

# Cancer-Related Distress: Revisiting the Utility of the National Comprehensive Cancer Network Distress Thermometer Problem List in Women With Gynecologic Cancers

Patricia I. Jewett, PhD<sup>1,2</sup>; Deanna Teoh, MD, MS<sup>1</sup>; Sue Petzel, PhD<sup>1</sup>; Heewon Lee, MS<sup>1</sup>; Audrey Messelt, MD<sup>1</sup>; Jeffrey Kendall, PsyD, LP<sup>3</sup>; Dorothy Hatsukami, PhD<sup>3</sup>; Susan A. Everson-Rose, PhD, MPH<sup>4</sup>; Anne H. Blaes, MD, MS<sup>2</sup>; and Rachel I. Vogel, PhD<sup>1</sup>

**QUESTION ASKED:** Does the National Comprehensive Cancer Network Distress Thermometer (DT) problem list identify problems most associated with distress and quality of life (QOL) among women with gynecologic cancers?

**SUMMARY ANSWER:** The DT problem list did not easily identify concerns most associated with distress and low QOL in patients with gynecologic cancer.

**WHAT WE DID:** We analyzed survey data from an ongoing cohort study of 355 survivors of gynecologic cancer at the University of Minnesota.

**WHAT WE FOUND:** The most commonly reported problems were fatigue (53.6%), worry (49.9%), and tingling (46.3%); the least common problems were childcare (2.1%), fevers (2.1%), and substance abuse (1.1%). Rankings by prevalence, however, differed substantially from rankings by distress or QOL. Those who reported the most prevalent problems did not have greater distress or lower QOL scores than those who did not report the problem; examples included tingling, sleep, memory, skin issues, and appearance. Some other problems were rare but associated with large distress or QOL differences, such as childcare, treatment decisions, eating, housing, school/work,

nausea, bathing/dressing, getting around, and loss of interest in usual activities.

**BIAS, CONFOUNDING FACTORS:** These data were collected from female patients diagnosed and treated for gynecologic cancers at a single academic institution in Minnesota and, therefore, are likely not generalizable, particularly among nonwhite survivors of cancer, men, or patients with different cancers.

**REAL-LIFE IMPLICATIONS:** The continuous distress score of the DT effectively identified survivors of gynecologic cancer experiencing cancer-related distress. However, our findings indicate that the DT problem list does not easily identify concerns most associated with high distress and low QOL. To achieve patient-centered care while facing time restrictions in the clinic, it is relevant to identify what concerns matter most to patients. Simple enhancements to the DT, such as adding free text questions before the current problem list or explicitly asking patients to identify what has been most distressing to them and what problems they hope to receive support for, could help formalize a clinical process to identify major sources of distress among patients with cancer.

## ASSOCIATED CONTENT

### Appendix

Author affiliations and disclosures are available with the complete article at [ascopubs.org/journal/op](https://ascopubs.org/journal/op).

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## abstract

**PURPOSE** The Distress Thermometer (DT) includes a measure of cancer-related distress and a list of self-reported problems. This study evaluated the utility of the DT problem list in identifying concerns most associated with distress and poorer quality of life (QOL) in survivors of gynecologic cancer.

**METHODS** Demographic, clinical, psychosocial functioning, and DT data were described among 355 women participating in a gynecologic cancer cohort. Problems from the DT list were ranked by prevalence, distress, and QOL. Logistic regression models explored factors associated with problems that were common ( $\geq 25\%$  prevalence) and associated with distress and QOL.

**RESULTS** The average age of participants was 59.9 years (standard deviation [SD], 10.8 years). Most participants were non-Hispanic white (97%) and had ovarian (44%) or uterine (42%) cancer. The mean DT score was 2.7 (SD, 2.7); participants reported a mean of 7.3 problems (SD, 5.9 problems). The most common problems were fatigue (53.6%), worry (49.9%), and tingling (46.3%); least common problems were childcare (2.1%), fevers (2.1%), and substance abuse (1.1%). Report of some common problems, including tingling, sleep, memory, skin issues, and appearance, was not associated with large differences in distress or QOL. In contrast, some rarer problems such as childcare, treatment decisions, eating, housing, nausea, and bathing/dressing were associated with worse distress or QOL. Younger age, lower income, and chemotherapy were risk factors across common problems that were associated with worse distress or QOL (fatigue, nervousness, sadness, fears, and pain).

