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Supportive Care in Cancer

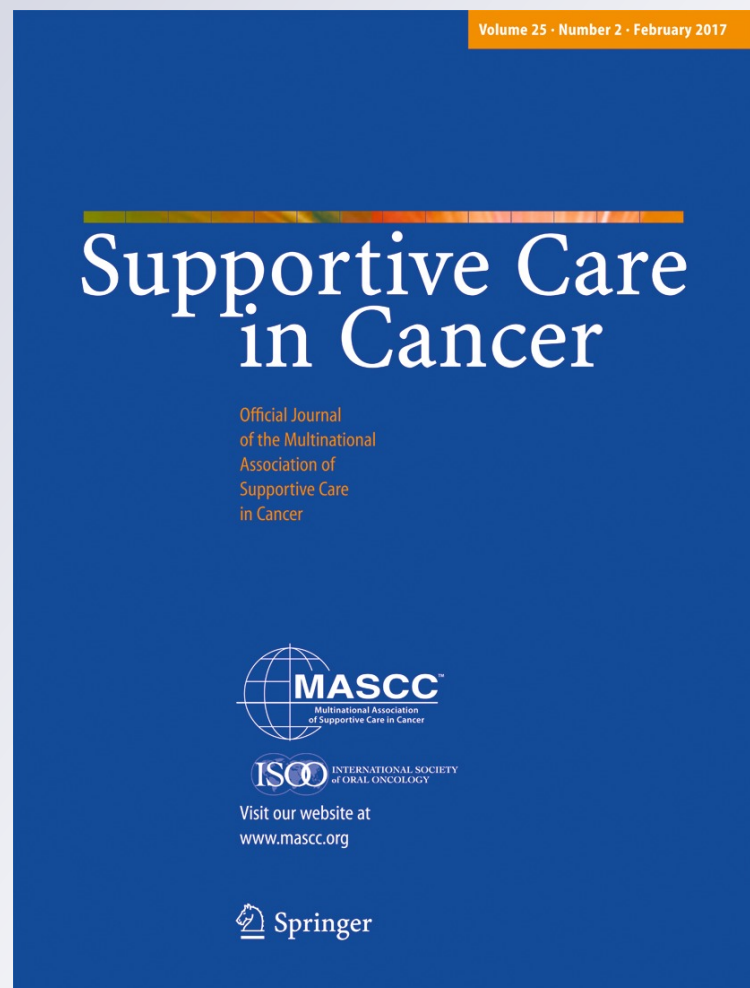
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Determining best methods to screen for religious/spiritual distress

Stephen D. W. King¹ · George Fitchett² · Patricia E. Murphy² · Kenneth I. Pargament³ · David A. Harrison⁴ · Elizabeth Trice Loggers⁵

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Abstract

Purpose This study sought to validate for the first time a brief screening measure for religious/spiritual (R/S) distress given the Commission on Cancer's mandated screening for psychosocial distress including spiritual distress.

Methods Data were collected in conjunction with an annual survey of adult hematopoietic cell transplantation (HCT) survivors. Six R/S distress screeners were compared to the Brief RCOPE, Negative Religious Coping subscale as the reference standard. We pre-specified validity as a sensitivity score of at least 85 %. As no individual measure attained this, two post hoc analyses were conducted: analysis of participants within 2 years of transplantation and of a simultaneous pairing of items. Data were analyzed from 1449 respondents whose time since HCT was 6 months to 40 years.

Results For the various single-item screening protocols, sensitivity ranged from 27 (spiritual/religious concerns) to 60 % (meaning/joy) in the full sample and 25 (spiritual/religious concerns) to 65 % (meaning/joy) in a subsample of those within 2 years of HCT. The paired items of low meaning/joy

and self-described R/S struggle attained a net sensitivity of 82 % in the full sample and of 87 % in those within 2 years of HCT but with low net specificities.

Conclusions While no single-item screener was acceptable using our pre-specified sensitivity value of 85 %, the simultaneous use of meaning/joy and self-described struggle items among cancer survivors is currently the best choice to briefly screen for R/S distress. Future research should validate this and other approaches in active treatment cancer patients and survivors and determine the best times to screen.

