

BMJ Open Assessing palliative care education in undergraduate medical students: translation and validation of the Self-Efficacy in Palliative Care and Thanatophobia Scales for Brazilian Portuguese

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ABSTRACT

Background As the global population ages, palliative care is ever more essential to provide care for patients with incurable chronic conditions. However, in many countries, doctors are not prepared to care for dying patients.

Palliative care education should be an urgent concern for all medical schools all around the world, including Latin America and Brazil. Advances in palliative care education require robust assessment tools for constant evaluation and improvement of educational programmes. Bandura's social cognitive theory proposes that active learning processes are mediated by self-efficacy and associated outcome expectancies, both crucial elements of developing new behaviour. The Self-Efficacy in Palliative Care (SEPC) and Thanatophobia Scales were developed using Bandura's theory to assess the outcomes of palliative care training.

Objectives We aimed to translate and validate these scales for Brazilian Portuguese to generate data on how well doctors are being prepared to meet the needs of their patients.

Design Cross-sectional study.

Setting One Brazilian medical school.

Participants Third-year medical students.

Methods The authors translated the scales following the European Organisation for Research and Treatment of Cancer's recommendations and examined their psychometric properties using data collected from a sample of 111 students in a Brazilian medical school in 2017.

Results The Brazilian versions of SEPC and Thanatophobia Scales showed good psychometric properties, including confirmatory factor analysis, replicating the original factors (factor range: 0.51–0.90), and acceptable values of reliability (Cronbach's alpha: 0.82–0.97 and composite reliability: 0.82–0.96). Additionally, the Brazilian versions of the scales showed concurrent validity, demonstrated through a significant negative correlation.

Conclusions The Brazilian version of the scales may be used to assess the impact of current undergraduate

Strengths and limitations of this study

- Translation and validation processes were guided through solid methodological basis.
- We choose validated instruments to assess medical student's self-efficacy in palliative care.
- Clarifying how students' performance regarding their palliative care training is key to enhance palliative care education of undergraduate medical students.

training and identify areas for improvement within palliative care educational programmes. The data generated allow Brazilian researchers to join international conversations on this topic and educators to develop tailored pedagogical approaches.

BACKGROUND

Global changes in the demographic patterns of the population have resulted in recognition of palliative care (PC) as a worldwide need.¹ Modern medicine deals with possibilities of sustaining life in circumstances unimaginable before.² However, life under these new circumstances demands for certain sacrifices that not all patients judge feasible or valuable.³ As people live longer and suffer from long-term and life-threatening diseases, the PC approach must be a core competency for doctors.^{4,5} Moreover, the decision-making in PC occurs as a process and not as 'yes or no' decisions, and patients and health professionals need time to deal with the uncertainties that are present until the best decision finally becomes clear. In this sense, PC education needs to acknowledge this complexity and uncertainty and go beyond the technical



possibilities of care to embrace ethics, symptom control, communication and spirituality.⁴ Accordingly, medical schools are introducing and improving their palliative medicine programmes for undergraduate medical students.^{6–9}

The WHO and the Asociación Latinoamericana de Cuidados Paliativos call for mandatory integration of PC into the medical curriculum. In Brazil, medical schools are just beginning to include PC topics in their curricula.^{10–12} As Brazil and other Latin American countries respond to this call and progressively introduce PC training into undergraduate medical courses,¹³ parallel evaluations of the outcomes of these courses need to be implemented to ensure that the new practice is succeeding on preparing doctors to deal with PC and end-of-life care.

Tremendous efforts are still needed to broaden access to and enhance the quality of PC for Latin America people.¹¹⁴ We will consider the Brazilian case. Brazil is the fifth most populous country in the world with 210 million inhabitants and approximately 600 000 people dying every year from conditions that should receive PC.^{1 15} A recent report identified only 177 PC services in the country, mostly in hospitals and few connected to medical schools.¹⁶ Therefore, the ratio of PC service per population is 1:1 180 790 inhabitants, much lower than the Netherlands ratio, for example, which is 1:56 000. At best, up to 10 000 Brazilians have received some PC in the last year, representing about 1.5% of all those who would eventually need PC.¹ These data illustrate the urgency and the dimension of the challenge of training new health professionals, especially doctors, to structure a quality PC network in Brazil and all Latin America.

