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Assessing palliative care education in undergraduate medical students: translation and validation of the Self-efficacy in Palliative Care and Thanatophobia scales to Brazilian Portuguese

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Complete List of Authors:	Gryschek, Guilherme; Universidade Estadual de Campinas Faculdade de Ciencias Medicas, Internal Medicine Cecilio-Fernandes, Dario; State University of Campinas Faculty of Medical Sciences; Groningen University Department of Health Sciences, CEDAR - Center for Educational Development and Research in Health Professions Mason, Stephen; Marie Curie Palliative Care Institute Liverpool de Carvalho-Filho, Marco Antonio; Groningen University Department of Health Sciences, CEDAR - Center for Educational Development and Research in Health Professions; Universidade Estadual de Campinas Faculdade de Ciencias Medicas, Internal Medicine
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Title: Assessing palliative care education in undergraduate medical students: translation and validation of the Self-efficacy in Palliative Care and Thanatophobia scales to Brazilian Portuguese

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Authors:

- Guilherme Gryschek, School of Medical Sciences, University of Campinas, Campinas-SP, Brazil; ggryschek@gmail.com
- Dario Cecilio-Fernandes, Center for Education Development and Research in Health Professions (CEDAR), research group LEARN, University of Groningen and University Medical Center Groningen, Groningen, the Netherlands and School of Medical Sciences, University of Campinas (UNICAMP), Campinas-SP, Brazil; dario.fernandes@gmail.com
- Stephen R Mason, Palliative Care Institute Liverpool, University of Liverpool, Liverpool, UK; stephen.mason@liverpool.ac.uk
- Marco Antonio de Carvalho Filho (corresponding author), Internal Medicine Department, School of Medical Sciences, University of Campinas; and Center for Educational Development and Research in Health Professions (CEDAR), research group LEARN, University of Groningen, The Netherlands; m.a.de.carvalho.filho@umcg.nl. Address: Antonius Deusinglaan 1 9713AV, Groningen, The Netherlands.

Abstract

Background: As the global population ages, Palliative care is ever more essential to provide care for those patients with incurable chronic conditions. However, in many countries, doctors are not prepared to care for dying patients. Palliative care education for undergraduate medical students should be an urgent concern for all medical schools, including Latin America and Brazil. Advances in palliative care education require robust assessment tools for constant evaluation and improvement of the medical schools' 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: To translate and validate SEPC and Thanatophobia scales into Brazilian Portuguese.

Design: Cross-sectional study.

Setting: One Brazilian medical School.

Participants: Third-year medical students.

Methods: The translation of the scales followed EORTC recommendations, and the authors examined the psychometric properties of the scales using data collected from a cross-sectional sample of 109 medical students in a Brazilian medical school in 2017.

Results: The Brazilian versions of Self-efficacy in Palliative Care and Thanatophobia scales showed good psychometric properties, replicating the original factors (Factor range: 0.51-0.90 and Cronbach's alpha: 0.82-0.97). These factors express the core competencies of palliative care for Brazilian medical students.

Conclusions: The Brazilian version of the scales may be used to assess the impact of current undergraduate training and identify areas for improvement within palliative care educational programmes. Data generated by the scales allow Brazilian researchers to join international conversations on this topic. Medical educators in Brazil could use these scales to tailor

appropriate pedagogical approaches for their medical students and better prepare doctors for PC.

Keywords: self-efficacy; palliative care; thanatophobia; undergraduate medical education;

Strengths and Limitations of this Study

- The translation and validation of SEPC and thanatophobia scales following rigorous methodology allow Brazilian researchers to join the conversation on palliative care education;
- The content validation of those scales in a different population of medical students broaden their usability;
- The scales were not tested to investigate the impact of courses or clinical rotations to explore whether the scales can capture changes in students' readiness to provide palliative care.

Background

Global changes in the demographic patterns of the population have resulted in recognition of palliative care (PC) as a worldwide need (1). As people live longer and suffer from long-term and life-threating diseases, the PC approach must be a core competency for doctors (2,3). Accordingly, medical schools are introducing and improving their palliative medicine programmes for undergraduate medical students (4–6). The World Health Organization (WHO) and the Asociación Latinoamericana de Cuidados Paliativos (ALCP) call for mandatory integration of PC into the medical curriculum. In Brazil, medical schools are just beginning to include PC topics in their curricula (7–9). As Brazil and other Latin American countries respond to this call and progressively introduce PC training into undergraduate medical courses, 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 (1,10). We will consider the Brazilian case. Brazil is the 5th most populous country in the world with 210 million inhabitants and approximately 600.000 people dying every year from conditions that should receive PC (1,11). A recent report identified only 177 PC services in the country, mostly in hospitals and few connected to medical schools (12). Therefore, the ratio of PC service per population is 1:1,180,790 habitants, 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 (13). 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 post-graduate training for all the new doctors, and by 2025, Brazil will have an additional amount of 23,500 doctors practising without any post-graduate training, mostly in primary care facilities and emergency departments (8,9,13). 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 (14,15). In one approach, Bandura's social cognitive theory explains how individuals learn and what drives behaviour change.

According to this theory, 'self-efficacy' and 'outcome expectancy' are central components in behavioural changes, which means that an individual is more likely to perform a specific behaviour successfully when he or she shows higher self-efficacy and the expected outcome is rewarding. Self-efficacy related to one particular subject relies on students` knowledge and skills, their previous experience, and their observation of other's performance. Self-efficacy reflects a bi-directional interaction of internal personal beliefs with students` behaviour and environment. The outcome expectancy is the self-perceived consequence of the student's performance, which can suggest the value this specific performance may have to the student. Appropriate training may strengthen one's confidence in their ability to achieve objectives (self-efficacy), enlighten the importance of desirable actions (outcome expectancies), encouraging the practice of these actions (behaviour/clinical practice). Furthermore, appropriate feedback from the supervisor during the training process may nurture a student's efficacy and modulate their outcome expectancies. Medical educators could use the self-efficacy concept to deliver comprehensive feedback and tailor their teaching approaches to fit students' needs (14,16).

In the context of PC, the Self-efficacy in PC (SEPC) and the Thanatophobia (TS) scales were developed to evaluate student's self-efficacy and their expectations of practice, respectively (14,17,18). The SEPC has three factors related to doctors' expected behaviours in PC: (1) effectively communicating with the patient and family, (2) appropriate assessment and management of patient's symptoms and needs, and (3) work within a multidisciplinary team. 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. (17,19).

Therefore, considering the potential use for PC education in Brazil, it is essential to make available instruments as reliable and valid as the original scales. This study aimed to translate and validate the SEPC and TS to Brazilian Portuguese, following established international procedures, which will contribute to future collaborative studies and meta-analysis in international PC education (20).

Methods

Setting

The validation study was conducted in a Medical School in the Southeast of Brazil. The undergraduate medical course is delivered over six 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 two first 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 two 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 two 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. 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, engaging students in discussions on breaking bad news and end of life ethics.

Participants

For validation analysis, we invited the third-year medical students of class 2017 to answer the translated and pre-tested scales in July 2017 and 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

Self-efficacy in Palliative Care Scale (SEPC) (17): 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 zero to 100, with higher values indicating higher confidence in that particular skill. The original study identified three factors from a number of items: communication (factor range: 0.70-0.89; Cronbach's alpha: 0.93), patient management (factor range: 0.55-0.84; Cronbach's alpha: 0.92) and multidisciplinary team working (factor range: 0.70-0.84; Cronbach's alpha: 0.92) in PC.

Thanatophobia Scale (TS) (19): 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 range from "strongly agree" to "strongly disagree" whether the outcomes. 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 and TS are in English, with no available translation or validation of the scales for the Brazilian Portuguese. Therefore, we proceeded to translate the scales following the *European Organization for Research and Treatment of Cancer* (EORTC) recommendations (20). Firstly, 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) in Brazilian Portuguese.

Phase 2: Pretesting

Both final versions were pilot-tested with ten 6th-year medical students. One of the researchers met the students in a group and explained the study. The students completed the scales and after the researcher asked if they had difficulties in comprehending any item. The students did not suggest any changes and assured they had a good comprehension of the aims and expectations of the scale. Once we had a final version, the scales were distributed to the 3rd 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, firstly, we checked Bartlett's test of sphericity and Kaiser-Meyer-Olkin (KMO) measure for sampling adequacy. Then, we conducted a Principal Component Analysis (PCA) with varimax rotated, to investigate the internal structure of both scales. Finally, we also calculated the reliability of the scales using Cronbach's alpha.

Ethics

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. Anonymity was assured during the process of data analysis. All students that agreed in participate signed written informed consent. The Research Ethics Committee (School of Medical Sciences/UNICAMP - 58198016.4.0000.5404/2016) analysed and approved the study before the data collection.

Results

From a possible 119 potential participants, two did not answer the survey, and eight did not sign the informed consent. Thus, 109 (response rate = 91.6%) were considered for the validation analysis. The sample had an average age of 20 years-old and 58 females (53%) and 51 males.

Psychometric Properties of SEPC-Br Scale

The necessary assumption of PCA was met with a KMO = 0.884, and Bartlett's Test of Sphericity was significant ($p < 0.001$). The PCA with varimax rotated demonstrated three distinct factors, explaining 71.8% of the variance. The factor coefficients ranged from 0.515 to 0.906 (Table 1).

