

Special Section: The PRISMA Symposium

The PRISMA Symposium 1: Outcome Tool Use. Disharmony in European Outcomes Research for Palliative and Advanced Disease Care: Too Many Tools in Practice

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Abstract

Context. As the European population ages and the number of cancer deaths annually increases, there is an urgent requirement to provide high-quality, effective care. The measurement of outcomes in advanced disease is complex, and to conduct comparative research and meta-analyses, appropriate tool selection is essential.

Objectives. This study aimed to identify the outcome tools currently in use in end-of-life care (both clinically and for research) across Europe and investigate the preferred features of outcome tools from the perspective of those who select and apply them.

Methods. A pan-European Internet-based survey of tool users was conducted in research and clinical populations. Respondents were asked to identify the tools they are using and describe ideal features of the measures. The study was conducted in accordance with guidance for best practice in web-based research.

Results. Of the 311 participants who completed a survey, 99 tools in clinical care and audit, and 94 in research, were cited by less than 10 participants. Further data revealed that respondents require the number of potential tools to be rationalized and that brief tools are favored.

Conclusion. The selection of valid and appropriate tools for palliative care populations requires expert guidance and support to ensure that clinicians and researchers are collecting data that have validity and potential for comparison

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Key Words

Outcome assessment, palliative care, terminal care, end-of-life care, research, Europe

Introduction

With an annual 1.7 million deaths from cancer in Europe and an aging population,^{1–4} there is an urgent need to improve care at the end of life for patients and families. However, end-of-life research is currently underresourced and underdeveloped across Europe. The World Health Organization Europe's guidance "Palliative Care: The Solid Facts" shows that, in many countries, less than 0.5% of research spending in cancer is allocated to end-of-life and palliative care⁵ and recommends collaboration in end-of-life research to enhance the evidence base.

There are barriers to the conduct of high-quality research in end-of-life cancer care.⁶ One central issue in the conduct of this research is the measurement of effects on and outcomes for patients. This is important for quality improvement, needs assessment, and evaluation of specific treatments or interventions, whether in practice or through specific trials. The lack of standardized measurement means that there are differences in the interpretation of study results; meta-analyses are often limited because no core measure is used, and, importantly, some studies fail because they have used inappropriate measures without adequate sensitivity.^{7–9} There may be differences among patients, carers, and health professionals in their views of the priorities at the end of life¹⁰ and even between professionals.¹¹

Populations toward the end of life are heterogeneous, and clinical interests include physiological, psychological, and social aspects of the phenomenon in question. The focus is not only the patient, but also the family. This heterogeneity represents a major challenge for research and especially when the population approaches the final year of the disease trajectory.¹² There also are challenges in undertaking measurement among patients who are in the last year of life and very ill, who may be confused

or cognitively impaired, and in capturing emotional, social, spiritual, and physical components. Some measures are, however, in more common use in these populations. The common uses could be enhanced and expanded, providing better guidance on the selection and use of measures through European collaboration.

The quantity of end-of-life research seems to be steadily increasing. However, the quality can be disputed.¹³ A systematic literature review of existing potential scales identified a number of measures with varying scientific validity,¹⁴ and few tools appear to meet the required standards of outcome measure development and validity.^{15,16} The selection of appropriate tools also should reflect the World Health Organization's acknowledgment that health care should be responsive to public preferences and expectations as one of the three intrinsic goals of any health system, alongside health and fairness.¹⁷ Preferences and priorities have always been central in end-of-life care, under the auspices of a person-centered and individualized approach to care.

The European Association for Palliative Care Research Network has conducted a preliminary survey of end-of-life and palliative care centers in Europe and has identified 143 active centers from 22 different countries.¹⁸ This suggests that there is a major potential for collaborative, coordinated research in Europe. However, there is a lack of coordination of measurement in Europe. PRISMA is a three-year project funded by the European Union with a special focus on outcome measurement in palliative care.^{19,20} One of the goals of PRISMA is to map and harmonize European approaches and experiences in end-of-life care measurement. To achieve this, one work package focused on best practice in outcome measurement. In an online survey, professionals working in palliative care in Europe and Africa were asked about their

experiences and use of outcome measures in palliative care. This survey showed that professionals across Europe, both in clinical care and in research, are, for the most part, using and positive about using outcome measures, but the survey also revealed that they are in urgent need of help (e.g., training and resources in the selection, implementation, and analysis of outcome tools).²¹

In this paper, we present data from this PRISMA study, which also aimed to identify the outcome tools currently in use in end-of-life care (both clinically and for research) across Europe, and investigate the preferred features of outcomes tools from the perspective of those who select and apply them.

