PROMs
Patient-Reported Outcome Measures

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PATIENT PERSPECTIVE

Disease

Patient
PRO = “outcome reported by the patient”

The outcome is generally understood as the impact of a health problem, of a specific health intervention, of a specific health service of the person, in its various components (physical, mental, social).

The patient "lives" directly and personally the burden of the cures in the immediate and is the one who best knows what it means living with a disease and what he needs. Patient experience should be a central component of any CML “service”.

The term "patient", understood in a broad sense, also includes the figures - caregivers - who offer support to the patient in various forms, such as family and friends, defined as "patient proxy".
On this basis I will briefly describe how we collect the PROs.

On the group's website we have a discussion forum where patients share their life experiences with the CML. Through the forum you can then interact with the patient community and gather information on what are the real needs of patients and the problems they face in everyday life.

So it is possible to gather the patient's point of view.
The «narrative medicine» is a useful methodology to gather the patients experience. This information allows us to build materials for the use of:

- Patients themselves
- Hematologists
- Journalists
- Citizenry
Since three years ago we have been organizing a national conference on hematological malignancies and we invite Patients, Patients Associations, Physicians, Scientifics Associations, Institution.

The purpose of the Conference is to outline the current state of the art of Hematologic Malignancies and in particular:

- the clinical-therapeutic aspects,
- the perspectives of care and life,
- social and work reintegration and again,
- the issues of sustainability and accessibility of care.

Through online surveys we collect unmet patients' needs, we analyze the data collected and we share with other stakeholders.

At the end of next week I will present the results of the survey which will be the basis for drafting the new programmatic document which will then be used to try to address the problems.
At the end of the month, we will present to the press, to the presidents of the parliamentary health commissions, the results of a survey whose objective is to capture the experiences of patients with Multiple Myeloma, with particular attention to understanding their needs and measuring the perception of the effects linked to the therapies in progress.

Semi-structured questionnaire administered by expert telephone interviewers, will touch on the following topics:

- Initial experiences of illness and treatment
- Experiences regarding therapies
- The perception of the effectiveness of the therapy followed
- The impact of the disease on social and work life
QoL in patients CML: How do we measure it

Wien
CMLHZ 2010


Abstract

BACKGROUND: Health-related quality of life (HRQOL) is a key aspect for chronic myeloid leukemia (CML) patients. The aim of this study was to develop a disease-specific HRQOL questionnaire for patients with CML to supplement the European Organization for Research and Treatment of Cancer (EORTC)-QLQ C30.

PATIENTS AND METHODS: The process followed a predefined and systematic stepwise iterative process as defined by the EORTC guidelines for questionnaire development. The process was divided into 3 phases: (1) generation of relevant HRQOL issues, (2) operationalization of the HRQOL issues into a set of items, and (3) pretesting the questionnaire for relevance and acceptability. Descriptive statistics and psychometric analyses were also performed.

RESULTS: Overall, 655 CML patients were enrolled in 10 countries including the USA and countries in Europe and Asia. Interviews with health-care professionals experienced in CML (n = 59) were also conducted. Results from the interviews, clinical experiences, and statistical analyses were used to develop the EORTC QLQ-CML24. The final module consists of 24 items assessing the following aspects: symptom burden, impact on daily life and on worry/mood, body image problems, and satisfaction with care and with social life. Internal consistency, assessed with Cronbach's alpha coefficients, ranged from 0.73 to 0.83 for the proposed scales.

CONCLUSION: The EORTC QLQ-CML24 is an internationally developed HRQOL questionnaire for CML patients, and its implementation in clinical research and practice can provide important information to facilitate clinical decision-making.
Why there is a need of a new PRO?

Patient with hematological malignancies (HM) often experience worsening of quality of life (QoL) due to both the disease and its treatments. Impaired QoL may have negative impact on treatment outcomes leading to change in treatment decision-making. However, this has not been captured in a systematic manner in routine clinical practice and there is no specific instrument for such purpose. Thus, there is the need of a new patient-reported outcome (PRO) measure.

The aims of this study were to identify issues important to patients with HM and to develop a new PRO measure for use in daily clinical practice.

European Hematology Association Scientific Working Group “Quality of Life and Symptoms”
PRO & CLINICAL RESEARCH

- Clinical data
  - blood pressure
  - body temperature

- Lab data
  - blood test
  - RX/MRI/CAT
  - lab tests

- Physician evaluation
  - functional autonomy
  - check drug toxicity

- Patient evaluation
  - Quality of Life

- informed consent
- patient information leaflet
- guidelines

Legend:
- ✓: Included

Chronic Myelogenous Leukemia

CML Advocacy - Learn, Share, Grow
16th International Conference for Organizations Representing People with CML

Warsaw, Poland 4-6 May 2018
There is a life after cancer?

Surviving cancer is not only a medical challenge. We need to increase the awareness of the socio-economic challenges faced by survivors for both researchers and society. To engage various stakeholders to join forces in research, deliver the best care for survivors and change practice.

Cancer survivors have continuing medical issues to think about, with regular checkups and tests following remission, but they have also other difficulties:

- have accessing work
- getting loans, mortgages a

Need to change the mind set about cancer survivorship and to create a 360° view on long term follow-up involving medical, physical, and psychological perspectives but also societal and financial ones. We need to involve different stakeholders in the research i.e. insurers, lawyers, policy makers.
Thank you for your attention

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