

Original Article

Cite this article: Bovero A, Cotardo F, Cito AL, Pidinchiedda AV, Pesce S, Chochinov HM, Carletto S (2023). The Italian versions of the This Is ME Questionnaire and the Patient Dignity Question: Understanding personhood and supporting dignity in patients with terminal cancer. *Palliative and Supportive Care*. <https://doi.org/10.1017/S1478951523001281>

Received: 18 July 2023
Accepted: 31 July 2023

Keywords:

This Is ME Questionnaire; Patient Dignity Question; Cancer patients; End-of-life; Italian validation

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The Italian versions of the This Is ME Questionnaire and the Patient Dignity Question: Understanding personhood and supporting dignity in patients with terminal cancer

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Abstract

Objectives. Patients with cancer at the end of life may suffer from high psychological distress, a sense of demoralization, and a lack of dignity related to their medical condition. The This Is ME (TIME) Questionnaire and the Patient Dignity Question (PDQ) are clinical tools developed to achieve comprehensive and personalized patient care and to deepen our understanding of personhood. The objective of this study was to translate and validate the TIME Questionnaire, which contains the PDQ, into Italian to evaluate patient satisfaction of the Italian version of these tools and to identify essential themes elicited by the tools.

Methods. The validation process consisted of a forward and back translation stage, data collection from a sample of 60 patients with terminal cancer, and a final consultation with a panel of experts to identify patient themes using the results of the tool.

Results. Overall, participants felt that the PDQ/TIME questionnaire captured their essence as a person, allowed them to express their values and beliefs, and helped the health care professionals (HCP) to take better care of them. Content analysis identified “family relationships,” “global pain,” and “family roles and accomplishments” as being of most importance to patients.

Significance of results. The Italian versions of the PDQ/TIME Questionnaire are clear, precise, understandable, and focused on understanding personhood in patients with advanced cancer. These tools should be used to proactively enhance patient–caregiver and patient–HCP relationships and to develop new perspectives of patient care focused on the critical dimension of personhood.

Introduction

The preservation of patient dignity is an important challenge facing the health-care system (Peičius et al. 2022). As pointed out by Julião et al. (2018), modern medicine can be perceived as impersonal and routinized, with insufficient attention paid to patient personhood or individual needs. Personhood is defined as “a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being” (Pan et al. 2016). Focusing on personhood means considering patients as whole persons rather than focusing primarily on their cancer related symptoms and clinical condition toward the end of life. Patients may feel that their beliefs and values are not being taken into consideration and safeguarded, affecting their autonomy, role in shared decision-making, and the subjective sense of being respected. Patients at end of life may experience profound existential suffering related to multiple existential concerns associated with their disease (Bovero et al. 2018; Kissane 2012). Patients with terminal illness may experience numerous limitations such as loss of physical independence, loss of autonomy, and increased dependency on others (Bovero et al. 2023a; Chochinov et al. 2008). Consequently, the physical aspects of cancer should not be separated from the psychological and psychosocial aspects of the disease, as highlighted illustrated by the model of dignity in the terminally ill (Chochinov 2002a; Thompson and Chochinov 2008; Uchida Miwa et al. 2023). In this context,

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the conservation of dignity is recognized as fundamental in providing ethically appropriate care. It consists of patient–carer shared decision-making, respect for the values of the patient and their family, and the reinforcement of patient autonomy (Andorno 2019). To support patients in the final stage of their life and to avoid provoking a sense of humiliation, degradation, and dehumanization (Stoecker 2011), it is fundamental that attention be directed toward respecting a patient’s personhood and not only addressing their physical symptoms. Houska and Loučka (2019) recently reported that in order to improve end-of-life care, decisions must be consistent with the patient’s personal preferences, identified by means of an individualized process. The tools developed by Chochinov *et al.* (2015) and Pan *et al.* (2016) have demonstrated efficacy at enhancing person-centered care and evaluating patients’ needs in relation to personhood (Hadler *et al.* 2022). The This is ME (TIME) Questionnaire constitutes a set of 10 open-ended questions aimed at eliciting various aspects of patients’ personhood. The questionnaire opens with the Patient Dignity Question (PDQ), which asks “What do I need to know about you as a person to give you the best care possible?”. Łabuś-Centek *et al.* (2020) demonstrated that administering the PDQ to patients receiving palliative care at home helped ensure that their well-being was being upheld and their dignity remained intact. In particular, the PDQ helped clinicians to understand their patients better, and to take into account personhood-related aspects of the patient and clinician.