Methods

The study used a web-based, cross-sectional survey design. Details of the methods are described elsewhere.²¹

Survey Development and Administration

The specifically developed questionnaire was designed within the multiprofessional PRISMA work package, and the electronic version was piloted in seven European countries (Austria, Germany, Italy, The Netherlands, Norway, Portugal, and the United Kingdom), with 20 professionals working in palliative care. The survey was conducted in English because of restricted resources; however, participants were invited to respond to open questions either in English or in their native language. Special attention was given to a user-friendly design, online support features during completion of the survey, such as alerts for unanswered questions and “back buttons” for reviewing answers, and data protection to ensure confidentiality and anonymity. Adaptive questioning was used, where certain questions were only displayed based on the responses to other items to reduce the number and complexity of the questions. To improve the completion rate, only one question was displayed per screen page. Overall, the questionnaire contained a maximum 59 pages (screens) for people who used outcome measures in both clinical care and research.

Survey Topics

The final questionnaire addressed the following areas of enquiry: first, respondent characteristics

(age, gender, and whether active in clinical use of tools, research use of tools, or both), clinical field and research field, and home country. Second, the outcome measures currently or ever used in the clinical care or research of palliative/end-of-life populations were identified (using both a list of common tools and a space for respondents to add other tools). Third, respondents were asked to identify their preferred features of an outcome measure (number of items, ranking of the possible domains, and whether patient/staff/carer versions are preferred). Lastly, respondents were asked their views of what they see as the required properties when selecting an outcome measure.

Sampling

The inclusion criteria for the survey sample were professionals working in palliative care (e.g., physicians, nurses, other allied professionals, and academics) in clinical care, audit, or research in Europe.

The following institutions and databases were used to sample potential participants for the survey: 1) national palliative care associations were contacted in eight countries of the PRISMA collaboration (Belgium, Germany, Italy, The Netherlands, Norway, Portugal, Spain, and the United Kingdom). To adjust for the different sizes of countries and associations, a weighted random sample of 20% of each group was drawn if the total number of clinicians (physicians, nurses, and other) in the association was more than 500 members and a sample of 33% if the total number was less than 500 members; 2) an existing database of outcome tool users was used (211 users); 3) authors of studies using common outcome tools were invited; 4) a list of 61 European chairpersons and researchers in palliative care and known to PRISMA was established. All contacts on this list were invited to participate in the survey; 5) all members of the U.K. Palliative Nursing Group of the Royal College of Nursing and the 28 known national nurse consultants were invited; and 6) all PRISMA members were invited (38 individuals).

Data Collection

The European online survey was conducted in October and November 2009. Invitation e-mails with information about the content and purpose of the survey, and the estimated

time for completion, were sent out to potential participants either by the palliative care associations or directly to named individuals. The invitation e-mail included a link to the web-based survey. In total, 2000 e-mails were sent, followed by two reminder e-mails.

Analysis

Following The Checklist for Reporting Results of Internet E-Surveys guidelines,²² the participation rate was calculated by dividing the number of replies to the first question by the number of unique site visitors (defined as those visiting the first page of the online survey), and the completion rate was calculated by the number of participants answering the first question divided by the number of people submitting the last question. Descriptive analyses of all questions were conducted using frequencies for categorical data and means and standard deviations (SD) for continuous variables. Answers from open-ended questions were analyzed using content analysis. First, the answer options were collated and then coded, searching for common themes.²³ SPSS version 17.0 (SPSS, Inc., Chicago, IL) was used for quantitative analysis and NVivo (QSR International, Southport, UK) to assist in qualitative data analysis.

Ethics

Ethical approval was obtained from the Research Ethics Committee at King's College London (BDM/08/09-102). Ethics approval from other countries was not needed because this survey did not include patients but only professionals.