Brazil has 289 medical schools and approximately 19 000 doctors graduated in 2018.¹⁷ The number of newly qualified doctors will continue to increase, and the projection is nearly 135 690 new doctors up to 2024. On the other side, the Brazilian health and educational systems do not offer postgraduate training for all the new doctors, and by 2025, Brazil will have an additional amount of 23 500 doctors practising without any postgraduate training, mostly in primary care facilities and emergency departments.^{11 12 17} Hence, broad PC services in Brazil will rely on teaching core PC competencies for undergraduate medical students, since providing enough specialists and services for PC seems a future, rather than an immediate target. Considering the social relevance of PC training, the effectiveness of the learning strategies to be implemented requires consideration and assessment. Hence, valid and reliable evaluation tools are needed to provide measurements of the strength and weaknesses of PC training.

A comprehensive evaluation of a training programme involves more than just measuring the acquired knowledge. Therefore, a successful training programme should provide enhancement of students' competence in PC, which consists of developing new attitudes and behaviours aligned with patients' needs.^{18 19} Bandura's social cognitive theory explains that 'self-efficacy

and 'outcome expectancy' are central components in behavioural changes. Self-efficacy corresponds to one's knowledge and skills, previous experience and observation of other's performance. Outcome expectancy is the self-perceived consequence of the performance and relates to the value this specific performance has to the person. The higher self-efficacy and outcome expectancy, the higher is the chance for behavioural change. Thus, appropriate training should strengthen one's confidence in their ability to achieve the objectives (self-efficacy) and enlighten the importance of developing the desirable behaviour (outcome expectancy). Medical educators could use the self-efficacy concept to deliver comprehensive feedback and tailor their teaching approaches to fit students' needs.^{18 20}

In the context of PC, the Self-efficacy in Palliative Care (SEPC) Scale and the Thanatophobia Scale (TS) were developed to evaluate student's self-efficacy and their expectations of practice, respectively.^{18 21 22} The SEPC Scale has three factors related to doctors expected behaviours in PC: (a) effectively communicating with the patient and family, (b) appropriate assessment and management of patient's symptoms and needs and (c) work within a multidisciplinary team. Thanatophobia, or 'fear of death', is related to the anxiety experienced by students or professionals who deal with dying patients. Previous studies have used the TS for outcome expectancy evaluation because it is related to healthcare professionals attitudes towards dying patients. We expected that doctors providing end-of-life care would present low levels of thanatophobia.^{21 23}

Considering the need to foster PC education in Brazil, it is essential to make available instruments as reliable and valid as the original scales. These instruments can be used by Brazilian educators to follow the development of medical students regarding their attitudes towards PC. Also, these instruments will allow Brazilian educators to engage in international conversations about this topic. This study aimed to translate and validate the SEPC Scale and TS for Brazilian Portuguese, following established international procedures, which will contribute to future collaborative studies and meta-analysis in international PC education.²⁴

METHODS

Setting

The validation study was conducted in a medical school in the Southeast of Brazil. The undergraduate medical course is delivered over 6 years, with a transversal axis curriculum, aimed to integrate student's learning to healthcare practices and services. Each year 120 new students enrol in the course. In the first 2 years, students' learning is focused on basic sciences, and they are introduced to patient care with regular activities in primary care facilities and hospital settings. During the next 2 years, students start clinical studies; first, students practice inside the hospital, in internal medicine wards, where

they learn about history taking, physical examination and clinical reasoning. Later, students start to perform full clinical consultations under expert supervision in primary care settings. In the final 2 years, students practice under specialist supervision in diverse medical areas, inside and outside the hospital, in different clinical rotations, such as internal medicine, paediatrics, surgery, gynaecology, primary care, medical emergencies and critical care. Nevertheless, in our context, during the last semester of the second year and the entire third year, students have contact with patients inside the hospital, including the emergency department and the internal medicine ward. Since the intensive care unit (ICU) in our university hospital does not have enough beds for all the patients in critical conditions, we end up with around 40 patients under mechanical ventilation outside of the ICU. So, even when our students had not cared directly for someone who died, they have contact with critical patients who eventually die. since early moments of the undergraduate course. This early contact with dying patients justifies why we choose this sample to validate our questionnaires. In the future, we are interested in following up their development throughout the course.

Despite this breadth of training, there is no formal palliative medicine programme in the curriculum, although some disciplines and clinical placements may include aspects related to fundamental approaches in PC. For example, students have an obligatory longitudinal course, along 6 years of medical school, on bioethics and clinical ethics, in which they discuss, among other topics, the concepts of euthanasia, dysthanasia, orthothanasia and end-of-life care. In the first 3 years, the course is mainly theoretical, and, in the last 3 years, students engage in the ethical decision-making of challenging patients. Also, students have contact with real patients since the first year, and several aspects of clinical communication are discussed, such as how to break bad news, the importance of being empathetic and offering rapport.

