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Translation and cross-cultural adaptation of the Dignity Therapy Question Protocol to Brazilian Portuguese

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Abstract

Objectives. Dignity therapy (DT) was developed to help patients at their end of life to reframe and give meaning to their illness process. The DT question protocol focuses on personhood and important aspects of the individual's life. This study aimed to translate and culturally adapt the Dignity Therapy Question Protocol (DTQP) to Brazilian Portuguese.

Methods. This was a descriptive and methodological study, and cross-cultural adaptation process comprised 4 stages: (1) translation and synthesis of English original version protocol into Brazilian Portuguese, (2) back translation, (3) experts committee, and (4) pretest.

Results. The Portuguese version of the DTQP – *Protocolo de Perguntas sobre Terapia da Dignidade* – demonstrated a content validity index of 1 for all equivalences. The initial sample consisted of 41 participants (9 [21.9%] refused to participate and 1 [2.43%] dropped out). The pretest was applied to 30 (73.1%) participants, 15 of them were female and the mean age was 53.4 years. The final version consisted of 10 questions that were approved by the original authors who affirmed that the DTQP Brazilian Portuguese version maintained the original English characteristics.

Significance of results. The Brazilian cultural adaptation of the DTQP was well understood by patients. It will be very useful in palliative care clinical practice for patients nearing end of life. The adapted version to Brazilian Portuguese will facilitate future studies using the DTQP.

Introduction

When illness generates a threat to personal integrity, human beings are naturally led to reflect on life and death, along with their own values, culture and identity (Lakasing 2014). As medicine became more focused on technology, end-of-life care gradually moved toward institutional care and away from communities, making discussions of death and dying uncomfortable and aversive. As paradoxical as it may seem, engaging in conversations about finitude reduces anxiety, feeling of loneliness, depression and fear in patients and their families (Death Education 2019; Kalish 2002). In addition, patients with depression, anxiety, and hopelessness are more likely to express a desire to die and a loss of sense of dignity (Chochinov 2012).

Dignity comprises both inherent and extrinsic components; the latter of which can be bolstered through personal relationships and notions of respect for oneself and others (Jacobson 2009; Tadd et al. 2002). With the advent of Model of Dignity in the Terminally Ill, it became possible to delineate features of dignity toward end of life (Chochinov 2002a, 2004, 2012, 2022b; Chochinov et al. 2002c; Julião 2014a). Based on this model, dignity therapy (DT) was developed in order to help dying patients reframe and give meaning to their illness process through narrative addressing of significant life stories and reflections. These are recorded, transcribed, and edited to produce a generativity document that patient can bequeath to their loved ones (Chochinov 2004, 2012; Chochinov et al. 2005).

After patients consent to doing DT, they are presented with a list of questions, stimulating the recollection of memories, thoughts, and feelings and words that need to be shared. The original English DT Question Protocol has been adapted for use in several countries such as China, Japan, Denmark, Portugal, Germany, and Sweden (Chochinov 2012). In order for DT to enable the creation of a reliable legacy document, it is essential that patients fully understand what they are being asked. To the best of our knowledge, the DT Question Protocol has never been adapted to Brazilian Portuguese. Hence, the aim of this study was to translate

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and culturally adapt the Dignity Therapy Question Protocol (DTQP) to Brazilian Portuguese.

Methods

Study design and setting

This study used descriptive methods for the process of cross-cultural adaptation. It took place within an inpatient palliative care unit at Barretos Cancer Hospital (Barretos, São Paulo, Brazil).

Ethical considerations

This study was approved by the Committee of Ethics in Research of Barretos Cancer Hospital, under the opinion no. 5.567.892/2022. All the participants invited to participate in the study signed an informed consent form.

Procedures

The translation from English into Brazilian Portuguese followed the internationally established standardized process proposed by Beaton et al. (2000) and Sousa and Rojjanasrirat (2011). It took place in 4 stages: (1) translation and synthesis of English original version protocol into Brazilian Portuguese, (2) back translation, (3) review by expert committee, and (4) pretest.