The PDQ/TIME Questionnaire were originally developed and validated in the English and then translated and validated in European Portuguese. The translation of these personhood instruments into more languages would undoubtedly enhance patient care and further help develop our understanding of personhood (Julião *et al.* 2018; Pan *et al.* 2016). The primary aim of this study was to translate and validate TIME, which is an instrument that elicits aspects of personhood commencing with the PDQ, into Italian. The second goal was to assess patients’ perception and satisfaction of the PDQ/TIME tool and to analyze the main themes emerging from their responses.

Methods

Instruments and translation procedure

The validity of the PDQ/TIME Questionnaire was assessed using a 3-stage research design: (1) translation and back-translation, involving input from a panel of experts; (2) data collection from patients with terminal cancer at end of life; and (3) a final consultation with the panel of experts (the panel included 3 experts in addition to the initial panel). Then, content analysis was performed to evaluate the essential themes and their prevalence in the patient sample.

The forward translation and subsequent back translation procedure aimed to obtain semantic and linguistic equivalence between the Italian and original version. Permission for translation was obtained from the original authors in advance. The initial independent forward translation of the English versions of the PDQ/TIME Questionnaire into Italian was performed by a bilingual native Italian researcher. This was then returned to 2 bilingual researchers, who developed the consensus version. These preliminary forward-translated versions were subsequently assigned to an external, blind bilingual translator for their back translation into English. These back-translated versions were compared with the original version, and any discrepancies resolved. The back-translated versions

were sent to the original author of TIME (HM Chochinov), who confirmed their accuracy.

Final consensus was obtained at 80% agreement among expert opinions. Further feedback was requested from 3 clinicians with expertise in oncology and palliative care to strengthen the face validity process. In accordance with Julião *et al.* (2018), initial and second expert panels were given the opportunity to add text comments to the final Italian version of the TIME Questionnaire on how it could assist their daily clinical practice and help them capture patients’ personhood to support them at end of life.

Data collection

Between October 2021 and June 2022, data were collected from “Città della Salute e della Scienza” Hospital and “Vittorio Valletta” Hospice in Turin. The study was approved by the Hospital and Hospice’s Ethics Committee protocol number 0034403, procedure number CS2/1178. The sample consisted of patients with end-stage cancer. Inclusion criteria were as follows: being 18 years or older; a diagnosis of cancer; capable of providing informed consent; meeting the criteria for receiving palliative care (National Law on Palliative Care and Pain Treatment, No. 38/2010); being in the terminal phase of cancer, with no feasible or appropriate curative treatments; an estimated life expectancy of less than 4 months; and a Karnofsky Performance Status (KPS) of 50 or lower. Some of the participants in the study were admitted from different wards of “Città della Salute e della Scienza” Hospital, such as oncology, radiotherapy, internal medicine and a palliative care unit. Other patients were admitted from the “Vittorio Valletta” Hospice, which offers palliative care for patients who are terminally ill. After introducing the patients to the study during an initial consultation and obtaining their informed consent, a psychologist administered the PDQ/TIME Questionnaire to each patient, audio recorded the answers, and then created a verbatim transcript. Each participant also completed a satisfaction questionnaire, based on the version published by Pan *et al.* (2016) and Julião *et al.* (2018). The satisfaction questionnaire included items relating to the preliminary instructions received, their understanding of the questions, their evaluation of the questionnaire in relation to its utility for themselves and for others, and whether or not they would consent to their responses being shared with specific individuals. Answers were ranked according to a 7-point Likert scale, where 1 = “strongly disagree” and 7 = “strongly agree.” Within 24 hours of completing the questionnaire, the researchers provided the patient with a final summary of their responses and asked them to confirm for accuracy.

Statistical analysis

Data analysis was performed using the Statistical Package for Social Sciences (SPSS®) software 25.0 for Windows®. Descriptive statistics were used to analyze the sociodemographic characteristics of the sample and the responses to the satisfaction questionnaire. Content analysis on the final summary documents was performed by 3 independent experts to identify the central themes and sub-themes of the patients and to calculate the response frequencies.

