

Enhancing patient-reported outcome measurement in research and practice of palliative and end-of-life care

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Abstract

Purpose Patient-reported outcome measurement (PROM) plays an increasing role in palliative and end-of-life (EOL) care but their use in EOL care and research remains varied and inconsistent. We aimed to facilitate pan-European

collaboration to improve PROMs in palliative and EOL care and research.

Methods The study includes a workshop with experts experienced in using PROMs in clinical care and research from Europe, North America, and Africa. Information from

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presentations, and plenary and group discussions was analysed using content analysis for extracting the main themes. *Results* Thirty-two professionals from 15 countries and eight different professional backgrounds participated in the workshop. The discussion identified: 1) the need for standardisation with improvement of existing PROMs, e.g., with a modular system and an optional item pool; 2) the aspects of further development with a multi-professional approach taking into account cultural sensitivity especially for translated versions; and 3) the need for guidance, training, and resources. An international network for sharing concepts, experiences, and solutions could enhance these steps of further development.

Conclusion PROMs must be based on rigorous scientific methods and respond to patient complexity. Coordinated pan-European collaboration including researchers and clinicians is required to develop and attain quality care and systematic research in outcome measurement in palliative and EOL care.

Keywords Outcome measurement · PROM · Cancer · Palliative care · End-of-life care · Research · Europe

Introduction

Patient-reported outcome measurement (PROMs) play an increasing role in palliative and end-of-life (EOL) care but their use in EOL care and research remains varied and inconsistent, with often diverse measures being used once or twice only [1–3]. EOL care faces various complexities influencing the measurement of outcomes: (i) patients may report multiple symptoms rather than one problem, (ii) problems and symptoms are often complex (e.g., fatigue and spiritual problems), and (iii) patients go through different stages in their disease trajectory including the experience of deterioration at the end of life, with changing priorities and reduced physical and cognitive function [4]. With an increasing ageing European population and a growing number of patients with cancer and other chronic conditions, there is an urgent need for international exchange and collaboration to identify barriers and priorities and to develop solutions, best science, and outcomes for European citizens. This could lead to an agreement on a standard core set of outcome measures to enable robust comparative research [5].

Our aim was to facilitate pan-European collaboration to improve PROMs in palliative and EOL care and research. The objectives were:

1. To engage experts in sharing experiences and to identify the best practice of PROM use in clinical care and research;
2. To develop a platform for the development of resources and support for those who use or want to use PROMs; and
3. To identify further direction and priorities regarding the development of PROMs.

Methods

An international 2-day workshop was held in Germany (Berlin) in March 2010 led by the German Association for Palliative Medicine (Deutsche Gesellschaft für Palliativmedizin) as part of a large European Commission funded project titled: PRISMA (Reflecting the Positive Diversities of European Priorities for Research and Measurement in End of Life Care). PRISMA aims to inform clinical practice and harmonise research in EOL cancer care across Europe through comparison and exchange of approaches and experiences in measurement and research priorities [6, 7].

Workshop

The workshop addressed: 1) experiences of PROMs in palliative and EOL care and research, 2) general issues of PROMs (cultural and language translational aspects), and 3) future of PROMs. We focused on PROMs that assess patients' needs, quality of life, quality of care, and those that focus on multiple symptoms within one measure (rather than measures that focus on one symptom only). Short presentations provided condensed input to initiate further discussion. Speakers were selected based on expertise and research experiences. Emerging topics were discussed in parallel group work at the end of each day. Notes were taken from all sessions. All presentations and discussions were audio-recorded for further analysis.

Sampling

To identify participants, a purposive sample was used to achieve diversity regarding country and profession to enable sharing of diverse experiences of using tools in palliative and EOL care [8]. An 'expert' was defined as having at least 6 years of experiences in use of PROMs either in clinical care or research in palliative and EOL care. These criteria were used to draw a sample from the respondents of an international online survey on outcome measures in palliative care of interest in the workshop [9]. In addition, experts were located through a literature search on publications on outcome measures in palliative and EOL care and invited for participation.

Data analysis

For the purpose of analysis, all information shared during the workshop was used including presentations, minutes from group discussions, plenary meetings, and audio recordings of sessions. Informed consent was obtained from all participants for analysis of this material. Content analysis (analytical hierarchy including descriptive and analytic accounts) was used for extracting the main themes and statements in order to summarise the results [8]. Analysis was conducted by two well-trained researchers with expertise in qualitative research.