Table 1 – Self-efficacy in Palliative Care Scale: original and translated items, with principal components with varimax rotation solutions

Item		F1	F2	F3
MT.3	*appropriately referring palliative care patients for occupational therapy* **Encaminhando pacientes em cuidados paliativos para terapia ocupacional no momento certo**	0.906		
MT.6	*appropriately referring palliative care patients for psychiatric evaluation* **Encaminhando pacientes em cuidados paliativos para avaliação psiquiátrica no momento certo**	0.886		
MT.4	*appropriately referring palliative care patients for complementary therapies* **Encaminhando pacientes em cuidados paliativos para terapias complementares (i.e. acupuntura, massoterapia, etc) no momento certo**	0.883		
MT.2	*appropriately referring palliative care patients for physiotherapy* **Encaminhando pacientes em cuidados paliativos para fisioterapia no momento certo**	0.882		
MT.5	*appropriately referring palliative care patients to a lymphedema service* **Encaminhando pacientes em cuidados paliativos para tratamento de linfedema no momento certo**	0.881		
MT.7	*appropriately referring palliative care patients to a spiritual advisor* **Encaminhando pacientes em cuidados paliativos para um conselheiro espiritual no momento certo**	0.841		
MT.1	*working in a multi-professional palliative care team* **Trabalhando com uma equipe multiprofissional de cuidados paliativos**	0.787		

CM.5	*discussing the patient's death (to occur) with the family* **Ao conversar com a família do paciente sobre a morte futura do paciente**		0.854	
CM.1	*discussing the likely effects of cancer with the patient* **Ao conversar os efeitos esperados do câncer com meu paciente**		0.848	
CM.4	*discussing the patient's death (to occur) with the patient* **Ao conversar com o paciente sobre a morte do próprio paciente**		0.842	
CM.2	*discussing the likely effects of cancer with the patient's family* **Ao conversar sobre os efeitos esperados do câncer com os familiares do seu paciente**		0.810	
CM.7	*answering the patient's questions "How long have I got to live?"* **Ao responder à pergunta do paciente: "Quanto tempo de vida eu tenho?"**		0.798	
CM.6	*discussing the patient's death with the family upon bereavement* **Ao conversar com a família enlutada sobre a morte do paciente**		0.789	
CM.3	*discussing the issues of death and dying* **Ao conversar assuntos relacionados à morte e ao processo de morrer**		0.783	
CM.8	*answering the patient's questions "Will there be much suffering or pain?"* **Ao responder à pergunta do paciente: "Eu passarei por muito sofrimento ou dor?"**		0.752	
PM.1	*in my ability to assess the patient's needs* **Com a minha habilidade de avaliar as necessidades do paciente**			0.815
PM.3	*in my ability to manage common symptoms experienced in palliative care patients* **Com minha habilidade de manejar sintomas comuns sofridos por pacientes em cuidados paliativos**			0.790
PM.2	*in my knowledge of the aetiology of common symptoms experienced by palliative care* **Com meus conhecimentos sobre a causa de sintomas comuns sofridos por pacientes em cuidados paliativos**			0.774
PM.4	*in my ability to prescribe appropriate and adequate pain control medication* **Com minha habilidade de prescrever medicação para controle da dor de modo adequado**			0.774
PM.5	*in my knowledge of the therapeutic and side effects of analgesic agents* **Com meu conhecimento dos efeitos terapêuticos e colaterais de medicações analgésicas**			0.769
PM.6	*in my ability to provide psychological care for the palliative care patient and their family* **Com minha habilidade de fornecer cuidado psicológico para o paciente em cuidado paliativo e sua família**			0.710
PM.7	*in my ability to provide social care for the palliative care patient and their family* **Com minha habilidade de fornecer cuidado social para o paciente em cuidado paliativo e sua família**			0.684
PM.8	*in my ability to provide spiritual care for the palliative care patient and their family*			0.515

	Com minha habilidade de fornecer cuidado espiritual para o paciente em cuidado paliativo e sua família			
MT: Multidisciplinary teamwork; CM: Communication; PM: Patient Management				

Each subsection of the SEPC was analysed independently for reliability on test scores. For the first factor, Multidisciplinary teamwork (MT), Cronbach's alpha was 0.97. For the second factor, Communication (CM), Cronbach's alpha was 0.93. For the third factor, Patient Management (PM), Cronbach's alpha was 0.92.

Psychometric Properties of Thanatophobia-Br Scale

The necessary assumption of PCA was met with a KMO = 0.823, and Bartlett's Test of Sphericity was significant ($p < 0.001$). One item was deleted because it isolated in another dimension on the reliability analysis. After removing one item, the Principal Component Analysis with varimax rotation demonstrated a unidimensional factorial structure with an eigenvalue of 3.22, explaining 53.6% of the variance; factor coefficients ranged from 0.666 to 0.827. Cronbach's alpha was 0.82. The TS-Br and coefficients factors are displayed below (Table 2).

Table 2 – Thanatophobia Scale: original and translated items and principal components with varimax rotation solutions

Original/Translation	***Coefficients***
Dying patients make me feel uneasy **Pacientes em processo de morrer me deixam desconfortável**	*0.730*
I feel pretty helpless when I have terminal patients on my ward **Eu me sinto desamparado quando tenho pacientes terminais sob meus cuidados**	*0.766*
It is frustrating to have to continue talking with relatives of patients who are not going to get better **É frustrante ter que continuar conversando com parentes de pacientes que não irão melhorar**	*0.721*
Managing dying patients traumatises me **Lidar com pacientes que estão morrendo me traumatiza**	*0.827*
It makes me uncomfortable when a dying patient wants to say goodbye to me **Quando um paciente terminal quer se despedir de mim eu me sinto desconfortável**	*0.666*

I don't look forward to being the personal physician of a dying patient **Eu não gostaria de me tornar o médico responsável por um paciente que está morrendo**	*Excluded item*
When patients begin to discuss death, I feel uncomfortable **Eu me sinto desconfortável quando os pacientes começam a conversar sobre morte**	*0.669*

In summary, Table 3 shows the factors and Cronbach's alphas of the Brazilian version compared to the original scale.

Table 3 – Comparison between the Original and Brazilian version of the scales

Scales	**Original Scale** (17)		**Brazilian version**	
Psychometrics properties	***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*
Thanatophobia Scale	*0.61-0.79*	*0.84*	*0.66-0.83*	*0.82*

Discussion

This study aimed to explore the reliability and validity of SEPC-Br and TS-Br. We can support their reliability by a high internal consistency, as demonstrated by the Cronbach's alpha coefficient. The PCA replicated the original factors of SEPC-Br and TS-Br, which supports the construct validity of the scales.

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 (14,16,17,21). The SEPC-Br showed good psychometric properties after the translation and validation process, replicating the original factors (17). These factors arguably express common core competencies 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 study, medical students were in the midst 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 (7).

About the TS, we had to exclude one item from the TS-Br to maintain the scales' validity. The excluded item was '*I don't look forward to being the personal physician of a dying patient*'. Interestingly, this specific item was discussed during the translation process. We choose the Portuguese translation that appeared to fit better on the original intention of the item. The researchers involved discussed how that specific idea of 'not looking forward' would best communicate in Portuguese. Nevertheless, in the validation process, the TS-Br held its properties after we excluded that item. Therefore, adapted from the original scale, the TS-Br has six items and can be used for future Brazilian studies related to medical education.

Our study was the first to examine the psychological properties of a Brazilian version of these scales. Making available a validated Brazilian version of these scales will allow medical educators to evaluate students' progress in their PC educational programmes. Recently two Brazilian studies have used modified Brazilian versions of SEPC for evaluation of medical students (22,23). Although they have not examined the psychological properties of the SEPC, 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, lectures are examples of these different pedagogical approaches (24–27) and 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 (3,28). As a result, future doctors will be better prepared for caring for dying patients. Whereas medical schools will use these instruments for improving

their PC programmes, this may show if and how future doctors have been prepared to practice more and better PC. 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.

Limitations

The participants' recruitment was by convenience, and this could result in selection bias. However, we had a high response rate, and our sample is, therefore, representative of the students in the mid of the medical course. Also, in our study, we did not evaluate whether the scales can capture the impact of courses or clinical rotations on PC competencies.

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.

List of abbreviations

- PC: Palliative Care
- SEPC: Self-Efficacy in Palliative Care
- TS: Thanatophobia Scale

- PCA: Principal Component Analysis
- KMO: Kaiser-Meyer-Olkin
- OSCE: Objective Structured Clinical Examination
- Mini-CEX: Clinical Evaluation Exercise

Ethics approval and consent to participate

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. Anonymity was assured during the process of data analysis. All students that agreed in participate signed written informed consent. The Research Ethics Committee (School of Medical Sciences/UNICAMP - 58198016.4.0000.5404/2016) analysed and approved the study before the data collection.

Consent for publication

Not applicable

Availability of data and materials

The datasets used and analysed during the current study are available from the corresponding author on reasonable request.

Competing interests

The authors declare that they have no competing interests.

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Author contributions

GG, SRM and MACF conceived and designed the study. GG collected the data. GG, DFC and MACF analysed the data. GG and MACF were the major contributors in manuscript writing. DFC and SRM provided meaningful inputs and critical review of the manuscript. All authors read and approved the final manuscript.

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Author's information

GG, M.Sc., M.D., G.P. is a PhD student at the School of Medical Sciences, UNICAMP, Brazil, in the field of medical education focused on palliative care education;

DCF, PhD is a researcher at Center for Education Development and Research in Health Professions (CEDAR), research group LEARN, University of Groningen and University Medical Center Groningen, Groningen, the Netherlands and at School of Medical Sciences, UNICAMP, Brazil;

SRM, PhD is Research Lead at Palliative Care Institute Liverpool, University of Liverpool, Liverpool, UK;

MACF, M.D., PhD is Associate Professor of Emergency Medicine at the School of Medical Sciences, the University of Campinas, Brazil and Senior Researcher at Center for Education

Development and Research in Health Professions (CEDAR), University of Groningen, Groningen, the Netherlands;

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Reporting checklist for cross sectional study.