Results

Sociodemographic and clinical characteristics of the sample

A total of 100 eligible patients were invited to take part in the study. Twenty patients did not wish to participate for personal

reasons, 15 declined after reading the questionnaire, 4 died before the start of the study, and 1 lacked Italian language fluency. The final sample consisted of 60 patients with end-stage cancer. The sociodemographic and clinical characteristics of the sample are present in Table 1.

The Italian version of the PDQ/TIME Questionnaire

The authors of the Italian version of PDQ and TIME Questionnaire decided to maintain the same name of the original version. The Italian version of questionnaire is presented in Table 2.

Participants' satisfaction of the PDQ/TIME Questionnaire

According to experts' evaluations, patients were satisfied with their experience of the PDQ/TIME Questionnaire. Seventy percent of the participants indicated the preliminary information to be clear and generally easy to understand. And 81.7% replied to have had enough time to answer the questions and 68.3% felt comfortable during the response process.

Regarding the possibility of sharing the data collected from the PDQ/TIME Questionnaire, 61.7% of the patients felt it was important that their answers be shared with the health-care professionals (HCP) looking after them (5.27 ± 1.858), whereas most did not feel inclined to give a copy of their answers to family member(s) or friend(s) (2.12 ± 1.842).

Overall, the Italian versions of the PDQ/TIME Questionnaire were considered clear, easy to understand, and able to capture the essence of patients in relation to oneself and others. Data regarding the participants' satisfaction with the PDQ/TIME Questionnaire are present in Table 3.

Content analysis

Content analysis was performed on the verbatim transcripts (by A.L.C., A.P., and S.P.) to identify each patient's emerging themes. The first step involved 3 researchers independently identifying and labelling clusters of frequently repeated keywords used in the patients' responses. These researchers then compared their labels and selected a definitive code for each emerged theme. The analysis began by detecting the frequencies of keywords related to the different themes among all patients' answers. A definition of the significant emerging themes and their frequency of occurrence are reported in Table 4.

Discussion

Based on previous studies (Chochinov et al. 2015; Julião et al. 2018; Pan et al. 2016), we focused on the development of the Italian version of the PDQ/TIME Questionnaire. Previous investigations indicate that patients place great value on the summary of their responses to the TIME Questionnaire, as it encompasses their fundamental identity, well beyond the confines of their health condition. Recognizing fundamental elements of a patient's identity has been shown to enhance their sense of dignity (Julião et al. 2018). Our own findings also highlight that nearly 90% of the participants acknowledged that the questionnaire transcends their health problems and places emphasis on personhood. This underscores the importance of integrating personhood into clinical practice during the final stages of life in patients with cancer. It is crucial for HCP to possess these insights in order

Table 1. Sociodemographic and clinical data of the patients ($N = 60$)

Characteristics	<i>n</i> (%)	Mean \pm SD
Sex		
Male	25 (41.67)	
Female	35 (58.33)	
Age		64.62 \pm 13.41
Site		
Hospital	54 (90)	
Hospice	6 (10)	
Education		
Primary school	13 (21.66)	
Middle school	12 (20)	
High school	29 (48.33)	
Graduate	6 (10)	
Marital status		
Married	45 (75)	
Single	5 (8.33)	
Divorced	5 (8.33)	
Widow(er)	5 (8.33)	
Employment status		
Employed	26 (43.33)	
Unemployed	8 (13.33)	
Retired	26 (43.33)	
Degree of relationship		
Spouse/Partner	32 (53.33)	
Parent	23 (38.33)	
Other family member	5 (8.33)	
Cancer site		
Respiratory	14 (23.33)	
Gastrointestinal	9 (15.00)	
Genitourinary	9 (15.00)	
Hepatic-pancreatic	6 (10)	
Breast	12 (20)	
Other	10 (16.67)	
Cancer stage		
Local	6 (10)	
Loco-regional	7 (11.67)	
Metastatic	47 (78.33)	
Religious practice		
Catholic	45 (75)	
Other	15 (25)	
Disease diagnosis and prognosis awareness		
No Diagnosis, no prognosis	3 (5)	

(Continued)

Table 1. (Continued.)

Characteristics	n (%)	Mean ± SD
Diagnosis (not aware of prognosis)	9 (15)	
Diagnosis, prognosis overestimation	16 (26.67)	
Prognosis, no diagnosis	32 (53.33)	
KPS		41 ± 10.85

n = absolute frequencies, % = percent frequencies, SD = standard deviation, KPS = Karnofsky Performance Status.

