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Factors associated with emotional distress in newly diagnosed prostate cancer patients

Heather Orom^{1,*}, Christian J. Nelson², Willie Underwood III³, Lynn D. Homish¹, and Deepak A. Kapoor^{4,5}

¹Department of Community Health and Health Behavior, University at Buffalo, 3435 Main St., Buffalo, NY 14214

²Department of Psychiatry and Behavioral Sciences, Memorial Sloan-Kettering Cancer Center, New York, NY

³Department of Urology, Roswell Park Cancer Institute, Carlton and Elm Streets, Buffalo, NY 14263

⁴Integrated Medical Professionals, PLLC, Melville NY

⁵Department of Urology, Icahn School of Medicine at Mount Sinai, New York, NY

Abstract

Objective—Early identification and intervention have been recommended for newly diagnosed prostate cancer patients who experience significant emotional distress; however, there is little empirical basis for designing or selecting interventions for these men. We sought to identify factors that are associated with distress in these men as a basis for identifying suitable intervention strategies.

Methods—Using cross-sectional data and validated scales, we investigated the extent to which clinical, demographic, belief, and personality characteristics are associated with emotional distress assessed with the Distress Thermometer in 1425 men newly diagnosed with clinically localized prostate cancer (pre-treatment).

Results—Beliefs potentially amenable to psycho-educational interventions [low self-efficacy for decision-making ($B=-0.11$, $p=.02$), low confidence in cancer control ($B=-0.03$, $p<.001$), and masculine identity threat ($B=-0.26$, $p=.001$)] were associated with higher emotional distress, as were personality factors [low optimism ($B=-0.04$, $p=.052$) and low resilience ($B=-0.83$, $p<.001$)].

Conclusions—Findings provide a framework for the development of interventions for prostate cancer patients with elevated emotional distress. These may include improving provider communication about prostate cancer prognosis for those with low confidence in cancer control; providing decision-making support to increase decision-making self-efficacy; or referral to brief cognitive behavioral interventions to help patients reframe masculine identity threat or those with low optimism or resilience reframe and adjust to the health threat.

*Corresponding author: Heather Orom, 304 Kimball Tower, 3435 Main St., Buffalo, NY 14214; Phone: 716-829-6682; Fax: 716-829-6040; horom@buffalo.edu.

Keywords

cancer; oncology; prostate neoplasm; emotional distress; Distress Thermometer; psychological factors

Cancer patients often experience elevated levels of emotional distress, not only at diagnosis and during treatment, but also long past initial treatment [1, 2]. There is growing consensus that identifying and intervening to reduce emotional distress is an essential component of cancer care [3, 4]. One strategy for preventing distress in later stages of survivorship is identifying those who experience significant distress soon after diagnosis and providing appropriate early intervention [5]. However, even though effective screening tools for emotional distress, anxiety or depression are available to identify those who could benefit from additional support [6, 7], less is known about the kinds of intervention components that are needed [8]. To match intervention and patient, we need a better understanding of factors underlying distress. The present work advances our understanding of the factors associated with emotional distress in newly diagnosed prostate cancer (PCa) patients, the second largest group of survivors in the U.S., numbering 2.8 million [9], so as to inform the design of suitable early interventions for these patients.

Studies investigating psychological wellbeing in men diagnosed with PCa have demonstrated two patterns. First, emotional distress, including anxiety, depression, and intrusive thoughts about cancer is highest at diagnosis and declines afterwards [7, 10, 11, 12], although levels may continue to be somewhat higher than for population norms [11, 13, 14]. Second, initially about a quarter to a third of men [10, 11, 15] experience clinically significant emotional distress, although lower percentages have been [16], and can continue to experience psychological issues throughout survivorship [5, 11]. To meet the needs of this second group, screening for emotional distress in cancer patients has been recognized as an important component of cancer care [17] and is now recommended by the National Comprehensive Cancer Network, the American Cancer Society, and others [3, 18, 19, 20].