Keywords Screening · Oncology · Cancer · Religious/spiritual · Distress · Hematopoietic cell transplant

Introduction

Religious and/or spiritual distress is a common and difficult problem, occurring in up to 50 % of cancer patients [1–3] and 27 % of long-term survivors [4]. Defined as religious or spiritual (R/S) tensions and struggles within oneself, with others, and with what one holds to be sacred [5], R/S distress may include feeling abandoned by God, being in conflict with others about R/S beliefs or practices, or struggling with ultimate meaning [4, 6–9]. R/S distress is also identified as R/S struggle [10], R/S pain [11], and negative religious coping [5]. This type of distress has been associated with physical and emotional pain and poorer quality of life in longitudinal as well as cross-sectional studies among cancer patients and those with other conditions [1, 6, 12–15]. The negative effects of R/S struggle on emotional distress and quality of life appear consistent across cancer types and phases of cancer treatment, including survivors

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of hematopoietic cell transplantation (HCT) [1–4, 15, 16].

Acknowledging the importance of psychosocial distress, including R/S distress, the American College of Surgeons' Commission on Cancer (CoC) mandated screening for all cancer patients effective January 1, 2015 [17, 18]. Leaders in psycho-oncology agreed with the CoC's new focus in a joint position statement of the American Psychosocial Oncology Society, the Association of Oncology Social Work, and the Oncology Nursing Society. Furthermore, they reinforced the importance of screening and appropriate referrals for treatment for cancer patients and survivors suffering from R/S distress [19]. Recognizing the importance of this issue, many cancer care organizations are using a variety of brief screens for R/S distress [11, 20–25].

Despite the known importance of R/S distress, there is little or no information regarding the validity or reliability of the R/S distress screeners commonly in use. Therefore, this study was designed to rigorously test for the first time a variety of methods of R/S distress screening to identify the best very brief screening items. We used the Brief RCOPE, Negative Religious Coping (NRC) subscale [5] as the reference standard. The NRC is the most commonly used measure of R/S distress, has good validity and reliability, and has been used in diverse patient populations (e.g., age, diagnoses) [5, 15, 26]. While most of what is known about R/S distress comes from studies that employed the Brief RCOPE or the NRC subscale, the subscale contains seven items that may be burdensome for vulnerable cancer patients who are being subjected to greater volumes of surveys and screening tools. Therefore, we compared results from the NRC to the commonly used screening tools for R/S distress to validate a single-item screening tool. Some of these screening tools use explicitly spiritual-religious language, e.g., a self-identified spiritual/religious struggle item. Others, such as items for meaning/joy or peace, use psycho-spiritual language, that is, they use psychologically meaningful constructs inviting spiritual reflection. This more implicit spiritual exploration may be especially useful for those with no explicit religious identity [27].

Methods

Data were collected as part of an annual Patient Recovery Questionnaire (PRQ) of adult survivors of hematopoietic cell transplantation (HCT) at a major cancer center in the Northwest United States. Survivors who were 18 to 89 years old inclusive, could read and write English, and were treated at this center were included. HCT survivors represent a reasonable sample for distress screening across the broader care continuum of cancer patients in treatment and cancer survivors because most HCT survivors do not return to their original baseline, continuing to face medical, physical, emotional,

and existential threats [28–30] increasing the likelihood of encountering R/S distress. Further, as previously stated, studies suggest that HCT survivors experience similar effects of R/S distress on emotional distress and quality of life as do other cancer patients [4, 15, 16].

The 2011–2012 PRQ included an additional R/S coping module that incorporated the NRC subscale of the Brief RCOPE and a number of R/S screening items. The PRQ and the module were paper surveys that were mailed at the same time to the long-term follow-up (LTFU) program's survivors during the month of their transplant anniversary with a request that they be completed and returned by mail. The study compared various screening questions to the NRC subscale. Items for comparison were selected on the basis of both a literature review and clinical experience.

The data collection for this study was approved by the local Institutional Review Board.

Measures

R/S struggle

The 7-item NRC subscale assesses struggle with the sacred (e.g., feeling unloved or abandoned by God/Higher Power) and interpersonal R/S struggle (e.g., feeling abandoned by one's R/S community) using response options of “not at all,” (scored 0) to “a great deal” (scored 3). A dichotomous variable of no R/S distress versus R/S distress was used in these analyses. The typical approach to scoring is to sum the item scores with any non-zero sum indicating some degree of R/S distress [13, 31]. However, to ensure that participants with very low R/S distress were not misclassified, we used a more stringent measure: to be identified as having R/S distress, participants had to score 1 (i.e., “somewhat”) on at least three items or have a score of at least 2 (i.e., “quite a bit”) on any one item.