Results

Sample Response and Characteristics

The total number of participants who began the questionnaire was 495 of 1291, and 311 of 495 completed the survey. The participation rate was 38%, and the completion rate was 63%. Respondents' mean age was 45.8 years (SD 8.93), and 187 (63.6%) were female. The majority were clinicians of varying professions ($n = 213$, 71.5%), with 27 identifying as researchers (9.1%) and around one-fifth actively both clinicians and researchers ($n = 58$, 19.5%). Respondents had the following years of experience in palliative care: 0–5 years,

$n = 106$ (35.6%); 6–10 years, $n = 82$ (27.5%), and more than 10 years, $n = 109$ (36.6%).

Clinician responders were primarily medical ($n = 164$, 60.3%), followed by nursing ($n = 69$, 25.4%), with the remaining professions returning 39 responses (14.3%). Researcher respondents also were primarily medical ($n = 47$, 55.3%), followed by nursing ($n = 12$, 14.1%), psychology ($n = 8$, 9.4%), social science ($n = 6$, 7.1%), and others ($n = 12$, 14.1%). The greatest number of responses came from the United Kingdom (95), followed by Italy (37), Germany (29), Portugal (20), Spain (19), Norway (12), Belgium (5), Ireland (3), Greece (2), The Netherlands (2), and one each from Austria, Denmark, France, Hungary, and Poland. Five were "Europe" unspecified and 14 "other."

Tools Used

The tools used by respondents are described in Tables 1 and 2.^{24–42} The five most

Table 1
Tools Used in Clinical Care/Audit^a

Tools Used and Reference	Clinical Care/Audit (n)
Karnofsky Performance Status (KPS) Scale ²⁴	187
Edmonton Symptom Assessment Scale (ESAS) ²⁵	120
PPS ²⁶	70
Palliative care Outcome Scale (POS) ^{27,28}	68
SDS ²⁹	40
Support Team Assessment Schedule (STAS) ³⁰	40
Palliative Care Assessment Tool ³¹	29
European Organization for Research and Treatment of Cancer Quality of Life Questionnaire-C30 (EORTC QLQ-C30) ³²	21
Measuring the Quality of Life of Seriously Ill Patients Questionnaire (QUAL-E) ³³	19
Barthel Index ³⁴	17
McGill Quality of Life Questionnaire (MQOL) ³⁵	16
Unspecified Visual Analogue Scale	16
European Organization for Research and Treatment of Cancer Quality of Life Questionnaire-C15-PAL (EORTC QLQ-C15-PAL) ³⁶	15
Hospital Anxiety and Depression Scale (HADS) ³⁷	15
Mini-Mental State Examination ³⁸	13
Therapy Impact Questionnaire ³⁹	11
Memorial Symptom Assessment Scale ⁴⁰	10
Cited less than 10 times	99
Total number of tools	116

^aMultiple answers possible.

Table 2
Tools Used in Research^a

Tools Used and Reference	Research (n)
KPS ²⁴	69
ESAS ²⁵	53
European Organization for Research and Treatment of Cancer Quality of Life Questionnaire-C30 (EORTC QLQ-C30) ³²	48
Palliative care Outcome Scale (POS or African POS) ^{27,28}	36
PPS ²⁶	30
European Organization for Research and Treatment of Cancer Quality of Life Questionnaire-C15-PAL (EORTC QLQ-C15-PAL) ³²	18
STAS ³⁰	18
MQOL ³⁵	15
Functional Assessment of Cancer Therapy-General ⁴¹	14
HADS ³⁷	14
SDS ²⁹	11
Schedule for the Evaluation of Individual Quality of Life ⁴²	10
Cited less than 10 times	94
Total number of tools	106

^aMultiple answers possible.

commonly used tools by clinicians in clinical care and audit were (in descending frequency) the Karnofsky Performance Status Scale, the Edmonton Symptom Assessment Scale, the Palliative Performance Scale, the Palliative Outcome Scale, and the Symptom Distress Scale. The most commonly cited tools by researchers were the Karnofsky Performance Status Scale, the Edmonton Symptom Assessment Scale, the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire-C30, the Palliative Outcome Scale, and the Palliative Performance Scale. It is noteworthy that for clinical care and audit, 99 tools were cited less than 10 times, and for research, 94 were cited less than 10 times.