Differences in coding were discussed, and consensus was achieved with a third reviewer [8]. Finally, the results were sent to all speakers of the workshop, comments were discussed, and integrated into the final results.

Results

Workshop participants

Invited participants (32/43) from various backgrounds (16 physicians, five social workers/sociologists, four psychologists, three nurses, and one each of music therapist, statistician, anthropologist, and health economist) and 15 different countries (eight English, six German, three Portuguese, three Italian, two Polish, and one each from Belgium, Canada, Georgia, Hungary, Ireland, Netherlands, Norway, Spain, Switzerland, and Uganda) participated. All had experiences in using PROMs in EOL care either in clinical practice, audit, and research or a combination of these.

Specific aspects of PROMs in palliative and EOL care

Workshop participants noted the lack of a clear roadmap or uniform approach to measuring outcomes in palliative and EOL care and the absence of standardisation hindering comparisons (e.g., between different patient groups or across countries). Furthermore, some of the key terms in palliative and EOL care such as quality of life, dignity, resilience, and spirituality are not easily understood or clearly defined making outcome measurement in these areas even more challenging. Regardless, EOL care providers must prove the quality of their care and, therefore, need valid and reliable measures. Also, PROMs play an important role for the use of quality indicators in EOL care in order to monitor and improve care [10].

The African participant reported about the enthusiasm, commitment, and success when incorporating a new PROM in clinical practice in Africa. The evaluation of the implementation process was also a useful example for change management [11, 12].

Future development of PROMs

The following topics evolved from the discussions during the workshop.

Guidance, training, and resources

A lack of guidance on how to choose PROMs and information about existing and validated measures was identified. There was also an urgent need for training and support for the use of PROMs in palliative and EOL care and research. This included assistance beginning with implementation through to analyses

and interpretation of findings. Materials should be provided online, in print versions, and face-to-face (e.g., courses or summer schools).

The ‘ideal measure’

Participants agreed that an ‘ideal measure’ in palliative care would contain six to ten questions; cover all (complex) aspects and dimensions of palliative and EOL care; be easy to use and brief to administer; understandable for cognitively impaired patients; non-burdensome to patients, carers and staff; and produce relevant and comparable results. All agreed that this ‘ideal measure’ does not exist and might not be able to be developed in the complex field of palliative and EOL care. However, there is a need to improve existing PROMs based on scientifically rigorous criteria to allow for comparisons across different studies and adaptation to the cultural diversity and local specificities. The development of a modular system with a set of core questions covering the main dimensions of palliative care and an optional item pool with additional dimensions and symptoms was proposed. Although this option was discussed controversially because of several disadvantages with loss of standardisation and validation difficulties, it was deemed feasible to balance practicability, quality, standardisation, and flexibility.

Translating PROMs with adaptation to cultural diversities

Translation includes not only the instrumental adaptation of objective information but involves a process of conveying meanings and concepts to a completely different culture. To assure this, members of the cultural groups studied should be involved in the translation process, and pilot testing with cognitive interviews incorporating think-aloud technique was suggested to get a balance of accuracy and relevance in the translation process [13].

Importance of involving nurses' views and competencies

For a better understanding of the day-to-day problems and quality improvement purposes, nurses need to be involved in the development and implementation process of PROMs. Inclusive participation and ownership will improve the relevance and acceptance of PROMs in clinical care and help overcome problems and barriers (e.g., gatekeeping and organisational concerns). These considerations also apply to other health professionals, e.g., psychologists.

International collaboration

An international network for sharing concepts, experiences, and solutions could enhance the required balance between standardisation and diversity, and develop recommendations

based on an international consensus to improve high quality of care. The collaborative project PRISMA could be a good platform to launch this network and develop an action plan to keep and enhance the current momentum. Involvement of key bodies such as the European Association for Palliative Care was deemed important to this process. This process should include external expertise and needs substantial funding. As a result of the discussion, a number of recommendations were formulated to inform future actions (Table 1).

Discussion

Growing evidence shows that the use of PROMs improves patient well-being and communication between patients and clinicians [14]. To facilitate pan-European collaboration in PROM in palliative and EOL care and research, we invited experts in the field to discuss challenges and barriers and to formulate recommendations for the future development of PROMs. Huge efforts have been undertaken in scale development within palliative care leading to a large number of tools, and some work exists on implementation of outcome measures into clinical practice [15, 16]. However, most are used inconsistently and a lack of coordination and standardisation hinders comparison of patient groups across studies and countries and precludes an appropriate definition of the palliative care patient population to determine which tools are useful with which population [16, 17].

