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PAPER

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Assessment of the wish to hasten death in patients with advanced cancer: A comparison of 2 different approaches

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Abstract

Introduction: The Desire for Death Rating Scale (DDRS) and the short form of the Schedule of Attitudes toward Hastened Death (SAHD-5) are different approaches to assessing the wish to hasten death (WTHD). Both have clinical threshold scores for identifying individuals with a meaningfully elevated WTHD. However, the agreement between the 2 measures and patient opinions about assessment of the WTHD are unknown.

Objectives: To compare the DDRS and SAHD-5 and to analyze patient opinions about assessment of the WTHD.

Methods: The WTHD was assessed in 107 patients with advanced cancer using both the DDRS and SAHD-5. Patients were subsequently asked their opinion about this assessment.

Results: Correlation between scores on the SAHD-5 and the DDRS was moderate, Spearman rho = 0.67 ($P < .01$). The SAHD-5 identified 13 patients (12.1%) at risk of the WTHD, and the DDRS identified 6 patients (5.6%) with a moderate-high WTHD ($P > .05$). Concordance between the DDRS and SAHD-5 in identifying individuals with an elevated WTHD was poor when using recommended cut-off scores, $\kappa = 0.37$ ($P < 0.01$) but could be improved by using different thresholds. Only 4 patients (3.8%) regarded the assessment questions as bothersome, and 90.6% considered it important that health-care professionals inquire about the WTHD.

Conclusions: The SAHD-5 and DDRS appear to be appropriate methods for assessing the WTHD and could provide complementary information in clinical practice: the SAHD-5 to screen for risk of the WTHD and the DDRS as a clinical interview to explore it in greater detail. Assessment of the WTHD is well accepted by palliative care cancer patients.

KEYWORDS

advanced cancer, assessment, cancer, desire to die, oncology, palliative care, patient perspective, wish to hasten death

1 | INTRODUCTION

Patients with advanced cancer sometimes express a wish to hasten death (WTHD).[1,2] Research into the WTHD may be relevant to understanding several diverse issues in palliative care (PC), such as the acceptance of death, the development of suicidal ideation, and the factors that lead to requests for euthanasia or assisted suicide. To date, this research shows that (1) an occasional, transient WTHD may be relatively common in patients with advanced cancer, although the majority report no WTHD[3-5]; (2) the WTHD is correlated with measures of depression and psychological distress, but not all patients who express it have mental health concerns[5]; and (3) the WTHD can change over time.[1,3,4,6] An international expert panel has reviewed the available data and defined the WTHD as "a reaction to suffering from which the patient can see no way out other than to accelerate his or her death. This wish may be expressed spontaneously or after being asked about it, but it must be distinguished from the acceptance of impending death or from a wish to die naturally, although preferably soon."[7]

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Although there may be some value in discussing the WTHD with patients, who might not report it spontaneously, health professionals (HPs) find it difficult to address in clinical practice.[8,9] In general, HPs tend to avoid the topic because they do not want to upset their patients or cause emotional harm.[10] In the Netherlands, for example, 50% of HPs report that the discussion of the WTHD is emotionally burdensome for HPs.[11] In Germany, HPs report that their avoidance is motivated, in part, by self-protection.[9] In fact, even in the specialized context of PC, where emotional problems at the end of life are addressed routinely, the WTHD is rarely explored or assessed.[9] In fact, assessing the WTHD may not be emotionally bothersome for patients,[3,12] but the importance of this assessment, or whether it may actually be beneficial, is as yet unknown.

In general, there are 2 broad approaches to assessment of the WTHD. The first approach involves the administration of a clinician-administered semistructured interview, the Desire for Death Rating Scale (DDRS). The DDRS was developed initially by Chochinov et al[1] to complement structured diagnostic interviews that are common in mental health research, and its format is modeled on the Schedule for Affective Disorders and Schizophrenia.[13] A slightly modified DDRS was incorporated into the Structured Interview of Symptoms and Concerns by Wilson et al.[14] Variants of the DDRS have been used in a number of studies internationally.[15] However, the DDRS has yet to be applied to Spanish speaking patients.