Stages of the study

Stage I: translation and synthesis of English original version protocol into Brazilian Portuguese

In this stage, 2 independent bilingual translators, one with native English and fluency in Brazilian Portuguese and the other with native Brazilian Portuguese and fluency in English, evaluated and translated the English version of the DT question protocol, generating 2 versions (T1 and T2), which were synthesized into a unique version (T12).

Stage II: back translation

The back translation process consisted of translating the synthesized Portuguese version back into English by 2 independent bilingual translators different from the translation phase ones, who evaluated and translated the synthesized Portuguese version (T12) and produced 2 versions of the back translation (BT TR1 and BT TR2), which were synthesized into a single English version almost identical to the original.

Stage III: experts committee

An expert committee, comprising 2 palliative doctors, 2 nurses and a psychologist, then examined and rated each question, using a Likert scale (1 = inaccurate, 2 = not very precise, 3 = precise, and 4 = very precise). They also proposed suggestions for better adaptation. Items were judged based on equivalence of meaning (semantic equivalence), cultural context (cultural equivalence), and concept (conceptual equivalence) (Beaton et al. 2000). This was followed by the calculation of the Content Validity Index (CVI), which measures the proportion of participants in the expert committee who are in agreement with the instrument's items. This procedure is performed by calculating the number of responses with a score of 3 or 4 on the Likert scale ("precise" or "very precise," respectively) divided by the total number of responses. In order to consider the item adequate, the minimum recommended agreement is 80% (Alexandre and Colucci 2011). The protocol was then considered suitable for pretest.

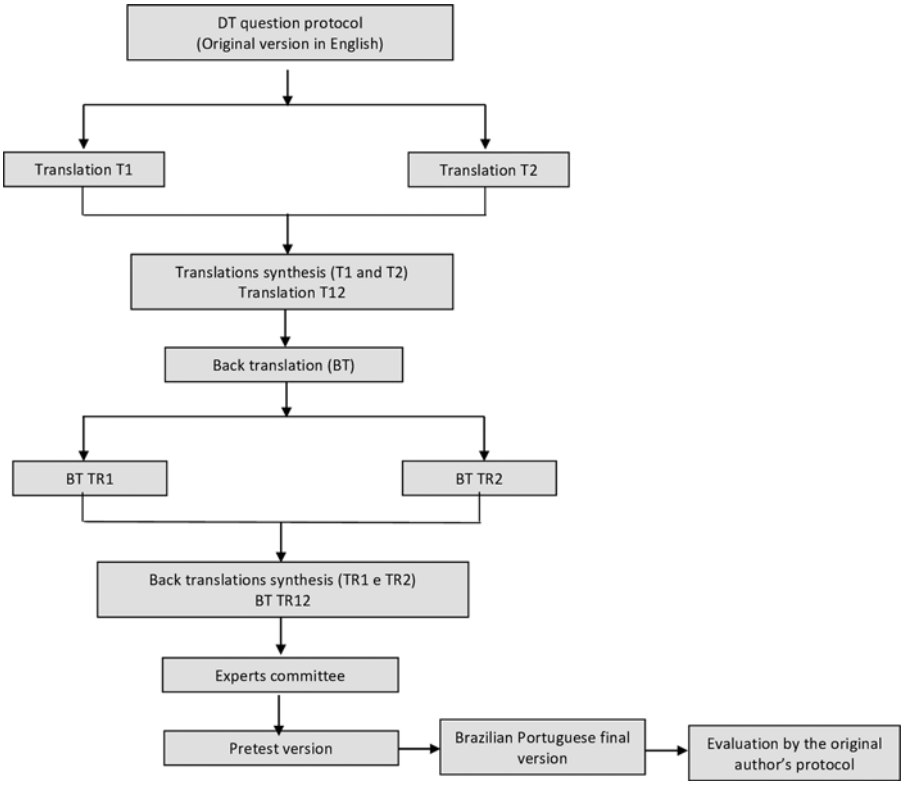

Fig. 1. DT question protocol process of translation and cultural adaptation flowchart.
BT: back translation.