Participants

For validation analysis, we invited the third-year medical students of class 2017 to answer the translated and pretested scales in July 2017, during their final exams on clinical semiology. All the students had experienced the same curricular activities. We included all students who agreed to participate.

Patient and public involvement

This study did not involve the participation of patients nor the general public in the design, conduct, reporting or dissemination of the findings.

Instruments

SEPC Scale²¹: in this 23-item scale, self-efficacy is recorded as students rate their confidence in performing PC practice on a 100 mm Visual Analogue Scale, ranging from 'very anxious' to 'very confident'. The point assigned on the Visual Analogue Scale is measured, and the score

ranges between 0 and 100, with higher values indicating higher confidence in that specific task. The original study identified three factors: (a) communication (factor range: 0.70–0.89 and Cronbach's alpha: 0.93), (b) patient management (factor range: 0.55–0.84 and Cronbach's alpha: 0.92) and (c) multidisciplinary team working (factor range: 0.70–0.84 and Cronbach's alpha: 0.92) in PC.

TS²³: the original scale was designed to assess the different feelings that clinicians may experience in caring for end-of-life patients, designating these feelings as 'thanatophobia'. The scale has one factor ranging between 0.61 and 0.79, and a Cronbach's alpha of 0.84. Each item of the scale is a statement related to outcomes of caring for dying patients, such as: 'Dying patients make me feel uneasy' and 'When patients begin to discuss death, I feel uncomfortable'. The participants rate each statement on a 7-point Likert Scale, which ranges from 'strongly agree' to 'strongly disagree'. The final score could range from 7 to 49, with higher scores indicating higher thanatophobia levels.

Procedures

Phase 1: translation and pretesting

The original SEPC Scale and TS are in English, with no available translation or validation of the scales for Brazilian Portuguese. Therefore, we proceeded to translate the scales following the European Organisation for Research and Treatment of Cancer (EORTC) recommendations.²⁴ First, we contacted the researchers who developed the original scales to assure there was not any other translation in progress and to obtain authorisation to develop our version. Then, two translators independently developed two Portuguese versions of the scales, according to EORTC procedure. We then produced an optimal Portuguese version through a reconciliation process of the two translations. This optimal version was sent to two independent English professional translators who produced two back-translation versions in English from the optimal Portuguese version. After discussions with the scales' developers on an optimised back translation, we reached a consensus and produced a final version of both scales (SEPC-Br and TS-Br—online supplementary appendices 1 and 2) in Brazilian Portuguese.

Phase 2: pretesting

Both final versions were pilot-tested in a focus group with 10 sixth-year medical students. One of the researchers met the students and explained the study. The students completed the scales and, after, the researcher asked if they had difficulties in comprehending any item. Small grammar corrections were proposed but the students did not suggest any major changes and assured that they had a good comprehension of the items, aims and expectations of the scale. Students did not engage in a content analysis of the scales. Once we had a final version, the scales were distributed to the third-year medical students

from the class of 2017, to generate data to enable the psychometric analysis of the scales.

Phase 3: statistical analysis for psychometric evaluation

For construct validity, first, we conducted a confirmatory factor analysis with maximum likelihood estimation to investigate the internal structure of both scales. To assess the confirmatory factor model, we used the following goodness of fit: χ^2 statistics, Comparative Fit Index (CFI), Tucker-Lewis Index (TLI) and root mean square error of approximation (RMSEA). The χ^2 statistics was used to assess the overall fit and discrepancy between the sample and the model. Both CFI and TLI were considered optimal with values above 0.90.²⁵ Optimal RMSEA is lower than 0.80.²⁶ The missing data were deleted for the analysis. Finally, we calculated the reliability of the scales using Cronbach's alpha and composite reliability, and, for concurrent validity, we calculated the correlation between the SEPC-Br and TS-Br.

The data were analysed using IBM-SPSS V.21.0 and R (lavaan and dplyr packages). The latter was used for the confirmatory factor analysis and calculating the composite reliability, respectively.

RESULTS

From a possible 119 potential participants, 8 did not sign the informed consent. Thus, 111 (response rate: 93.2%) were considered for the SEPC validation analysis and, due to the absence of data, 109 (response rate: 91.6%) were considered for TS validation. Their mean age was 22.02 (SD: 2.11) and the majority were females (53.2%). The proportion of male and female follows the current ratio of gender in Brazilian medical school. Asking about students' previous experience, 47.7% said they had participated in the care of a dying patient during their medical studies. This finding is coherent with educational experience they have in their medical school.

Psychometric properties of SEPC-Br Scale

Confirmatory factor analysis (CFA) demonstrated that the base model for the SEPC-Br Scale (model A) displayed poor fit index values, based on the CFI, TLI and RMSEA. When the correlation between the items' errors was added (model B), the model achieved a satisfactory level of model fit (table 1).

