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Letter to the Editor

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Operationalizing dignity therapy for adolescents

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Dear Editor: Dignity Therapy (DT) is a brief, individualized intervention, which provides terminally ill patients with an opportunity to convey memories and essential disclosures that culminate in a legacy document. DT often broaches psychosocial and existential issues, hence bolstering a sense of meaning and purpose (Chochinov et al., 2005). During DT, trained therapists guide a psychotherapeutic session based on a framework of questions developed from key tenets of the Dignity Model (Chochinov et al., 2002). DT is presently well established in adult populations, but its application to younger people has received little attention (Rodriguez et al., 2018; Julião et al., 2020). To address this gap, Julião and colleagues adapted the Portuguese DT question framework to make it applicable to adolescents (ages 10–18) (Julião et al., 2020).

To operationalize the revision of DT for adolescents (DT-QF-Adol) two investigators (A.S. and S.A.), both children psychologists working with children and adolescents experiencing grief and loss, developed various facilitating techniques consisting of various metaphors, tasks, and support phrases. Their aim was to better enable clinicians to carry out DT-QF-Adol and make it more suitable and engaging for adolescent patients facing life-threatening or life-limiting conditions. These facilitative techniques, summarized in Table 1, were submitted to an expert committee panel familiar with DT, comprised of three adult and pediatric palliative care physicians (M.J., M.A.S., D.S.S.), two pediatric palliative care physician (C.C., M.J.P.), one pediatric palliative care nurse (E.F.), one adult psychologist (B.A.), and one child psychiatrist (M.C.). Panel members were asked to provide feedback regarding the following: (a) overall approval of the initial DT-QF-Adol revisions; (b) belief that the metaphors, tasks, and support phrases would clarify and facilitate the revised question framework; (c) believe that the techniques summarized in Table 1 captured fundamental dimensions of personhood and dignity for adolescents and their lived experience; (d) clarity, comprehensibility, and ambiguity; and (e) other comments, amendments or revisions to better operationalize DT-QF-Adol.

After receiving all the expert input, a final consensus version of the table was created with more than 90% agreement. A linguistic expert was consulted, and no changes were deemed necessary. The final consensus table was then sent to the originator of DT (H.M.C.), who agreed that this additional tool could be useful in supporting DT interviews and that its content captured the fundamental elements of the Dignity Model itself.

We believe that these additional techniques will help, both for clinicians and researchers engaged in palliative care. Next steps will be to recruit adolescent patients approaching death, in order to determine the feasibility, acceptability, and efficacy of DT-QF-Adol, informed by these facilitative techniques uniquely designed for this unique and often understudied patient population.

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Table 1. The Portuguese Dignity Question Framework for Adolescents — additional supporting table