Six screening measures were studied based upon their prevalence in the literature and/or clinical experience. (1) “Do you struggle with the loss of meaning and joy in your life?” (meaning/joy) and (2) “Do you currently have what you would describe as religious or spiritual struggles?” (self-described struggle) were created with response options “not at all,” “somewhat,” “quite a bit,” and “a great deal.” (3) Steinhäuser and colleagues developed a single item, “Are you at peace” (peace), with responses in a 5-point Likert scale format of “not at all” “a little bit,” and “a moderate amount,” “quite a bit,” and “completely” [25]. (4) The Revised Rush Religious Struggle Protocol (Rush Protocol) screens for R/S distress by asking about the importance of R/S in the person's life and, depending upon the response, asks one of two follow-up questions. Pathway 1 asks those for whom R/S is important, how much support it is providing them as they cope. If not all they need, possible R/S distress is indicated. Pathway 2 asks those for whom R/S is not important if that has always

been the case with the assumption that perhaps R/S distress triggered the change [24]. (5) A single item similar to Pathway 1 of the Rush Protocol, “Does your religion/spirituality provide you all the comfort and strength you need from it right now?” (comfort/strength) was created with response options of “not applicable” (n/a), “not at all,” “somewhat,” “quite a bit,” and “a great deal.” (6) Finally, one of the most well-known screeners is the checklist item, “spiritual/religious concerns” (R/S concerns) in The National Comprehensive Cancer Network’s (NCCN) distress thermometer and problem checklist [20]. It was used here with a yes or no option. Given the low prevalence of individual items of the NRC, they were not considered further as individual screeners.

Disease information and socio-demographics

To help insure accuracy, the study used data from the long-term follow-up database for medical information such as diagnosis, year of diagnosis, and year of transplant and demographics such as age, gender, and race. For ethnicity and when the database had missing information, this study used self-reported information that the study had collected in the survey. Religious identity (e.g., faith tradition) and spiritual identity (e.g., spiritual and religious, spiritual only, religious only, or neither) were also collected in the survey.

Statistical methods

Descriptive statistics were used to characterize the sample and the prevalence of responses to each screening item. Screening item responses were grouped based on degree of distress they appeared to indicate. Dichotomous variables were then created for each item. Sensitivity and specificity percentages are reported for each item. Because we wanted to identify as many of those with potential R/S distress as possible even at the expense of having false positives, the study team determined that sensitivity was the most important factor in screening for R/S distress. Therefore, we set sensitivity of 85 % as the threshold for “screening positive,” with the expectation that this would lead to a referral to a chaplain, or other team member with appropriate expertise, for further assessment for R/S distress.

Still, because of the expense in staff time and the potential additional burden to patients of further face-to-face assessment, specificity or correctly identifying persons without distress is important as well. Consequently, a specificity as close to 85 % as possible was desired. These thresholds are common [32] and are similar to those for the widely used Patient Health Questionnaire-9 (PHQ-9) (e.g., sensitivity and specificity both of 88 %) [33]. The finding of relatively low sensitivity and specificity for all the screeners in the initial analyses led us to conduct two post hoc analyses. Because R/S distress, and factors associated with it, may vary for very long-term

survivors, our first post hoc analysis restricted the sample to participants who were 2 years or less since their transplant. We chose 2 years because of its proximity to active treatment, increasing the likelihood that any observed R/S distress would be cancer associated (rather than associated with other stressors). It is widely recognized that the simultaneous use of two screening questions (distress indicated by at least one of two items) can increase net sensitivity [34]. Thus, the second post hoc analysis tested the net sensitivity and specificity of various combinations of two of the screening questions.

Of 2113 survivors who returned the PRQ (52 % response rate), 83 % returned the R/S module survey ($n = 1745$). Eighty-one survivors completed the surveys twice due to the nature of their transplant; our analysis omitted their second survey leaving 1664 first surveys returned. Of the 1664 R/S surveys that were returned, 215 (13 %) were omitted from the analysis: 73 either did not receive HCT or did not receive HCT at our center, and 142 cases had missing data on one of the study variables, including 54 cases with more than three missing NRC items. In 38 returns, data were missing for either one or two NRC items. For these cases, regression equations were used to predict parameter estimates for each of the missing items based on the responses to the remaining NRC items [35]. The final sample for these analyses was 1449. All analyses were done using SPSS 19.