Based on the STROBE cross sectional guidelines.

Instructions to authors

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		Reporting Item	Page Number
Title and abstract			
Title	#1a	Indicate the study's design with a commonly used term in the title or the abstract	1
Abstract	#1b	Provide in the abstract an informative and balanced summary of what was done and what was found	2
Introduction			
Background / rationale	#2	Explain the scientific background and rationale for the investigation being reported	3-5
Objectives	#3	State specific objectives, including any prespecified hypotheses	5-6
Methods			
Study design	#4	Present key elements of study design early in the paper	1 / 7-8
Setting	#5	Describe the setting, locations, and relevant dates, including periods of	6

		recruitment, exposure, follow-up, and data collection	
Eligibility criteria	#6a	Give the eligibility criteria, and the sources and methods of selection of participants.	6
	#7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	6
Data sources / measurement	#8	For each variable of interest give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group. Give information separately for for exposed and unexposed groups if applicable.	7-8
Bias	#9	Describe any efforts to address potential sources of bias	7-8
Study size	#10	Explain how the study size was arrived at	7-8
Quantitative variables	#11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen, and why	8
Statistical methods	#12a	Describe all statistical methods, including those used to control for confounding	8
Statistical methods	#12b	Describe any methods used to examine subgroups and interactions	n/a
Statistical methods	#12c	Explain how missing data were addressed	9
Statistical methods	#12d	If applicable, describe analytical methods taking account of sampling strategy	8
Statistical methods	#12e	Describe any sensitivity analyses	n/a
Results			
Participants	#13a	Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed. Give information separately for for exposed and unexposed groups if applicable.	9
Participants	#13b	Give reasons for non-participation at each stage	9
Participants	#13c	Consider use of a flow diagram	n/a

Descriptive data	#14a	Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders. Give information separately for exposed and unexposed groups if applicable.	9
Descriptive data	#14b	Indicate number of participants with missing data for each variable of interest	9
Outcome data	#15	Report numbers of outcome events or summary measures. Give information separately for exposed and unexposed groups if applicable.	n/a
Main results	#16a	Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	n/a
Main results	#16b	Report category boundaries when continuous variables were categorized	n/a
Main results	#16c	If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	n/a
Other analyses	#17	Report other analyses done—e.g., analyses of subgroups and interactions, and sensitivity analyses	n/a
Discussion			
Key results	#18	Summarise key results with reference to study objectives	12-14
Limitations	#19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias.	14
Interpretation	#20	Give a cautious overall interpretation considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence.	12-14
Generalisability	#21	Discuss the generalisability (external validity) of the study results	14
Other Information			
Funding	#22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	16

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Assessing palliative care education in undergraduate medical students: translation and validation of the Self-efficacy in Palliative Care and Thanatophobia scales to Brazilian Portuguese

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Title: Assessing palliative care education in undergraduate medical students: translation and validation of the Self-efficacy in Palliative Care and Thanatophobia scales to Brazilian Portuguese

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Authors:

- Guilherme Gryschek, School of Medical Sciences, University of Campinas, Campinas-SP, Brazil; ggryschek@gmail.com
- Dario Cecilio-Fernandes, Department of Medical Psychology and Psychiatry, School of Medical Sciences, University of Campinas (UNICAMP), Campinas-SP, Brazil; dario.fernandes@gmail.com
- Stephen R Mason, Palliative Care Institute Liverpool, University of Liverpool, Liverpool, UK; stephen.mason@liverpool.ac.uk
- Marco Antonio de Carvalho Filho (corresponding author), Internal Medicine Department, School of Medical Sciences, University of Campinas; and Center for Educational Development and Research in Health Professions (CEDAR), research group LEARN, University of Groningen, The Netherlands; m.a.de.carvalho.filho@umcg.nl. Address: Antonius Deusinglaan 1 9713AV, Groningen, The Netherlands.

Abstract

Background: Palliative care education for undergraduate medical students should be an urgent concern for all medical schools, including in Latin America and Brazil. Advances in palliative care education require robust assessment tools for constant evaluation and improvement of the 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: To translate and validate SEPC and Thanatophobia scales into Brazilian Portuguese.

Design: Cross-sectional study.

Setting: One Brazilian medical School.

Participants: Third-year medical students.

Methods: the authors translated the SEPC and Thanatophobia scales following the *European Organization for Research and Treatment of Cancer* recommendations and examined the psychometric properties of the scales using data collected from a cross-sectional sample of 119 medical students in a Brazilian medical school in 2017.

Results: Confirmatory factor analyses demonstrated that both the Brazilian versions of SEPC and Thanatophobia scales followed the same structure as the original versions. In addition, there was a negative correlation between both scales, indicating that higher students' fear of death, lower their self-efficacy. Cronbach's alpha and Composite reliability were adequate for both scales, ranging from 0.82 to 0.97.

Conclusions: The Brazilian version of the scales may be used to assess the impact of current undergraduate training and identify areas for improvement within palliative care educational programmes. Data generated by the scales allow Brazilian researchers to join international conversations on this topic. Medical educators in Brazil could use these scales to tailor

appropriate pedagogical approaches for their medical students and better prepare doctors for PC.

Keywords: self-efficacy; palliative care; attitude to death; undergraduate medical education; psychometrics;

Strengths and Limitations of this Study

- The translation and validation processes were grounded on solid methodological basis;
- SEPC and Thanatofobia scales showed good psychometric properties and can be used in the Brazilian context of PC education;
- There was a significant negative correlation between the scales – a new evidence of their validity.
- Longitudinal studies are needed to explore how the scales could be used to support students' development in PC education.

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 brought new possibilities of sustaining life in circumstances that were unimaginable before (2). However, life under these new circumstances demands for certain sacrifices that not all patients judge feasible or valuable (3). Thus, as people live longer and suffer from long-term and life-threating diseases, the PC approach has become a core competency for doctors (4,5). The decision-making in palliative care occurs as a process and not as "yes/no" decisions, and patients and health professionals need time to deal with the uncertainties that are present until the best course of action becomes clear. PC education needs to acknowledge this complexity and uncertainty and go beyond the technical possibilities of care to embrace its ethical, moral, and

spiritual dimensions while striving for controlling symptoms and alleviating suffering (4). Accordingly, medical schools are introducing and improving their palliative medicine programmes for undergraduate medical students (6–9).

The World Health Organization (WHO) and the Asociación Latinoamericana de Cuidados Paliativos (ALCP) 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 (1,14). We will consider the Brazilian case. Brazil is the 5th 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 habitants, 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 post-graduate training for all the new doctors, and by 2025, Brazil will have an additional amount of 23,500 doctors practising without any post-graduate 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. 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 expectancies). 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 PC (SEPC) and the Thanatophobia (TS) scales were developed to evaluate student's self-efficacy and their expectations of practice, respectively (18,21,22). The SEPC 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 palliative care. Also, these instruments will allow Brazilian educators to engage in international conversations about this topic. This study aimed to translate and validate the SEPC and TS to 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 six 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 two first 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 two 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 two 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.

In the medical school where this study was performed, 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 the university hospital does not have enough beds for all the patients in critical conditions, there are 40 patients in average under mechanical ventilation outside of the ICU

daily. So, students often have contact with critical patients who eventually die since early moments of the undergraduate course. This early contact with dying patients justifies why this sample was chosen to validate the 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, engaging students in discussions on breaking bad news and end of life ethics.

Participants

For validation analysis, we invited the third-year medical students of class 2017 to answer the translated and pre-tested 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 (n=111, response rate=93.2%).

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

Self-efficacy in Palliative Care Scale (SEPC) (21): 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 zero to 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; Cronbach’s alpha: 0.93), (B) patient management (factor range: 0.55-0.84; Cronbach’s alpha: 0.92) and (C) multidisciplinary team working (factor range: 0.70-0.84; Cronbach’s alpha: 0.92) in PC.

Thanatophobia Scale (TS) (23): 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 range from "strongly agree" to "strongly disagree" whether the outcomes. 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 and TS are in English, with no available translation or validation of the scales for the Brazilian Portuguese. Therefore, we proceeded to translate the scales following the *European Organization for Research and Treatment of Cancer* (EORTC) recommendations (24). Firstly, 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) in Brazilian Portuguese. The translated version of both scales are in Appendices 1 and 2.

Phase 2: Pretesting

Both final versions were pilot-tested with ten 6th-year medical students. One of the researchers met the students in a group and explained the study. The students completed the

scales and after the researcher asked if they had difficulties in comprehending any item. The students did not suggest any changes and assured they had a good comprehension of the aims and expectations of the scale. Once we had a final version, the scales were distributed to the 3rd 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, firstly, 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: Chi-square statistics, Comparative Fit Index (CFI), Tucker Lewis Index (TLI) and Root Mean Square Error of Aproximation (RMSEA). The Chi-square 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). 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.

Ethics

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 that agreed in participate signed written informed consent. The Research Ethics Committee (School of Medical Sciences/UNICAMP - 58198016.4.0000.5404/2016) analysed and approved the study before the data collection.

Results

From a possible 119 potential participants, eight did not sign the informed consent. Thus, 111 (response rate = 93.2%) were considered for the SEPC validation analysis and, due to absence of data, 109 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 gender distribution in Brazilian medical schools. Considering participants' previous experience, 47,7% said they had participated in the care of a dying patient during their medical studies.

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 χ2/df ratio, the Comparative Fit Index (CFI), Tucker Lewis Index (TLI) and Root Mean Square Error of Approximation (RMSEA). When the correlation between the items' errors was added (model B), the model achieved a satisfactory level of model fit (Table 1).