In order to develop or select appropriate interventions for men who are highly distressed at diagnosis –and improve clinical practice for all PCa patients-- we need to understand the factors associated with high distress at this time-point. There are several studies of emotional distress in PCa patients after treatment [12, 13, 21, 22, 23], but few assessed distress in newly diagnosed PCa patients prior to treatment [10, 11, 16, 24, 25], identifying only a handful of factors associated with distress in this population: being satisfied with communication with one's medical team [25], neurotic personality, [24], generalized self-efficacy, [26], and older age [16].

To build on these studies, we investigated four classes of factors that could influence distress in men recently diagnosed with PCa: 1) cancer aggressiveness and disease prognosis (Gleason score), 2) demographic variables (e.g., employment and marital status, education, age), 3) beliefs that could influence distress during the diagnosis and decision-making process (concerns about cancer control, low decision making self-efficacy, masculine identity threat), and 4) personality resources that tend to be protective in stressful circumstances (resilience, optimism). For each category we tested individual variables that

have been associated with, or for which there were compelling rational for an association with psychological well-being in prostate cancer patients. Threat to masculine identity [27] has been associated with worse adjustment and optimism [28] and resilience [29] with better adjustment. Among demographic variables, younger age has been associated with higher distress [16]. Although Gleason score was not a significant predictor in two previous studies [16, 26]; we wanted to further test this possibility as our study sample was larger, and included more participants with high grade cancer (Gleason score = 8–10) than previous studies, making it more likely we could detect an effect if one exists. As it is possible that patients do not equate Gleason score with prognosis, we also included a subjective assessment of concern about prognosis, worry about cancer control.

Approaches to ameliorating adjustment could be informed by knowledge of which of these classes of factors are associated with emotional distress. For example, if clinical indicators of disease severity are associated with distress, it may be that patients with more aggressive disease require additional counseling about treatment options and prognosis, with the goal of reducing uncertainty and anxiety. Demographic predictors of distress would be helpful for identifying those at greater risk for distress. Knowledge and schema-based beliefs may be modifiable with psychoeducational interventions or cognitive behavioral therapy. Personality or trait vulnerabilities may be ameliorable with cognitive restructuring or buffered with pharmaceutical interventions.

Methods

Procedure

Patients who were newly diagnosed with clinically localized PCa were recruited from five clinical facilities (2 academic cancer centers and 3 community practices) between July 2010 and September 2013, as part of a larger study of treatment decision-making and survivorship. For this study we used data from a baseline questionnaire that was completed at, or shortly after consent, and prior to the start of treatment. Study procedures were Institutional Review Board-approved.

Participants

Between the start of recruitment and when the data were analyzed, 3990 eligible patients had been seen at the five participating facilities. We were able to approach 2692 (67.5%) and of these, 73.5% (n= 1978) were enrolled in the study. The questionnaire used for the present study was returned by 79.6% (N=1575) of those enrolled. Participants were excluded from analyses if they had missing data on any of the multivariable predictors or the main outcome, distress (n=150), yielding a final study N of 1425. The percent missing for these variables ranged from 0.1% to 5.1%. There were no differences in level of distress between those who were included versus excluded from the analyses. Non-Hispanic blacks were more likely to have been excluded (13.9%) compared to non-Hispanic whites (7.9%), as were those reporting Gleason score 8–10 disease more likely to have been excluded (14.9%) than those with Gleason score ≤ 6 disease (8.2%) ($p < .05$).

Measures

Beliefs—*Decision making self-efficacy* (confidence) was assessed with 3 items on which participants rated their confidence in their ability to ‘ask your doctor(s) questions about your treatment options that concerned you,’ ‘discuss openly with your doctor(s) questions/ concerns about developing any side effects after treatment,’ and ‘make the decision about which treatment is best for you after discussing options with your doctor,’ using 3-point Likert-type response formats (1=not at all confident, 3=extremely confident) ($\alpha = 0.83$). Responses have been associated with decision-making difficulty and satisfaction [30].

Confidence in cancer control was assessed with the cancer control subscale of Clark and colleagues’ [31] multidimensional PCa quality of life scale. Two items were slightly adapted to be more appropriate for patients who have not yet been treated. Participants responded to five statements using a 5-point Likert-type response format (1=strongly agree, 5=strongly disagree) ($\alpha=0.75$).