Table 2. Italian version of the PDQ/TIME Questionnaire

1. Cosa dobbiamo sapere di lei come persona per darle la migliore assistenza possibile? ^a What do we need to know about you as a person in order to provide you with the best possible care? ^a
2. Ci sono particolari relazioni o rapporti personali che le piacerebbe che conoscessimo? Are there particular relationships or personal connections you would like us to be aware of?
3. Ci sono specifiche realizzazioni o ruoli che le piacerebbe che conoscessimo? Are there specific accomplishments or roles you would like us to be aware of?
4. Ci sono valori importanti che vorrebbe condividere con noi? Are there important values you would like to share with us?
5. Ci sono particolari qualità o caratteristiche che vorrebbe che noi conoscessimo di lei? Are there qualities or characteristics related to you that you would like us to be aware of?
6. Ci sono credenze, pratiche religiose o spirituali che dovremmo sapere? Are there beliefs, religious or spiritual practices we should be aware of?
7. Ci sono particolari preoccupazioni o problemi di cui vorrebbe che fossimo a conoscenza? Are there particular worries or concerns you would like us to be aware of?
8. Ci sono particolari responsabilità o doveri che vorrebbe che noi sapessimo? Are there particular responsibilities or duties you would like us to be aware of?
9. Ci sono cose che dovremmo sapere di lei che potrebbero influenzare il modo di prenderci cura di lei (ad esempio: problemi di vista o udito; difficoltà cognitive; problemi di salute mentale; altro)? Are there things we should know about you, which might affect the way we take care of you (e.g., vision or hearing issues; cognitive impairments; mental health issues; other)?
10. C'è qualcos'altro che riguarda lei come persona che vorrebbe che noi sapessimo, in modo da fornirle la migliore assistenza possibile? Are there something else about you as a person you would like us to be aware of, in order to provide you with the best possible care?

The English version of the PDQ/TIME Questionnaire is presented below each Italian sentence.

^aPDQ.

to provide optimal support during end-of-life care (Bovero *et al.* 2022b). The results of the Satisfaction Questionnaire underscore that being able to share their suffering and feeling close to their HCP are important issues for patients as they near the end of their life, and can, therefore, help HCP take better care of them. Pan *et al.* (2016) showed that, among residents living in a nursing home, the TIME Questionnaire was perceived as a means of influencing

Table 3. Participants' satisfaction with the PDQ and TIME Questionnaire (N = 60)

	Mean ± SD	Mode
Preliminary instructions		
1. The preliminary information provided by the psychologist was clear	6.58 ± 0.720	7
Understanding of the questions		
2. The questionnaire is generally easy to understand	6.45 ± 1.032	7
3. I had enough time to answer the questions	6.77 ± 0.533	7
4. I felt comfortable answering the questions in the questionnaire	6.55 ± 0.746	7
5. The questionnaire looks beyond my health problems by focusing on me as a person	5.85 ± 1.219	7
Evaluation of the questionnaire in relation to oneself		
6. The questionnaire allowed me to express my values and beliefs	6.03 ± 1.025	7
7. Answering the questions in the questionnaire helped me cope with my situation better	5.40 ± 1.368	7
8. My answers to the questionnaire helped me better understand what is important to me	5.42 ± 1.197	6
9. I think that my answers to the questionnaire will help health-care professionals to take better care of me	5.68 ± 1.066	6
Evaluation of the questionnaire in relation to its utility for others		
10. My answers to the questionnaire will allow others to better understand what is important to me	5.83 ± 0.994	6
11. In my opinion, the questionnaire helps me to share/express my suffering with others	5.85 ± 1.087	6
12. Answering the questionnaire made me feel closer to the health-care professionals looking after me	5.58 ± 1.253	6
Consent for share questionnaire responses		
13. I would like to receive a copy of the summary of my answers to the questionnaire	3.42 ± 2.651	1
14. I would like a copy of my answers to the questionnaire to be given to someone important to me (family member(s), friend(s), etc.,)	2.12 ± 1.842	1
15. It is important to me that health professionals read the summary of my answers to the questionnaire	5.27 ± 1.858	7
16. I would recommend the questionnaire to others	6.23 ± 0.981	7

SD = standard deviation.

