

ESH 2020 Abstract

TITLE

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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Background

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

Through this study, we sought to obtain quantitative evidence of CML patient experience and to identify areas of unmet needs.

Method

A global survey translated into eleven languages was designed by an expert panel of eight CML patients to capture the experiences of people along all phases of the TFR journey.

Results

A total of 1016 responses were collected from CML patients across 68 countries.

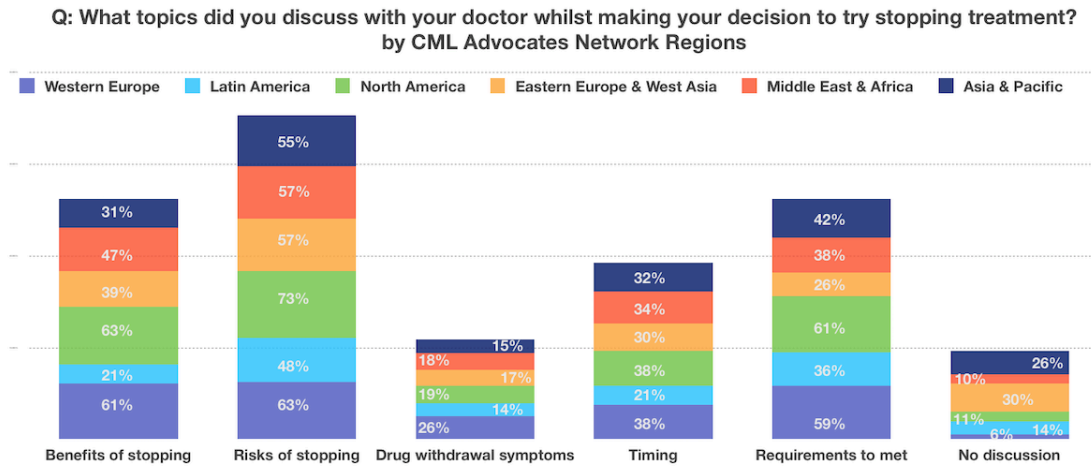
The majority of respondents reported first hearing about the possibility of stopping treatment through a healthcare professional 49% (n=476).

However, there is variation between the CML Advocates Network group regions: Western Europe, 57% (n=385) and Latin America, 53% (n=49) had the highest proportion of patients first being told about TFR by a health professional.

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

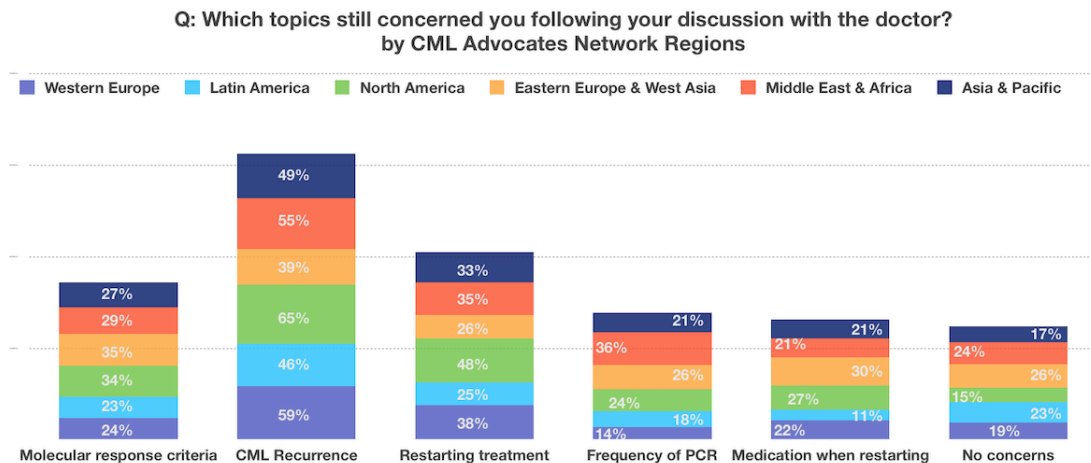
There are interesting differences between regions about which topics were more discussed with doctors. (Figure 1)



- Figure 1 -

In all regions, the more discussed topic with doctors was the risks of stopping.

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 2).



- Figure 2 -

Conclusions

The majority of respondents had a discussion with their doctor while making the decision to try to stopping treatment.

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.