The second approach involves the administration of the Schedule of Attitudes Toward Hastened Death (SAHD).[16] The SAHD was developed originally as a 20-item self-report questionnaire, although it has sometimes been administered by an HP. Recently, short forms of the SAHD have been developed in English and Spanish, with the aim of reducing the response burden on patients.[17,18] The Spanish short form contains 5 items obtained via an item reduction process guided by Rasch analysis.[18]

Both the DDRS and the SAHD have skewed distributions, with most respondents showing little or no WTHD.[14,18] Both also have clinical threshold scores for identifying specific individuals who appear to have a meaningfully elevated WTHD.[14,18] This is useful information because some clinical decisions require a binary classification, for example, that an individual should or should not be treated. Although both measures purport to assess the WTHD, little is known about the degree to which they correlate with one another in the same group of patients.

The main goal of the present study is to compare the DDRS and Spanish short form of the SAHD (SAHD-5) in a cohort of patients receiving PC for cancer. In addition, we inquired about patients' experience of being asked about the WTHD, to determine whether it is indeed an area of assessment that they find emotionally difficult. Finally, we also asked whether patients consider the assessment to provide information that is relevant to their care.

2 | METHODS

2.1 | Subjects

Patients were eligible for the study if they had been diagnosed with advanced stage cancer (metastatic or relapse). Recruitment took place between December 2015 and June 2016 at 3 participating services of a comprehensive cancer center in Barcelona, Spain: an outpatient PC program, an inpatient oncology unit, and an inpatient PC unit. The inclusion criteria were (a) diagnosis of an advanced neoplasm (defined by the American Society of Clinical Oncology as either the presence of distant metastasis and/or an estimated life expectancy ≤12 months),[19] (b) age ≥ 18 years, (c) ability to communicate in Spanish, (d) informed of their diagnosis and/or the prognosis of their illness, and (e) stable clinically according to the judgment of the attending physician. The exclusion criteria were cognitive impairment (Pfeiffer test >3 errors),[20] diagnosis of a major psychiatric illness, or acute social or emotional crisis, as determined by the clinical staff.

2.2 | Ethical approval

This study was approved by the ethics committee of the hospital (PR216/15), and all participants gave written informed consent.

2.3 | Procedures and measurements

The physicians responsible for the patients' treatment, or experienced clinical nurses with research training, initially approached eligible patients and introduced the possibility of participating in the study. Those who agreed subsequently met with a researcher, who conducted an in-person interview. For the assessment of the WTHD, both the DDRS and the SAHD-5 were administered. Both were also readministered 8–15 days later in a subsample of stable patients, to establish test-retest reliability. In both cases, the DDRS and the SAHD-5 were administered in the same order; first the SAHD-5 and then HADS and the DDRS.

2.3.1 | ·Schedule of Attitudes Hastened Death-5

The Spanish short form has five true/false items and a range of [0–5]. Higher scores indicate a greater desire to die. The cut-off point for detecting a risk of the WTHD is ≥2.[18]

2.3.2 | Desire to Die Rating Scale

The DDRS is a semistructured interview that begins with an open-ended introductory question about the WTHD. If the respondent answers that he or she never experiences a WTHD this question, then the rating is scored as 0 (no desire for early death). Positive responses trigger a series of follow-up questions to clarify the severity and consistency of the experience. The interviewing HP then makes a global rating of the patient's WTHD, which can range from 1 to 6 (higher scores indicate extreme desire).[14]

After administering the DDRS and SAHD-5, the patients were asked to what extent the assessment of the WTHD had been bothersome and to what extent it seemed important to them. The responses to both questions were rated on a 5-point Likert scale (1 = not at all; 5 = very much so).

2.3.3 | Hospital Anxiety and Depression Scale

The HADS is a 14-item self-report scale that uses a 4-point Likert-type response format (0–3). Higher scores (range: 0–42) indicate higher levels of anxiety and depression. The HADS provides separate scores

for anxiety (HADS-A) and depression (HADS-D). A score from 0 to 7 indicates no depression or anxiety; a score between 8 and 10 indicates possible depression or anxiety, and a score of 11 indicates probable depression or anxiety requiring professional assessment. In cancer patients, different cutoff scores have been proposed: ≥5 for depression subscale, ≥7 for anxiety subscale, and ≥13 for total score.[21-23]

2.3.4 | ·Barthel Index

The Barthel index (BI) assesses the degree of functional independence in performing activities of daily living. The BI comprises 10 items and yields a total score ranging between 0 and 100, with higher scores indicating a greater degree of independence.[24,25]

2.4 | Statistical Analysis

Categorical variables are presented as frequencies and percentages. Continuous variables are presented as means and standard deviations unless their distributions were markedly skewed; this included both the DDRS and the SAHD. In these cases, medians and interquartile ranges (IQR1–IQR3) are presented. Relationships between variables were assessed by using Pearson correlation coefficients or Spearman's rho in cases requiring nonparametric analysis.