Table 1 - Fit index for the SEPC and Thanatophobia scales

		χ^2(df) Sig.	**Ratio χ^2/df**	**TLI**	**CFI**	**RMSEA (HI90)**
SEPC	Model A	$\chi^2(227) = 776.018$; $p<0.001$	3.418	0.782	0.804	0.143 (0.155)
	Model B	$\chi^2(211) = 356.934$; $p<0.001$	1.691	0.934	0.945	0.079 (0.093)
Thanatophobia	Model A	$\chi^2(14) = 42.058$; $p<0.001$	3.004	0.824	0.883	0.136 (0.184)
	Model B	$\chi^2(11) = 12.579$; $p>0.05$	1.143	0.987	0.993	0.036 (0.110)

Abbreviations: SEPC = Self-efficacy in Palliative Care; χ^2(df) Sig. = Chi-square (degree of freedom) Significance; TLI = Tucker-Lewis Index; CFI = Comparative Fit Index; RMSEA (HI90) = Root Mean Square Error of Approximation (Upper limit of 90% of confidence).

Each subsection of the SEPC was analysed independently for reliability on test scores. For the first factor, Multidisciplinary Teamwork (MT), Cronbach's alpha and Composite reliability were 0.97 and 0.96, respectively. For the second factor, Communication (CM), Cronbach's alpha and Composite reliability were 0.93 and 0.93, respectively. For the third factor, Patient Management (PM), Cronbach's alpha and Composite reliability were 0.92 and 0.91 respectively.

Psychometric Properties of Thanatophobia-Br Scale

Confirmatory Factor Analysis (CFA) revealed that the base model for the Thanatophobia_BR scale (model A) displayed poor fit index values, based on the χ2/df ratio, the Comparative Fit Index (CFI), Tucker Lewis Index (TLI) and Root Mean Square Error of Approximation (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 to the original scale.

Table 2 – Comparison between the Original and Brazilian version of the scales

Scales	**Original Scale** (17)		**Brazilian version**	
Psychometrics properties	***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*
Thanatophobia Scale	*0.61-0.79*	*0.84*	*0.66-0.83*	*0.82*

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).

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<0.01; Abbreviations: SEPC = Self-efficacy in Palliative Care;

Discussion

This study aimed to explore the reliability and validity of SEPC-Br and TS-Br. We can support their reliability by a high internal consistency, as demonstrated by the Cronbach's alpha and Composite reliability coefficient. 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 process, replicating the original factors (21). These factors arguably express common core competencies 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 study, medical students were in the midst 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 shown good psychometric properties after the translation and validation process, 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 Confirmatory Factor Analysis for both scales. This is important since confirmatory factor analysis is theory-driven, meaning that it tests the theory behind the scales. In addition, confirmatory factor analysis makes an explicit relation between the latent variable and score. Therefore, our study also adds to the international literature by demonstrating another type of evidence of validity based on confirmatory factor analysis.

Making available a validated Brazilian version of these scales will allow medical educators to evaluate students' progress in their PC educational programmes. Recently two Brazilian studies have used modified Brazilian versions of SEPC for evaluation of medical students (28,29). Although they have not examined the psychological properties of the SEPC, 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. Whereas medical schools will use these instruments for improving their PC programmes, this may show if and

how future doctors have been prepared to practice more and better PC. 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 choose validated instruments that were based on solid theoretical basis, to assess medical students` attitudes towards palliative care. The translation and validation process were based on a recommended protocol. 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 representative of the students in the mid of the medical course.

The use of self-assessment instruments is not enough by themselves for a final evaluation of learning outcomes and future performance in PC. Therefore, OSCE, 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 palliative care competencies in different Portuguese speaking countries and to compare the development of palliative care competencies in curricula with and without structured palliative care 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 in senior medical students and residents to check their validity for these more experienced populations. Additionally, future research in this area should investigate how the improvement measured by the SEPC 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.

List of abbreviations

- CFA: Confirmatory Factor Analysis
- CFI: Comparative Fit Index
- EORTC: European Organization for Research and Treatment of Cancer
- Mini-CEX: Clinical Evaluation Exercise
- OSCE: Objective Structured Clinical Examination
- PC: Palliative Care
- RMSEA: Root Mean Square Error of Aproximation
- SEPC: Self-Efficacy in Palliative Care
- TLI: Tucker Lewis Index
- TS: Thanatophobia Scale

Declarations

Ethics approval and consent to participate

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 that agreed in participate signed 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.

Consent for publication

Not applicable

Availability of data and materials

The anonymized 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.

Competing interests

The authors declare that they have no competing interests.

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Author contributions

GG, SRM and MACF conceived and designed the study. GG collected the data. GG, DCF and MACF analysed the data. GG and MACF were the major contributors in manuscript

writing. DCF and SRM provided meaningful inputs and critical review of the manuscript. All authors read and approved the final manuscript.

Data availability statement

The anonymized 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. No additional data available.

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Author's information

GG, M.Sc., M.D., G.P. is a PhD student at the School of Medical Sciences, UNICAMP, Brazil, in the field of medical education focused on palliative care education;

DCF, PhD is a young investigator at Department of Medical Psychology and Psychiatry, School of Medical Sciences, UNICAMP, Brazil;

SRM, PhD is Research Lead at Palliative Care Institute Liverpool, University of Liverpool, Liverpool, UK;

MACF, M.D., PhD is Associate Professor of Emergency Medicine at the School of Medical Sciences, the University of Campinas, Brazil and Senior Researcher at Center for Education Development and Research in Health Professions (CEDAR), University of Groningen, Groningen, the Netherlands;

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Appendix 1 – Self-efficacy in Palliative Care Scale: original and Brazilian Portuguese translation (CM: Communication; PM: Patient Management; MT: Multidisciplinary teamwork)

Item	Original	Translation
CM1	*discussing the likely effects of cancer with the patient*	**Ao conversar os efeitos esperados do câncer com meu paciente**
CM2	*discussing the likely effects of cancer with the patient's family*	**Ao conversar os efeitos esperados do câncer com os familiares do seu paciente**
CM3	*discussing the issues of death and dying*	**Ao conversar assuntos relacionados à morte e ao processo de morrer**
CM4	*discussing the patient's death (to occur) with the patient*	**Ao conversar com o paciente sobre a morte do próprio paciente**
CM5	*discussing the patient's death (to occur) with the family*	**Ao conversar com a família do paciente a morte futura do paciente**
CM6	*discussing the patient's death with the family upon bereavement*	**Ao conversar com a família enlutada a morte do paciente**
CM7	*answering the patient's questions "How long have I got to live?"*	**Ao responder à pergunta do paciente: "Quanto tempo de vida eu tenho?"**
CM8	*answering the patient's questions "Will there be much suffering or pain?"*	**Ao responder à pergunta do paciente: "Eu passarei por muito sofrimento ou dor?"**
PM1	*in my ability to assess the patient's needs*	**Com a minha habilidade de avaliar as necessidades do paciente**
PM2	*in my knowledge of the aetiology of common symptoms experienced by palliative care*	**Com meus conhecimentos sobre a causa de sintomas comuns sofridos por pacientes em cuidados paliativos**
PM3	*in my ability to manage common symptoms experienced in palliative care patients*	**Com minha habilidade de manejar sintomas comuns sofridos por pacientes em cuidados paliativos**
PM4	*in my ability to prescribe appropriate and adequate pain control medication*	**Com minha habilidade de prescrever medicação para controle da dor de modo adequado**
PM5	*in my knowledge of the therapeutic and side effects of analgesic agents*	**Com meu conhecimento dos efeitos terapêuticos e colaterais de medicações analgésicas**
PM6	*in my ability to provide psychological care for the palliative care patient and their family*	**Com minha habilidade de fornecer cuidado psicológico para o paciente em cuidado paliativo e sua família**
PM7	*in my ability to provide social care for the palliative care patient and their family*	**Com minha habilidade de fornecer cuidado social para o paciente em cuidado paliativo e sua família**
PM8	*in my ability to provide spiritual care for the palliative care patient and their family*	**Com minha habilidade de fornecer cuidado espiritual para o paciente em cuidado paliativo e sua família**
MT1	*working in a multi-professional palliative care team*	**Trabalhando com uma equipe multiprofissional de cuidados paliativos**
MT2	*appropriately referring palliative care patients for physiotherapy*	**Encaminhando pacientes em cuidados paliativos para fisioterapia no momento certo**
MT3	*appropriately referring palliative care patients for occupational therapy*	**Encaminhando pacientes em cuidados paliativos para terapia ocupacional no momento certo**

MT4	*appropriately referring palliative care patients for complementary therapies*	**Encaminhando pacientes em cuidados paliativos para terapias complementares (i.e. acupuntura, massoterapia, etc) no momento certo**
MT5	*appropriately referring palliative care patients to a lymphedema service*	**Encaminhando pacientes em cuidados paliativos para tratamento de linfedema no momento certo**
MT6	*appropriately referring palliative care patients for psychiatric evaluation*	**Encaminhando pacientes em cuidados paliativos para avaliação psiquiátrica no momento certo**
MT7	*appropriately referring palliative care patients to a spiritual advisor*	**Encaminhando pacientes em cuidados paliativos para um conselheiro espiritual no momento certo**

Appendix 2 – Thanatophobia Scale: original and Brazilian Portuguese translation

Original/**Translation**
Dying patients make me feel uneasy **Pacientes em processo de morrer me deixam desconfortável**
I feel pretty helpless when I have terminal patients on my ward **Eu me sinto desamparado quando tenho pacientes terminais sob meus cuidados**
It is frustrating to have to continue talking with relatives of patients who are not going to get better **É frustrante ter que continuar conversando com parentes de pacientes que não irão melhorar**
Managing dying patients traumatises me **Lidar com pacientes que estão morrendo me traumatiza**
It makes me uncomfortable when a dying patient wants to say goodbye to me **Quando um paciente terminal quer se despedir de mim eu me sinto desconfortável**
I don't look forward to being the personal physician of a dying patient **Eu não gostaria de me tornar o médico responsável por um paciente que está morrendo**
When patients begin to discuss death, I feel uncomfortable **Eu me sinto desconfortável quando os pacientes começam a conversar sobre morte**

Reporting checklist for cross sectional study.