Perguntas do Protocolo da Terapia da Dignidade para Adolescentes *(Portuguese Dignity Question Framework for Adolescents)*	Metáforas, Tarefas e Frases de Suporte	Metaphors, Tasks, and Support Phrases
1. Fala-me um pouco da tua história. Que partes da tua vida é que achas que foram as mais importantes ou em que te sentiste mais feliz? (por exemplo: festas, torneios, férias, escola, *etc*) *(Tell me a little about your story. What parts of your life do you think were the most important or did you feel most happy about? (for example, parties, tournaments, holidays, school, etc.).*	• Metáforas: ▪ Livro, filme, linha de vida ▪ Câmara de filmar — rebobinando o filme da tua vida (puxar atrás e olhar para os papéis pessoais) ▪ Ser o narrador (ver-se de fora) ▪ Ser o actor (ver-se de dentro/estar envolvido) • Tarefas: ▪ Desenhar juntos uma linha de vida ▪ Escolher fotografias reais relevantes e representar o momento na fotografia com uma palavra ou frase • Frases de Suporte: ▪ "Se a tua vida fosse um filme, quais eram as imagens principais que apareceriam?" ▪ "Como seria o trailer do teu filme?" ▪ "Se a tua vida fosse um livro, quais seriam os capítulos principais?" ▪ "Consegues pensar num momento em que percebeste: "É muito bom estar vivo!"? + "Lembras-te o que tornou esse momento tão especial?"	• Metaphors: ▪ Book, movie, lifeline ▪ Camera shoot — rewinding the film of your life (going backwards and looking at personal roles) ▪ Being the narrator (seeing yourself from the outside) ▪ Being the actor (seeing yourself from the inside/being involved) • Tasks: ▪ Designing a brief lifeline review together ▪ Choosing real relevant pictures and represent each one using a short sentence or word • Support phrases: ▪ "If your life were a movie, what would be the main images that would appear?" ▪ "What would your movie trailer look like?" ▪ "If your life were a book, what would be the main chapters?" ▪ "Can you think of a moment(s) when you realized: "It is really good to be alive!"? + "Can you remember what made that moment(s) so special?"
2. Existem coisas especiais que quisesses que a tua família, amigos ou outras pessoas importantes na tua vida soubessem sobre ti? *(Are there any special things you want your family, friends, or other important people in your life to know about you?)*	• Metáforas: ▪ O cofre das memórias • Frases de Suporte: ▪ "Imagina que podias dizer, sem medo, às pessoas de quem gostas: "Tenho coisas que nunca te consegui dizer, mas gostava de dizê-las agora. O que lhes dirias?" ▪ "Se as tuas memórias estivessem guardadas num cofre, como seria esse cofre?" ▪ "Todos temos muitas memórias (umas mais sérias e especiais do que outras). Se pudesses abrir esse cofre de memórias agora, o que gostarias que ficassem a saber sobre ti?"	• Metaphors: ▪ The memories vault • Support phrases: ▪ "Imagine you could say, without fear, to the people you care about: "I have things I've never been able to say to you, but I'd like to say them now. What would you say to them?" ▪ "If your memories were stored in a vault, what would that vault look like?" ▪ "We all have many memories (some more serious and special than others). If you could open that memories vault now, what would you like others to know about you?"
3. Existem coisas especiais que quisesses que a tua família, amigos ou outras pessoas importantes na tua vida recordassem sobre ti? *(Are there any special things you would like your family, friends, or other important people in your life to remember about you?)*	• Metáforas: ▪ Festa de aniversário • Frases de Suporte: ▪ "Imagina que é a tua festa de anos e a tua família faz um discurso: o que gostarias que te dissessem sobre ti?" ▪ "Imagina que a tua família e amigos mais próximos estão a falar sobre ti e de coisas que fizeste, mas não sabem que estás a ouvi-los. O que gostarias que dissessem?"	• Metaphors: ▪ Birthday party • Support phrases: ▪ "Imagine it is your birthday party, and your family makes a speech: what would you like to be told about you?" ▪ "Imagine that your family and close friends are talking about you and the things you have done, but they do not know you are listening to them. What would you like them to say?"

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Table 1. (*Continued.*)