Responses were rated on a 7-point Likert scale, where 1 = "strongly disagree" and 7 = "strongly agree."

how their HCP might come to know and appreciate who they are as a person. In particular, residents reported a significant boost in their sense of dignity through engagement with TIME. They recognized the importance of the information the questionnaire provided enabling HCP to take better care of them. Furthermore,

Table 4. Main themes that emerged, definitions, and frequency of responses

Themes	Definition	n(%)
1. Personal characteristics	The need to share personal values through empathic and active listening (compassion, (self)confidence, sense of security, fighting spirit, desire to live).	20 (33.33)
2. Family relationships	The necessity to maintain significant relationships with relatives or other significant people within their social network.	50 (83.33)
3. Family roles and accomplishments	The need for the roles the patient has played during his/her life to be acknowledged, and the need for others to be interested in what he/she has accomplished and values the most.	27 (45)
4. a. Transgenerational wisdoms	The importance for patients to know that their values and beliefs are preserved by their family members and passed on to the next generation after their death.	18 (30)
b. Dignity	Feeling like a person, not just a patient (including factors related to their illness, continuity of self, social context); feeling in control of decisions regarding his/her life and death.	18 (30)
5. Positive attitude	The importance of having a positive and constructive mindset (including hope, optimism, courage, and kindness) even at the end of life.	19 (31.67)
6. Religious beliefs and personal practices	The patients' need to share and include aspects of their spirituality and personal spiritual practices in the care process to be comforted.	21 (35)
7. Worries and responsibility toward family	The wish not to be a burden to the family, maintaining normalcy, and continuing to have a voice in one's life and dying process.	21 (35)
8. Responsibility toward oneself	The possibility to maintain a role in organizing and resolving personal affairs.	24 (40)
9. Global pain	The importance of considering aspects of physical, psychological, and social pain as crucial parts of the person's identity during clinical practice.	33 (55)
10. Self-determined in coping with end of life phase	The importance for patients to assume an active role until the end of their life and feel worthy of honour, respect, and esteem.	15(25)

n = absolute frequencies, % = percent frequencies.

residents believed that the summary provided by TIME could influence how HCP looked after and better understand what matters to them. Julião found that the Portuguese version of TIME captured the true essence of non-institutionalized, active elderly individuals, and enhanced their sense of dignity. These patients expressed the importance of HCP having access to TIME summaries, given this information could affect the way HCP perceive and care for them (Julião et al. 2018). In line with the previous

studies regarding elderly patients (Julião et al. 2018; Pan et al. 2016), our results show that terminally ill patients with cancer would like to share the summary of their TIME responses with HCPs, considering it important to share their essence and to feel close to them at the end of life. On the other hand, our findings revealed that these patients seemed less inclined to receive a copy of their PDQ/TIME summary than elderly patients included in the studies of Pan and Julião. In those, almost all patients wanted to receive a copy of their responses to give it to someone important to them (Julião et al. 2018; Pan et al. 2016). (Julião et al. 2018; Pan et al. 2016). This could be related to differences in the key worries and concerns expressed by participants in both Pan and Julião studies. Indeed, our patients with terminal cancer are likely to feel more death anxiety than institutionalized elderly, which might be associated with greater distress as they approach their end of life (Bovero et al. 2022a). Furthermore, these differences could also stem from societal practices and cultural beliefs, including the desire to manage their illness concerns on their own. Although patients consider their caregivers important in their care journey, it could be that patients preferred not to share their PDQ/TIME summary with family caregivers so as not to burden them. In addition, there might be other cultural dimensions such as the degree of diagnostic/prognostic awareness (most patients reported a partial awareness) and patients' specific perceptions that family caregivers may find it difficult to engage with their suffering. Consequently, they might feel reluctant to express and discuss their most personal needs and emotions, also fearing potential judgment for being ill or for their own reactions to the clinical condition. At the same time, our study participants felt the PDQ/TIME Questionnaire could help care providers (both family caregivers and HCP) comprehend aspects of personhood, values, and special needs relevant at this time of life. According to Chochinov (2007), patients look to care providers for a positive reflection of themselves, as they would a mirror, affirming their continued sense of self-worth. In turn, HCP need to be aware that their attitudes and assumptions can shape those all-important reflections. A more recent study (Chochinov et al. 2015) showed that reading patients' PDQs allowed HCP to learn something new about them, eliciting feelings of connectedness, and respect toward their patients, which in turn influenced their sense of empathy and the quality of their care.