Results

Fifty percent of the subjects were between ages 50 and 64 inclusive, 51 % male, 93 % White people, 68 % Christian (with 19 % atheist/agnostic/none/no preference) (Table 1). The responses of the study participants to negative religious coping items indicated that 14 % had some R/S distress. Across the various screening protocols, the proportion with potential R/S distress ranged from 38 % (meaning/joy) to 13 % (R/S concerns) (Table 2). For the various screening protocols, the sensitivity ranged from 60 % (meaning/joy) to 27 % (R/S concerns), and specificity ranged from 89 % (R/S concerns) to 65 % (meaning/joy). As can be seen in Table 3, though two of the screeners had a specificity of at least 85 %, none of the very brief screeners approached our pre-specified minimum of 85 % for sensitivity.

Since there were no acceptable single item measures for R/S distress, our first post hoc analysis focused on the subsample of participants who had received their transplant within the last 2 years. In this subsample, the sensitivity of the various screeners was somewhat higher than for the whole sample. Sensitivity ranged from 65 % (meaning/joy) to 25 % (R/S concerns). Specificity ranged from 90 % (Rush Protocol) to 58 % (meaning/joy). Again, though some of the screeners had a specificity of at least 85 %, none of the

Table 1 Sample characteristics ($n = 1449$)

Age category	
18–39	172 (12 %)
40–49	228 (16 %)
50–64	724 (50 %)
≥ 65	325 (22 %)
Gender	
Male	744 (51 %)
Female	705 (49 %)
Race ($n = 1413$)	
White people	1316 (93 %)
^a Other	97 (7 %)
Religion ($n = 1435$)	
Christian	980 (68 %)
^b Other	188 (13 %)
No preference/none	179 (13 %)
Agnostic/Atheist	88 (6 %)
Spirituality	
Both spiritual and religious	729 (50 %)
Religious/not spiritual	85 (6 %)
Spiritual/not religious	472 (33 %)
Neither spiritual nor religious	163 (11 %)
Diagnosis	
Leukemia	678 (47 %)
Lymphoma/Hodgkin's disease	263 (18 %)
Multiple myeloma	218 (15 %)
Aplastic anemia	63 (4 %)
MDS	157 (11 %)
Other	44 (3 %)
Solid tumors	26 (2 %)
Year of diagnosis ($n = 1446$)	
1966–1994	421 (29 %)
1995–2004	531 (37 %)
2005–2011	494 (34 %)
Years since transplant	
2 years or less	341 (24 %)
3–10 years	498 (34 %)
11–20 years	387 (27 %)
21 or more years	223 (15 %)

^a Other includes Black or African American, 21 (1.5 %), Asian, 50 (3.5 %), Mixed, 15 (1.1 %), American Indian or Alaskan Native, 8 (.6 %), Native Hawaiian, 3 (.2 %)

^b Other includes Jewish, 60 (4.2 %), LDS 27 (1.9 %), Buddhist 19 (1.3 %), Muslim 8 (0.6 %), Native American/Aboriginal 4 (.3 %), Hindu 2 (.1 %), other affiliation, 68 (4.7 %)

screening protocols provided sensitivity that approached our criteria of 85 % (Table 3).

In our second post hoc analysis, the simultaneous use of two screening items was assessed (the Rush Protocol was omitted from these analyses because it is not a single-item

screener, single items being necessary for this type of analysis). Combining the meaning/joy item with the self-described struggle produced the highest sensitivity (82 % sensitivity) followed by the pair of meaning/joy and the peace item (78 % sensitivity) in the whole sample (Table 4).

In the sample of participants within 2 years of transplant, those same pairs were the best at identifying people with R/S distress with the meaning/joy and self-described struggle paired items at 87 % net sensitivity (net specificity 44 %) and the meaning/joy and peace paired items at 84 % (net specificity 47 %). The combination of the peace and self-described struggle items produced relatively high net specificity, especially in the subsample (sensitivity 83 %; specificity 60 %) (Table 4).

Discussion

This study is the first to evaluate the validity of various screening items to identify R/S distress in cancer survivors. While no single item was acceptable using our predetermined sensitivity value of 85 %, the two-item combination of meaning/joy and self-described R/S distress is promising based upon a net sensitivity of 82 % in the full sample and of 87 % in those within 2 years of hematopoietic cell transplantation. Furthermore, the meaning/joy item may discover some spiritual/existential distress not revealed by the NRC. Unfortunately, the net specificity was low for this pairing which may have important implications for resource use in cancer care organizations attempting to efficiently screen for R/S distress.

