

Challenging but beneficial: using outcome measurement in routine care for patients with advanced disease

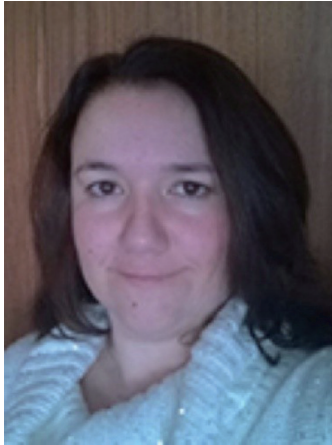
The aim of this focused issue is to discuss the current state of outcome measurement for patients with advanced disease in palliative care clinical practice and research. The field has been evolving and has grown in the last decade. The range of authors who gracefully accepted our invitation to contribute are from different disciplines, countries and settings which, hopefully, secure a wider coverage of research as well as practice developed in the field. Different measures are discussed as well as their multiple uses/purposes. From the importance of measurement to many applications in the field, on how to best implement patient-centred outcome measures in practice, regardless of diagnosis and context, maintaining them as part of daily routine, we hope this focused issue is useful for all readers.

It is important to know where and how a field of science started, to understand why and where we are now and where we might be heading, thus, this focused issue includes three reviews, the first of which explores the historical development of outcome measurement use in the past 5 centuries. From simple collection of mortality rates in 1532, evolving to developing the structure-process-outcome model and taking this forward relating it to quality of care provided and quality of life, to finally, discussing developing specific measures and implementing them in palliative care clinical practice. The second review on ethical challenges of outcome measurement in palliative care clinical practice highlights how poorly addressed these ethical issues are in existing systematic reviews. The only ethical challenge/issue identified in included systematic reviews was cognitive impairment, particularly in patients with dementia addressed via proxy (family caregivers or health professionals). The third review looks at development of integrated models where palliative care interventions occur early in the disease progression. The evidence of effectiveness of early involvement is presently being developed and one of the main challenges for the future seems to be increasing the awareness of professionals, patients and families that referral for palliative care early in the disease trajectory is beneficial. The five original articles focus on perspectives of patients, family caregivers and healthcare professionals on the use of PCOMs in practice, highlighting that outcome data needs to be fed back to and interpreted for professionals to improve and sustain outcome data collection, and drive meaningful improvements in palliative care. Next, a comprehensive paper on what has been developed in paediatric palliative care, namely that the measurement of outcomes in this population is an imperative, whilst recognizing that there are challenges in developing outcome tools and utilizing them in practice, which cannot prevent advancement in the field. This is followed by, a comparative cross-sectional study exemplifying how these measures are useful, specifically to identify palliative needs in vulnerable palliative populations, such as older people with multi-morbidity. The need for training in the use of these measures and raising awareness of palliative care in other specialties is explored using an online survey sent to members of the Brazilian Society of Nephrology, and finally, how short measures can be extremely informative of patients' wishes, as well as, give insight into whom these people being cared for are and what matters most to them. The two perspectives enrich this focused issue contributing to, first an understanding of ways to measure patient outcomes in the last days of life and several pitfalls to avoid, and second, looking at the current state of affairs of economic outcomes in palliative and end of life care. Finally, the commentary focuses on patient centered outcome measurement in health economics beyond the EQ-5D and the Quality-Adjusted Life-Year and the final brief report describes how clinical teams can go about starting to implement outcome measurement in their clinical practice from the very beginning, considering that sometimes it may be preferable to use a more pragmatic approach to get it going and fine tune it as the use of measures and the use of results progresses across time.

Though for some reluctant healthcare professionals, the belief that systematic measurement of palliative needs may seem like additional paper work with no benefit for patient care, training on the use of these measures and proper, timely feedback of results, make patient centred outcome measures powerful tools to quickly make a holistic assessment and act upon the most distressful issues, whilst assisting on developing a therapeutic plan by benefiting communication among all involved. Introducing change is never an easy, smooth process, but more and more, evidence points towards the benefits of using such measures in practice. Given that most patients with palliative needs are in non-specialized palliative care services and evidence strongly suggests that referring patients and families to palliative care earlier in the disease trajectory benefits quality of life, patient-centred outcome measures may assist in the identification of patients with palliative needs in those settings.

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