

Original Article

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The European Portuguese Posthumous Dignity Therapy Schedule of Questions: Initial development and validation

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Abstract

Objective. Dignity therapy (DT) is a brief psychotherapeutic intervention with beneficial effects in the end-of-life experience. Since it provides a continuing bond between the bereaved and their loved ones, we speculated that it could be offered as a novel bereavement intervention following the patient's death. We aimed to develop, translate, and validate the Posthumous DT Schedule of Questions (*p*-DT-SQ), for administration with bereaved relatives or friends.

Method. The original DT-SQ was adapted for application with bereaved relatives or friends. It was translated and back-translated to European Portuguese and revised by an expert committee. Content validity was assessed by the Content Validity Coefficient (CVC). The instrument was tested in a sample of 50 individuals from a large Senior Residence in Lisbon (10 elderly people and 40 healthcare professionals), who assessed face validity.

Results. The *p*-DT-SQ showed very good CVC (0.94) and face validity: it was considered clear, easy to understand, reasonable in length, and not difficult to answer. Participants felt comfortable answering the *p*-DT-SQ and felt it could positively affect the way themselves or others would remember their loved ones, allowing an understanding of the deceased's concerns, interests, and values.

Significance of results. We created and validated an adapted version of the DT-SQ to be used posthumously by bereaved family and friends. The European Portuguese version of the *p*-DT-SQ is clear, comprehensible, and aligned with the fundamentals of DT. While our data suggest its beneficial effects for those who are bereft, future research is needed to examine the impact of *p*-DT-SQ for those who are grieving.

Introduction

Dignity therapy (DT) is one of the most studied brief psychotherapeutic interventions in palliative care today, designed to address the psychosocial, spiritual, and physical issues of terminally ill patients (Chochinov et al., 2005; Fitchett et al., 2015). DT enables patients nearing death to share memories, wisdom, hopes, wishes, and dreams with those who will soon grieve their loss by preparing a legacy document. Based on the notion of legacy and generativity, DT allows patients to leave a lasting mark on the world, while also contributing to the well-being of their soon to be bereft loved ones (Chochinov, 2011).

There is current evidence supporting DT's application on adults with life-threatening illnesses, largely with end-stage cancer, with significant benefits on outcomes such as dignity-related distress, meaning of life, sense of purpose, and psychosocial distress such as depression, anxiety, will to live, and desire for death (Chochinov et al., 2011; Hall et al., 2011; Johnston et al., 2012; Julião et al., 2013, 2014, 2017). Given its ability to enhance end-of-life experience and overwhelming acceptability that is rare for any psychosocial intervention (Fitchett et al., 2015), research on DT's applicability on different populations has

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gained interest. There are now studies that have applied DT to nonterminally ill patients with chronic conditions, patients with mental disorders (Avery and Baez, 2012; Lubarsky and Avery, 2016; Julião, 2019), and dying children and adolescents (Rodriguez et al., 2018; Schuelke and Rubenstein, 2020; Julião et al., 2020a, 2020b; Chochinov and Julião, 2021).

In the clinical and research setting, DT is performed by trained therapists that conduct face-to-face sessions with patients using a framework of questions [DT Schedule of Questions (DT-SQ)]. These questions provide a framework that is used to guide a legacy-based therapeutic intervention (Chochinov, 2011).

The effect of DT on families has been very favorable, demonstrating that DT can be useful for patients, their families, and caregivers. A study conducted on bereft family members reported that DT was therapeutic, moderating their bereavement experiences (McClement et al., 2007).