Based on the STROBE cross sectional guidelines.

Instructions to authors

Complete this checklist by entering the page numbers from your manuscript where readers will find each of the items listed below.

Your article may not currently address all the items on the checklist. Please modify your text to include the missing information. If you are certain that an item does not apply, please write "n/a" and provide a short explanation.

Upload your completed checklist as an extra file when you submit to a journal.

In your methods section, say that you used the STROBE cross sectionalreporting guidelines, and cite them as:

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		Reporting Item	Page Number
Title and abstract			
Title	#1a	Indicate the study's design with a commonly used term in the title or the abstract	1
Abstract	#1b	Provide in the abstract an informative and balanced summary of what was done and what was found	2
Introduction			
Background / rationale	#2	Explain the scientific background and rationale for the investigation being reported	3-5
Objectives	#3	State specific objectives, including any prespecified hypotheses	5-6
Methods			
Study design	#4	Present key elements of study design early in the paper	1 / 7-8
Setting	#5	Describe the setting, locations, and relevant dates, including periods of	6

		recruitment, exposure, follow-up, and data collection	
Eligibility criteria	#6a	Give the eligibility criteria, and the sources and methods of selection of participants.	6
	#7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	6
Data sources / measurement	#8	For each variable of interest give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group. Give information separately for for exposed and unexposed groups if applicable.	7-8
Bias	#9	Describe any efforts to address potential sources of bias	7-8
Study size	#10	Explain how the study size was arrived at	7-8
Quantitative variables	#11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen, and why	8
Statistical methods	#12a	Describe all statistical methods, including those used to control for confounding	8
Statistical methods	#12b	Describe any methods used to examine subgroups and interactions	n/a
Statistical methods	#12c	Explain how missing data were addressed	9
Statistical methods	#12d	If applicable, describe analytical methods taking account of sampling strategy	8
Statistical methods	#12e	Describe any sensitivity analyses	n/a
Results			
Participants	#13a	Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed. Give information separately for for exposed and unexposed groups if applicable.	9
Participants	#13b	Give reasons for non-participation at each stage	9
Participants	#13c	Consider use of a flow diagram	n/a

Descriptive data	#14a	Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders. Give information separately for exposed and unexposed groups if applicable.	9
Descriptive data	#14b	Indicate number of participants with missing data for each variable of interest	9
Outcome data	#15	Report numbers of outcome events or summary measures. Give information separately for exposed and unexposed groups if applicable.	n/a
Main results	#16a	Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	n/a
Main results	#16b	Report category boundaries when continuous variables were categorized	n/a
Main results	#16c	If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	n/a
Other analyses	#17	Report other analyses done—e.g., analyses of subgroups and interactions, and sensitivity analyses	n/a
Discussion			
Key results	#18	Summarise key results with reference to study objectives	12-14
Limitations	#19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias.	14
Interpretation	#20	Give a cautious overall interpretation considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence.	12-14
Generalisability	#21	Discuss the generalisability (external validity) of the study results	14
Other Information			
Funding	#22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	16

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Assessing palliative care education in undergraduate medical students: translation and validation of the Self-efficacy in Palliative Care and Thanatophobia scales to Brazilian Portuguese

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Title: Assessing palliative care education in undergraduate medical students: translation and validation of the Self-efficacy in Palliative Care and Thanatophobia scales to Brazilian Portuguese

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Authors:

- Guilherme Gryschek, School of Medical Sciences, University of Campinas, Campinas-SP, Brazil; ggryschek@gmail.com
- Dario Cecilio-Fernandes, Department of Medical Psychology and Psychiatry, School of Medical Sciences, University of Campinas (UNICAMP), Campinas-SP, Brazil; dario.fernandes@gmail.com
- Stephen R Mason, Palliative Care Institute Liverpool, University of Liverpool, Liverpool, UK; stephen.mason@liverpool.ac.uk
- Marco Antonio de Carvalho Filho (corresponding author), Internal Medicine Department, School of Medical Sciences, University of Campinas; and Centre for Educational Development and Research in Health Professions (CEDAR), research group LEARN, University of Groningen, The Netherlands; m.a.de.carvalho.filho@umcg.nl. Address: Antonius Deusinglaan 1 9713AV, Groningen, The Netherlands.

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 Organization for Research and Treatment of Cancer* 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 Self-efficacy in Palliative Care and Thanatophobia scales showed good psychometric properties, including confirmatory factor analysis, replicating the original factors (Factor range: .51-.90), and acceptable values of reliability (Cronbach's alpha: .82-.97 and Composite reliability .82-.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 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.

Keywords: self-efficacy; palliative care; attitude to death; undergraduate medical education; psychometrics;

Article Summary: Strengths and Limitations of this Study

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

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-threating diseases, the PC approach must be a core competency for doctors (4,5). Moreover, the decision-making in palliative care 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 World Health Organization (WHO) and the Asociación Latinoamericana de Cuidados Paliativos (ALCP) 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 (1,14). We will consider the Brazilian case. Brazil is the 5th 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 habitants, 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 post-graduate training for all the new doctors, and by 2025, Brazil will have an additional amount of 23,500 doctors practising without any post-graduate 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 expectancies). 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 PC (SEPC) and the Thanatophobia (TS) scales were developed to evaluate student's self-efficacy and their expectations of practice, respectively (18,21,22). The SEPC 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 palliative care. Also, these instruments will allow Brazilian educators to engage in international conversations about this topic. This study aimed to translate and validate the SEPC and TS to 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 six 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 two first 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 two 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 two 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 the six years of medical school, on bio- and clinical ethics, in which they discuss, among other topics, the concepts of euthanasia, dysthanasia, orthothanasia, and end-of-life care. In the first three years, the course is mainly theoretical, and, in the last three 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 brake 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 pre-tested 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

Self-efficacy in Palliative Care Scale (SEPC) (21): 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 zero to 100, with higher values indicating higher confidence in that specific task. The original study identified three factors: (A) communication (factor range: .70 - .89; Cronbach's alpha: .93), (B) patient management (factor range: .55 - .84; Cronbach's alpha: .92) and (C) multidisciplinary team working (factor range: .70- .84; Cronbach's alpha: .92) in PC.

Thanatophobia Scale (TS) (23): 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 .61 and .79, and a Cronbach’s alpha of .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 range from "strongly agree" to "strongly disagree" whether the outcomes. 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 and TS are in English, with no available translation or validation of the scales for the Brazilian Portuguese. Therefore, we proceeded to translate the scales following the *European Organization for Research and Treatment of Cancer* (EORTC) recommendations (24). Firstly, 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) in Brazilian Portuguese.

Phase 2: Pretesting

Both final versions were pilot-tested in a focus group with ten 6th-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 (appendices 1 and 2), the scales were distributed to the 3rd 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, firstly, 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: Chi-square statistics, Comparative Fit Index (CFI), Tucker Lewis Index (TLI) and Root Mean Square Error of Approximation (RMSEA). The Chi-square 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 .90 (25). Optimal RMSEA is lower than .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.

Data were analyzed using IBM-SPSS 21.0 and R (lavaan and dplyr packcages). The latter was used for the confirmatory factor analysis and calculating the Composite reliability, respectively.

Ethics

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 that agreed in participate signed written informed consent. The Research Ethics Committee (School of Medical

Sciences/UNICAMP - 58198016.4.0000.5404/2016) analysed and approved the study before the data collection.

Results

From a possible 119 potential participants, eight did not sign the informed consent. Thus, 111 (response rate = 93.2%) were considered for the SEPC validation analysis and, due to 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 Comparative Fit Index (CFI), Tucker Lewis Index (TLI) and Root Mean Square Error of Approximation (RMSEA). When the correlation between the items' errors was added (model B), the model achieved a satisfactory level of model fit (Table 1).

Table 1 - Fit index for the SEPC and Thanatophobia scales

		χ^2(df) Sig.	**CFI**	**TLI**	**RMSEA (LO90; HI90)**
SEPC	Model A	$\chi^2(227) = 776.018$; $p<0.001$	.804	.782	.143 (.132; .155)

	Model B	$\chi^2(211) = 356.934$; $p<0.001$	.945	.934	.079 (.065; .093)
Thanatophobia	Model A	$\chi^2(14) = 42.058$; $p<0.001$	.883	.824	.136 (.090; 0.184)
	Model B	$\chi^2(11) = 12.579$; $p>0.05$	.993	.987	.036 (.000; .110)

Abbreviations: SEPC = Self-efficacy in Palliative Care; χ^2(df) Sig. = Chi-square (degree of freedom) Significance; TLI = Tucker-Lewis Index; CFI = Comparative Fit Index; RMSEA (HI90) = Root Mean Square Error of Approximation (Lower and Upper limit of 90% of confidence).

Each subsection of the SEPC was analyzed independently for reliability on test scores. For the first factor, Multidisciplinary teamwork (MT), Cronbach's alpha and Composite reliability were .97 and .96, respectively. For the second factor, Communication (CM), Cronbach's alpha and Composite reliability were .93 and .93, respectively. For the third factor, Patient Management (PM), Cronbach's alpha and Composite reliability were .92 and .91 respectively.

Psychometric Properties of Thanatophobia-Br Scale

Confirmatory Factor Analysis (CFA) revealed that the base model for the Thanatophobia_BR scale (model A) displayed poor fit index values, based on the Comparative Fit Index (CFI), Tucker Lewis Index (TLI) and Root Mean Square Error of Approximation (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 .82 and .82, respectively. In summary, Table 2 shows the factors and Cronbach's alphas of the Brazilian version compared to the original scale.