**CONCLUSION** The DT problem list did not easily identify concerns most associated with distress and low QOL in patients with gynecologic cancer. Adaptations that enable patients to report their most distressing concerns would enhance clinical utility of this commonly used tool.

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## INTRODUCTION

Distress, a common complication of cancer and its treatment,<sup>1,2</sup> represents a broad multifactorial continuum of negative emotions and outcomes, including symptoms of depression, anxiety, fears, and social and functional problems.<sup>3</sup> Distress reduces quality of life (QOL) and satisfaction with quality of care and is associated with reduced treatment adherence, which may mediate worse cancer outcomes.<sup>2,4,5</sup> Therefore, the psychosocial sequelae of cancer and their management have increasingly been recognized as integral to cancer care.<sup>2,6</sup> Since 2012, the Commission on Cancer has mandated to cancer centers that patients with cancer be screened for distress during the first course of treatment at least one time.<sup>7</sup>

The National Comprehensive Cancer Network (NCCN) Distress Thermometer (DT) has been widely adopted to measure distress in patients with cancer. The DT consists of a single-item continuous scale, which is an accurate, efficient, and acceptable short screening tool for patients to self-quantify distress<sup>8,9</sup>; and an accompanying problem list on which patients identify specific problems they have recently encountered. According to the NCCN distress management guidelines, the intention of the DT problem list is to “identify key issues of concern and ... determine the best resources ... to address the patient’s concerns.”<sup>14</sup>

Across studies, the continuous scale component of the DT is far more commonly reported than the problem list.<sup>12</sup> The few previous studies that have evaluated the

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problem list reported the problem list items as predictors, with the DT score or other psychosocial measures as outcomes.<sup>13-16</sup> Few studies have considered the problem items as outcomes themselves, so their clinical utility is lesser known than that of the DT distress score.<sup>1,17-19</sup> One possible explanation for the underreporting of the DT problem list is that its interpretation and clinical application are less straightforward than those of the DT score. In addition, many cancer programs do not have the staff to address all problems patients may report, and studies have shown that screening positive for elevated distress on the DT does not always lead to referrals to appropriate services.<sup>20</sup> This raises the question of whether simply checking problems from a predetermined list fulfills the NCCN's intended purpose of identifying patients' key problems. For the purposes of our study, we translated "key" to mean "urgent," defining urgency as being associated with higher DT scores and lower QOL.

Our goals were to assess self-reported DT problems based on a cohort of individuals with gynecologic cancers along with self-reported DT and QOL scores and to identify factors associated with the most prevalent and potentially urgent problems. Gynecologic cancers include uterine, ovarian, cervical, and vaginal and vulvar cancers. In the United States, currently approximately 1.3 million individuals live with a gynecologic cancer diagnosis, and this number is projected to increase to > 1.5 million by 2026.<sup>21</sup> Emotional distress varies significantly by cancer type and sex, with women demonstrating higher rates than men.<sup>22</sup> Patients with gynecologic cancers report higher DT scores than patients with many other cancers, and these patients also have a diverse set of concerns, making them an important and ideal population in which to examine the DT problem list.

## METHODS

### Study Design and Population

The Gynecologic Oncology–Life After Diagnosis (GOLD) study is an ongoing prospective cohort study initiated in March 2017 at the University of Minnesota with planned follow-up surveys every 6 months for up to 5 years. English-speaking individuals age 18 years and older diagnosed with ovarian, cervical, uterine, vaginal, or vulvar cancer and recruited through the University of Minnesota Gynecologic Oncology service line are eligible to participate in the study. Time since diagnosis is not an eligibility criterion, although the majority of patients have been recruited after treatment and/or in surveillance.

The GOLD study was approved by the University of Minnesota Institutional Review Board (No. 1612S01581). All participants provided written informed consent before being enrolled on the study and have signed a Health Insurance Portability and Accountability Act form agreeing to have their medical record data accessed by the GOLD research team for clinical data abstraction.