A recent systematic review on the effects of DT on family members concluded that only a small body of literature examined the effects of DT on families and that future studies should be designed to investigate areas like sense of dignity and purpose, family communication, transgenerational connections, and bereavement (Scarton et al., 2018). Another systematic review to explore the outcomes of DT in palliative care patients' family members concluded that they generally believed that DT helped them to better prepare for end of life and overcome the bereavement phase, and that the legacy document was considered a source of comfort (Grijó et al., 2021). Given the salutary effects of DT on bereft family members, we wondered if there would be a benefit to having families or friends respond to a revised version of the DT-SQ following the death of their loved one, as a means of remembering them and creating a lasting legacy. The concept of legacy has been defined as "the process of leaving something behind" (Hunter, 2007). In a recent systematic review on the legacy perceptions and interventions for adults and children receiving palliative care, Boles and Jones (2021) suggest that "legacy is an enduring representation of the self — its qualities, experiences, effects, and relationships — built and bestowed across generations. Whether concrete or intangible, intentional, or serendipitous, legacies are avenues of connection, education, inspiration, or transformation." They conclude that legacy interventions are associated with modest to significant improvements in social, emotional, and spiritual variables for patients and caregivers. The theory of continuing bonds (Klass et al., 1996) highlights the ongoing nature of relationships between the bereaved and the deceased that do not end after death. There is a process of emotional construction between the bereaved and the deceased that is in a continual state of flux. Individuals establish a dynamic and ongoing inner representation of the deceased to maintain a link or some sort of relationship after the death. Unruh (1983) describes the ways in which mourners preserve the identities of the deceased through the continuation of bonding activities and emotional attachments via a variety of legacies and memories, through which the deceased are remembered.

Given the results in the creation of a lasting legacy and the provision of a means of creating a continuing bond with the deceased, we explored how DT could be offered primarily as a novel bereavement intervention applied after the patient's death.

The aim of this research was to develop a framework of questions suitable for application posthumously with bereaved relatives and friends and to examine the face and content validity of the posthumous DT-SQ (*p*-DT-SQ) for Portuguese adults.

Methods

What triggered this research

The principal investigator (MJ), who is a palliative care physician and practices DT, was approached on two different occasions by two bereaved caregivers, asking if they could perform DT for their deceased relatives, i.e., to respond on their behalf, posthumously.

Dignity therapy and the dignity question framework for terminally ill adults

Developed by Chochinov et al. (2005), DT is a brief psychotherapeutic intervention designed to bolster the patient's sense of meaning and purpose, reinforcing a continued sense of worth within a framework that is supportive, nurturing, and accessible for those near death. Patients enrolled in DT are guided through a conversation, in which aspects of their lives they would most want their loved ones to know about or remember are audio-recorded. DT offers patients the opportunity to talk about issues that matter most to them, to share moments that they feel are most important and meaningful, to speak about things they would like to be remembered by, or to offer advice to their family and friends. These recorded sessions provide the basis of an edited transcript or generativity document, which is returned to patients for them to share with individuals of their choosing. Therapeutic sessions are guided using a question framework (DT-SQ) comprised of questions that are based on the fundamental tenets of the Dignity Model (Chochinov et al., 2002; Figure 1). Each question is meant to elicit some aspect of personhood, provide an opportunity for affirmation, or help patients reconnect with elements of self that were, or perhaps remain, meaningful or valued. This framework provides a guide to eliciting a legacy-based therapeutic intervention.

Developing the new measure: Posthumous dignity therapy schedule of questions

Research phases

The development of our study consisted of six stages, based on guidelines by Beaton and colleagues (2000) although some minor protocol deviations were taken due to logistical challenges, including the COVID-19 pandemic (Figure 2). This work all took place between February and April 2021. This study received ethical approval from the Inválidos do Comércio IPSS Internal Advisory Board (of.17, 2021.03.04).

Phase 1: Creation of the *p*-DT-SQ for adults and translation to European Portuguese

Following two bereaved relative's requests to engage in DT posthumously as proxies for their deceased loved ones, we undertook adapting DT-SQ for this purpose. Besides Dignity Therapy, Dr. Chochinov has developed other personhood eliciting question frameworks, designed for application within palliative care (Pan et al., 2016; Guo et al., 2018). The prototype posthumous Dignity Therapy Question Framework was created by rewording the entire DT question framework, targeting each question toward the bereaved family member, and framing the question in terms of their deceased loved one. This resulted in questions suitable for bereaved family members or friends based on the fundamental elements of the Dignity Model and DT itself.

This initial adapted framework of questions (*p*-DT-SQ) was independently translated to European Portuguese by a bilingual

Tell me a little about your life history; particularly the parts that you either remember most or think are the most important? When did you feel most alive?

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?