Masculine identity threat was assessed with an item from the functional assessment of cancer therapy- prostate (FACT-P): ‘I am able to feel like a man’ rated on a 5-point response format (1=strongly agree, 5=strongly disagree). This item was reverse-coded (higher scores indicate lower masculine identity threat) to parallel the other psychosocial predictors in the model for which higher scores represent greater adaptiveness.

Personality Characteristics—*Resilience* was assessed with the Brief Resilience Scale (6-item) that captures people’s generalized (i.e., trait-based) ability to bounce back or recover from stress [32]. Participants rated themselves using a 5-point item response format (1=strongly agree, 5=strongly disagree) ($\alpha=0.85$).

Optimism was assessed with the Life Orientation Test—Revised [33] that assesses dispositional optimism, or the generalized tendency to expect positive outcomes in important domains of life. It includes 6 test items (e.g., ‘I hardly ever expect things to go my way,’) and 4 filler items to which participants respond using a 5-point Likert-type response format (1=strongly disagree, 5=strongly agree) ($\alpha=0.82$).

Clinical characteristics—Participants self-reported Gleason score, an indicator of tumor aggressiveness (5/6/7/8–10/don’t know), and PSA at time of diagnosis (4/5–6/10–14/15–20/ 20/don’t know). We collapsed the 5 and 6 Gleason score categories and the PSA 8 categories.

Demographic characteristics—Participants self-reported years of education completed, household income, health care coverage status, marital status, employment status, age, and race/ethnicity.

Emotional distress—The outcome, emotional distress, was measured with the Distress Thermometer, an 11-point single-item visual analog scale ranging from 0 (no distress) to 10 (extreme distress) with 5 (moderate distress) as a mid-point anchor. The Distress Thermometer has been validated as a screening tool for use in PCa patients [7, 34], including newly diagnosed patients [7], with good specificity and sensitivity for detecting

cancer-specific distress measured by the Revised Impact of Events Scale (IES-R), anxiety measured by the Hospital Anxiety and Depression Scale (HADS), and depressed affect measured by the Brief Symptom Index 18 (BSI-18) [7]. It is among the screening tools recommended by the National Comprehensive Cancer Network [3] and the American Cancer Society [18]. Cut-off points between 3 to 6 may provide good sensitivity and specificity, with higher cutoffs providing better specificity for recently diagnosed patients [7]. Chambers et al. found that the best cutoff in newly diagnosed PCa patients who had not yet been treated (Study 1 sample at baseline) was 5 [7].

Statistical Analyses

We modeled distress two ways. First, to identify factors associated with level of distress, we conducted a hierarchical linear regression. Self-reported Gleason score (disease aggressiveness) was the only predictor in the first model; and demographic characteristics (education, marital status, race/ethnicity, employment status, and mean age at diagnosis) were added in the second model. Beliefs (decision making self-efficacy, worry about cancer control, masculine identity threat) were added to the third model, and personality factors (resilience, optimism) were added to the fourth model. Household income was not included in the multivariable models because of the high percentage of missing responses (15.9%) and correlation with education ($r=0.42$); nor was health care coverage, as nearly all participants had health care coverage (99.6%). Results were unaffected by the addition of self-reported PSA to the models and it in itself was not a significant predictor of distress; therefore, to not reduce our sample size further due to missing data on this variable it was not included in the multivariable models. Second, we wanted to identify those factors that predicted significant emotional distress. We conducted a hierarchical logistic regression using 5 as the cutoff for significant distress. Participants were recruited from five clinical facilities; we accounted for this source of non-independence by using robust standard errors in all multivariable models. Analyses were conducted using Stata 12.

Results

Participant characteristics and bivariate associations with distress

Demographic and clinical characteristics are reported in the Appendix included in the Supplemental Material, along with mean level of distress as a function of these characteristics. Younger age ($p<.001$) and lower income ($p=.04$) were statistically significantly associated with greater distress (Appendix; Supplemental Material).