### Recruitment

Participants were identified using the electronic medical record and invited in person to participate at a follow-up clinic visit (March 2017 to present) or via mail (June to October 2018). To date, 408 participants have enrolled in the GOLD study, of whom 156 (95% of patients approached) were recruited in clinic and 252 (42% of patients approached) were recruited by mail. Of these 408 individuals, 381 (93%) completed the baseline survey before this analysis.

### Data Collection

At study entry, participants were invited to complete a comprehensive baseline survey. The survey was administered by paper or online via REDCap<sup>23</sup> based on participant preference. The survey collected information on demographics; self-reported clinical data; QOL; emotional health measures including depression, anxiety, distress, posttraumatic stress disorder, posttraumatic growth, hopelessness, resilience, self-efficacy, and coping; and health behaviors. Clinical data were abstracted from the electronic medical record, including cancer type, International Federation of Gynecology and Obstetrics stage at diagnosis, histology, treatments received (chemotherapy, surgery, or radiation), and outcomes including recurrence and death.

### Measures

The main outcome of this study was self-reported sources of distress (problems) endorsed by participants completing the problem list of the DT, version 1.2016.<sup>24</sup> The DT is composed of 2 components. First is a single-item visual analog scale on which patients rate their overall distress, phrased as follows: "Please select the number that best describes how much distress you have been experiencing in the past week including today. (0 = No Distress, 10 = Extreme Distress)"; a cutoff score of 4 or higher is deemed as likely reflecting clinically significant distress.<sup>8,24</sup> The second component is an accompanying problem list including 39 items in practical, family, emotional, spiritual/religious, and physical domains, phrased as follows: "Please indicate if any of the following has been a problem for you in the past week including today. Be sure to mark YES or NO for each."<sup>25</sup>

We measured QOL in this patient population using the Functional Assessment of Cancer Therapy–General (FACT-G) scale, which measures QOL outcomes in the following 4 domains: physical, social, emotional, and functional well-being.<sup>26,27</sup> Totals scores (0-108) across subscales are aggregated from the individual items, with higher scores indicating greater QOL.

Clinical and demographic predictors of self-identified problems were categorized as follows: cancer type (ovarian, cervical, uterine, vaginal, or vulvar cancer); stage at diagnosis (early stage I and II or advanced stage III and IV),

time since diagnosis (< 1, 1 to < 2, 2 to < 5, or ≥ 5 years); receipt of chemotherapy including targeted therapies or immunotherapy (yes or no); receipt of radiation (yes or no); age at baseline (continuous); receipt of college degree (yes or no); annual household income (< \$50,000, \$50,000-\$99,999, ≥ \$100,000, or prefer not to answer); partner status (married or partnered or single including separated, divorced, widowed, or never married); and residence (urban or rural) based on zip or Rural-Urban Commuting Area codes.<sup>28</sup>

### Statistical Analysis

Analyses were restricted to baseline data. Demographic and clinical characteristics of the cohort were summarized using descriptive statistics; means and standard deviations (SDs) and frequencies and percentages are provided. We visualized full DT and QOL score distributions for different subpopulations as violin plots. To describe how commonly each problem was reported in our population, we ranked the self-reported items on the DT problem list by prevalence. We also compared average distress and QOL (total FACT-G scores) in participants who did and did not endorse a particular problem to describe the potential urgency of each problem. We then explored demographic and clinical factors associated with the presence of selected problems using univariable and multivariable logistic regression models. Given restrictions in available degrees of freedom, we excluded residence, time since diagnosis, and receipt of radiation from our final model, which were not statistically significantly associated with any of the outcomes in the univariable or reduced multivariable models. Our final model included age, partner status, having a college degree, annual household income, advanced stage, receipt of chemotherapy, and cancer type. Data were analyzed using SAS version 9.4 (SAS Institute, Cary, NC) and R software.  $P < .05$  was considered statistically significant.