Perguntas do Protocolo da Terapia da Dignidade para Adolescentes *(Portuguese Dignity Question Framework for Adolescents)*	Metáforas, Tarefas e Frases de Suporte	Metaphors, Tasks, and Support Phrases
4. Que coisas na tua vida é que gostas mais de fazer? Quando as fazes o que é que sentes? Por que é que são tão importantes para ti? *(What things in your life do you most enjoy doing? When you do them what do you feel? Why are they so important to you?)*	• Metáforas: ■ Medalha de ouro/Pódio ■ Todo o dinheiro do mundo • Tarefas: ■ Desenhar e atribuir medalhas aos momentos, atividades e sucessos que são felizes e importantes na vida • Frases de Suporte: ■ "Dos momentos que tens na tua vida, a quais é que darias uma medalha de ouro por te sentires tão bem?" ■ "Imagina que já tinhas todo o dinheiro do mundo. Que coisas é que mesmo assim ias continuar a fazer, viver e partilhar? Essas são as coisas mais importantes da tua vida, certo? Então, pensa bem em cada uma delas e como te fazem sentir."	• Metaphors: ■ Gold medal/Podium ■ All the money in the world • Tasks: ■ Drawing and awarding medals to moments, activities and successes that are happy and important in life • Support phrases: ■ "Of the moments you have in your life, which ones would you give a gold medal for feeling so good?" ■ "Imagine you already had all the money in the world. What things would you still keep doing, living and sharing? Those are the most important things in your life, right? So, think about each one of them and how you feel."
5. Existe algum momento na tua vida em que te sentiste muito feliz, importante e orgulhoso de ti próprio? Qual foi esse momento? *(Is there a moment in your life when you felt very happy, important and proud of yourself? What was that moment?)*	• Metáforas: ■ O alpinista ■ O herói ■ A cerimónia dos Óscares • Tarefas: ■ Pensar e/ou desenhar a mochila do alpinista e descrever/escrever o que está lá dentro ■ Pensar e descrever como é um herói • Frases de Suporte: ■ "Imagina que és um alpinista e que estás a subir a uma montanha, o que é uma tarefa difícil e exigente! Levas uma mochila carregada. Chegaste ao topo e sentes-te orgulhoso de ti próprio e, possivelmente, tiveste que usar algumas estratégias especiais, como aliviar algum do peso da tua mochila" ■ "Na verdade, um herói não faz nada sozinho. Portanto, como aprendeste (e com quem) a fazer as tuas maiores conquistas?" ■ "Se pensares nos momentos mais difíceis ou desafiantes em que conseguiste algo muito importante na vida, quais foram esses momentos?" ■ "Como é que dirias que conseguiste fazê-lo? Que truques ou ferramentas usaste?" ■ "Imagina que estás na cerimónia de entrega dos Óscares. Que Óscar gostarias de ganhar? Quem gostarias que to entregasse?"	• Metaphors: ■ The climber ■ The hero ■ The Oscars ceremony • Tasks: ■ Thinking and/or drawing the climber's backpack and describe/write what is inside it ■ Thinking and describing what a hero looks like • Support phrases: ■ "Imagine you are a climber and you are climbing a mountain, which is a difficult and demanding task! You are carrying a loaded backpack. You have reached the top and you are proud of yourself and perhaps you had to use some special strategies, like releasing some of the backpack´s weight" ■ "In fact, a hero does nothing by themselves. So, how did you learn (and from whom) to do your greatest achievements?" ■ "If you think about the most difficult, or challenging moments when you achieved something very important in life, what were they?" ■ "How would you say you achieved it? What tricks or tools did you use?" ■ "Imagine you're at the Oscars ceremony. What Oscar would you like to win? Who would you like to give it to you?"
6. Existe algum conselho ou palavra especial que quisesses dizer a cada uma das pessoas de quem mais gostas (pai, mãe, irmãos, tios, primos, avós, amigos, namorado(a), professores, *etc*)? *(Is there any advice or special word you would like to tell each of the people you care the most? (father, mother, siblings, uncles, cousins, grandparents, friends, boy/girlfriend, teachers, etc.)*	• Metáforas: ■ A chave e a fechadura: a importância dos outros • Tarefas: ■ Escrever uma carta ■ Gravar uma mensagem (áudio ou vídeo) ■ Desenhar ■ Deixar um *post-it*: – "Para ti eu desejo … "	• Metaphors: ■ The key and the door lock: the importance of others • Tasks: ■ Writing a letter ■ Recording a message (audio or video) ■ Drawing ■ Leaving a post-it: – "For you I wish … "

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	– "Para ti eu quero … " – "Eu desculpo-te por … " – "Agradeço-te por … " – "Desculpa-me por … " • *Frases de Suporte:* ■ "Quando pensas no que ainda queres poder dizer à tua família (ou amigos) o que seria?" ■ "O que falta dizer?" ■ "Às vezes deixamos coisas guardadas no nosso pensamento e coração, ou por medo, ou por vergonha, mas que achamos que seria bom conseguir dizer." ■ "O que aprendeste com algumas pessoas e que gostarias de lhes agradecer?" ■ "Por exemplo: Mãe: foi tão importante quando me ensinaste … " ■ "Avô: foi contigo que aprendi … " ■ "Que conselhos gostarias de lhes dar?"	– "For you I want … " – "I forgive you for … " – "I thank you for … " – "Forgive me for … " • Support phrases: ■ "When you think about what you still want to be able to tell your family (or friends) what would it be?" ■ "What's left to say?" ■ "Sometimes we leave things in our thoughts and hearts — either out of fear, or out of shame —, but that we think would be good to be able to say." ■ "What have you learned from some people and would you like to thank them?" ■ "For example: Mom: it was so important when you taught me … " ■ "Grandpa: it was with you I learned so many things from … " ■ "What advices would you like to give them?"
7. O que é que desejas para o futuro das pessoas de quem gostas? *(What do you wish for the future of the people you care about?)*	• Metáforas: ■ Sonhar não paga impostos ■ O mágico e as poções mágicas • Frases de Suporte: ■ "Como se costuma dizer, sonhar não custa e não paga impostos. O que mais desejas ou sonhas para o futuro das pessoas que são importantes para ti?" ■ "Se pensares que és um mágico com a possibilidade de deixares poções mágicas para quem mais amas, o que lhes deixarias?" ■ "Por exemplo… Pai, o que quero para ti é que tu …. "	• Metaphors: ■ Dreaming doesn´t pay taxes ■ The magician and the magic potions • Support phrases: ■ "As they say, dreaming doesn't cost and pays no taxes. What do you wish or dream more than anything for the future of the people who are important to you?" ■ "If you think you are a magician with the possibility of leaving magic potions for those you love the most, what would you leave them?" ■ "For example: Dad, what I want for you is … "
8. O que é que tens aprendido com a vida que gostasses de dizer aos outros? *(What have you learned from the life you would like to tell others?)*	• Metáforas: ■ O discurso depois de apagar as velas de aniversário ■ O publicitário • Tarefas: ■ Escrever uma frase ■ Gravar uma mensagem forte e significativa (áudio ou vídeo) ■ Desenhar/criar um cartaz • Frases de Suporte: ■ "Imagina que tens que fazer um discurso depois de apagares as velas do teu bolo de aniversário e que estão a ouvir-te apenas as pessoas da tua família e amigos. Nesse discurso, que mensagem é que gostarias de passar? O que dirias?" ■ "Se tivesses que fazer um cartaz com uma ideia ou uma mensagem forte sobre a vida e o que aprendeste com ela, o que farias? Que cartazes farias para deixar as tuas mensagens?" ■ "Daquilo que foste aprendendo durante a tua vida, que mensagens gostarias de passar aos outros?"	• Metaphors: ■ The speech after blowing out the birthday candles ■ The advertiser • Tasks: ■ Writing a phrase ■ Recording a strong and meaningful message (audio or video) ■ Drawing/creating a poster • Support phrases: ■ "Imagine you have to make a speech after you blow out the candles on your birthday cake and only your family and friends are listening to you. In that speech, what message would you like to send? What would you say?" ■ "If you had to make a poster with an idea or a strong message about life and what you learned from it, what would you do? What posters would you make to leave your messages?" ■ "Of what you have learned throughout your life, what messages would you most like to pass on to others?"