A kappa value was computed to determine the concordance between the SAHD-5 and the DDRS in the identification of individuals who scored above or below the respective cut-off values. Finally, the test-retest reliabilities of the SAHD-5 and DDRS were examined by using intraclass correlations (ICCs) conducted among participants who had completed the measure twice.

A value of $P < .05$ was considered statistically significant. The statistical analysis was performed by using SPSS 21.0 for Windows.

3 | RESULTS

3.1 | Participant characteristics

A total of 1040 patients were admitted to the participating units during the study period. Of these, 166 (15.9%) met eligibility criteria, and 107 (64.4% of those eligible) agreed to take part. The main reasons for exclusion were lack of symptom control (15.1%), emotional instability (10.4%), cognitive impairment (6%), patient not informed of his/her clinical situation (2.5%), communication problems (0.6%), and others (ie, admittance to emergency department, reluctance of the patient to participate, and reluctance/difficulty of the physician/nurse to recruit) (65.4%).

Of the 107 participants, 59 (55.1%) were inpatients (56 from the oncology unit and 3 from the PC unit) and 48 (44.9%) were outpatients of the PC program. As shown in Table 1, the most frequent individual diagnosis was lung cancer (n = 32, 29.9%). On the BI, 59 (55.1%) were independent in basic activities of daily living.

The mean total score for the HADS was 9.3 ± 7.3. Twenty-nine patients (27.1%) had a total score of ≥13, suggesting clinically significant mood disorders.[21] Thirty-two patients (29.9%) scored ≥7 on the HADS anxiety scale, and 41 (38.3%) scored ≥5 on the depression scale. Singer et al[21] have identified these values as clinically relevant cut-off

TABLE 1 Clinical Characteristics of the Patients

Variables	Value
Male/female	n 65/42
Age	mean ± SD 64.1 ± 9.9
Marital status	n (%)
Married/common law	83 (77.5%)
Divorced/separated	11 (10.2%)
Single	8 (7.4%)
Widow/widower	5 (4.6%)
Family situation	n (%)
Lives alone	8 (7.5)
Lives with partner/family	90 (84.1)
Lives with children	4 (3.7)
Lives in an institution	0 (0)
Other	5 (4.7)
Education	n (%)
No education	15 (14.0)
Primary education	66 (61.7)
High school education	17 (15.9)
Higher education	9 (8.4)
Cancer diagnosis	n (%)
Lung	34 (31.1)
Gastric and colon	30 (28.0)
Kidney and genitourinary tract	11 (10.2)
Breast	10 (9.3)
Female reproductive system	7 (6.5)
Musculoskeletal system	6 (5.6)
Head and neck	4 (3.7)
Skin	2 (1.8)
Blood and hematological system	2 (1.8)
Other	1 (0.9)
Date of diagnosis	n (%)
<3 months	11 (10.3)
4–6 months	9 (8.4)
6–12 months	21 (19.6)
1–3 years	33 (30.8)
>3 years	33 (30.8)
Study measures	mean ± SD
I. Barthel [0–100]	90 ± 14.8
HADS total [0–42]	9.3 ± 7.3
*HADS anxiety [0–21]	4.8 ± 3.7
*HADS depression [0–21]	4.5 ± 4.1
	Median (IQ25-IQ75)
SAHD-5 [0–5]	n (%)
Total score = 0	79 (73.8)
Total score = 1	15 (14)
Total score = 2	5 (4.7)
Total score = 3	5 (4.7)
Total score = 4	2 (1.9)
Total score = 5	1 (0.9)

(Continues)

TABLE 1 (Continued)

Variables	Value
DDRS [0–6]	n (%)
No desire for death	81 (75.7)
Minimal	12 (11.2)
Mild	8 (7.5)
Moderate	5 (4.7)
Strong	0 (0)
Severe	1 (0.9)
Extreme	0 (0)

scores for patients with cancer. It should be noted that 57% of the patients did not score above these clinically relevant cutoff scores for mood disorders.