### RESULTS

At the time of analysis, 381 individuals completed the baseline survey, of whom 355 completed the DT questionnaire. Baseline demographic and clinical characteristics are listed in [Table 1](#). The average age at the time of the survey was 59.9 years (SD, 10.8 years), and the majority of participants were non-Hispanic white (97%). Most participants were diagnosed with ovarian cancer (44%) or uterine cancer (42%); the remaining were diagnosed with cervical cancer (10%) or vaginal or vulvar cancer (5%). Less than half of participants (43%) had at least a college degree, and 34% had annual household incomes of < \$50,000. Most participants (96%) were diagnosed within 5 years of study enrollment, and 60% were originally diagnosed with early-stage cancer. Among all participants, 93% had surgery, 61% had chemotherapy, and 25% had radiation therapy.

Approximately one third of the participants (30%) reported a DT score of ≥ 4, indicating clinically meaningful distress. The average number of self-identified problems was 7.3 (SD, 5.9 problems), and this increased to 12.6 problems (SD, 5.7 problems) among participants with a DT score ≥ 4. DT scores (higher DT scores indicated greater distress) and QOL scores (higher QOL scores signified greater QOL) were inversely correlated in our study population ( $r = -0.66$ ,  $P < .0001$ ), suggesting that distress and QOL are related but distinct concepts. Visualization of the scores by demographic and treatment groups indicated scores were skewed for all groups (right-skewed DT scores and complementary left-skewed QOL scores; [Appendix Fig A1](#), online only). Some subgroups indicated higher than average distress and lower than average QOL, such as individuals currently in treatment, with low incomes, without employment, or with vaginal or vulvar cancers.

[Table 2](#) lists all problems from the DT ranked by prevalence. We also ranked problems by differences in average distress and QOL scores, comparing those reporting to those not reporting each problem. The most commonly reported problems were fatigue (53.6%), worry (49.9%), and tingling (46.3%); the least common problems were childcare (2.1%), fevers (2.1%), and substance abuse (1.1%). Rankings by prevalence, however, differed substantially from rankings by distress or QOL. Those who reported the most prevalent problems did not have greater distress or lower QOL scores than those who did not report the problem; examples included tingling, sleep, memory, skin issues, and appearance. Some other problems were rare but associated with large distress or QOL differences, such as childcare, treatment decisions, eating, housing, school/work, nausea, bathing/dressing, getting around, and loss of interest in usual activities. Rankings by distress and QOL score differences were generally similar, with the exception of a few problems that ranked high by QOL but not by distress, including getting around and bathing/dressing, or that ranked high by distress but not QOL, such as school/work and nervousness.

Only 5 problems were both common (at least 25% prevalence) and ranked within the top 10 by either distress or QOL; these were fatigue, sadness, nervousness, fears, and pain. Multivariable associations of potential risk factors for these 5 problems are listed in [Table 3](#). Older age was associated with lower odds of reporting any of these problems (per additional 5 years; odds ratio [OR], range, 0.77-0.86; 95% CI, 0.68 to 0.97). Lower annual household incomes were associated with greater odds of reporting all 5 problems (< \$50,000  $v$  > \$100,000: OR, range, 3.01-3.86; 95% CI, 1.32 to 8.75), and middle incomes were associated with greater odds of reporting fatigue, sadness, and nervousness (\$50,000-100,000  $v$  > \$100,000: OR, range, 2.13-2.49; 95% CI, 1.04 to 4.96). Receipt of

**TABLE 1.** Demographic and Clinical Characteristics at Baseline, GOLD Study 2017-2019

Characteristic	No. of Patients (N = 355)	%
Age at survey, years		
< 40	20	5.6
40-49	42	11.8
50-59	85	23.9
60-69	156	43.9
≥ 70	52	14.6
Race		
White, non-Hispanic	343	96.9
Other	11	3.1
Missing	1	
Education		
No college degree	194	57.1
At least college degree	146	42.9
Missing	15	
Marital status		
Married/partnered	199	59.2
Widowed/divorced/never married	137	40.8
Missing	19	
Income, \$		
< 50,000	115	33.9
50,000-99,000	113	33.3
≥ 100,000	74	21.8
Prefer not to say	37	10.9
Missing	16	
Employment		
Yes, full time	127	37.5
Yes, part time	48	14.2
No	35	10.3
Retired	129	38.1
Missing	16	
Diagnosis		
Ovarian	155	43.7
Uterine	148	41.7
Cervical	35	9.9
Vaginal/vulvar	17	4.8
Time since first diagnosis, years		
< 1	99	28.0
1 to < 2	107	30.2
2 to < 5	134	37.9
≥ 5	14	4.0
Missing	1	