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Stage IV: pretest

In order to maintain a good generalizability, the pretest aims to test the questionnaire in a sample from the same population in which this instrument will be applied in studies that envisage larger samples.

For the pretest, we used convenience sampling. The pretest took place in a sample of 30 participants, with eligibility criteria including the following: (1) at least 18 years old, (2) with an incurable disease, (3) receiving palliative treatment, with or without oncology follow-up, (4) with awareness of illness and incurable, (5) fluent in Brazilian Portuguese, orally and in writing.

The final translation of the DTPQ was evaluated by the authors of the original protocol, who approved the Brazilian Portuguese version, indicating that it maintained the essence of the original English version, which was based on the Model of Dignity in the Terminally Ill (Chochinov 2004, 2012; Chochinov et al. 2005) (see Figure 1).

Pretest data collection

Sociodemographic characteristics

The following data were collected: age (years), gender, religion, educational level, marital status, number of children, primary caregiver, diagnosis, time since diagnosis, and Palliative Performance Scale (PPS).

Dignity therapy question protocol

The DTQP is a question guide that is presented to patients before the DT application itself and aims to encourage the participant to reflect on subjects that can be discussed during DT. This is done to reduce patient's anxiety about the process one will go through during this intervention. This protocol is meant to be flexible, adapting to patient's preferences, and not necessarily being addressed in its entirety. It is meant to guide and facilitate a dialogue between the therapist and participant (Chochinov 2012).

Pretest protocol

A pretest protocol was designed to elicit participant ratings on each item in terms of textual clarity. Each participant rated the protocol title and questions for the criteria "doubts" and "discomfort, annoyance, and/or embarrassment" using a dichotomous scale (YES or NO). Items that were classified as not understandable or unpleasant were reformulated by way of consensus among the researchers who evaluated the participants' suggestions (Sousa and Rojjanasrirat 2011)

Statistical analysis

Descriptive statistics were used to describe sociodemographic variables and responses to the feedback questionnaire. Semantic, cultural, and conceptual equivalences were determined by calculating the content validity index.

Study data were managed using REDCap electronic data capture tools (Harris et al. 2009), hosted at *Barretos Cancer Hospital*, and analyzed using IBM Statistical Package for the Social Sciences (SPSS), version 27.

Results

Translation and cross-cultural adaptation

The translation and back translation were carried as per the previously described. This resulted in the emergence of the Portuguese version *Protocolo de Perguntas sobre Terapia da Dignidade* ("Protocol of Questions about Dignity Therapy"); all 11 questions from the original question protocol were retained.

Questionnaire items 1, 3, 4, 5, 6, 7, 8, 10, and 11 received score of 3, and the experts committee proposed suggestions for modifying the respective items. No item received a score lower than 3, and therefore the content validity index was 1 for all equivalences (semantic, cultural, and conceptual). The remaining items received a score of 4. Table 1 shows the item-specific expert committee recommendations.

Table 1. Description of the items with modifications requested by the expert committee