3.2 | Evaluation of the SAHD-5

The distribution of scores on the SAHD-5 is shown in Table 1. Most patients (n = 79, 73.8%) endorsed no WTHD on any of the 5 items (Mdn = 0, IQR = 0–1). The prevalence of positive responses on individual items ranged from 4 (3.7%) participants for item 1 ("I am seriously considering asking my doctor for help in ending my life") to 17 (15.8%) participants for item 5 ("Dying seems like the best way to relieve the emotional suffering my illness causes"). The item-total correlations ranged from 0.34 to 0.78, and the internal consistency was fair at $\alpha = .72$.[26]

Scores on the SAHD-5 were correlated positively and significantly with the HADS total score (rho = 0.52, $P < .01$), as well as with both the anxiety (rho = 0.42, $P < .01$) and depression (rho = 0.55, $P < .01$) subscales. Scores on the SAHD-5 were also correlated negatively with those on the BI (rho = −0.24, $P < .01$), such that patients with lower functional performance status had higher scores on the SAHD-5. No significant correlations were found between the SAHD-5 and other clinical or sociodemographic variables ($P > .05$).

An elevated level of WTHD (SAHD ≥ 2) was identified in 13 patients (12.1%). Of these, 12 (92.3%) showed scores indicative of depression on the HADS.

To assess the test-retest reliability of the SAHD-5, 60 patients were readministered the scale 8–15 days after the initial evaluation. The ICC = 0.85, which is considered to be excellent according to conventional criteria.[26]

3.3 | Evaluation of the DDRS

The distribution of scores on the DDRS is also shown in Table 1. Again, the Mdn = 0 (IQR = 0 to 0), with 81 patients (75.7%) expressing no WTHD. Twenty-six patients (24.3%) received scores ≥1, indicating at least a fleeting, occasional WTHD. Of these, only 6 patients (5.6%) had scores of ≥3, the threshold identified by Chochinov as reflecting a "serious and pervasive" WTHD.[1] All of them also had elevated depression scores on the HADS. A positive correlation was observed between the DDRS and the HADS total score ($r = 0.47$, $P < .01$), as well as between the DDRS and HADS anxiety ($r = 0.45$, $P < .01$) and depression ($r = 0.4$, $P < .01$) subscales. No significant correlations were observed between the DDRS and the other clinical and sociodemographic variables, although the negative correlation between the DDRS and the BI ($r = -0.18$, $P = .056$) showed a trend.

The test-retest reliability of the DDRS was excellent, ICC = 0.82.

3.4 | Concordance Between the SAHD-5 and the DDRS

The DDRS and SAHD-5 total scores were correlated significantly, rho = 0.66 ($P < .01$). The correlations of each measure with the HADS were not significantly different from one another (Steiger's $z = -0.73$, $P > .10$).

At the categorical level, the 12.1% prevalence of an elevated WTHD on the SAHD-5 was not significantly different than the 5.6% prevalence observed with the DDRS ($\chi^2 = 3.27$, $P > .05$).

Table 2 shows the contingency between the 2 measures in identifying individuals with an elevated WTHD. The 2 measures made identical classifications of 96 patients, for an overall rate of agreement of 89.7%. There was good agreement between measures in classifying individuals with no WTHD, with 86.0% of participants receiving scores = 0 on both. There was less agreement in the identification of individuals with a high WTHD. There were 15 individuals who scored above the recommended cut-off score on one or both of the measures, but agreement on only 4 of these. This resulted in a concordance between the 2 measures of kappa = 0.37, which is considered poor for clinical purposes.[26] This could be improved by changing cut-off scores. For example, when cut-offs ≥1 were used for both measures (ie, any indication of a WTHD, regardless of degree), the resulting kappa = 0.60. With a less stringent cut-off applied to the DDRS only (≥2), a good level of agreement was obtained, kappa = 0.62.[26] When a less stringent cut-off was applied to the SAHD-5 (≥1) and the original cut-off for the DDRS (≥3) was applied, the SAHD-5 identified all the

TABLE 2 Contingency Between the DDRS (Cut-off ≥ 3) and SAHD-5 With 2 Different Cut-offs: (a) SAHD-5 ≥ 2 and (b) SAHD-5 ≥ 1

		DDRS (cut-off ≥ 3)	
		WTHD	Non-WTHD
(a)			
SAHD-5 (cut-off ≥ 2)	WTHD	4	9
	Non-WTHD	2	92
(b)			
SAHD-5 (cut-off ≥ 1)	WTHD	6	22
	Non-WTHD	0	79

patients identified by DDRS, but with 22 false positives (see Table 2). This resulted in a concordance of kappa = 0.29.