(continued in next column)

**TABLE 1.** Demographic and Clinical Characteristics at Baseline, GOLD Study 2017-2019 (continued)

Characteristic	No. of Patients (N = 355)	%
Cancer stage		
Early stage (stage I or II)	208	59.6
Advanced stage (stage III or IV)	141	40.4
Missing	6	
Surgery		
Yes	331	93.2
No	24	6.8
Chemotherapy		
Yes	216	60.8
No	139	39.2
Radiation		
Yes	89	25.1
No	266	74.9
Current treatment status		
Receiving initial treatment	22	6.6
Receiving treatment of disease progression/recurrence	51	15.2
Not currently receiving treatment	262	78.2
Missing	20	
Mean NCCN Distress Thermometer score (SD)	2.7 (2.7)	
Mean FACT-G total score (SD; n = 352)	83.4 (16.5)	
Mean No. of problems identified on problem list (SD)	7.3 (5.9)	

NOTE. Values are numbers and percentages, unless otherwise indicated.

Abbreviations: FACT-G, Functional Assessment of Cancer Therapy-General; GOLD, Gynecologic Oncology-Life After Diagnosis; NCCN, National Comprehensive Cancer Network; SD, standard deviation.

chemotherapy was associated with increased odds of reporting fatigue, sadness, fears, and pain (chemotherapy yes v no: OR, range, 2.01-3.66; 95% CI, 1.01 to 7.77). A vaginal or vulvar cancer diagnosis was associated with greater odds of reporting pain in the univariable but not the multivariable analysis (results not shown; vaginal or vulvar v uterine cancer: unadjusted OR, 2.92; 95% CI, 1.08 to 7.90). Having cervical cancer was associated with increased odds of reporting fears in the univariable but not the multivariable model (results not shown; cervical v uterine cancer: unadjusted OR, 2.23; 95% CI, 1.04 to 4.79). In addition, having cervical cancer was associated with decreased odds of reporting pain (cervical v uterine cancer: OR, 0.19; 95% CI, 0.06 to 0.62), and having a partner was associated with greater odds of reporting nervousness (OR, 1.95; 95% CI, 1.1 to 3.44)

## DISCUSSION

An abundance of studies support using the continuous DT score to screen for distress in patients with cancer. However, the clinical utility of the DT problem list has been understudied. Our data indicate that some problems that were frequently endorsed were not associated with substantially worse distress or QOL when comparing women with and without these problems. Conversely, some of the less common problems were associated with large differences in distress and QOL scores.

Given the large number of concerns that patients with cancer face, particularly those with gynecologic cancers, health care providers often cannot address all problems indicated on the DT. Although listing all patient concerns may be justified, it is necessary to meaningfully prioritize patients' most urgent issues during a clinical visit. Rare problems may be at greater risk of being overlooked, which could be detrimental if they are deeply distressing to patients, such as problems related to parenting with cancer,<sup>29-33</sup> fertility,<sup>34-36</sup> and work<sup>37,38</sup> or potential housing, financial, insurance, and transportation issues, which may be more prevalent in lower income populations.<sup>39,40</sup> In addition, the problem list may not be complete. For example, a potential problem that has been identified in previous work but is not on the DT problem list is loneliness.<sup>41,42</sup> Finances and insurance are aggregated as one item on the problem list, although they may be distinct problems with distinct approaches to mitigate them. Spirituality may be intended as an umbrella term for both religious and existential concerns, but among non-religious patients who may object to the term *spirituality*, existential concerns may go unnoticed in the screening process.<sup>43,44</sup> In addition, a problem may be highly distressing, but the patient may or may not be looking for additional support.

One simple way to address these limitations could be to start the DT problem list with open-ended questions, such as the following: "In your own words, what has been most distressing to you, including problems that are not directly related to your cancer?" and "Which of these concerns would you like to talk about with your care team?" This could then be complemented by the DT problem list to help patients identify any additional problems that did not immediately come to mind.