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Table 1. (*Continued.*)

Perguntas do Protocolo da Terapia da Dignidade para Adolescentes *(Portuguese Dignity Question Framework for Adolescents)*	Metáforas, Tarefas e Frases de Suporte	Metaphors, Tasks, and Support Phrases
9. Se pudesses deixar uma mensagem para o mundo inteiro o que gostavas de dizer, antes de terminarmos esta nossa conversa? *(If you could leave a message to the whole world what would you like to say, before we finish our conversation?)*	• Metáforas: ■ O discurso do Rei (ou uma figura pública relevante para o adolescente) ■ O mural da vida • Tarefas: ■ Imaginar um palco ou um púlpito para fazer um discurso ■ Gravar uma mensagem forte e significativa (áudio ou vídeo) ■ Escrever uma frase principal (ou várias) que construam um mural • Frases de Suporte: ■ "Imagina que és um Rei (ou alguma figura pública importante para ti) e vais fazer um discurso para todo o Mundo. Nesse discurso, que mensagem é que querias passar a todas as pessoas que te estivessem a ouvir? O que dirias?" ■ "Se tivesses que fazer um mural com uma ideia ou uma mensagem forte sobre a vida e o que aprendeste com ela, o que farias?" ■ "Antes de terminarmos esta nossa conversa, o que achas que fica a faltar dizer, depois destas perguntas e destas ideias que tivemos?" ■ "Queres acrescentar aqui alguma ideia, ou objeto, para deixares com as pessoas de quem gostas?" ■ "O que gostarias que agora fosse feito com este material que criámos? Entregar a alguém em particular, guardar em algum sítio? Que instruções queres deixar?"	• Metaphors: ■ The King´s speech (or a public figure relevant to the adolescent) ■ The life´s mural • Tasks: ■ Imagine a stage or a pulpit where you can make a speech ■ Recording a strong and meaningful message (audio or video) ■ Writing a main phrase (or several) that put together a mural • Support phrases: ■ "Imagine you're a King (or some important public figure you admire) and you're going to give a speech to the whole world. In that speech, what message did you want to get across to everyone who was listening to you? What would you say?" ■ "If you had to make a mural with an idea or a strong message about life and what you learned from it, what would you do?" ■ "Before we finish our conversation, what do you think is missing for you to say, after these questions and these ideas that we have had?" ■ "Do you want to add an idea, or object, to leave with the people you care about?" ■ "What would you like me to do with all this material we created together? Would you like to give it to someone in particular, or keep it somewhere? What instructions do you want to leave?"

English translations are merely indicative for readers to understand.

Author's Contributors. M.J., A.S., S.A., and B.A. were responsible for the conception and design. M.J., A.S., S.A., B.A., M.C., M.A.S., D.S.S., C.C., E.F., M.J.P., and H.M.C. were responsible for supervising the study's protocol, analyzing and writing the final manuscript. All co-authors supervised the final analysis, revision of the final report and had full access to all of the data.

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