Various initiatives exist in oncology defining the importance of PROMs in cancer research and practice (e.g., Patient-Reported Outcome Measurement Information System

(PROMIS), Common Terminology Criteria for Adverse Events (CTCAE), and International Society of Pharmacoeconomics and Outcomes (ISPOR)) but the focus is more on active cancer treatment including documentation of adverse effects rather than the end of life. Although PROMs have been increasingly included in clinical trials of cancer treatment, survival or surrogates are often used as the main outcome variables rather than symptom- or health-related quality of life (HRQOL) assessment. Taking into account these challenges, the National Cancer Institute in the US has established a steering committee for symptom management and HRQOL assessment to improve the development, use, and implementation of PROMs in clinical care and clinical trials [18]. Our results also highlight the importance of multiprofessional outcome measurement initiatives within Europe through the integration of nurses within development and implementation processes. Previous findings have shown that nurses and physicians share similar views regarding outcome measurement in EOL care and, therefore, multiprofessional initiatives may be possible [19].

For an appropriate balance between standardisation and flexibility, the development of item banks (e.g., for psychological distress in cancer) or the cancer sites' specific HRQOL measures by the EORTC might be good examples to follow [5, 20]. Cultural competences and the need for adaptation to local differences might be more relevant to palliative and EOL care because of the wide scope these areas of care cover and the importance of culture when coping with a diagnosis of incurable illness or facing death. Therefore, more attention to developing culturally sensitive PROMs in palliative and EOL care is recommended. In addition, the focus of the discussions

Table 1 Recommendations of the international workshop for the future improvement of patient-reported outcome measures (PROMs)

Need for standardization	<ol style="list-style-type: none"> 1. Given the high number of different tools with various validation qualities, there is need for standardization and agreement of a core set of tools in palliative and EOL care 2. Standardization should be based on scientific rigorous criteria rather than consensus only 3. Standardization needs to be balanced with diversity and flexibility
Development, validation and adaption	<ol style="list-style-type: none"> 4. Further development of PROMs needs a multiprofessional approach to include the different competencies of all professional groups in palliative and EOL care 5. Future development of PROMs needs to focus on cultural sensitivity and attention to local differences 6. Translation of PROMs needs to extend beyond a merely linguistic exercise to a broader and rigorous approach taking inter-cultural differences into account
Guidance and training	<ol style="list-style-type: none"> 7. Guidance needs to be developed and should include: <ul style="list-style-type: none"> • The setting in which the measure is to be used (e.g. hospital ward and home) • The purpose of PROMs (e.g., screening, assessment and quality assurance) • The background, context and training of professional administering the measure (e.g., nurses and physicians) • How PROM findings will be used (e.g., care evaluation, communication aid amongst service users and clinicians) 8. Training is required in relation to: <ul style="list-style-type: none"> • Implementation of PROMs in daily routine of an organization or clinical team • Strategies to manage and overcome barriers and staff reluctance regarding the use of PROMs • Analysis and interpretation of PROM data

so far has been on the gold standard measure, i.e., PROMs, rather than proxy measures. It is acknowledged that this also needs to be considered in the future.

The creation of an international network regarding outcome measures in palliative and EOL care has the potential to encounter these challenges in order to improve the quality and outcome of clinical care. Although the workshop was facilitated by the European coordination project PRISMA, we invited participants from Eastern Europe, Canada, and Africa to strengthen international links. This placed the discussions in a collaborative and international framework that allowed formulating an action plan on further development and support of PROMs in palliative and EOL care across Europe [3]. The findings and conclusions of the workshop could have been strengthened by a formal consensus process (e.g., Delphi) based upon the qualitative results of findings and discussions. However, the aim of the workshop was to represent a range of perspectives in using PROMs in palliative and EOL care and in research, thus the aims were achieved.

Conclusion

Outcome measurement must be based on rigorous science and meet the complexity of patients' needs at the same time to improve the quality of care of patients with advanced and life-limiting diseases. The balance between the need of standardisation and diversity will be a challenge; however, consensus building and multiprofessional developments and initiatives will help us overcome these challenges.

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