

22nd International Congress on Palliative Care, Montreal, 2-5 October 2018

What does spiritual wellbeing mean to you? Understandings of international participants in the validation study for the EORTC QLQ-SWB32: an EORTC measure of spiritual wellbeing for palliative care patients

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Published in: *Journal of Pain and Symptom Management*, 56(6): e45. December 2018.

Background

The EORTC QLQ-SWB32, a measure of spiritual wellbeing for people receiving palliative care for cancer, recently completed international validation, with 501 participants in 14 countries and ten languages. Study participants had advanced cancer, and were receiving supportive care and/or treatment with no curative intent.

Methods

All participants completed a provisional 36-item measure (translated into a suitable language), and then participated in debriefing interviews, with a structured interview schedule, translated if necessary, followed by all research interviewers. The last two items of the measure use the phrase “spiritual wellbeing”, but no definition of this term is provided. The debriefing interviews asked participants: “What does spiritual wellbeing mean to you?”

For this subsidiary study, participants’ responses were translated into English if necessary, study data checked and cleaned, and responses to this question analysed qualitatively for themes. We then investigated whether there were any relationships between participants’ responses to this question and their ages, genders, religions and countries.

Results

We obtained clean and comprehensible answers to this question from 307 participants in ten countries (Australia, Chile, France, Iran, Italy, Mexico, Norway, Singapore, Spain and the UK), and six original languages (English, French, Italian, Norwegian, Persian, and Spanish). Thematic analysis identified three primary themes: Self, Others, and Religion, and two subsidiary themes: Death/Dying/Life after death and Philosophical/Existential. Each participant’s understandings fell into at least one of these five themes. The Self theme occurred most frequently for most participants, but Religion occurred more frequently for Iranian and Singaporean participants, and for Muslim participants, who were mostly Iranian.

Conclusions

Our participants’ understandings of spiritual wellbeing were individual, but all fit into a few common themes, differing only in the frequency in which responses from participants in some countries and religions fit these themes.