What are the most important roles you have played in your life (family roles, vocational roles, community service roles, etc)? Why were they so important to you, and what do you think you accomplished within those roles?

What are your most important accomplishments, and what do you feel most proud of?

Are there particular things that you feel still need to be said to your loved ones, or things that you would want to take the time to say once again?

What are your hopes and dreams for your loved ones?

What have you learned about life that you would want to pass along to others? What advice or words of guidance would you wish to pass along to your [son, daughter, husband, wife, parents, other(s)]?

Are there words or perhaps even instructions you would like to offer your family, in order to provide them with comfort or solace?

In creating this permanent record, are there other things that you would like included?

Fig. 1. Dignity therapy question framework.

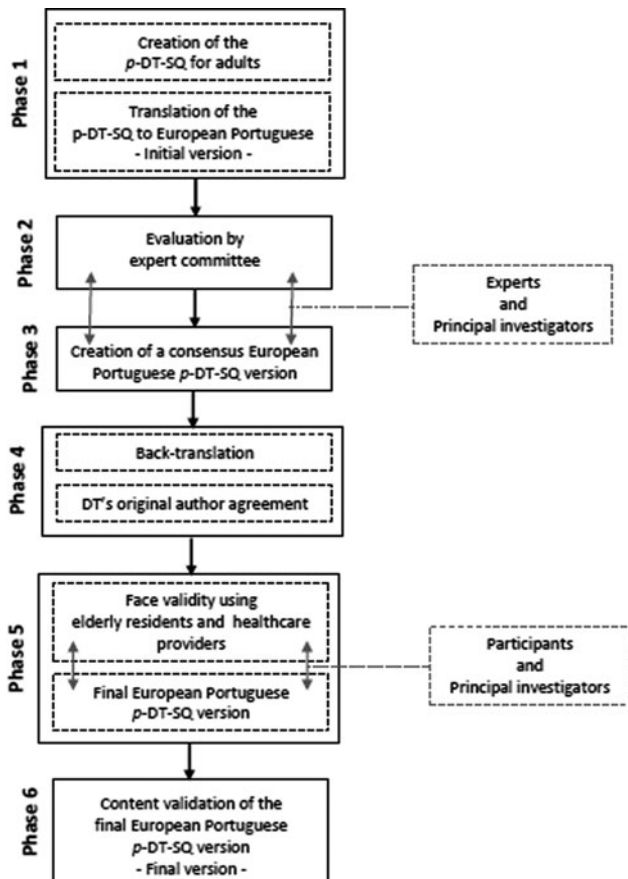


Fig. 2. Flowchart of the study.

native Portuguese researcher who was unaware of the original DT-SQ and did not have knowledge or training in DT-related themes.

Phase 2: Expert committee adaptations

This two-round phase consisted of an expert committee analysis of the initial European Portuguese version of the *p*-DT-SQ. The committee was comprised of 12 members, four of whom were familiar with the Dignity Model and formally trained in DT. Committee membership included adult palliative care physicians, family physicians, adult psychologists, palliative care nurses, and palliative care researchers and academics. Committee members were asked to provide and send their feedback questionnaires on the European Portuguese *p*-DT-SQ initial version regarding: (1) belief that the newly created questions framework captured the fundamental dimensions of the Dignity Model and DT evaluated by a “yes/no” question; (2) belief that the *p*-DT-SQ could be answered by bereaved relatives or friends, serving as a useful clinical tool and bereavement intervention evaluated by a “yes/no” question; (3) overall comprehensibility of each item, including linguistic relevance (Mokkink et al., 2010), was evaluated using free responses at the end of the survey and not for each particular item; (4) general comments, revisions, and possible inclusion of other relevant questions or ideas. Each panel member was then asked if they agreed to provide overall approval of the adapted version during a final individual meeting with the principal investigators to discuss any conflicting items. Due to COVID restrictions, all communications were made by email and telephone.

Phase 3: Creation of a consensus European Portuguese *p*-DT-SQ version

After receiving all the experts’ inputs and versions in the second round, MJ and BA developed a single consensus version of the *p*-DT-SQ. To further strengthen this phase, a linguistic expert

was consulted to revise the finalized consensus version and no changes were deemed necessary.