Given this, the higher net specificity of the peace/self-described struggle dyad might suggest use of this pairing for a screener. While there may be some merit to this choice as one attempts to balance the value of sensitivity relative to that of specificity, one concern might be the timing. In our clinical experience, cancer patients who were newly diagnosed were much more likely to screen positive for R/S distress using the peace question than those who are months along in active treatment [King S. One Department's Collection and Use of Data to Advance Chaplaincy Care. Presented at the Association of Professional Chaplains Annual Conference, Orlando, Florida, June 28, 2013]. This suggests that using the peace question early in the treatment trajectory may lead to more false positives due to confounding of anxiety with R/S distress.

While this study is the first to examine the validity of diverse approaches to R/S distress screening, it also has several limitations. Although the percentage of Christians in our sample is similar to the USA [36], our sample is more White than the national census [37]. Our sample is limited by the racial distribution within the LTFU program that we studied and this may limit generalizability. In addition, although the Brief RCOPE, NRC subscale has been the gold standard for identifying and studying R/S distress, it has some limitations. Six of its seven

Table 2 Distribution of scores for religious/spiritual (R/S) screeners

	Number (percent)
Do you struggle with the loss of meaning and joy in your life? (n = 1447)	
Not at all	895 (62%)
Somewhat	467 (32%)
Quite a bit	64 (4%)
A great deal	21 (2%)
Do you currently have what you would describe as religious or spiritual struggles? (n = 1444)	
Not at all	1052 (73%)
Somewhat	334 (23%)
Quite a bit	41 (3%)
A great deal	17 (1%)
Are you at peace? (n = 1445)	
Not at all	16 (1%)
A little bit	67 (5%)
A moderate amount	224 (16%)
Quite a bit	651 (45%)
Completely	487 (34%)

Rush Screening Protocol	
Path 1 (R/S is currently important but issues with strength/comfort) (n = 1037)	
Yes	151 (15%)
No	886 (85%)
Path 2 (R/S not currently important was important in the past) (n = 360)	
Yes	155 (43%)
No	205 (57%)
Possible struggle either Path 1 or Path 2 (n = 1397)	
Yes	306 (22%)
No	1091 (78%)
Does your religion/spirituality provide you all the strength and comfort you need from it right now? (n = 1441)	
Not applicable	219 (15%)
Not at all	36 (3%)
Somewhat	234 (16%)
Quite a bit	359 (25%)
A great deal	593 (41%)
Do you have any spiritual/religious concerns? (n = 1437)	
No	1248 (87%)
Yes	189 (13%)

Shaded rows were coded as indicators of possible R/S struggle, unshaded rows as no R/S struggle

Table 3 Properties of religious/spiritual (R/S) screeners whole sample and subsample 2 years or less since transplant

Screening items	Whole sample					Subsample: 2 years or less since transplant				
	Total Sample n (percent)	Struggle (14 %)	No Struggle (86 %)	Sensit-ivity	Speci-ficity	Total Sample n (percent)	Struggle (14 %)	No Struggle (86 %)	Sensit-ivity	Speci-ficity
Do you struggle with the loss of meaning and joy in your life?				60 %	65 %				65 %	58 %
Somewhat/Quite a bit/A great deal	552 (38 %)	119 (22 %)	433 (78 %)			153 (45 %)	32 (21 %)	121 (79 %)		
Not at all	895 (62 %)	78 (9 %)	817 (91 %)			187 (55 %)	17 (9 %)	170 (91 %)		
Do you currently have what you would describe as religious or spiritual struggles?				54 %	77 %				61 %	75 %
Somewhat/Quite a bit/A great deal	392 (27 %)	106 (27 %)	286 (73 %)			103 (30 %)	30 (29 %)	73 (71 %)		
Not at all	1052 (73 %)	90 (9 %)	962 (91 %)			237 (70 %)	19 (8 %)	218 (92 %)		
Are you at peace?				45 %	83 %				55 %	80 %
Not at all/A little bit/A moderate amount	307 (21 %)	88 (29 %)	219 (71 %)			85 (25 %)	27 (32 %)	58 (68 %)		
Quite a bit/Completely	1138 (79 %)	109 (10 %)	1029 (90 %)			256 (75 %)	22 (9 %)	234 (91 %)		
Rush Protocol				42 %	81 %				31 %	90 %
Potential struggle	306 (22 %)	80 (27 %)	226 (74 %)			42 (13 %)	15 (36 %)	27 (64 %)		
No struggle	1093 (78 %)	110 (10 %)	983 (90 %)			287 (87 %)	33 (11 %)	254 (89 %)		
Does your religion/ spirituality provide you all the strength and comfort you need from it right now?				42 %	85 %				43 %	85 %
Not at all/somewhat	270 (19 %)	81 (30 %)	189 (70 %)			64 (19 %)	21 (33 %)	43 (67 %)		
*Not applicable/Quite a bit/A great deal	1171 (81 %)	113 (10 %)	1058 (90 %)			277 (81 %)	28 (10 %)	249 (90 %)		
Do you have any spiritual/religious concerns?				27 %	89 %				25 %	87 %
Yes	189 (13 %)	52 (28 %)	137 (73 %)			50 (15 %)	12 (24 %)	38 (76 %)		
No	1248 (87 %)	141 (11 %)	1107 (89 %)			287 (85 %)	36 (13 %)	251 (88 %)		