Our risk factor analyses for selected problems support prior research and raise additional research questions. First, the association of older age with fewer problems is consistent with previous studies that reported worse psychosocial outcomes among younger populations with cancer.<sup>29,30,34,45</sup> Second, the association of lower incomes with fears, sadness, fatigue, and pain requires further research. Cancer-related financial toxicity may exacerbate finance- and cancer-related stress and reduce QOL.<sup>46-51</sup> The association between lower incomes and pain also

points to the need for future research on potential income disparities in cancer pain management and to possible interaction effects of stressors that might exacerbate the experience of pain. Third, albeit limited by small sample size, patients with vaginal and vulvar cancer emerged as a potentially vulnerable group. Understudied, the rarity of these cancers and social stigma related to having a malignancy in the vulva or vagina may isolate these patients.<sup>41,52</sup> Exploratory findings from the limited studies on individuals diagnosed with vaginal and vulvar cancer suggest restrictions in activities of daily living,<sup>53</sup> feelings of stigma and embarrassment,<sup>52,54,55</sup> relationship disruptions, and frequent sexual dysfunction in this patient group.<sup>52,56-58</sup>

On the basis of our findings, future work should examine the use of the problem list in clinical settings and whether the processes envisioned in clinical guidelines (identifying and discussing key problems with subsequent appropriate referrals) are being practiced and truly maximize patient QOL. Previous studies have shown that an elevated distress score does not always lead to subsequent referrals.<sup>20,59</sup> Clinical studies that reported using the problem list have demonstrated that it is possible to integrate the problem list into clinical services in an effective way, emphasizing that the successfulness of that endeavor relies on carefully designed procedures, including staff education, meaningful integration of social and clerical services into clinical services, and thoughtful timing when the tool is applied to patients.<sup>60-62</sup>

Given sample size restrictions, we could not run in-depth analyses of rare problems associated with large differences in distress or QOL. Similarly, there were only 17 participants with vaginal or vulvar cancers in our study population; however, our findings suggest that these patients may face disproportionate sources of distress. Further, these data were collected from female individuals diagnosed and treated for gynecologic cancers at a single academic institution in Minnesota and, therefore, are likely not generalizable, particularly among nonwhite survivors of cancer, men, or patients with different cancers. Finally, our cross-sectional analysis did not allow us to establish causality in estimated associations.

The continuous distress score of the DT effectively identified survivors of gynecologic cancer experiencing cancer-related distress. However, our findings indicate that the DT problem list does not easily identify concerns most associated with high distress and low QOL. To achieve patient-centered care while facing time restrictions in the clinic, it is relevant to identify what concerns matter most to patients. We believe that simple enhancements to the DT, such as adding free text questions before the current problem list and explicitly asking patients to identify what has been most distressing to them and what problems they hope to receive support for, could help formalize a clinical process to identify major sources of distress among patients with