Phase 4: Back-translation and DT's original author agreement

The European Portuguese *p*-DT-SQ consensus version was back-translated to English and sent to Dr. Chochinov for approval.

Phase 5: Face validity

The *p*-DT-SQ consensus version was used to conduct face validation. Potential eligible people comprised of elderly residents and their healthcare providers from a large Senior Residence in Lisbon were approached between March and April 2021. We used convenience sampling. The following inclusion criteria had to be met: (1) aged 18 or older; (2) absence of a major depressive disorder assessed using the DSM-V criteria; (3) mini-mental state examination ≥ 20 ; (4) ability to provide written informed consent; and (5) ability to read, speak, and understand Portuguese. Subsequently, the research assistant verified eligibility, obtained the informed consent and socio-demographic data, along with the Inventory of Complicated Grief (ICG; Prigerson et al., 1995; Frade et al., 2010). This scale measures maladaptive symptoms of loss and ICG scores >25 indicate maladaptive symptoms of loss. The ICG was used to gauge the extent and intensity of any underlying grieving process. This is important given that the *p*-DT-SQ is being developed to be used as a potential intervention for people who are bereft. We did not exclude participants based on ICG scores, given we wanted input from participants with varying degrees of grief, including those who were or were not actively grieving.

Next, each eligible person was introduced to the study protocol and the *p*-DT-SQ, allowing the necessary time to read it and to clarify any emerging questions. Each participant was reassured that emotional support would always be available during the interview or afterwards if needed. After agreeing to participate and completing the initial part of the protocol, participants were asked to complete a feedback questionnaire on their appreciation, perceptions, and possible effectiveness of *p*-DT-SQ (rated on a 7-point Likert scale from 1 [strongly disagree] to 7 [strongly agree]). They were also invited to write any additional comments at the end of the questionnaire.

Phase 6: Content validity

Further content validity was undertaken by three independent experts, consisting of two palliative care physicians and one nurse, all active clinicians with advanced palliative care training and acquainted with DT. The Content Validity Coefficient (CVC) was calculated based on the common formula to evaluate language clarity, practical relevance, and theoretical relevance (each rated on a 5-point rating scale ranging from 1 [not clear/pertinent] to 5 [very clear/pertinent]) (Hernández-Nieto, 2002). A CVC > 0.8 was considered acceptable (Hernández-Nieto, 2002).

Statistical analysis

Data analysis was performed using the Statistical Package for Social Sciences (SPSS®) software 27.0 for Windows®. Descriptive statistics was used to describe the socio-demographic characteristics of the participants and responses to the feedback questionnaire.

Results

The European Portuguese version of the *p*-DT-SQ was coined *Protocolo de Perguntas da Terapia da Dignidade Póstuma* (Posthumous Dignity Therapy Schedule of Questions).

The full European Portuguese and English questionnaires are presented in Figure 3.

Data collection

Participants

Our study was conducted in a large Senior Residence in Lisbon. From the 63 eligible participants, 50 agreed to take part in the study (elderly people = 10; healthcare professionals = 40). Eight participants declined participation ($n = 2$, no reason given; $n = 6$, feared that their participation in the study could affect their psychological wellbeing and bereavement process) and five did not meet inclusion criteria ($n = 3$, major depressive disorder; $n = 2$, mini-mental state < 20) (response rate = 79%). Seventy-eight percent of participants were female ($n = 39$). Participants' overall characteristics are outlined in Table 1. Among the healthcare professionals, most were female (83%), had a mean age of 39 (SD = 11.2). Elderly people were also mostly female (60%) and had a mean age of 82 (SD = 9.2).

Phase 2: Expert committee adaptations

All panelists considered the newly created questions framework captured the fundamental dimensions of the Dignity Model and DT and that the *p*-DT-SQ could be answered by bereaved relatives or friends, serving as a useful clinical tool and bereavement intervention; five panelists had no changes to suggest on any item, the remaining offered minimal suggestions regarding the use of synonyms and the use of plural and/or singular use verb forms in two items. Four panelists suggested adding one item in relation to fulfillment or unfulfillment of wishes of the deceased patient. One panelist suggested replacing "loved one" with a blank space for their name.