3.5 | Differences Between Inpatients and Outpatients

On the DDRS, 13 of the 48 outpatients (27.1%) had scores ≥1, as compared with 13 of the 59 inpatients (22%); this difference between the groups was not statistically significant X^{21} = 0.367, P > .10.

Similarly, on the SAHD-5, 14 of the 48 outpatients (29.2%) had some evidence of a WTHD (cut-off ≥ 1), while in the inpatient group, 14 of the 59 inpatients (23.7%) showed some evidence of WTHD. This difference between the groups was not statistically significant, X^{21} = 0.405, P > .10.

3.6 | Patients' Perception Assessment of the WTHD

As shown in Table 3, 97.2% (n = 104) of the patients considered the questions about the WTHD to be "not at all bothersome." Moreover, 90.6% of the patients (n = 97) considered it to be "quite," "very," or "extremely" important that HPs ask them about the WTHD. No patients responded that the discussion was "very" or "extremely" bothersome. Interestingly, even individuals with an elevated WTHD, as assessed by either the SAHD-5 or the DDRS, reported that talking about the WTHD was "not bothersome."

4 | DISCUSSION

This study addressed 2 important questions regarding the assessment of the WTHD in patients with advanced cancer. The first question pertains to the extent of agreement between 2 main assessment measures that have been used in previous research, the SAHD and the DDRS. The second question pertains to the degree to which patients find the WTHD to be intrusive, bothersome, or emotionally upsetting.

TABLE 3 Opinions of Patients About Assessing the WTHD by the SAHD-5 and DDRS

Cut-off		SADH-5 <2	SADH-5 ≥2	DDRS <3	DDRS ≥3
Was talking about the WTHD bothersome?	Not at all	91	13	98	6
	Not very	2	0	2	0
	Quite	1	0	1	0
	Very	0	0	0	0
	Extremely	0	0	0	0
Do you think that talking about the WTHD during the visit is important for you? If yes, to what extent?	Not at all	2	0	2	0
	Not very	7	1	8	0
	Quite	35	4	39	0
	Very	29	5	30	4
	Extremely	21	3	22	2

WTHD, wish to hasten death; SADH-5, Schedule of Attitudes toward Hastened Death (<2 = no WTHD; ≥2 = WTHD present); DDRS, Desire for Death Rating Scale (<3 = no WTHD; ≥3 = WTHD present).

With regard to the first question, we found that the SAHD-5 and the DDRS correlated with one another at about the same level as has been observed in previous research by using the SAHD long form. For example, in a series of relevant studies, Rosenfeld et al[6,16,27] found correlations between the SAHD and DDRS that were in the range of r = 0.60 to 0.69. Correlations in this moderate range suggest that the 2 measures do address a common construct but they are not redundant or completely overlapping.

This was particularly evident in the identification of individuals who scored above the recommended cut-off values for each measure. Although agreement between the measures was generally adequate for the identification of those patients who clearly had no WTHD—which was most of the sample—the concordance was poor for identifying those whose WTHD was elevated. This is an important discrepancy for clinical purposes because patients with a high WTHD are likely to require greater support and possible clinical intervention. For research purposes, different studies that focus on the experience of patients with a high WTHD may not be identifying the same group of individuals when they use the DDRS versus the SAHD.

There are several methodological issues that could contribute to the discrepancy. First, the cut-off score for the SAHD-5 was determined on the basis of psychometric considerations, whereas the DDRS cut-off is based on the interviewer's judgment of clinical significance. Thus, a patient could respond affirmatively to some SAHD-5 items, but be considered by the DDRS interviewer to have only an occasional, transient WTHD. In this sense, the DDRS interview prompts encourage the interviewer to engage in a dialog with the respondent to clarify the nature and persistence of the WTHD experience. This probing may permit greater investigation of the patient's meaning and intent, but it could also be influenced by the skill of the interviewer.

