Abstract

Background: Patient-reported outcome measurement (PROM) plays an increasingly important role in palliative care. A variety of measures exists and is used in clinical care, audit and research. However, little is known about professionals’ views using these measures. The aim of this study is to describe the use and experiences of palliative care professionals with outcome measures.

Methods: A web-based online survey was conducted in Europe and Africa. Professionals working in clinical care, audit and research in palliative care were invited to the survey via national palliative care associations and various databases. Invitation e-mails were sent with a link to the questionnaire.

Results: Overall participation rate 42% (663/1592), overall completion rate 59% (392/663). The majority of respondents were female (63.4%), mean age 46 years (SD 9). 68.1% respondents from Europe and 73.3% from Africa had experiences with outcome measures in palliative care. Non-users reported time constraints, burden, lack of training and guidance as main reasons. In clinical care/audit, assessment of patients’ situation, monitoring changes and evaluation of services were main reasons for use. Choice of OMs for research was influenced by validity of the instrument in palliative care and comparability with international literature. Main problems were related to patient characteristics, staff, and outcome measures. Participants expressed the need for more guidance and training in the use of PROMs.

Conclusions: Professionals need more support for the use and implementation of PROMs in clinical practice and research through training and guidance in order to improve patient care.

Strengths

- Well-designed web-based survey in accordance with CHERRIES checklist
- Large sampling frame with proportional sampling (n=2,487)
- Use of two reminders plus incentive to increase response rate

Weaknesses/Limitations

- Low participation rate (663/1592; 42%) and completion rate (392/663; 59%)
- Length of questionnaire (59 questions) may have influenced study participation – unable to determine extent of missing data
- Potential for biased responses as “only professionals with positive attitudes towards PROMs may have participated” (authors’ comment)
- Survey was conducted in English only (authors’ comment)
- Dominance of physicians and nurses (authors’ comment)

Relevance to Palliative Care

The use of systematic approaches for symptom assessment provides important information for assessing patients’ and family members’ needs, as well as for monitoring the effectiveness of clinical interventions and conducting research in palliative care. This study provides timely information about the prevalence of, as well as advantages and barriers for, implementation of patient reported outcome measures. It would be worthwhile to conduct a similar study in Canada to determine the extent to which symptom assessment/outcome measures are being used in clinical practice and research, as well as to identify potential barriers and training needs.