Phase 3: Creation of a consensus European Portuguese *p*-DT-SQ version

MJ and BA developed a single consensus version of the *p*-DT-SQ reaching 98% agreement. In the process of creating the consensus version of the *p*-DT-SQ, the new item was added related to the "fulfillment of unfulfilled wishes" of the deceased (Question #11). The Portuguese expression "*ente querido*" (loved one) was replaced with a blank space for the participant to fill in the person's name, making the question framework more personalized.

Phase 4: Back-translation and DT's original author agreement

Dr. Chochinov approved the consensus version created for posthumous use, meriting further testing and consideration as a novel bereavement intervention based on the elements of the Dignity Model and DT itself.

Phase 5: Face validity

As reported in Table 2, participants considered that the *p*-DT-SQ was clear ($M = 6.48$, $SD = 0.81$), easy to understand ($M = 1.38$, $SD = 0.88$) and that questions were not difficult to answer ($M = 1.78$; $SD = 1.33$). Participants perceived that the instrument was not lengthy ($M = 1.88$, $SD = 1.52$) and the questions did not make them feel uncomfortable ($M = 1.54$, $SD = 1.42$). They also indicated that answering the *p*-DT-SQ could positively affect the

As seguintes perguntas foram feitas para que as possa responder em memória de alguém muito querido para si e que já tenha falecido, como por exemplo o seu marido ou a sua mulher, um filho, um irmão, um amigo.

Como poderá ler, algumas perguntas dão a possibilidade de colocar o nome desta pessoa para que, ao responder, as perguntas fiquem mais personalizadas.

A resposta a estas perguntas pode ser feita apenas por si ou com a ajuda de um profissional treinado em Terapia da Dignidade que lhe lê as perguntas.

No final, pode criar um registo com as respostas que deu, para guardar ou para entregar às pessoas mais importantes na vida da pessoa que já faleceu.

The following questions were written for you to answer in memory of someone dear to you who has already passed away, such as your husband or wife, a child, a sibling or a friend.

Some of the questions allow you to add the name of that person so that the questions become more personalized.

These questions may be answered by you alone or with the help of a trained professional in Dignity Therapy, who will read you the questions.

At the end, a record containing your answers can be created, for you to save or share with the most important people in your deceased loved one's life.

1. Fale-me um pouco da história de vida do(a) _____ (nome da pessoa), particularmente as fases ou momentos que recorda ou pensa terem sido as mais importantes.

Tell me about _____ (person's name)'s life story, particularly the phases or moments that you remember or think were the most important.

2. Quando é que acha que o(a) _____ (nome da pessoa) terá vivido mais intensamente?

When do you think _____ (person's name) lived the most intensely?

3. Existem coisas específicas que quisesse dar a conhecer (à sua família, amigos, etc) sobre o(a) _____ (nome da pessoa)?

Existem coisas em particular que quisesse que fossem recordadas?

Are there specific things you would want other people (family, friends, etc) to know about _____ (person's name)? Are there specific things you would want other people to remember?

4. Quais foram os papéis mais importantes que o(a) _____ (nome da pessoa) desempenhou na vida? (familiares, profissionais, comunitários, etc)?

What were the most important roles _____ (person's name) played in his/her life? (family, job, community, etc).

5. Porque é que acha que esses foram tão importantes para o(a) _____ (nome da pessoa) e o que pensa que ele(a) alcançou com eles?

Why do you think these roles were so important to _____ (person's name) and what do you think he/she achieved through them?

6. Quais foram os maiores feitos do(a) _____ (nome da pessoa) e de quais é que se sentia mais orgulhoso?

Which were the biggest achievements of _____ (person's name) and which made them the proudest?

7. Existem coisas específicas que o(a) _____ (nome da pessoa) quisesse deixar ditas em seu nome?

Are there specific things that _____ (person's name) would have want to have said on his/her behalf?

8. Quais os desejos do(a) _____ (nome da pessoa) para o futuro das pessoas de quem gostava (família, amigos, etc)?

What were the wishes of _____ (person's name) for the future of the people he/she cared about (family, friends, etc)?