Item	Committee's suggestions	Modifications
1	Discussion for the choice between the adverb "particularly" and "mainly"	Chosen to keep the adverb "particularly," as in the original version in English and European Portuguese.
		"Tell me a little about your life story; particularly the parts you remember the most or think are the most important."
3	Word replacement to "particular" from "specific"	"Are there specific things you want your family to know about you, and are there specific things you want them to remember?"
4	Word replacement to "roles" from "functions"	What are the most important functions you have performed in your life (family, professional, community service)? Why were they so important to you and what do you think you accomplished within those functions?
5	Perception of redundancy in the expression "feel most proud of or take most pride in"	"What are your most important accomplishments and which ones are you most proud of?"
6	Word replacement to "particular" from "specific"	"Are there specific things that need to be said to your loved ones or things that you wish you could take the time to say one more time?"
7	Word replacement to "hopes" from "wishes" and the expression addition of "for the future"	"What are your wishes and dreams for the future of your loved ones?"
8	Discussion for the choice between the verb mode "would like" and "want"	Chosen to keep the verb mode "would like," as in the original version in English and European Portuguese.
		"What have you learned about life that you would like to pass on to others?"
10	Word replacement to "instructions" from "guidance"	"Are there important words or guidance you would like to offer your family?"
11	Remove the expression "When creating this permanent record"	"Would you like to include other things in this record?"

Pretest

From all the possible participants screened, 262 patients did not meet the eligibility criteria, mainly due to delirium and the process

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Table 2. Sociodemographic characteristics of the participants who completed the pretest

Variable	Patients	
	N	%
Sex		
Female	15	50
Male	15	50
Marital status		
Single	5	16.7
Married/stable union	19	63.3
Divorced	4	13.3
Widower	2	6.7
Number of children		
None	3	10
1	5	16.7
2	5	16.7
3	6	20
≥4	11	36.7
Education		
Primary	13	43.3
Secondary	11	36.7
Higher	6	20
Religion		
Catholic	14	46.7
Evangelical	10	33.3
Spiritist	4	13.3
Ignored	2	6.7
Primary caregiver		
Spouse	11	36.7
Children	11	36.7
Brother/Sister	3	10
Parents	2	6.7
Others[a]	5	16.7
Diagnosis (neoplasms)		
Gastrointestinal tract	10	33.3
Lung	4	13.3
Breast	3	10
Genitourinary	6	20
Sarcomas	3	10
Hematological	1	3.3
Others[b]	3	10
Time since diagnosis (years)		
<1	9	30
1–5	16	53.3
6–10	5	16.7
PPS		
30	4	13.3
40	10	33.3
50	5	16.7
60	9	30
70	2	6.7
Age, mean (SD)	53.4 (14.4)	

[a]Others: brother-in-law, mother-in-law, friend.
[b]Others: Nasopharynx, urachus, adrenal; PPS: Palliative Performance Scale.

of actively dying (25%), dysfunctional coping (12%), impaired cognition (12%), uncontrolled symptoms (11%), contact isolation (4%), psychiatric disorder (2%), family dysfunctional coping (2%), unaware of prognosis (2%), social issues (1%), foreigners (1%), and illiteracy.

The initial sample consisted of 41 participants; 10 (24%) refused to participate because they were not feeling well and one (2%) dropped out during the interview. The pretest was administered to 30 (73%) participants, 15 of them were female with the mean age of 53.4 years, ranging from 28 to 80. The patients' sociodemographic characteristics are shown in Table 2. All participants answered a questionnaire with questions related to the understanding of each item. In the final version, the protocol title and items 7 and 8 were not changed. In addition, almost 50% of participants suggested that item 10 should be removed as they considered it had the same meaning as item 9. In contrast, recommendations for changes in wording were suggested for items 1, 2, 3, 4, 5, 6, and 9. These recommendations are shown in Table 3. The original and Brazilian DT question protocol versions are shown in Table 4.

The interviews lasted an average of 50 minutes, mainly because several participants, in addition to collaborating with the pretest process, wanted to make personal reflections on the DT protocol questions, which generated several reports of a feeling of well-being at the end of the interview.

In view of this, it is recommended that, in the face of the pretest process, the researcher reinforces to the participant the difference between judging the understanding of the question and answering itself. From this understanding, there is no need to interrupt the participants in their narratives, since the authors understand that these reflections can help the participant in their process of coping with the disease.

