PB2362 BEST PRACTICES ON EMPOWERING AND INVOLVING PATIENTS LIVING WITH HEMATOLOGICAL MALIGNANCIES ON THE DEVELOPMENT OF NOVEL PATIENT-REPORTED OUTCOME MEASURES

Topic: 35. Quality of life, palliative care, ethics and health economics

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Background:
Empowering patients is prioritized in research and clinical practice for improving patient outcomes. Patient-reported outcome measures (PROMs) have been highlighted as a means of involving people living with hematological malignancies in the decision process and thus helping them shape their care plans. Despite the clinical significance of PROMs, patients are rarely involved in their development.

Aims:
Our aim was to assist in overcoming this limitation and offer best practices that empower patients living with hematological malignancies by increasing their involvement in the development of novel PROMs.

Methods:
To this end, in the context of the Patient Empowerment Program of ERIC (European Research Initiative on CLL), we developed a Knowledge Questionnaire and a Treatment Preference Questionnaire for patients with Chronic Lymphocytic Leukemia (CLL). Reflections on the processes of their development and best practices from the literature were considered within a multidisciplinary team to develop lessons learned and a concise list of steps. These allow for coherence and consistency across future studies.

Results:
The steps include: (i) to identify unmet clinical needs by drawing from the literature, clinical experience and the experience of patients; (ii) to systematically review the literature for existing PROMs (in this or similar area) towards identifying both tools and methodologies of their development; (iii) to bring together a multidisciplinary panel of experts (e.g., hematologists, nurses, psychologists, statisticians), including patients (experts by experience), the public or family/caregivers (as appropriate). A structure (e.g., Delphi process method or focus groups) and a series of meetings are recommended to best address the following: a) critically discuss existing PROMs, b) decide on an aim (e.g., clinical or research oriented PROM) and group, c) decide on methodology (replicate or diverge from existing methodologies), d) review theoretical models to guide the PROM content, e) develop the initial domains, structure, items, f) develop a statistical analysis plan, g) decide on the instructions of the PROM (e.g., rationale of administration); (iv) to complete readability tests, aiming at a final score of 6th grade and reword accordingly; (v) to format the PROM structure and the overall layout (e.g., spacing, font size) according to the condition (e.g., visual impairments, cognitive abilities) and preferences of the patient group; (vi) to invite a separate patient group to review comprehensibility, ease, and timing of completion, rate the content in terms of relevance and offer any further suggestions around the items (including addition or removal); (vii) to repeat the steps above as appropriate depending on the extent of changes made; (viii) to pilot test the PROM with a third group of patients and run initial analyses; (ix) conduct the full study for further testing (e.g., validity, reliability) of the PROM and its content (e.g., factor analysis, Cronbach’s alpha and kappa).

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Summary/Conclusion:

The above steps provide a practical outline, which may vary depending on the aims. Nevertheless, empowering patients by solidifying their position as co-developers and drawing from their experiences can be an invaluable part of developing new tools. Increasing their involvement in the process is expected to improve the tools (e.g., measurement accuracy, quantity, and quality of collected data), which in turn can better inform and facilitate clinical practice.