Table 2 – Comparison between the Original and Brazilian version of the scales

Scales	**Original Scale** (17)	**Brazilian version**

Psychometrics properties	*Factors*	*Cronbach's alpha*	*Factors*	*Cronbach's alpha*
SEPC Communication	*.70 - .89*	*.93*	*.75 - .85*	*.93*
SEPC Patient Management	*.55 - .84*	*.92*	*.51- .81*	*.92*
SEPC Multidisciplinary teamwork	*.70 - .84*	*.92*	*.78 - .90*	*.97*
Thanatophobia Scale	*.61 - .79*	*.84*	*.66 - .83*	*.82*

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).

Table 3 – Correlation between SEPC and Thanatophobia scales

	Thanatophobia
SEPC Communication	-.516*
SEPC Patient Management	-.370*
SEPC Multidisciplinary teamwork	-.262**
SEPC Total	-.499*

*p=0.000; **p=0.006 Abbreviations: SEPC = Self-efficacy in Palliative Care;

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 alfa 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 process, replicating the original factors (21). These factors arguably express common core competencies 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 study, medical students were in the midst 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 process, 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 Confirmatory Factor Analysis for both scales. This is important since confirmatory factor analysis is theory-driven analysis, meaning that it tests the theory behind the scales. In addition, confirmatory factor analysis 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 confirmatory factor analysis 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. Recently two Brazilian studies have used modified Brazilian versions of SEPC for evaluation of medical students (28,29). Although they have not examined the psychological properties of the SEPC, 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, 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. Whereas medical schools will use these instruments for improving their PC programmes, this may show if and how future doctors have been prepared to practice more and better PC. 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 choose validated instruments that were based on a solid theoretical basis, to access medical students` attitudes towards palliative care. 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, OSCE, 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 palliative care competencies

in different Portuguese speaking countries and to compare the development of palliative care competencies in curricula with and without structured palliative care 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 in senior medical students and residents to check their validity for these more experienced populations. Additionally, future research in this area should investigate how the improvement measured by the SEPC 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.

List of abbreviations

- CFA: Confirmatory Factor Analysis
- CFI: Comparative Fit Index
- EORTC: European Organization for Research and Treatment of Cancer
- Mini-CEX: Clinical Evaluation Exercise

- OSCE: Objective Structured Clinical Examination
- PC: Palliative Care
- RMSEA: Root Mean Square Error of Approximation
- SEPC: Self-Efficacy in Palliative Care
- TLI: Tucker Lewis Index
- TS: Thanatophobia Scale

Declarations

Ethics approval and consent to participate

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 that agreed in participate signed 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.

Consent for publication

Not applicable

Availability of data and materials

The datasets used and analysed during the current study are available from the corresponding author on reasonable request.

Competing interests

The authors declare that they have no competing interests.

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Author contributions

GG, SRM and MACF conceived and designed the study. GG collected the data. GG, DCF and MACF analysed the data. GG and MACF were the major contributors in manuscript writing. DCF and SRM provided meaningful inputs and critical review of the manuscript. All authors read and approved the final manuscript.

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Author's information

GG, M.Sc., M.D., G.P. is a PhD student at the School of Medical Sciences, UNICAMP, Brazil, in the field of medical education focused on palliative care education;

DCF, PhD is a young investigator at Department of Medical Psychology and Psychiatry, School of Medical Sciences, UNICAMP, Brazil;

SRM, PhD is Research Lead at Palliative Care Institute Liverpool, University of Liverpool, Liverpool, UK;

MACF, M.D., PhD is Associate Professor of Emergency Medicine at the School of Medical Sciences, the University of Campinas, Brazil and Senior Researcher at Center for Education

Development and Research in Health Professions (CEDAR), University of Groningen, Groningen, the Netherlands;

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Appendix 1 – Self-efficacy in Palliative Care Scale: original and Brazilian Portuguese translation (CM: Communication; PM: Patient Management; MT: Multidisciplinary teamwork)

Item	Original	Translation
CM1	*discussing the likely effects of cancer with the patient*	**Ao conversar os efeitos esperados do câncer com meu paciente**
CM2	*discussing the likely effects of cancer with the patient's family*	**Ao conversar os efeitos esperados do câncer com os familiares do seu paciente**
CM3	*discussing the issues of death and dying*	**Ao conversar assuntos relacionados à morte e ao processo de morrer**
CM4	*discussing the patient's death (to occur) with the patient*	**Ao conversar com o paciente sobre a morte do próprio paciente**
CM5	*discussing the patient's death (to occur) with the family*	**Ao conversar com a família do paciente a morte futura do paciente**
CM6	*discussing the patient's death with the family upon bereavement*	**Ao conversar com a família enlutada a morte do paciente**
CM7	*answering the patient's questions "How long have I got to live?"*	**Ao responder à pergunta do paciente: "Quanto tempo de vida eu tenho?"**
CM8	*answering the patient's questions "Will there be much suffering or pain?"*	**Ao responder à pergunta do paciente: "Eu passarei por muito sofrimento ou dor?"**
PM1	*in my ability to assess the patient's needs*	**Com a minha habilidade de avaliar as necessidades do paciente**
PM2	*in my knowledge of the aetiology of common symptoms experienced by palliative care*	**Com meus conhecimentos sobre a causa de sintomas comuns sofridos por pacientes em cuidados paliativos**
PM3	*in my ability to manage common symptoms experienced in palliative care patients*	**Com minha habilidade de manejar sintomas comuns sofridos por pacientes em cuidados paliativos**
PM4	*in my ability to prescribe appropriate and adequate pain control medication*	**Com minha habilidade de prescrever medicação para controle da dor de modo adequado**
PM5	*in my knowledge of the therapeutic and side effects of analgesic agents*	**Com meu conhecimento dos efeitos terapêuticos e colaterais de medicações analgésicas**
PM6	*in my ability to provide psychological care for the palliative care patient and their family*	**Com minha habilidade de fornecer cuidado psicológico para o paciente em cuidado paliativo e sua família**

PM7	*in my ability to provide social care for the palliative care patient and their family*	**Com minha habilidade de fornecer cuidado social para o paciente em cuidado paliativo e sua família**
PM8	*in my ability to provide spiritual care for the palliative care patient and their family*	**Com minha habilidade de fornecer cuidado espiritual para o paciente em cuidado paliativo e sua família**
MT1	*working in a multi-professional palliative care team*	**Trabalhando com uma equipe multiprofissional de cuidados paliativos**
MT2	*appropriately referring palliative care patients for physiotherapy*	**Encaminhando pacientes em cuidados paliativos para fisioterapia no momento certo**
MT3	*appropriately referring palliative care patients for occupational therapy*	**Encaminhando pacientes em cuidados paliativos para terapia ocupacional no momento certo**
MT4	*appropriately referring palliative care patients for complementary therapies*	**Encaminhando pacientes em cuidados paliativos para terapias complementares (i.e. acupuntura, massoterapia, etc) no momento certo**
MT5	*appropriately referring palliative care patients to a lymphedema service*	**Encaminhando pacientes em cuidados paliativos para tratamento de linfedema no momento certo**
MT6	*appropriately referring palliative care patients for psychiatric evaluation*	**Encaminhando pacientes em cuidados paliativos para avaliação psiquiátrica no momento certo**
MT7	*appropriately referring palliative care patients to a spiritual advisor*	**Encaminhando pacientes em cuidados paliativos para um conselheiro espiritual no momento certo**

Appendix 2 – Thanatophobia Scale: original and Brazilian Portuguese translation

Original/**Translation**
Dying patients make me feel uneasy **Pacientes em processo de morrer me deixam desconfortável**
I feel pretty helpless when I have terminal patients on my ward **Eu me sinto desamparado quando tenho pacientes terminais sob meus cuidados**
It is frustrating to have to continue talking with relatives of patients who are not going to get better **É frustrante ter que continuar conversando com parentes de pacientes que não irão melhorar**
Managing dying patients traumatises me **Lidar com pacientes que estão morrendo me traumatiza**
It makes me uncomfortable when a dying patient wants to say goodbye to me **Quando um paciente terminal quer se despedir de mim eu me sinto desconfortável**
I don't look forward to being the personal physician of a dying patient **Eu não gostaria de me tornar o médico responsável por um paciente que está morrendo**
When patients begin to discuss death, I feel uncomfortable **Eu me sinto desconfortável quando os pacientes começam a conversar sobre morte**

Reporting checklist for cross sectional study.

Based on the STROBE cross sectional guidelines.

Instructions to authors

Complete this checklist by entering the page numbers from your manuscript where readers will find each of the items listed below.

Your article may not currently address all the items on the checklist. Please modify your text to include the missing information. If you are certain that an item does not apply, please write "n/a" and provide a short explanation.

Upload your completed checklist as an extra file when you submit to a journal.

In your methods section, say that you used the STROBE cross sectionalreporting guidelines, and cite them as:

von Elm E, Altman DG, Egger M, Pocock SJ, Gotzsche PC, Vandenbroucke JP. The Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) Statement: guidelines for reporting observational studies.