**TABLE 2.** NCCN DT Problems by Prevalence and Differences in DT and FACT-G Scores, GOLD Study 2017-2019

DT Problem	Prevalence (%)	DT Score Difference <sup>a</sup>	FACT-G QOL Score Difference <sup>a</sup>	Prevalence Rank	DT Rank	FACT-G QOL Rank
Fatigue <sup>b</sup>	53.6	2.51	-17.65	1	16	10
Worry	49.9	2.81	-15.38	2	11	17
Tingling	46.3	0.58	-5.05	3	38	39
Sleep	45.5	1.79	-12.93	4	27	25
Sadness <sup>b</sup>	36.3	2.83	-16.31	5	10	13
Memory	35.3	2.06	-14.54	6	24	20
Nervousness <sup>b</sup>	33.7	2.98	-14.67	7	6	19
Skin	32.1	1.27	-9.33	8	35	37
Fears <sup>b</sup>	29.7	2.84	-17.28	9	9	11
Appearance	26.6	1.13	-12.05	10	36	29
Pain <sup>b</sup>	25.1	2.56	-19.86	11	15	8
Swelling	23.9	1.28	-12.39	12	34	28
Depression	23.8	3.02	-21.14	13	4	5
Insurance/finances	22.1	2.08	-12.60	14	22	26
Constipation	20.6	1.59	-9.92	15	30	33
Nose	20.4	1.05	-9.49	16	37	36
Interest	20.3	2.99	-23.71	17	5	2
Indigestion	17.1	1.73	-11.22	18	29	31
Family health	17.0	1.55	-5.07	19	31	38
Diarrhea	16.4	1.33	-9.66	20	32	35
Partner	14.3	1.88	-15.23	21	26	18
Sex	13.1	2.06	-12.59	22	23	27
Nausea	12.8	2.72	-19.05	23	13	9
Eating	12.5	2.96	-15.91	24	7	15
Work schedule	12.4	3.09	-16.71	25	3	12
Urination	11.9	2.02	-16.07	26	25	14
Mobility	10.7	2.33	-22.16	27	19	4
Breathing	8.5	1.76	-14.39	28	28	22
Children	7.6	2.17	-9.72	29	20	34
Treatment decisions	7.4	3.79	-22.17	30	2	3
Transportation	5.6	2.66	-14.46	31	14	21
Mouth sores	5.3	2.14	-11.52	32	21	30
Spirituality	4.9	2.81	-15.65	33	12	16
Hygiene	4.5	2.45	-20.79	34	17	6
Housing	4.0	2.84	-19.97	35	8	7
Childbearing	3.0	2.42	-13.88	36	18	23
Childcare	2.1	4.39	-27.98	37	1	1
Fevers	2.1	1.30	-13.16	38	33	24
Substance abuse	1.1	0.27	-10.21	39	39	32

Abbreviations: DT, Distress Thermometer; FACT-G, Functional Assessment of Cancer Therapy–General; GOLD, Gynecologic Oncology–Life After Diagnosis; NCCN, National Comprehensive Cancer Network; QOL, quality of life.

<sup>a</sup>Score differences comparing individuals reporting versus not reporting each problem, based on DT and FACT-G total scores.

<sup>b</sup>Problem with at least 25% prevalence and ranked within top 10 by either distress or QOL.

**TABLE 3.** Factors Associated With DT Problems That Are Common and Associated With High DT and Low FACT-G QOL Scores, GOLD Study 2017-2019

Factor	OR (95% CI; N = 355) <sup>a</sup>				
	Fatigue	Sadness	Nervousness	Fears	Pain
Age, per 5 years	0.86 (0.76 to 0.97)	0.77 (0.68 to 0.87)	0.78 (0.69 to 0.88)	0.79 (0.70 to 0.90)	0.83 (0.73 to 0.95)
Partnered <sup>b</sup>	1.09 (0.65 to 1.83)	1.64 (0.95 to 2.85)	1.95 (1.1 to 3.44)	1.27 (0.72 to 2.25)	1.01 (0.55 to 1.84)
College degree <sup>b</sup>	0.83 (0.52 to 1.33)	0.99 (0.60 to 1.62)	0.81 (0.49 to 1.35)	1.07 (0.64 to 1.79)	1.07 (0.61 to 1.86)
Income, \$					
< 50,000	3.13 (1.50 to 6.53)	3.15 (1.43 to 6.95)	3.86 (1.7 to 8.75)	3.01 (1.32 to 6.85)	3.36 (1.41 to 7.96)
50,000-100,000	2.16 (1.15 to 4.05)	2.49 (1.25 to 4.96)	2.13 (1.04 to 4.38)	1.87 (0.90 to 3.86)	1.28 (0.58 to 2.85)
> 100,000	1.0 (Ref)	1.0 (Ref)	1.0 (Ref)	1.0 (Ref)	1.0 (Ref)
Prefer not to say	1.69 (0.72 to 3.94)	2.18 (0.87 to 5.47)	2.91 (1.14 to 7.43)	2.11 (0.81 to 5.53)	1.84 (0.66 to 5.17)
Advanced stage <sup>c</sup>	0.83 (0.46 to 1.51)	0.79 (0.43 to 1.47)	0.99 (0.53 to 1.87)	1.26 (0.67 to 2.37)	0.70 (0.36 to 1.36)
Chemotherapy <sup>p</sup>	2.51 (1.33 to 4.75)	2.39 (1.24 to 4.62)	1.67 (0.86 to 3.25)	2.01 (1.01 to 3.99)	3.66 (1.73 to 7.77)
Cancer type					
Ovarian	0.84 (0.47 to 1.5)	0.66 (0.37 to 1.2)	0.75 (0.41 to 1.37)	0.95 (0.51 to 1.75)	0.59 (0.31 to 1.12)
Cervical	0.68 (0.29 to 1.62)	0.70 (0.28 to 1.72)	1.18 (0.48 to 2.89)	1.12 (0.46 to 2.76)	0.19 (0.06 to 0.62)
Vaginal/vulvar	2.40 (0.71 to 8.15)	2.93 (0.95 to 8.99)	2.08 (0.7 to 6.19)	2.35 (0.75 to 7.31)	3.00 (0.97 to 9.29)
Uterine	1.0 (Ref)	1.0 (Ref)	1.0 (Ref)	1.0 (Ref)	1.0 (Ref)