In bivariate analyses, beliefs and personality were significantly associated with distress. Participants with distress scores above a cutoff of 5 had lower levels of adaptive beliefs (decision-making self-efficacy, confidence about cancer control, masculine identity) and personality factors (optimism, resilience) than those with distress scores below the cutoff (all p -values $<.001$; Table 1). Pairwise correlations between the belief and personality variables were, for the most part, modest, ranging from $r = -0.18$ to 0.36 , p -values $<.001$, with the exception that optimism and resilience were strongly correlated $r=0.65$, $p<.001$.

Multivariable models of distress

Results of a hierarchical regression model of continuous distress are presented in Table 2. The final model accounted for 23% of the variance in distress. Most of the constructs in the model are conceptualized as protective factors (i.e., higher scores are more adaptive) and associations with distress are negative (Table 2); however, we were interested in factors that predict higher distress, therefore results are summarized accordingly. As is shown in Table 2, Model 4, having more aggressive disease (Gleason 8–10 versus ≤6 disease), younger age, lower decision making self-efficacy, confidence in cancer control, greater masculine identity threat, and lower resilience and optimism were independently associated with higher distress.

We were also interested in whether the same factors predicted significant clinical distress defined by a score of ≥5 on the Distress Thermometer. Results for the hierarchical logistic regression modeling distress above and below the cutoffs of ≥5 were similar to those for the linear distress outcome. In the final model, having high risk (Gleason 8–10), rather than low risk disease (Gleason ≤6) was associated with greater odds of having significant distress (OR=1.69, SE=0.36, $p=.01$). Age (OR=0.96, SE=0.01, $p<.001$), confidence in cancer control (OR=0.98, SE=0.00, $p<.001$), masculine identity (OR=0.82, SE=0.06, $p=.006$), and resilience (OR=0.57, SE=0.07, $p<.001$) were associated with lower distress. Given concern that a cutoff of ≥5 may overestimate distress in a newly diagnosed sample, a cutoff of ≥6 might be warranted. In a model in which the cutoff for significant distress was ≥6, the pattern of results was identical, except lower optimism was also a predictor of significant distress (OR=0.93, SE=0.02, $p=.002$).

We did not include household income as a predictor in the multivariable models because 16.6% of participants were missing responses for this item. When we repeated the multivariable analyses with income included in the models, results for distress were nearly identical except that self-efficacy for decision making was not a significant predictor of distress. Income did not predict distress.

Discussion

We identified a set of beliefs (decision-making self-efficacy, confidence about cancer control, masculine identity threat) and personality variables (optimism, resilience) that, along with self-reported disease aggressiveness and younger age, were associated with distress in newly diagnosed PCa patients. As most belief and personality predictors were uniquely associated with distress and were only modestly associated with one another, PCa patients may vary with respect to the reasons they are distressed.

Understanding the factors associated with distress allows us to think in nuanced ways about the kinds of support needed by PCa patients and when such support should be offered. Support for those with low decision-making efficacy, concern about cancer control, or among those with aggressive disease might be best provided during the treatment decision-making phase. Decision-making support may ultimately result in lower likelihood of regretting one's treatment choice and better coping with any treatment side-effects as ambivalence about treatment choice has been associated with treatment regret [35]. We

might speculated that individuals with high threat to masculine identity might benefit from a brief psychoeducational reframing intervention that helps patients reinterpret perceived threats to their masculinity and identity more generally. Confidence about cancer control, resilience and optimism all had the strongest bivariate associations with distress. As clinically localized PCa has a good prognosis compared to some other cancers, we may be able to efficiently reduce distress if providers communicate information about recurrence and survival in a clear and accurate manner. Those with low resilience or low optimism may be best targeted with brief cognitive behavioral therapy to help them cope with PCa-related stressors, including treatment side-effects and fear of recurrence. Pharmaceutical intervention may also be helpful. In addition, although optimism and resilience were initially conceptualized as stable individual-difference dimensions, recent evidence indicates that resilience, optimism, or the underlying cognitive beliefs and processes of these attributes, can be improved with intervention, including with relatively brief, or online interventions [36, 37].