		Reporting Item	Page Number
Title and abstract			
Title	#1a	Indicate the study's design with a commonly used term in the title or the abstract	1
Abstract	#1b	Provide in the abstract an informative and balanced summary of what was done and what was found	2
Introduction			
Background / rationale	#2	Explain the scientific background and rationale for the investigation being reported	3-5
Objectives	#3	State specific objectives, including any prespecified hypotheses	5-6
Methods			
Study design	#4	Present key elements of study design early in the paper	1 / 7-8
Setting	#5	Describe the setting, locations, and relevant dates, including periods of	6

		recruitment, exposure, follow-up, and data collection	
Eligibility criteria	#6a	Give the eligibility criteria, and the sources and methods of selection of participants.	6
	#7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	6
Data sources / measurement	#8	For each variable of interest give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group. Give information separately for for exposed and unexposed groups if applicable.	7-8
Bias	#9	Describe any efforts to address potential sources of bias	7-8
Study size	#10	Explain how the study size was arrived at	7-8
Quantitative variables	#11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen, and why	8
Statistical methods	#12a	Describe all statistical methods, including those used to control for confounding	8
Statistical methods	#12b	Describe any methods used to examine subgroups and interactions	n/a
Statistical methods	#12c	Explain how missing data were addressed	9
Statistical methods	#12d	If applicable, describe analytical methods taking account of sampling strategy	8
Statistical methods	#12e	Describe any sensitivity analyses	n/a
Results			
Participants	#13a	Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed. Give information separately for for exposed and unexposed groups if applicable.	9
Participants	#13b	Give reasons for non-participation at each stage	9
Participants	#13c	Consider use of a flow diagram	n/a

Descriptive data	#14a	Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders. Give information separately for exposed and unexposed groups if applicable.	9
Descriptive data	#14b	Indicate number of participants with missing data for each variable of interest	9
Outcome data	#15	Report numbers of outcome events or summary measures. Give information separately for exposed and unexposed groups if applicable.	n/a
Main results	#16a	Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	n/a
Main results	#16b	Report category boundaries when continuous variables were categorized	n/a
Main results	#16c	If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	n/a
Other analyses	#17	Report other analyses done—e.g., analyses of subgroups and interactions, and sensitivity analyses	n/a
Discussion			
Key results	#18	Summarise key results with reference to study objectives	12-14
Limitations	#19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias.	14
Interpretation	#20	Give a cautious overall interpretation considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence.	12-14
Generalisability	#21	Discuss the generalisability (external validity) of the study results	14
Other Information			
Funding	#22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	16

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Assessing palliative care education in undergraduate medical students: translation and validation of the Self-efficacy in Palliative Care and Thanatophobia scales to Brazilian Portuguese

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Authors:

- Guilherme Gryschek, School of Medical Sciences, University of Campinas, Campinas-SP, Brazil; ggryschek@gmail.com
- Dario Cecilio-Fernandes, Department of Medical Psychology and Psychiatry, School of Medical Sciences, University of Campinas (UNICAMP), Campinas-SP, Brazil; dario.fernandes@gmail.com
- Stephen R Mason, Palliative Care Institute Liverpool, University of Liverpool, Liverpool, UK; stephen.mason@liverpool.ac.uk
- Marco Antonio de Carvalho Filho (corresponding author), Internal Medicine Department, School of Medical Sciences, University of Campinas; and Centre for Educational Development and Research in Health Professions (CEDAR), research group LEARN, University of Groningen, The Netherlands; m.a.de.carvalho.filho@umcg.nl. Address: Antonius Deusinglaan 1 9713AV, Groningen, The Netherlands.

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 Organization for Research and Treatment of Cancer* 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 Self-efficacy in Palliative Care and Thanatophobia scales showed good psychometric properties, including confirmatory factor analysis, replicating the original factors (Factor range: .51-.90), and acceptable values of reliability (Cronbach's alpha: .82-.97 and Composite reliability .82-.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 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.

Keywords: self-efficacy; palliative care; attitude to death; undergraduate medical education; psychometrics;

Article Summary: Strengths and Limitations of this Study

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

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-threating diseases, the PC approach must be a core competency for doctors (4,5). Moreover, the decision-making in palliative care 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 World Health Organization (WHO) and the Asociación Latinoamericana de Cuidados Paliativos (ALCP) 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 (1,14). We will consider the Brazilian case. Brazil is the 5th 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 habitants, 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 post-graduate training for all the new doctors, and by 2025, Brazil will have an additional amount of 23,500 doctors practising without any post-graduate 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 expectancies). 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 PC (SEPC) and the Thanatophobia (TS) scales were developed to evaluate student's self-efficacy and their expectations of practice, respectively (18,21,22). The SEPC 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 palliative care. Also, these instruments will allow Brazilian educators to engage in

international conversations about this topic. This study aimed to translate and validate the SEPC and TS to 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 six 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 two first 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 two 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 two 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 the six years of medical school, on bio- and clinical ethics, in which they discuss, among other topics, the concepts of euthanasia, dysthanasia, orthothanasia, and end-of-life care. In the first three years, the course is mainly theoretical, and, in the last three 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 brake 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 pre-tested 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

Self-efficacy in Palliative Care Scale (SEPC) (21): 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 zero to 100, with higher values indicating higher confidence in that specific task. The original study identified three factors: (A) communication (factor range: .70 - .89; Cronbach’s alpha: .93), (B) patient management (factor range: .55 - .84; Cronbach’s alpha: .92) and (C) multidisciplinary team working (factor range: .70- .84; Cronbach’s alpha: .92) in PC.

Thanatophobia Scale (TS) (23): 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 .61 and .79, and a Cronbach's alpha of .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 range from "strongly agree" to "strongly disagree" whether the outcomes. 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 and TS are in English, with no available translation or validation of the scales for the Brazilian Portuguese. Therefore, we proceeded to translate the scales following the *European Organization for Research and Treatment of Cancer* (EORTC) recommendations (24). Firstly, 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 – Appendices 1 and 2)) in Brazilian Portuguese.

Phase 2: Pretesting

Both final versions were pilot-tested in a focus group with ten 6th-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 3rd 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, firstly, 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: Chi-square statistics, Comparative Fit Index (CFI), Tucker Lewis Index (TLI) and Root Mean Square Error of Approximation (RMSEA). The Chi-square 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 .90 (25). Optimal RMSEA is lower than .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.

Data were analyzed using IBM-SPSS 21.0 and R (lavaan and dplyr packages). The latter was used for the confirmatory factor analysis and calculating the Composite reliability, respectively.

Ethics

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 that agreed in participate signed written informed consent. The Research Ethics Committee (School of Medical

Sciences/UNICAMP - 58198016.4.0000.5404/2016) analysed and approved the study before the data collection.

Results

From a possible 119 potential participants, eight did not sign the informed consent. Thus, 111 (response rate = 93.2%) were considered for the SEPC validation analysis and, due to 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 Comparative Fit Index (CFI), Tucker Lewis Index (TLI) and Root Mean Square Error of Approximation (RMSEA). When the correlation between the items' errors was added (model B), the model achieved a satisfactory level of model fit (Table 1).

Table 1 - Fit index for the SEPC and Thanatophobia scales

		χ^2(df) Sig.	CFI	TLI	RMSEA (LO90; HI90)
SEPC	Model A	$\chi^2(227) = 776.018$; $p<0.001$	.804	.782	.143 (.132; .155)
	Model B	$\chi^2(211) = 356.934$; $p<0.001$	.945	.934	.079 (.065; .093)

Thanato phobia	Model A	$\chi^2(14) = 42.058$; p<0.001	.883	.824	.136 (.090; .184)
	Model B	$\chi^2(11) = 12.579$; p>0.05	.993	.987	.036 (.000; .110)

Abbreviations: SEPC = Self-efficacy in Palliative Care; χ^2(df) Sig. = Chi-square (degree of freedom) Significance; TLI = Tucker-Lewis Index; CFI = Comparative Fit Index; RMSEA (HI90) = Root Mean Square Error of Approximation (Lower and Upper limit of 90% of confidence).

Each subsection of the SEPC was analyzed independently for reliability on test scores. For the first factor, Multidisciplinary teamwork (MT), Cronbach's alpha and Composite reliability were .97 and .96, respectively. For the second factor, Communication (CM), Cronbach's alpha and Composite reliability were .93 and .93, respectively. For the third factor, Patient Management (PM), Cronbach's alpha and Composite reliability were .92 and .91 respectively.

Psychometric Properties of Thanatophobia-Br Scale

Confirmatory Factor Analysis (CFA) revealed that the base model for the Thanatophobia_Br scale (model A) displayed poor fit index values, based on the Comparative Fit Index (CFI), Tucker Lewis Index (TLI) and Root Mean Square Error of Approximation (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 .82 and .82, respectively. In summary, Table 2 shows the factors and Cronbach's alphas of the Brazilian version compared to the original scale.

Table 2 – Comparison between the Original and Brazilian version of the scales

Scales	**Original Scale (17)**		**Brazilian version**	
Psychometrics properties	***Factors***	***Cronbach's alpha***	***Factors***	***Cronbach's alpha***
SEPC Communication	*.70 - .89*	*.93*	*.75 - .85*	*.93*
SEPC Patient Management	*.55 - .84*	*.92*	*.51- .81*	*.92*

SEPC Multidisciplinary teamwork	*.70 - .84*	*.92*	*.78 - .90*	*.97*
Thanatophobia Scale	*.61 - .79*	*.84*	*.66 - .83*	*.82*

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).

Table 3 – Correlation between SEPC and Thanatophobia scales

	Thanatophobia
SEPC Communication	-.516*
SEPC Patient Management	-.370*
SEPC Multidisciplinary teamwork	-.262**
SEPC Total	-.499*

*p=0.000; **p=0.006 Abbreviations: SEPC = Self-efficacy in Palliative Care;

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 alfa 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 process, replicating the original factors (21). These factors

arguably express common core competencies 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 study, medical students were in the midst 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 process, 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 Confirmatory Factor Analysis for both scales. This is important since confirmatory factor analysis is theory-driven analysis, meaning that it tests the theory behind the scales. In addition, confirmatory factor analysis 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 confirmatory factor analysis 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. Recently two Brazilian studies have used modified Brazilian versions of SEPC for evaluation of medical students (28,29). Although they have not examined the psychological properties of the SEPC, 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, 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. Whereas medical schools will use these instruments for improving their PC programmes, this may show if and how future doctors have been prepared to practice more and better PC. 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 choose validated instruments that were based on a solid theoretical basis, to access medical students` attitudes towards palliative care. 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, OSCE, 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 palliative care competencies in different Portuguese speaking countries and to compare the development of palliative care competencies in curricula with and without structured palliative care 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 in 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 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.