Previous studies of the TIME Questionnaire established that TIME significantly enhanced the relationship between HCP and patients (Julião et al. 2018; Pan et al. 2016). This approach facilitated a renewed perspective on how professionals perceive and approach the concept of personhood within the clinical environment. Our study found that patients' relationships with their families and caregivers plays a key role in preserving a sense of dignity during end-of-life experiences. Specifically, 83% of the participants expressed the importance of maintaining meaningful connections with their relatives or other significant individuals within their social network. This recurring theme aligns with one of the central categories of the dignity model: the social dignity inventory. This category encompasses social considerations and relationship dynamics that either enhance or diminish a patient's sense of dignity (Chochinov 2002a; Chochinov et al. 2002b). Even during the final stages of life, patients expressed a deep desire to nurture profound and compassionate connections within their social circles, as these connections reinforced their sense of empowerment and feeling of being supported (Choo et al. 2020). The presence of loving support from others throughout the dying process can facilitate meaningful moments toward end of life. By maintaining relationships with others, patients can discover and construct personal meaning and

significance that resonates with the entirety of their life narrative. Patients living with advanced cancer need to receive help from others to avoid feeling hopeless or becoming socially isolated, as well as to avoid other forms of suffering such as psychosocial distress and demoralization (Bovero et al. 2023b). Indeed, connection with and social support from family members is essential throughout the course of a patient's illness, as being with family members can enhance the patient's sense of dignity, continuing to affirm their active roles within their family system.

Philipp et al. (2016) provided evidence of this in a prospective study among patients with cancer. They found that loss of interactions between patients and people close to them represented a significant predictor of loss of dignity, which often related to patients' perception of their autonomy and feelings of dependency/lack of autonomy (Philipp et al. 2016). Other recent studies also recognized autonomy and independence as important themes related to death with dignity (Bovero et al. 2023a; Martí-García et al. 2023; Xiao et al. 2021). Further studies should be carried out to identify other variables related to dignity-related distress in patients with end-stage cancer, such as attachment and social support (Philipp et al. 2016; Rodin et al. 2007; Scheffold et al. 2018).

Another crucial theme that emerged in the present study was "family roles and accomplishments," which refers to the need to be acknowledged and receive interest from others regarding their accomplishments and the roles they played that they most value. Patients might feel that their roles are valued and preserved until the end of their life, enabling them to make their own choices until the end and leave a spiritual legacy for their loved ones. A recent study found autonomy to be important for patients receiving palliative care, especially in relation to physical and existential distress, continuity in one's own personal identity, and being able to make choices until the end of life (Bovero et al. 2023a).

The present study also found "responsibility toward oneself," which involves maintaining a role in the organization and resolution of personal affairs, to be an important theme in 40% of the sample. Specifically, in the context of serious illnesses like cancer, physical and emotional experiences can significantly impact the capacity to make decisions autonomously (Gómez-Virseda et al. 2019). Patients often wish to maintain an active role in their clinical and everyday concerns, as well as having their values and responsibilities recognized (Bovero et al. 2023a). These factors are closely tied to decision-making throughout the course of their illness, right up until the end of life. As a result, this process can enhance their sense of purpose and allow them to feel that they are still fulfilling their roles, thereby enhancing sense of dignity, while garnering respect from loved ones and HCP.

In nearly 55% of the participants, "global pain" emerged as a crucial theme in patients' responses to the PDQ/TIME Questionnaire. Dame Cicely Saunders described total pain to include suffering comprised of that includes physical symptoms, mental distress, social problems and emotional problems, managing cancer-related pain requires an integrative approach that fully considers the complexity and individuality of a patient facing the end of life (Ehrlich and Vallerand 2023). In fact, these issues also contribute to a patient's perception of self as assessed during clinical practice (Bovero et al. 2022a).