Each subsection of the SEPC Scale was analysed independently for reliability on test scores. For the first factor, multidisciplinary teamwork, Cronbach's alpha and composite reliability were 0.97 and 0.96, respectively. For the second factor, communication, Cronbach's alpha and composite reliability were 0.93 and 0.93, respectively. For the third factor, patient management, Cronbach's alpha and composite reliability were 0.92 and 0.91, respectively.

Psychometric properties of TS-Br

CFA revealed that the base model for the TS-Br (model A) displayed poor fit index values, based on the CFI,

Table 1 Fit index for the SEPC and Thanatophobia Scales

	χ^2 (df) significance	CFI	TLI	RMSEA (LO90; HI90)
SEPC				
Model A	$\chi^2(227)=776\ 018$; $p<0.001$	0.804	0.782	0.143 (0.132; 0.155)
Model B	$\chi^2(211)=356\ 934$; $p<0.001$	0.945	0.934	0.079 (0.065; 0.093)
Thanatophobia				
Model A	$\chi^2(14)=42\ 058$; $p<0.001$	0.883	0.824	0.136 (0.090; 0.184)
Model B	$\chi^2(11)=12\ 579$; $p>0.05$	0.993	0.987	0.036 (0.000; 0.110)

CFI, Comparative Fit Index; RMSEA (LO90; HI90), root mean square error of approximation (lower and upper limit of 90% of confidence); SEPC, Self-Efficacy in Palliative Care; TLI, Tucker-Lewis Index.

TLI and RMSEA. When the correlation between the items' errors was added (model B), the model achieved a satisfactory level of model fit (table 1). Cronbach's alpha and composite reliability were 0.82 and 0.82, respectively. In summary, table 2 shows the factors and Cronbach's alphas of the Brazilian version compared with the original scale.

Concurrent validity

We found a negative and significant correlation between the SEPC-Br and TS-Br and its dimensions. The magnitude ranged from weak to moderate (table 3).

DISCUSSION

This study aimed to explore the reliability and validity of SEPC-Br and TS-Br. Both scales had a high reliability coefficient measured by Cronbach's alpha and composite reliability. The principal component analysis replicated the original factors and items of SEPC-Br and TS-Br, which supports the construct validity of the scales. We also found a negative correlation between SEPC-Br and TS-Br, indicating that higher the fear of death, the lower the self-efficacy in PC. This result was expected, since students who are uncomfortable with the idea of death may feel more anxious and less confident to take care of dying patients.

In medical education, assessing behaviour change in clinical practice is challenging. Nevertheless, an appropriate theoretical model can provide the means for practical evaluation of the learning process. As previous studies suggest, scales that assess self-efficacy and outcome expectancies may provide valid measurements of the possible impact of an educational programme.^{18 20 21 27} The SEPC-Br showed good psychometric properties after the translation and validation processes, replicating the original factors.²¹ These factors arguably express common core competencies

Table 2 Comparison between the original and Brazilian versions of the scales

Scales	Original scale ¹⁷		Brazilian version	
	Factors	Cronbach's alpha	Factors	Cronbach's alpha
SEPC communication	0.70–0.89	0.93	0.75–0.85	0.93
SEPC patient management	0.55–0.84	0.92	0.51–0.81	0.92
SEPC multidisciplinary teamwork	0.70–0.84	0.92	0.78–0.90	0.97
TS	0.61–0.79	0.84	0.66–0.83	0.82

SEPC, Self-Efficacy in Palliative Care; TS, Thanatophobia Scale.

of PC, and the Brazilian students recognised the same competencies. Although PC education is not well established in Brazilian medical schools, the factors' similarity with the original scale may be explained because of the sample likeness. In both the original and the Brazilian studies, medical students were in the mid of their medical studies, probably aware of the vital role of the communication between doctor and patient, the patient's well-being and the required multidisciplinary work to achieve high standards of care.¹⁰ The TS has also showed good psychometric properties after the translation and validation processes, replicating the original structure of the scale.²¹ This indicates that the scale may be used in the Brazilian context for PC education evaluation based on social cognitive theory.

Our study was the first to examine the psychological properties of a Brazilian version of these scales and the first study to use CFA for both scales. This is important since CFA is theory-driven analysis, meaning that it tests the theory behind the scales. In addition, CFA makes an explicit relation between the latent variable and score. Therefore, our study also adds to the international literature by presenting another type of evidence of validity based on CFA and concurrent validity between the SEPC and thanatophobia.

Making available a validated Brazilian version of these scales will allow medical educators to evaluate students' progress in their PC educational programmes.

