QUALITY OF LIFE, PALLIATIVE & SUPPORTIVE CARE, ETHICS AND HEALTH ECONOMICS

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(EP1730) CML PATIENTS' VIEWS ON PSYCHOLOGICAL SUPPORT THROUGHOUT THE TREATMENT-FREE REMISSION JOURNEY

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Background:

While first recommendations exist about how to manage stopping and re-starting chronic myeloid leukemia (CML) therapy, based on data from the EURO-SKI study, much is still unknown about the experiences of those considering and undertaking treatment-free remission (TFR).

Aims:

We sought to obtain quantitative evidence of patient experience that has previously only been anecdotal and to identify areas of unmet needs. One strong theme to emerge was patients' differing views on the need for psychological support.

Methods:

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.

Results:

A total of 1016 responses were collected from CML patients across 68 countries. Patients only answered the sections of the questionnaire that were relevant for them. All 1016 had experience of Phase I, 494 (49%) had

experience of Phase II, 159 (16%) had experience of Phase IIIA, and 203 (20%) had experience of IIIB. Of the 494 patients who stopped treatment, 32% said disease reoccurred and 41% reported being in long-term remission. During Phase I, 22% said they would have liked to have received information on psychological effects. During Phase II: 18% of respondents said they discussed how to deal with psychological aspects with their doctor; 31% of respondents said they felt fear or anxiety before and/or after PCR monitoring tests, and overall 56% of respondents said they felt fear or anxiety and some point during the phase. 45% of males said they felt fear and anxiety during this phase, compared to 63% of females. There were differences in reported psychological and/or emotional support received across Phases II, IIIA and IIIB. Phase II had the smallest proportion of patients who said they received support (20%), from the following: friends or family 74% (males), 70% (females); patient organisations 35% (males) 23% (females); social media groups 22% (males) 26% (females); counselling 17% (males) 21% (females); other 4% (males) 6% (females).

In Phase IIIA, this was 26% and in Phase IIIB, 25%. Phase IIIA had the largest proportion of patients who wanted support but didn't receive it (25%); in Phase II, it was 23%, and it was lowest in Phase IIIB, 16%. While the highest proportion of patients answered that psychological/emotional support was not necessary; this varies by gender and across the TFR journey. Phase IIIA had the smallest proportion of patients who said they did not need support (48%); in Phase II this was 57%, and in Phase IIIB it was 59%. Across all phases, a larger proportion of male respondents said support was not necessary, compared to female respondents.

Summary/Conclusion:

There are opportunities for more communication and support around psychological issues to be given through the provision of information during the decision-making stage and/or discussions between doctors and patients during the stopping stage. A considerable proportion of patients feel fear or anxiety during stopping treatment, and not all patients who want psychological and/or emotional support receive it. The psychological well-being of patients should be a consideration of healthcare professionals and addressed at all stages of the TFR journey, to ensure patients receive support through personalised care.

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(EP1769) SELECTION OF A SET OF QUALITY INDICATORS (QIS) ON THE CARE PATHWAY IN ONCO-HEMATOLOGY USING A PANEL OF EXPERTS

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Background:

There are currently very few quality indicators (QIs) assessing the care pathway in onco-hematology. The existing QIs focus primarily on the inpatient setting and do not capture the coordination links between non-hospital professionals (GPs, pharmacists and private nurses) and the hospital.

Aims:

Our objective is to select a set of QIs on the care pathway in onco-hematology by involving all relevant stakeholders: hospital professionals (oncologists and hematologists), patient associations and non-hospital professionals. In this abstract we present the research conducted with hematologists.

Methods:

A literature review (included gray literature) of available QIs relating to the care pathway was conducted. 5731 QIs were identified and 131 selected after application of selection criteria to extract onco-hematology care pathway QIs.

In a first stage, these 131 QIs were presented to a panel of oncologists. They selected 10 QIs by consensus (nominal group) on the basis of their rating on relevance and feasibility. In a second stage, the list of 131 identified QIs and the 10 QIs selected by oncologists were presented to a panel of hematologists. They considered those set of indicators using the same methodology in order to validate, modify and add QIs.

Results:

13 QIs were selected by hematologists (table). The set of selected QIs includes 8 structure QIs, 3 process QIs and 2 QIs. 6 are identical to the QIs

selected by the oncologists, 4 correspond to a modification/addition to those selected by the oncologists and 3 are new QIs.

QI	Description	Type
1	Symptoms and disease progression	Structure
2	Assessment of tolerance to treatment	Process
3	Management of patients receiving oral therapy	Structure
4	Quality of the liaison document for the initiation of a cancer treatment	Process
5	Composite score for supportive care	Structure
6	Actions of patients therapeutic education	Structure
7	Medication reconciliation - therapeutic continuum	Process
8	Unscheduled admissions	Outcome
9	Declaration and follow-up upon serious and unexpected adverse events	Structure
10	Patient's experience	Outcome – PREMS
11	Clinical Trial Accessibility	Structure
12	Access times for a first consultation	Structure
13	Management of complex patients	Structure

Summary/Conclusion:

This project made possible to take into account the vision of hospital professionals (oncologists and hematologists) and to reach a consensus on a set of QIs. The choice made was to select general indicators that could be applied to a variety of specialties.

This study was also carried out with 11 patient associations by following the same methodology (presentation of the 131 QIs and selection). The next step will be to do the same work of selection with non-hospital professionals (GPs, pharmacists and private nurses).

A synthesis meeting with all the participants in the project (hospital professionals, primary care providers and patient associations) will be held to pool the QIs and reach a consensus on the set of QIs to be retained at the end.