9. Que lições de vida é que o(a) _____ (nome da pessoa) deixou e que gostaria de transmitir aos outros?

What life lessons has _____ (person's name) passed on and would want others to know about?

10. Que conselhos ou palavras se lembra que o(a) _____ (nome da pessoa) partilhava e teria gostado de transmitir às pessoas de quem gostava (filhos, esposa, marido, amigos, colegas de trabalho, outros)?

What words of advice did _____ (person's name) use to share and would have liked to pass on to the people he/she cared about (children, wife, husband, friends, co-workers, others)?

11. Gostaria de realizar algum desejo (ou desejos) do(a) _____ (nome da pessoa), que este(a) não tenha realizado em vida?

Would you like to fulfill any of _____ (person's name)'s life wishes that he didn't fulfilled in life?

12. Que palavras ou instruções acha que o(a) _____ (nome da pessoa) diria à sua família (ou a outras pessoas de quem gostava) para os ajudar a preparar para o futuro?

What words or instructions would _____ (person's name) give to his/her family (and loved ones) to help them prepare for the future?

13. Na criação deste documento, existem outras coisas que gostasse de incluir?

Is there anything else you would like to include in this document?

Fig. 3. The European Portuguese Posthumous Dignity Therapy Schedule of Questions.

way themselves ($M = 5.69$, $SD = 1.90$) or others ($M = 5.66$, $SD = 1.87$) would remember their loved ones, allowing them to understand the deceased's concerns ($M = 5.48$, $SD = 1.49$), interests ($M = 5.62$, $SD = 1.46$), and values ($M = 5.80$, $SD = 1.36$). Participants felt that answering the protocol posthumously could be a good

starting point for a conversation about the deceased with people who were important in their loved one's life ($M = 6.04$, $SD = 1.53$) and would recommend it to others who have also lost someone they love ($M = 6.30$, $SD = 1.11$). When asked about the preferred format for their responses, 80.0% preferred written text,

Table 1. Summary characteristics of the participants

	Total (N = 50)	Healthcare professionals (n = 40)	Elderly (n = 10)
Age, years, mean (SD)	47.2 (20.6), range = 24–98	38.5 (11.2), range = 24–70	81.9 (9.2), range = 70–98
Gender, n (%)			
Female	39 (78.0)	33 (82.5)	6 (60.0)
Education, n (%)			
Primary school	3 (6.0)	1 (2.5)	2 (20.0)
Basic school	7 (14.0)	2 (5.0)	5 (50.0)
High school	8 (16.0)	7 (17.5)	1 (10.0)
Higher education	32 (64.0)	30 (75.0)	2 (20.0)
Marital status, n (%)			
Single	17 (34.0)	15 (37.5)	2 (20.0)
Married/living with a partner	24 (48.0)	21 (52.5)	3 (30.0)
Divorced/widowed	9 (18.8)	4 (10.0)	5 (50.0)
Household arrangements, n (%)			
Alone	8 (16.0)	8 (20.0)	0
Spouse	7 (14.0)	7 (17.5)	0
Spouse and/or sons	22 (44.0)	22 (55.0)	0
Parents	3 (6.0)	3 (7.5)	0
Institution	8 (16.0)	0	8 (80.0)
Spouse in an institution	2 (4.0)	0	2 (20.0)
Occupation			
Primary sector	1 (2.0)	1 (2.6)	0
Secondary sector	2 (4.1)	2 (5.1)	0
Tertiary sector	37 (75.5)	36 (92.3)	1 (10.0)
Retired	9 (18.4)	9 (90.0)	9 (90.0)
Religion			
Catholic	42 (84.0)	33 (91.7)	9 (100.0)
Others	8 (16.0)	3 (8.3)	0
Complicated grief inventory, mean (SD)	12.6 (11.1)	12.0 (11.4)	14.8 (9.9)
Medical conditions ^a , n (%)			
Cardiovascular	7 (14)	3 (7.5)	4 (40.0)
Endocrine	4 (8)	2 (5.0)	2 (20.0)
Osteoarticular	4 (8)	2 (5.0)	2 (20.0)
Cancer	1 (2)	1 (2.5)	0
Pulmonary	1 (2)	0	1 (10.0)
Neurologic	2(2)	0	2 (20.0)
Others	1 (2)	1 (2.5)	0
None	38 (76)	35 (87.5)	3 (30.0)

SD, Standard Deviation; some categories do not add up to 40 (healthcare professionals) or to 10 (elderly) due to missing data.