List of abbreviations

- CFA: Confirmatory Factor Analysis
- CFI: Comparative Fit Index
- EORTC: European Organization for Research and Treatment of Cancer
- Mini-CEX: Clinical Evaluation Exercise
- OSCE: Objective Structured Clinical Examination
- PC: Palliative Care

- RMSEA: Root Mean Square Error of Approximation
- SEPC: Self-Efficacy in Palliative Care
- TLI: Tucker Lewis Index
- TS: Thanatophobia Scale

Declarations

Ethics approval and consent to participate

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 that agreed in participate signed 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.

Consent for publication

Not applicable

Availability of data and materials

The datasets used and analysed during the current study are available from the corresponding author on reasonable request.

Competing interests

The authors declare that they have no competing interests.

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Author contributions

GG, SRM and MACF conceived and designed the study. GG collected the data. GG, DCF and MACF analysed the data. GG and MACF were the major contributors in manuscript writing. DCF and SRM provided meaningful inputs and critical review of the manuscript. All authors read and approved the final manuscript.

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Author's information

GG, M.Sc., M.D., G.P. is a PhD student at the School of Medical Sciences, UNICAMP, Brazil, in the field of medical education focused on palliative care education;

DCF, PhD is a young investigator at Department of Medical Psychology and Psychiatry, School of Medical Sciences, UNICAMP, Brazil;

SRM, PhD is Research Lead at Palliative Care Institute Liverpool, University of Liverpool, Liverpool, UK;

MACF, M.D., PhD is Associate Professor of Emergency Medicine at the School of Medical Sciences, the University of Campinas, Brazil and Senior Researcher at Center for Education Development and Research in Health Professions (CEDAR), University of Groningen, Groningen, the Netherlands;

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Appendix 1 – Self-efficacy in Palliative Care Scale: original and Brazilian Portuguese translation (CM: Communication; PM: Patient Management; MT: Multidisciplinary teamwork)

Item	Original	Translation
CM1	*discussing the likely effects of cancer with the patient*	**Ao conversar os efeitos esperados do câncer com meu paciente**
CM2	*discussing the likely effects of cancer with the patient's family*	**Ao conversar os efeitos esperados do câncer com os familiares do seu paciente**
CM3	*discussing the issues of death and dying*	**Ao conversar assuntos relacionados à morte e ao processo de morrer**
CM4	*discussing the patient's death (to occur) with the patient*	**Ao conversar com o paciente sobre a morte do próprio paciente**
CM5	*discussing the patient's death (to occur) with the family*	**Ao conversar com a família do paciente a morte futura do paciente**
CM6	*discussing the patient's death with the family upon bereavement*	**Ao conversar com a família enlutada a morte do paciente**
CM7	*answering the patient's questions "How long have I got to live?"*	**Ao responder à pergunta do paciente: "Quanto tempo de vida eu tenho?"**
CM8	*answering the patient's questions "Will there be much suffering or pain?"*	**Ao responder à pergunta do paciente: "Eu passarei por muito sofrimento ou dor?"**
PM1	*in my ability to assess the patient's needs*	**Com a minha habilidade de avaliar as necessidades do paciente**
PM2	*in my knowledge of the aetiology of common symptoms experienced by palliative care*	**Com meus conhecimentos sobre a causa de sintomas comuns sofridos por pacientes em cuidados paliativos**
PM3	*in my ability to manage common symptoms experienced in palliative care patients*	**Com minha habilidade de manejar sintomas comuns sofridos por pacientes em cuidados paliativos**
PM4	*in my ability to prescribe appropriate and adequate pain control medication*	**Com minha habilidade de prescrever medicação para controle da dor de modo adequado**
PM5	*in my knowledge of the therapeutic and side effects of analgesic agents*	**Com meu conhecimento dos efeitos terapêuticos e colaterais de medicações analgésicas**
PM6	*in my ability to provide psychological care for the palliative care patient and their family*	**Com minha habilidade de fornecer cuidado psicológico para o paciente em cuidado paliativo e sua família**

PM7	*in my ability to provide social care for the palliative care patient and their family*	**Com minha habilidade de fornecer cuidado social para o paciente em cuidado paliativo e sua família**
PM8	*in my ability to provide spiritual care for the palliative care patient and their family*	**Com minha habilidade de fornecer cuidado espiritual para o paciente em cuidado paliativo e sua família**
MT1	*working in a multi-professional palliative care team*	**Trabalhando com uma equipe multiprofissional de cuidados paliativos**
MT2	*appropriately referring palliative care patients for physiotherapy*	**Encaminhando pacientes em cuidados paliativos para fisioterapia no momento certo**
MT3	*appropriately referring palliative care patients for occupational therapy*	**Encaminhando pacientes em cuidados paliativos para terapia ocupacional no momento certo**
MT4	*appropriately referring palliative care patients for complementary therapies*	**Encaminhando pacientes em cuidados paliativos para terapias complementares (i.e. acupuntura, massoterapia, etc) no momento certo**
MT5	*appropriately referring palliative care patients to a lymphedema service*	**Encaminhando pacientes em cuidados paliativos para tratamento de linfedema no momento certo**
MT6	*appropriately referring palliative care patients for psychiatric evaluation*	**Encaminhando pacientes em cuidados paliativos para avaliação psiquiátrica no momento certo**
MT7	*appropriately referring palliative care patients to a spiritual advisor*	**Encaminhando pacientes em cuidados paliativos para um conselheiro espiritual no momento certo**

Appendix 2 – Thanatophobia Scale: original and Brazilian Portuguese translation

Original/**Translation**
Dying patients make me feel uneasy **Pacientes em processo de morrer me deixam desconfortável**
I feel pretty helpless when I have terminal patients on my ward **Eu me sinto desamparado quando tenho pacientes terminais sob meus cuidados**
It is frustrating to have to continue talking with relatives of patients who are not going to get better **É frustrante ter que continuar conversando com parentes de pacientes que não irão melhorar**
Managing dying patients traumatises me **Lidar com pacientes que estão morrendo me traumatiza**
It makes me uncomfortable when a dying patient wants to say goodbye to me **Quando um paciente terminal quer se despedir de mim eu me sinto desconfortável**
I don't look forward to being the personal physician of a dying patient **Eu não gostaria de me tornar o médico responsável por um paciente que está morrendo**
When patients begin to discuss death, I feel uncomfortable **Eu me sinto desconfortável quando os pacientes começam a conversar sobre morte**

Reporting checklist for cross sectional study.

Based on the STROBE cross sectional guidelines.

Instructions to authors

Complete this checklist by entering the page numbers from your manuscript where readers will find each of the items listed below.

Your article may not currently address all the items on the checklist. Please modify your text to include the missing information. If you are certain that an item does not apply, please write "n/a" and provide a short explanation.

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		Reporting Item	Page Number
Title and abstract			
Title	#1a	Indicate the study's design with a commonly used term in the title or the abstract	1
Abstract	#1b	Provide in the abstract an informative and balanced summary of what was done and what was found	2
Introduction			
Background / rationale	#2	Explain the scientific background and rationale for the investigation being reported	3-5
Objectives	#3	State specific objectives, including any prespecified hypotheses	5-6
Methods			
Study design	#4	Present key elements of study design early in the paper	1 / 7-8
Setting	#5	Describe the setting, locations, and relevant dates, including periods of	6

		recruitment, exposure, follow-up, and data collection	
Eligibility criteria	#6a	Give the eligibility criteria, and the sources and methods of selection of participants.	6
	#7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	6
Data sources / measurement	#8	For each variable of interest give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group. Give information separately for for exposed and unexposed groups if applicable.	7-8
Bias	#9	Describe any efforts to address potential sources of bias	7-8
Study size	#10	Explain how the study size was arrived at	7-8
Quantitative variables	#11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen, and why	8
Statistical methods	#12a	Describe all statistical methods, including those used to control for confounding	8
Statistical methods	#12b	Describe any methods used to examine subgroups and interactions	n/a
Statistical methods	#12c	Explain how missing data were addressed	9
Statistical methods	#12d	If applicable, describe analytical methods taking account of sampling strategy	8
Statistical methods	#12e	Describe any sensitivity analyses	n/a
Results			
Participants	#13a	Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed. Give information separately for for exposed and unexposed groups if applicable.	9
Participants	#13b	Give reasons for non-participation at each stage	9
Participants	#13c	Consider use of a flow diagram	n/a

Descriptive data	#14a	Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders. Give information separately for exposed and unexposed groups if applicable.	9
Descriptive data	#14b	Indicate number of participants with missing data for each variable of interest	9
Outcome data	#15	Report numbers of outcome events or summary measures. Give information separately for exposed and unexposed groups if applicable.	n/a
Main results	#16a	Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	n/a
Main results	#16b	Report category boundaries when continuous variables were categorized	n/a
Main results	#16c	If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	n/a
Other analyses	#17	Report other analyses done—e.g., analyses of subgroups and interactions, and sensitivity analyses	n/a
Discussion			
Key results	#18	Summarise key results with reference to study objectives	12-14
Limitations	#19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias.	14
Interpretation	#20	Give a cautious overall interpretation considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence.	12-14
Generalisability	#21	Discuss the generalisability (external validity) of the study results	14
Other Information			
Funding	#22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	16