A second consideration is that the internal consistency of the SAHD-5 is only fair, suggesting that individual items are not all equivalent in assessing the WTHD. Some items may correspond more closely to the DDRS than others. In this case, a patient could achieve a SAHD-5 score ≥ 2 by endorsing individual items that have a lower concordance with the DDRS.

A third, related issue is that some individuals could score positively on only 1 item of the SAHD-5 but still be considered clinically to have a significant WTHD. For example, the SAHD-5 item with the greatest apparent similarity to the DDRS lead question states, "*I hope my disease will progress rapidly because I would prefer to die than continue living with my illness*." A patient who agreed with this statement would almost certainly receive a high score on the DDRS if it was confirmed that this hope was consistent over time and serious. However, their WTHD would be considered low on the SAHD-5 unless they also agreed with a second question that brought the total score above the threshold of ≥2.

Finally, each item of the SAHD-5 uses a binary true/false response scale that requires the respondent to commit to 1 answer or the other. In reality, the WTHD can be transient, fluctuating, and ambivalent. This variability in the WTHD can be accounted for in the DDRS assessment, but it is not reflected in the forced-choice format of the SAHD-5.

The discrepancies suggest that, in practice, a 2-stage assessment of the WTHD may provide an optimal approach. The SAHD-5 is a brief and easily administered measure that could be used to screen patients

for a possible WTHD (SAHD-5 ≥ 1) or definite risk of WTHD (SAHD-5 ≥ 2). Patients who score positively on the screen could then be interviewed in-person with the DDRS to establish the intensity and significance of the WTHD. When applied to the current data, all 6 individuals with a DDRS ≥3 would have been identified on the initial screen, but with 22 false positives. Although this level of disagreement still results in poor concordance for using the SAHD-5 as a substitute for the DDRS, it is noteworthy that there are no false negatives. With this approach, the assessment could follow a format that is common for the identification of clinical depressive disorders, in which a positive score on a self-report scale of depressive symptoms is followed with a confirmatory structured diagnostic interview.[28]

The second major question of this study pertains to patients' views of the assessment of the WTHD. Overall, we found that these views were overwhelmingly accepting. Most patients could see the relevance of the assessment in the context of PC, thus supporting conclusions about the value of assessing the WTHD in clinical practice.[29,30] Moreover, fully 97.2% of respondents reported that the questions were "not at all bothersome." Thus, it does not appear to be justified to avoid discussions of the WTHD based on the assumption that doing so will cause emotional distress or increase the risk of suicide.[9] Moreover, the fact that most patients considered the questions about the WTHD either quite or very important suggests that it would be advisable to explore it in clinical practice. More routine assessment of the WTHD may actually facilitate communication with the patient around concerns that might not be offered spontaneously. Further research is necessary to address this point.

4.1 | Study Limitations

This study has several limitations. First, it is possible that the participants represent a biased sample from the PC population. In the end, only 64.4% of the eligible patients participated (10.3% of the patients seen in the participating programs). Approximately 20% of eligible patients were not approached for the study because of clinical instability due to physical or emotional symptoms. Unfortunately, the difficulties in recruiting research participants who have very fragile health are well known.[31,32]

In addition, the results obtained are limited to the patients with advanced cancer in oncological ward and outpatients in the PC program, as in the end only 3 inpatients were included in the study. Furthermore, it will be important to confirm the extent of concordance between different measures of the WTHD in other PC populations for whom it is relevant.[16,27,33-37] If the present results generalize to other groups, we would expect that these patients will also see the relevance of discussions around the WTHD and regard them as acceptable aspects of assessment in PC.

4.2 | Clinical Implications

This study provides the first in-depth evaluation of the WTHD by using both the DDRS and SAHD-5 in patients with advanced cancer. The results show that the SAHD-5 is a reliable instrument for the exploration of the WTHD, which correlates moderately with the DDRS. Moreover, the assessment of the WTHD was rated as not at all bothersome by most patients, who could appreciate its relevance for clinical care. The assessment of the WTHD could help early detection and could contribute to the development of more effective health care plans for these patients.

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CONFLICTS OF INTEREST

The authors declare no conflict of interest.

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