Original Article

Meaning in Life Experience at the End of Life: Validation of the Hindi Version of the Schedule for Meaning in Life Evaluation and a Cross-Cultural Comparison Between Indian and German Palliative Care Patients

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Abstract

Context. The experience of Meaning in Life (MiL) is a major protective factor against feelings of hopelessness and wishes for hastened death in palliative care (PC) patients. However, most instruments for MiL assessment have been developed only in Western countries so far. Little is known about MiL experience in Asian PC patients.

Objectives. This study aimed to provide a Hindi version of the Schedule for Meaning in Life Evaluation (SMiLE), test its feasibility and validity in Indian PC patients, and compare the results with previous studies in Germany.

Methods. Indian PC patients in a hospice for the destitute were eligible to participate in this cross-sectional study. In the SMiLE instrument, respondents individually listed MiL-giving areas before rating their satisfaction with and importance of these areas. Overall indices of satisfaction (IoS, range 0-100), weighting (IoW, range 0-100), and weighted satisfaction (IoWS, range 0-100) were calculated.

Results. A Hindi forward-backward translation of the SMiLE was made. Two hundred fifty-eight Indian PC patients took part in the study (response rate 93.5%). Convergent validity of the SMiLE was found with the World Health Organization Quality of Life-Brief version (r=0.17; P=0.008) and the Idler Index of Religiosity (public religiousness: r=0.25, P<0.001 and private religiousness: r=0.29, P<0.001). Indian PC patients' IoW was 65.8 ± 22.1 , IoS 68.6 ± 17.4 , and IoWS 70.2 ± 17.0 . In multivariate analyses of covariance, they differed significantly from German PC patients only in IoW (IoW: 84.8 ± 11.5 ,

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P < 0.001; IoS: 70.2 ± 19.7 ; IoWS: 72.0 ± 19.4). Compared with Germans, Indians more often listed *spirituality* (P < 0.001) and *social commitment* (P < 0.001) and less often *social relations* (P = 0.008).

Conclusion. Preliminary results indicate good feasibility and validity of the Hindi version of the SMiLE. MiL experience also seems to be a coping resource for Indian PC patients. J Pain Symptom Manage 2015;49:79–88. © 2015 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.

Key Words

Meaning in Life, Schedule for Meaning in Life Evaluation, palliative care, cross-cultural comparison, India, Germany

Introduction

In India, 138 hospices and palliative care (PC) organizations provide services for more than 1.2 billion people. Less than 3% of the population have the possibility to access PC. The interest in PC in India is increasing, and there is a considerable need for its further development; the need for services, education, and research is immense. Hilliteracy, poverty, lack of resources and awareness, population density, and limited national PC policies are the major challenges for PC development. In 19 Indian states, no PC services are available; in West Bengal, there is only one PC unit providing outpatient care exclusively.

Up to 20% of patients confronted with a terminal illness have the desire to hasten their death. Meaning in Life (MiL) experience has been shown to be a safeguard against feelings of hopelessness, distress, suicidal intentions, depression, and demoralization at the end of life. Unless of order, coherence and purpose in one's existence, the pursuit and attainment of worthwhile goals and an accompanying sense of fulfillment. Therefore, it comprises cognitive (meaning framework), motivational (commitment), and emotional components (fulfillment).

The Schedule for Meaning in Life Evaluation (SMiLE) is an instrument for individual MiL assessment. Respondents are asked to qualitatively list areas that give meaning to their lives before rating their current levels of satisfaction and importance of these areas in quantitative scores. Therefore, different aspects of MiL are represented in the SMiLE:

the MiL framework (individual areas), commitment (importance ratings), and fulfillment (satisfaction ratings). The SMiLE has been validated and used in different samples comprising healthy Germans, as well as PC, cancer, amyotrophic lateral sclerosis, and progressive supranuclear palsy patients. ^{13–17} Language adaptations are available in English, German, French, and Spanish. ^{16–19}

MiL experience seems to strongly depend on cultural and ethnic backgrounds. However, a systematic review found that cultural differences are rarely considered in existing MiL instruments. Most of them were developed in the U.S. or Europe (93%) and were designed in English (69%). There is a need to investigate MiL in other languages and ethnic groups and to stimulate cross-cultural comparisons. 21–24

The aim of this study was to provide a valid Hindi version of the SMiLE to assess MiL in Indian PC patients and to compare it with German PC patients.

Methods

Study Design and Participants

The study was designed as a cross-sectional study and done in September and October 2012. Patients who were being cared for at Jesu Ashram, a hospice for the scheduled castes and tribes in Matigara, West Bengal, India, and were suffering from an incurable disease (life expectancy less than six months rated by the medical staff) were eligible to participate. Patients were excluded if they were younger than 16 years, had insufficient knowledge of Hindi, showed cognitive impairment, or

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