Respondent Views on Preferred Tool Properties

The quantitative and qualitative data identified the ideal properties of an outcome tool in palliative and end-of-life care. With respect to the number of items, the preferred range was between six and 10 items. Responses were as follows: between one and five, $n = 43$ (14.0%); between six and 10, $n = 154$ (50.0%); between 11 and 15, $n = 79$ (25.6%); between 16 and 20, $n = 21$ (6.8%); and more than 20, $n = 11$ (4.6%).

A number of common themes emerged from the open-ended data. First respondents

commented that too many tools are in existence: "There are too many, they need to be rationalised so that everywhere is using the same one(s)." (Clinician, U.K.). "Would it be possible to REDUCE the number of tools?!" (Researcher, Italy).

A priority for collaboration was identified, using appropriate tools in common:

Yes - we need multicentre collaborations within countries to test the reliability, validity, utility, etc. of existing tools before we start inventing more! (Clinician and researcher, U.K.).

Cooperation of all associations worldwide. Maybe in this way, asking people which do the work and use actual tools. (Clinician, Germany).

However, this collaboration and shared use of tools must include best science in selecting and adapting tools to local settings:

A reference group (expert in PC tools) to contact when tools are to be chosen for research or clinical aims would really be useful. It can prevent researchers to reinvent the wheel by reviewing the literature at any time. (Clinician and researcher, unknown country).

Local country organisations should evaluate the available tools and discuss in workshops how they fit with the daily practice, enabling their continuity. (Clinician, Portugal).

Further data described the preferred content and structure of an outcome tool. Not only should the tool include those matters of greatest importance to both carers and families but to those responsible for service design:

Include domains generated by patients and carers concerns. Ensure domains are congruent with the information [of] strategists/purchasers of palliative care services to save effort. (Clinician, U.K.).

To ensure that tools meet the multiple outcomes of interest in palliative and end-of-life care, the provision of modules that can be included as necessary was advocated:

Yes. It would be very useful to have a toolkit which worked together, and had been tested and validated as such. So for instance, symptom tool/QoL tool/functional status tool

which followed a similar format, and could be used together or separately, and had consistency of time frame and format. (Clinician and researcher, U.K.).

Lastly, with respect to tool format, respondents called for simplicity: "They should be short and easy to understand for patients." (Clinician, Germany). "They should be short, not complicated. Easy to take." (Clinician, Spain).

Discussion

This is the first pan-European survey describing the views of professionals on the use and preferred features of outcome measures in palliative care. The data demonstrate a very clear challenge for collaboration and the advancement of clinical practice and evidence generation. Among our sample, over 100 tools were cited that had been used, and nearly one hundred were only cited less than 10 times. A challenge to palliative and end-of-life care is that we have multiple endpoints across very different domains and that patient populations (and diagnoses) are heterogeneous. Therefore, it would be inappropriate to propose that all clinical services and studies use a specified set of tools without the possibility of introducing additional tools as needed. However, it is clear that there is an urgent need to rationalize core tools to those that have been developed and validated within our population and have sound psychometric properties. The data from this study propose the use of core and additional batteries of items, and this may address the problems of specific services and studies needing to further investigate and measure specific outcomes of interest.

The need to provide effective and appropriate care for patients facing life-limiting and life-threatening disease is growing and if this is to be achieved, then larger, robust studies are needed to overcome the historic methodological failures of experimental studies in palliative care.⁴³ This requires the use of appropriate tools, collaborative studies, and meta-analyses of existing data sets. None of these requirements can be achieved if common, robust tools are not selected and applied.

There are a number of limitations to our study. Although we followed best practice

guidance for web-based surveys, a number of methodological limitations have been noted, including possible participation bias (in our case, those with an interest in outcome tools) and the potential for individuals to complete multiple submissions.⁴⁴ The requirement to participate in the English language also may have reduced participation. However, our participation and completions rates are acceptably high.

If outcomes for patients and families facing life-limiting and life-threatening diseases are to be measured and improved in Europe (and beyond), then those selecting tools must be enabled to make informed choices about the most appropriate tool for their aims and the field. It cannot be expected that individuals can easily access the necessary volume of information to be able to identify, locate, and appraise potential tools. Conversely, those developing tools should ensure that the tools being recommended meet the requirements for brevity, validity that enables collaboration, and the provision of modules that meet individual service/study needs. Lastly, the data presented here suggest that new tools are not required but that judicious selection and refinement of existing tools with appropriate scientific properties should be advocated.

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