However, since being a patient with end-stage cancer was a prerequisite in our study, the results can only be applied to this population. Further investigations and research are needed relate our findings across the broader spectrum of malignant illness. Future studies could be carried out to evaluate how the PDQ/TIME Questionnaire impacts Italian HCP and determine how they might

apply it in the service of better patient care. It would also be important to determine if this tool might influence the attitudes, care, respect, empathy, and compassion of Italian HCP for their patients; and how this might influence their job satisfaction. Administering TIME could offer a novel way to improve patient-HCP relationships through a better understanding of patients' personhood and needs that extend beyond their illness. This could heighten patients' sense of dignity and self-compassion, emerging from dignity conserving, person-centered care.

Conclusion

The Italian version of the TIME Questionnaire, which includes the PDQ, is clear, precise, and understandable. The questions are designed to focus on facets of personhood among patients living with cancer. This tool has the potential to improve patients' perception of care at the end of life and the attitudes of HCP toward them, by way of enhanced presence, compassion, and respect. The results of this study provide evidence that the Italian version of the PDQ/TIME Questionnaire is equivalent to the original Canadian English version and that its use could protect and enhance dignity in patients facing advanced, end-stage cancer.

Acknowledgments. The authors would like to thank for the time given the individuals who participated in the study. The authors are also grateful to Stephanie Parsley for the proofreading of the manuscript.

Funding. This research received no specific grant from any funding agency, commercial, or not-for-profit sector.

Competing interests. The authors have no conflict of interest to declare.

References

- Andorno R (2019) Human dignity and human rights as a common ground for a global bioethics. *The Journal of Medicine and Philosophy: A Forum for Bioethics and Philosophy of Medicine* 34(3), 223–240. doi:10.1093/jmp/jhp023
- Bovero A, Botto R, Mellano E, et al. (2023a) Loss of personal autonomy and dignity-related distress in end-of-life cancer patients. *The American Journal of Hospice & Palliative Care*, 10499091231166373. doi:10.1177/10499091231166373
- Bovero A, Digiovanni Y, Botto R, et al. (2022a) End-of-life cancer patients' total pain: The necessity to supplement pharmacology with psycho-socio-spiritual treatments. *Pain Management* 12(8), 895–906. doi:10.2217/pmt-2022-0015
- Bovero A, Opezzo M and Tesio V (2023b) Relationship between demoralization and quality of life in end-of-life cancer patients. *Psycho-Oncology* 32(3), 429–437. doi:10.1002/pon.6095
- Bovero A, Sedghi NA, Opezzo M, et al. (2018) Dignity-related existential distress in end-of-life cancer patients: Prevalence, underlying factors, and associated coping strategies. *Psychooncology* 27(11), 2631–2637. doi:10.1002/pon.4884
- Bovero A, Tosi C, Botto R, et al. (2022b) A qualitative study to explore health-care providers' perspectives on end-of-life patients' dignity. How can dignity be defined, and which strategies exist to maintain dignity? *Journal of Cancer Education* 37(2), 280–287. doi:10.1007/s13187-020-01808-z
- Chochinov HM (2002a) Dignity-conserving care - A new model for palliative care: Helping the patient feel valued. *Journal of the American Medical Association* 287(17), 2253–2260. doi:10.1001/jama.287.17.2253
- Chochinov HM (2007) Dignity and the essence of medicine: The A, B, C, and D of dignity conserving care. *British Medical Journal* 335(7612), 184–187. doi:10.1136/bmj.39244.650926.47
- Chochinov HM, Hack T, McClement S, et al. (2002b) Dignity in the terminally ill: A developing empirical model. *Social Science & Medicine* 54(3), 433–443. doi:10.1016/S0277-9536(01)00084-3