Discussion

The translation and cross-cultural adaptation of the DTQP was carried out in order to maintain the original characteristics of DT application procedures. This process took place according to the international standard by Beaton et al. (2000) to preserve the implementation of DT in Brazil.

The process of adaptation demands consideration of the mindset, belief system, and established habits and cultural practices, so that the translation and adaptation are applicable to the reality and context of Brazilian people (Epstein et al. 2015; Sousa and Rojjanasrirat 2011). This is critical, given that elements of clarity, meaning, and relevance can affect the ability of individuals

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Table 3. Pretest

Item	Participants' suggestions, *n* (%)	Comments	Suggestions	Change
1	3 (10)	Tendency to focus on the moment after illness	Replace the excerpt from "particularly the parts that you either remember most or think are the most important" to "what would you like to remember?"	Tell me a little about your life story; particularly what you would like to remember or the parts you think are most important.
2	11 (36.6)	Doubt regarding the meaning of the word "alive" The word "alive" may refer to the stigma of the disease	Replace the word "alive" to "important"	When did you feel most important?
3	14 (46.6)	It seems that one is asking about the existence of a secret that can be revealed because of the expression "particular things" Very long question	Replace the expression "particular things" to "special things"	Are there special moments or things you'd like to share with your family or anything you'd like them to remember about you?
4	7 (23.3)	Doubt regarding the meaning of the word "roles"	Replace the word "roles" to "activities"	What are the most important activities you have done in your life (family, work, community service)? Why were these activities so important to you?
5	6 (20)	Doubt regarding the meaning of the word "accomplishments"	Replace the word "accomplishments" to "achievements"	What are your most important accomplishments (achievements) and which ones are you most proud of?
6	7 (23.3)	Doubt regarding the meaning of the expression "particular things" The expression "you had the time to say once again" generates discomfort due to the sense of urgency	Replace the expression "you had the time to say once again" to "didn't have time to say?"	Are there important things you've been wanting to talk about to your loved ones or things you wish you'd said but didn't have time to say?
9	5 (16.6)	The verb "to pass along" generates discomfort because it refers to farewell	Replace the verb "to pass along" to "offer"	What advice or words of guidance would you like to offer to [son, daughter, husband, wife, parents, others]?
10	14 (46.6)	Practically the same meaning as item 9	Remove item 10	Item 10 removed
11	8 (26.6)	The word "record" generated difficulty in understanding	Change to "Would you like to say anything else?"	Would you like to say anything else?

to partake in DT (Houmann et al. 2010). To help arrive at an adaptation that was culturally sensitive and easily comprehended, our expert committee evaluated semantic, cultural, and conceptual issues, proposing minimal modifications leading to a CVI of 1 for all the overall framework.

Most of the changes in the DTQP Brazilian Portuguese version related to comprehension difficulties regarding meaning of words and expressions such as "alive" (11/36.6%), "roles" (7/23.3%), "accomplishments" (6/20%), "particular things" (7/23.3%), and "records" (8/26.6%). Some participants expressed discomfort that some items alluded to goodbyes (5/16.6%), feeling of urgency by the lack of time (7/23.3%), and memories of events after the disease onset (3/10%), hence informing possible modifications. This may reflect limited vocabulary or fluency, since most participants did not conclude elementary school (10/33.3%). Furthermore, reports of discomfort related to matters of death and dying underscore how these topics are still very much taboo (Death Education 2019; Kalish 2002; Lakasing 2014). Interestingly, a Danish translation and cultural adaptation of DTQP demonstrated the importance of customs and education. They reported that some items were existentially challenging, and topics related to one's own achievements and matters of pride were interpreted as being boastful and having a sense of grandiosity (Houmann et al. 2010). A German adaptation of the DTQP found that the words "alive" and "accomplishment" were considered adequate and had positive connotations; they also proposed an additional question: "What has been your mission in your life?" (Mai et al. 2018).

