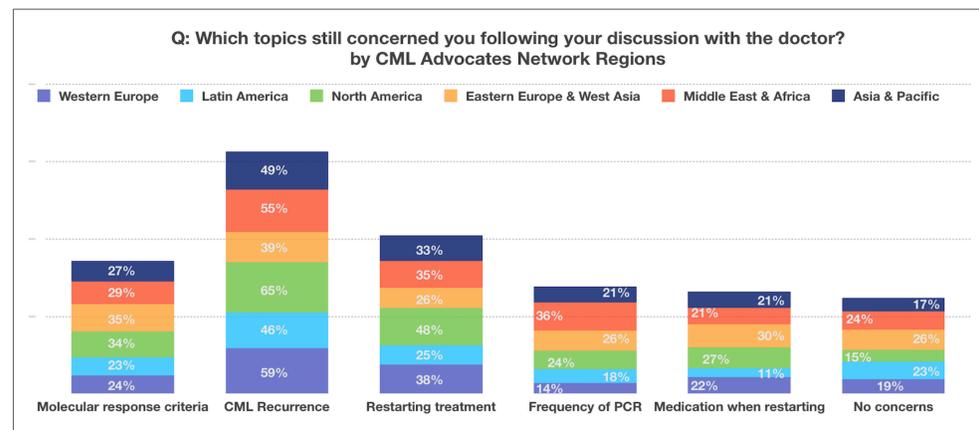


Figure 4

RESULTS

A total of 1016 responses were collected from CML patients across 68 countries (Figure 2).

The majority of respondents reported first hearing about the possibility of stopping treatment through a healthcare professional 49% (n=476).

Respondents were asked what topics they discussed with their doctor whilst making their decision to try stopping treatment.

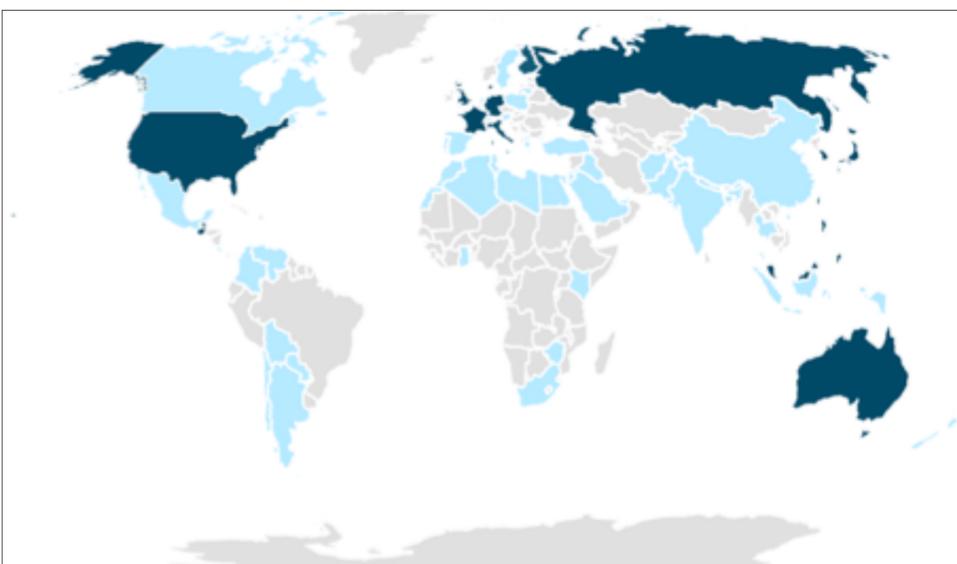


Figure 2

CONCLUSIONS

Risks of stopping treatment was the most discussed topic between patients and doctors however a low percentage of patients discussed withdrawal symptoms with their physicians.

The topic that most concerned patients after discussing with the doctor is the recurrence of the disease during the TFR journey.

This study indicates that there are opportunities to improve patient-doctor communication around treatment-free remission. In particular, there are differences between regions on the key topics that need to be better discussed between both doctors and CML patients.

REFERENCES

1. Sharf, G., Marin, C., Bradley, J.A. et al. Treatment-free remission in chronic myeloid leukemia: the patient perspective and areas of unmet needs. *Leukemia* 34, 2102–2112 (2020). <https://doi.org/10.1038/s41375-020-0867-0>

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