- Chochinov HM, Hassard T, McClement S, et al.** (2008) The patient dignity inventory: A novel way of measuring dignity-related distress in palliative care. *Journal of Pain and Symptom Management* **36**(6), 559–571. doi:10.1016/j.jpainsymman.2007.12.018
- Chochinov HM, McClement S, Hack T, et al.** (2015) Eliciting personhood within clinical practice: Effects on patients. *Families and Health Care Providers, Journal of Pain and Symptom Management* **17**, 1–28.
- Choo PY, Tan-Ho G, Dutta O, et al.** (2020) Reciprocal dynamics of dignity in end-of-life care: A multiperspective systematic review of qualitative and mixed methods research. *American Journal of Hospice and Palliative Medicine* **37**(5), 385–398. doi:10.1177/1049909119878860
- Ehrlich O and Vallerand AH** (2023) Patient goals in hospice cancer pain management: A total pain case scenario. *Journal of Hospice & Palliative Nursing* **25**(2), 75–81. doi:10.1097/NJH.0000000000000929
- Gómez-Virseda C, de Maeseneer Y and Gastmans C.** (2019) Relational autonomy: what does it mean and how is it used in end-of-life care? A systematic review of argument-based ethics literature. *BMC Medical Ethics* **20**, 76. doi:10.1186/s12910-019-0417-3
- Hadler RA, Goldshore M, Rosa WE, et al.** (2022) “What do I need to know about you?”: The Patient Dignity Question, age, and proximity to death among patients with cancer. *Supportive Care in Cancer* **30**(6), 5175–5186. doi:10.1007/s00520-022-06938-2
- Houska A and Loučka M** (2019) Patients’ autonomy at the end of life: A critical review. *Journal of Pain and Symptom Management* **57**(4), 835–845. doi:10.1016/j.jpainsymman.2018.12.339
- Julião M, Courelas C, Costa MJ, et al.** (2018) The Portuguese versions of the This Is ME Questionnaire and the Patient Dignity Question: Tools for understanding and supporting personhood in clinical care. *Annals of Cardiothoracic Surgery* **7**, S187–S195. doi:10.21037/apm.2018.04.04
- Kissane DW** (2012) The relief of existential suffering. *Archives of Internal Medicine* **172**(19), 1501. doi:10.1001/archinternmed.2012.3633
- Łabuś-Centek M, Krajnik M and Krajnik M** (2020) The meaning of dignity patient question and changes in the approach to this issue of cancer patients during home hospice care. *Palliative Medicine in Practice* **14**(2), 89–94. doi:10.5603/PMPI.2020.0011
- Martí-García C, Fernández-Férez A, Fernández-Sola C, et al.** (2023) Patients’ experiences and perceptions of dignity in end-of-life care in emergency departments: A qualitative study. *Journal of Advanced Nursing* **79**(1), 269–280. doi:10.1111/jan.15432
- Pan JL, Chochinov HM, Thompson G, et al.** (2016) The TIME Questionnaire: A tool for eliciting personhood and enhancing dignity in nursing homes. *Geriatric Nursing* **37**(4), 273–277. doi:10.1016/j.gerinurse.2016.03.001
- Peičius E, Urbonas G, Harrison WD, et al.** (2022) Dignity violations and barriers to dignity assurance for terminally ill patients at the end of life: A cross-sectional analysis. *Medicina* **58**(2), 294. doi:10.3390/medicina58020294
- Philipp R, Mehnert A, Lehmann C, et al.** (2016) Detrimental social interactions predict loss of dignity among patients with cancer. *Supportive Care in Cancer* **24**(6), 2751–2758. doi:10.1007/s00520-016-3090-9
- Rodin G, Walsh A, Zimmermann C, et al.** (2007) The contribution of attachment security and social support to depressive symptoms in patients with metastatic cancer. *Psycho-Oncology* **16**(12), 1080–1091. doi:10.1002/pon.1186
- Scheffold K, Philipp R, Koranyi S, et al.** (2018) Insecure attachment predicts depression and death anxiety in advanced cancer patients. *Palliative & Supportive Care* **16**(3), 308–316. doi:10.1017/S1478951517000281
- Stoecker R** (2011) Three crucial turns on the road to an adequate understanding of human dignity. In Kaufmann P, Kuch H, Neuhaeuser C, et al. (eds), *Humiliation, Degradation, Dehumanization*. Library of Ethics and Applied Philosophy, vol 24. Dordrecht: Springer, 7–17.
- Thompson GN and Chochinov HM** (2008) Dignity-based approaches in the care of terminally ill patients. *Current Opinion in Supportive and Palliative Care* **2**(1), 49–53. doi:10.1097/SPC.0b013e3282f4cb15
- Uchida Miwa M, Paiva C, Ferreira A, et al.** (2023) Translation and cross-cultural adaptation of the Dignity Therapy Question Protocol to Brazilian Portuguese. *Palliative & Supportive Care*, 1–7. doi:10.1017/S147895152300041X
- Xiao J, Ng MSN, Yan T, et al.** (2021) How patients with cancer experience dignity: An integrative review. *Psycho-Oncology* **30**(8), 1220–1231. doi:10.1002/pon.5687