Table 3 Correlation between SEPC and Thanatophobia Scales

	Thanatophobia
SEPC communication	–0.516*
SEPC patient management	–0.370*
SEPC multidisciplinary teamwork	–0.262**
SEPC total	–0.499*

*p=0.000; **p=0.006.

SEPC, Self-Efficacy in Palliative Care.

Recently, two Brazilian studies have used modified Brazilian versions of SEPC Scale for evaluation of medical students.^{28 29} Although they have not examined the psychological properties of the SEPC Scale, its use suggests a growing interest in improving PC education for undergraduate students using the self-efficacy concepts. Indeed, PC education in Brazil is increasing, and further efforts for its enhancement are required.

Ongoing evaluation and review of PC educational programmes are necessary since there is no gold standard programme in PC education. Clinical simulation, bedside teaching, e-learning, self-directed study, reflexive learning, small group discussions and lectures are examples of these different pedagogical approaches to teach PC.^{9 30–34} Evaluations of educational outcomes using instruments, such as SEPC-Br and TS-Br, may help educators in shaping the best methods and curriculum composition for their students' needs.^{5 9 34} As a result, future doctors will be better prepared for caring for dying patients. This may show if and how future doctors have been prepared to practice more and better PC, whereas medical schools will use these instruments for improving their PC programmes. Besides, validated versions of the scales and publishing of the resultant data generated inform Brazilian medical educators and may stimulate other countries in Latin America to do the same, supporting future research in PC education and providing data for further improvement in PC training.

Strengths and limitations

We chose validated instruments that were based on a solid theoretical basis, to assess medical students attitudes towards PC. The translation and validation processes were based on a recommended guideline protocol and we worked close to the original authors. Those aspects gave to our study a strong methodological grounding.

One limitation that we should acknowledge is that we used a convenience sample, which could result in selection bias, especially considering that we selected third-year students, with few clinical experiences. However, we had a high response rate, and our sample is, therefore, representative of the students in the mid of the medical course with initial clinical learning and experience, and exposure to critical and dying patients.

The use of self-assessment instruments is not enough by themselves for a final evaluation of learning outcomes and future performance in PC. Therefore, Objective Structured CLinical Examinations (OSCEs), mini-Clinical Evaluation Exercises (mini-CEX) or other external evaluation methods should be used in addition to self-efficacy assessment for a thorough evaluation of learning outcomes.²⁰ Regarding the follow-up of students, these scales could be used for understanding the development of PC competencies in different Portuguese-speaking countries and to compare the

development of PC competencies in curricula with and without structured PC training.

Although this study has mainly focused on the translation and investigation of scales' internal structure and reliability, further studies are necessary to explore and confirm their validity. For example, it is also important to apply these scales on senior medical students and residents to check their validity for these more experienced populations. Also, using strong words at the beginning of each sentence may produce variance beyond the measured construct, the so-called method effects, and future research is needed to clarify this issue.³⁵ Additionally, future research in this area should investigate how the improvement measured by the SEPC Scale and TS persists after PC training and how it influences actual doctors' performance when caring for dying patients.

CONCLUSION

Brazilian medical schools are gradually incorporating PC in their curricula, indicating a recognition of the importance of PC education for Brazilian medical doctors. The original scale developed in English intended to evaluate medical students' self-efficacy in PC and thanatophobia as the outcome expectancy. Using these measurements, we can assess students' self-perceived belief in their performance and measure if and how PC educational programmes are increasing students' self-efficacy. The Brazilian Portuguese version of the scales showed good psychometric properties and may be used to assess PC educational programmes. Medical educators in Brazil and Latin America could use this process and these scales to tailor appropriate pedagogical approaches for their medical students and better prepare doctors for delivering PC.

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Competing interests None declared.

Patient and public involvement Patients and/or the public were not involved in the design, or conduct, or reporting, or dissemination plans of this research.

Patient consent for publication Not required.

Ethics approval We conducted this research in accord with the Declaration of Helsinki. We assured that any student who was not comfortable with the subject would not feel obliged to participate in the study. As exploring themes related to death could be sensitive to some people, if any students demanded support on this subject, they could contact the research team to receive proper aid. For analysis purposes, anonymity was preserved. All students who agreed in participation signed a written informed consent. The Research Ethics Committee (School of Medical Sciences/UNICAMP - 58198016.4.0000.5404/2016) analysed and approved the study prior to the data collection.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement The data are available upon reasonable request. The anonymised data related to this work (students scores in both scales and their demographics) are available and can be requested for the corresponding author email m.a.de.carvalho.filho@umcg.nl.

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