Table 4 Two screening items used simultaneously

Items	Full sample		Less than or equal to 2 years	
	Net sensitivity	Net specificity	Net sensitivity	Net specificity
Meaning/joy and self-described struggle	82 %	50 %	87 %	44 %
Peace and meaning/joy	78 %	54 %	84 %	47 %
Comfort/strength and meaning/joy	77 %	56 %	80 %	50 %
Peace and self-described struggle	75 %	64 %	83 %	60 %
Comfort/strength and self-described struggle	73 %	65 %	78 %	64 %
R/S concerns and meaning/joy	71 %	58 %	74 %	51 %
Comfort/strength and peace	68 %	70 %	74 %	68 %
R/S concerns and self-described struggle	66 %	69 %	71 %	65 %
Peace and R/S concerns	60 %	73 %	66 %	70 %
Comfort/strength and R/S concerns	58 %	76 %	57 %	74 %

Full sample and less than or equal to 2 years after transplant

items focus upon struggles with the sacred (including one item that mentions the demonic) and one item focuses upon conflict with an R/S community. R/S struggles in other domains such as ultimate meaning, doubts, and morals are not included in this measure [38]. Because of this, R/S struggle may be underestimated, especially among those who are more spiritual rather than religious or have more existential concerns as opposed to theistic concerns. This study's best single screening item, meaning/joy, is limited in that it measures two themes simultaneously. This study also does not include those in active treatment, and we have not studied how well these screeners will generalize to that population. Further, there is limited literature on the trajectory of R/S distress in either survivors or those in active treatment [15, 39]. Consequently, we do not know the best times to screen, how often to screen, or how having different types of cancer may impact this trajectory. Further research is needed that addresses these lacunae.

Unlike many other studies, we identified clear cutoff values for each screening item and pre-specified our target sensitivity and specificity. Other strengths of the study include the large and geographically diverse sample used in the analyses and consistency of the findings in the full sample and the subsample.

Despite this, there is much more to study and learn. First, our results should be replicated (with or without other potential screeners), including using clinical interviews by a chaplain or other professional with expertise in R/S distress as a reference standard. Furthermore, a new Religious and Spiritual Struggles Questionnaire [38] has been developed which assesses six domains of R/S distress rather than the Brief RCOPE's three domains thus expanding the comprehensiveness of R/S distress measurement. Assessing the performance of this questionnaire in comparison to the NRC subscale, clinical interviews and brief screening tools will be important.

While this study did not identify a valid single item screener for R/S distress, the simultaneous use of the meaning/joy

and self-described distress items is currently the best choice for screening for R/S distress in cancer patients and survivors. Until further study identifies another method, we recommend this pair be considered for all clinical screening for R/S distress, even among cancer patients in active treatment, when only a minimal number of items are permitted.

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Compliance with ethical standards

Ethical approach All procedures in this study were in accordance with the ethical standards of the institutional review committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Conflict of interest The authors declare no conflict of interest. We do not have full control of all the primary data.

Disclaimers The views expressed in the submitted article are the authors' and not an official position of their respective institutions.

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