Abbreviations: DT, Distress Thermometer; FACT-G, Functional Assessment of Cancer Therapy–General; GOLD, Gynecologic Oncology–Life After Diagnosis; OR, odds ratio; Ref, reference.

<sup>a</sup>Model adjusted for all variables in the table (age, partner status, education, income, disease stage, chemotherapy, cancer type).

<sup>b</sup>Yes v no.

<sup>c</sup>Advanced stage (stage III or IV) v early stage (stage I or II).

cancer. Our study also indicates that there is a need to characterize vulnerabilities of different patient subgroups, for example, by cancer type, socioeconomic

status, or life stage. Knowing which sources of distress are likely in different patient groups may help clinicians address urgent patient concerns more efficiently.

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## AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST AND DATA AVAILABILITY STATEMENT

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**AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST**

**Cancer-Related Distress: Revisiting the Utility of the National Comprehensive Cancer Network Distress Thermometer Problem List in Women With Gynecologic Cancers**

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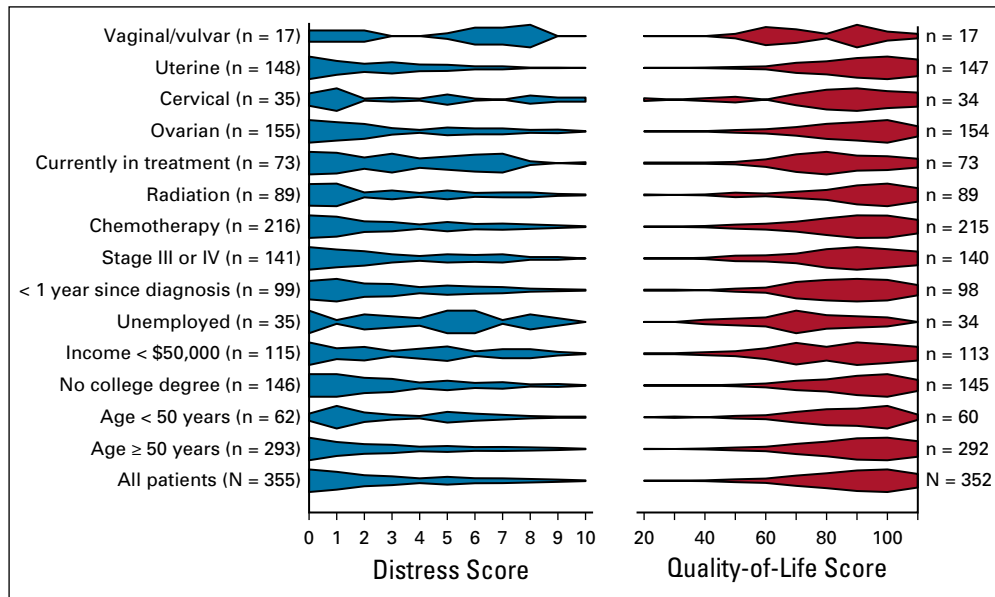
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APPENDIX



**FIG A1.** Distress and quality-of-life score distributions for different subgroups (N = 355) from the Gynecologic Oncology–Life After Diagnosis (GOLD) study (2017-2019).