^aParticipants could report more than one medical condition.

followed by video and audio recording (14% and 12%, respectively). Eighty-one percent of participants mentioned they would prefer to answer the *p*-DT-SQ alone and 19.1% would like to be accompanied by someone from their family, a friend, or a therapist. No participant reported a need for emotional support during or after completing

the study protocol. Only 12 participants added brief comments in the open question of the feedback questionnaire, hence, no qualitative analysis was performed (see Figure 4). After the analysis of all participants' answers, no changes were deemed necessary on the *p*-DT-SQ final consensus version created after phases 2 and 3.

Table 2. Participants' appreciations on the posthumous dignity therapy schedule of questions (N = 50)

	Mean (SD) ^a	Mode
Questions' comprehensibility		
Clarity?	6.48 (0.81)	7
Difficult to understand?	1.38 (0.88)	1
There are questions I don't know how/what to answer	1.78 (1.33)	1
There are questions I would prefer to be taken out of the protocol	1.22 (0.76)	1
Uncomfortable questions	1.54 (1.42)	1
p-DT-SQ's length		
Too long?	1.88 (1.52)	1
Answering the p-DT-SQ ...		
Could positively affect the way I remember my loved one	5.69 (1.90)	7
Could positively affect the way others remember my loved one	5.66 (1.87)	7
Would allow others to know my loved one's concerns	5.48 (1.49)	7
Would allow others to know my loved one's interests	5.62 (1.46)	
Would allow others to know my loved one's most relevant values	5.80 (1.36)	7
Would be a good starting point for a conversation with people who were important to my loved one	6.04 (1.53)	7
Would recommend to other people who have lost their loved ones	6.30 (1.11)	7
Answers registration format, n (%)		
Written text	40 (80.0)	
Audio	6 (12.0)	
Video	7 (14.0)	
Presence of someone while responding		
Preference to be alone	39 (80.9)	
Preference to be with someone (family, friend, or a therapist)	9 (19.1)	

p-DT-SQ, Posthumous Dignity Therapy Schedule of Questions; SD, Standard Deviation.

^aResponses rated on a Likert scale: 1 "strongly disagree" to 7 "strongly agree".

"I felt at peace and it was as if I had been with my grandmother." (P#01)

"Answering the questions allowed me to see my loved-one from a different perspective, changing the way I saw him. It also gave me the chance to experience my grieving process differently, allowing a new consciousness and feelings." (P#03)

"The schedule of questions is clear and brief. I have nothing to add." (P#05)

"While the researcher asked me the questions I felt that during that time I was remembering my father and speaking for his memory." (P#11)

"I believe that answering and thinking about these questions would help me overcome my loss and all the feelings that still live in my thoughts. I managed to wander in my memory and that reassured me." (P#17)

"I think this therapy should be applied to all the elderly in the institution where I live." (P#19)

"I felt very comfortable with the questions." (P#24)

"When I was confronted with the question protocol I felt closer to my loved ones. This was something I had never experienced before." (P#25)

"I believe that the protocol is very well structured and with significant clarity for its understanding. At another stage in my life, I think it would have helped me to resolve my grief" (P#26)

"It has the right length, not becoming too intense." (P#29)

"It promotes remembrance ..." (P#42)

"The protocol seems to be very complete and interesting. For me, in particular, it made me emotionally sensitive because it made me remember and even relive moments tell me a lot." (P#47)

Fig. 4. Written comments by the participants in the feedback questionnaire.

Table 3. The content validity coefficient per item of the *p*-DT-SQ

<i>p</i> -DT-SQ item	CVC		
	Language clarity	Practical relevance	Theoretical relevance
1	1.00	1.00	1.00
2	0.93	1.00	0.93
3	1.00	1.00	1.00
4	1.00	0.93	0.93
5	0.93	0.87	0.93
6	1.00	0.93	1.00
7	1.00	1.00	1.00
8	1.00	1.00	1.00
9	1.00	1.00	1.00
10	1.00	1.00	1.00
11	1.00	0.87	0.93
12	0.93	0.93	0.93
13	1.00	1.00	1.00

CVC, Content Validity Coefficient; *p*-DT-SQ, Posthumous Dignity Therapy Schedule of Questions.