These diversified results raise questions regarding the main objective of translation and the process of cross-cultural adaptation. Wherever this takes place, the goal is to generate a framework of questions for conducting DT that is readily understandable and culturally sensitive, thus providing maximal benefits within that particular setting. Both Danish and German versions of the DTQP have undergone minor modifications and appear to be manageable, acceptable, and feasible to administer (Houmann et al. 2010; Mai et al. 2018). Despite the importance of the rigor of this procedure, the DTQP is meant as a framework for conducting DT. The questions were designed to address facets concerning personhood, helping individuals connect with their essence. Specific language must always be sensitive to the patients' level of acceptance and

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Table 4. Original dignity therapy question protocol and Brazilian version

Original	Brazilian version
Dignity Therapy Question Protocol	Protocolo de Perguntas sobre Terapia da Dignidade
1. Tell me a little about your life history, particularly the parts that you either remember most or think are the most important.	1. Conte-me um pouco sobre sua história de vida; particularmente o que você gostaria de lembrar ou as partes que pensa que são as mais importantes.
2. When did you feel most alive?	2. Em que momento da sua vida você se sentiu mais importante?
3. Are there particular things that you would want your family to know about you, and are there particular things you would want them to remember?	3. Existem momentos ou coisas especiais que você gostaria de compartilhar com sua família ou algo que gostaria que eles se lembrassem sobre você?
4. What are the most important roles you have played in your life (eg, Family roles, vocational roles, community service roles)? Why were they so important to you and what do you think you accomplished within those roles?	4. Quais são as atividades mais importantes que você realizou na sua vida (familiares, profissionais, serviço comunitário)? Por que essas atividades foram tão importantes para você?
5. What are your most important accomplishments, and what do you feel most proud of or take most pride in?	5. Quais são suas realizações (conquistas) mais importantes e de quais você se orgulha mais?
6. Are there particular things that you feel need to be said to your loved ones or things that you would want to take the time to say once again?	6. Existem coisas importantes que você tem vontade de falar para seus entes queridos ou coisas que gostaria de ter dito e não teve tempo para dizer?
7. What are your hopes and dreams for your loved ones?	7. Quais são seus desejos e sonhos para o futuro de seus entes queridos?
8. What have you learned about life that you would want to pass along to others?	8. O que você aprendeu sobre a vida que gostaria de passar aos outros?
9. What advice or words of guidance would you wish to pass along [son, daughter, husband, wife, parents, other(s)]?	9. Que conselho ou palavras de orientação você gostaria de oferecer para [filho, filha, marido, esposa, pais, outros(as)]?
10. Are there important words, or perhaps even instructions, you would like to offer your family?	Item 10 removed
11. In creating this permanent record, are there other things that you would like included?	10. Você gostaria de dizer mais alguma coisa?

topics shaped according to their interests and needs (Chochinov 2012; Houmann et al. 2010; Julião 2014a).

Previous randomized clinical trials have taken place in several countries such as Canada, Portugal, Spain, and England. Results indicate that DT is able to reduced anxiety and depression, make life more meaningful, increase sense of purpose and peace of mind, desire to live, quality of life, sense of dignity, and decreased suffering (Chochinov et al. 2011; Hall et al. 2011; Julião et al. 2013, 2014b, 2017; Rudilla et al. 2015).

The main limitations of our study are that the participants were recruited from a single health center with an exclusive diagnosis of cancer. However, our institution offers health care to the 5 regions of the country, which means our sample was likely representative of the different sociocultural characteristics of Brazil.

Based on our results, we conclude that the Brazilian Portuguese DTQP is a robust adaptation, with all items being well understood by patients. It will be very useful in the clinical practice of palliative care, helping patients near end of life reflect on their life stories while giving meaning to their illness experience The adapted version to Brazilian Portuguese will facilitate future studies using the DTQP.

Data availability statement. All data relevant to the study are included in the article or uploaded as supplementary information.

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