Phase 6: Content validity

Table 3 shows the CVC regarding language clarity, practical, and theoretical relevance of the *p*-DT-SQ. All items presented CVC values above the acceptable recommended level (>0.80). The CVCs of the scale, by rater, were high: 0.99 for rater 1, 0.98 for rater 2, and 0.95 for rater 3. The CVC for the total scale was 0.94.

Discussion

Since its development, DT has shown beneficial effects on several dimensions of end-of-life experience, for both patients and their caregivers. To the best of our knowledge, this is the first study to create and validate an adapted version of the DT-SQ to be used posthumously by bereaved family and friends. Both elderly participants and healthcare providers reported overwhelming support for the proposed application of DT as a posthumous bereavement intervention.

The creation of the *p*-DT-SQ was the result of a rigorous process, which included input from both seniors and healthcare professional participants. The evidence from participants and our expert panel indicated high content validity, indicating that all items were deemed appropriate, clear, and easy to answer; and the questionnaire reasonable in length. The broad age range in our sample ensured that the assessment of this instrument was made by people with different life experiences and at different stages in their life cycle. Although we asked participants to think about their responses to questions in reference to deceased loved ones, this did not seem to cause distress, which is consistent with the ICG mean scores below 25, indicating low degrees of grief-related distress.

No questions were considered uncomfortable and no participant asked for psychological support during or after the study closed. It is possible that participants who accepted our invitation were more comfortable with these issues, given that six eligible participants declined participation fearing it could affect their

psychological wellbeing and possibly bereavement process. We did not exclude participants with higher ICG scores, given the possibility that this new application of DT might have clinical utility in those specific individuals. Interestingly, some comments in the open questions section seem to indicate that during the present study some participants recalled their deceased loved ones in a very vivid, intense way and almost seemed to be at peace or had resolved their grief. This should be explored in future research applying posthumous DT in bereaved people.

Most participants indicated that they were happy to answer the *p*-DT-SQ alone, without the presence of a therapist, friend, or family member, reporting that they would feel confident to answer, write, and record their responses on their own, perhaps reflecting comfort regarding the nature of the items. We cautiously interpret this as a sign of clinical applicability and safety; again, this would have to be explored and tested in the future studies.

As with many other DT-related instruments, such as the Patient Dignity Questionnaire, and the This Is ME Questionnaire (Chochinov et al., 2015; Pan et al., 2016; Julião et al., 2018; Lemos Caldas and Julião, 2018; Lemos Caldas et al., 2020), the *p*-DT-SQ seems to have the capacity to serve as a starting point for conversations among those who have lost their loved ones, unlocking memories regarding the deceased's interests, concerns, and values.

This study has limitations, namely being conducted in a single center and during the COVID-19 pandemic, which may have caused some eligible participants to decline participation, given the strenuous emotional circumstances. It is also the case that we used a questionnaire that elicited binary "yes/no" feedback from the expert committee; using a numerical scoring system might have added further robustness to our findings.

Future interviews with bereaved family members may also provide more information about their comprehension of the *p*-DT-SQ, thus refining this clinical tool before introducing it into future trials. Most notably, while we developed a framework of questions to enable a posthumous application of DT for those who are bereft, the validation study we conducted took place among elderly residents and healthcare professionals. Clearly future studies to test this novel intervention in those who are actually grieving are now warranted.

Conclusion

The European Portuguese *p*-DT-SQ is clear, comprehensible, acceptable, and well aligned with the fundamentals of DT. Our data suggest that it may be beneficial for those who are grieving. Future research is warranted on the impact of *p*-DT-SQ as an intervention for those trying to cope with the death of loved ones. Implementing the *p*-DT-SQ could offer a unique and pragmatic alternative for people navigating their way through bereavement. This posthumous form of Dignity Therapy provides an outlet that honours the deceased, while also providing a means for the bereft to assuage their own grief.

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