Although income was not uniquely associated with distress in the multivariable models, in bivariate analyses, those with very low incomes (<25,000) had higher mean distress than those with the highest income. Others have found that cancer patients, including PCa patients, with low socioeconomic status are more vulnerable to emotional distress than those with higher status [38]. Low income may be a risk factor for distress. Future research should explore whether there are proximal determinants of distress that are unique to lower income patients and test what kinds of support are most beneficial for distressed patients with few financial resources.¹ They may benefit most from tangible support in the form of subsidies, transportation, or navigation to financial resources.

While there has been a number of studies that explored the threat that prostate cancer poses to masculine self-esteem, as described in recent studies, threat to masculinity has been rarely assessed quantitatively alongside quantitative assessment of psychosocial adjustment [27, 39]. Adding to the literature, our findings indicate that masculine identity is associated with emotional distress in newly diagnosed patients.

Black, compared to white race was associated with higher distress in the final model; however, the bivariate association between black race and distress was not significant. We caution against interpreting this finding as evidence that black race is associated with higher distress. Non-Hispanic blacks had significantly higher optimism, resilience, and confidence in cancer control than Non-Hispanic whites and controlling for these attributes likely results in a suppressor effect, strengthening the association between black race and distress. We reported a similar pattern of results for difficulty and satisfaction with treatment decision-making [30].

Finally, ours is the first study to find that patients who self-reported Gleason score 8–10 disease, more emotionally distressed than those reporting Gleason 6 disease. Because of the study's relatively large sample size, 131 participants reported having Gleason scores

¹We tested whether any of the beliefs, personality characteristics, demographic and clinical characteristics interacted with income in predicting distress. They did not, indicating that other factors may be unique predictors of distress in patients with low socioeconomic status.

between 8 and 10 at diagnosis, a much larger number than in previous studies. This might have made it easier to detect what would seem to be a logical relationship between disease severity and emotional distress. It is also the case that we assessed patient recalled Gleason score, reasoning that, where they differed, patient's perceptions of disease severity might be a relatively more important determinant of distress than medical record-abstracted Gleason.

Limitations

As with all cross-sectional studies, it is not possible to infer causality from our findings. Some of the predictors in our models are characteristics (e.g., optimism, resilience) that, given their temporal stability, likely are antecedents of emotional distress; however, other beliefs such as perceived masculinity or decision-making self-efficacy could be the consequence of, or reciprocally related to emotional distress. Our measure of disease severity was self-reported Gleason score, while potentially inaccurate, it has the advantage that it captures patients' perceptions and recollection of their Gleason score which should be associated with their perceptions of disease severity, the construct of greater interest for the present study.

The use of the single-item Distress Thermometer has both drawbacks and strengths. The Distress Thermometer is becoming a widely used screening tool for emotional distress and has been shown to have good sensitivity and specificity, especially among newly diagnosed and early patients [7]. As guideline practice recommends screening cancer patients for distress, including with the Distress Thermometer [3, 18], it is highly likely that in the future, interventions will be aimed at those who are identified as having significant distress using this tool. On the other hand, there is likely greater noise in our measurement of distress than if we had used a longer scale such as the HADS. Caution is recommended in interpreting our conclusions as we may not have fully or as accurately characterized relationships between our predictors and emotional distress as we could have had we used a multi-dimensional and more psychometrically robust measure of emotional distress. A similar critique is true for our single item assessment of masculine identity threat and future research would benefit from the use of a quantitative multidimensional measure of masculine identity threat such as the one recently developed by Hoyt and colleagues [39]. Finally, non-Hispanic blacks and individuals with more aggressive disease were disproportionately excluded from our analyses due to missing data on variables of interest. It is possible that their perspectives are under-represented in our findings.

Conclusions

As guidelines now recommend periodic screening for emotional distress, resources may become available for intervening with those who have high emotional distress. Interventions tested to date have not necessarily proven effective [40], perhaps in part due to lack of match between patient and intervention. By identifying determinants of distress, our results suggest alternative and novel intervention strategies. Importantly, we identified determinants of distress in newly diagnosed patients who had not yet been treated. This is one time-point at which we might want to screen for and enroll men in early interventions. At this stage men may be more motivated to participate in an intervention, they may be easier to contact and recruit, and we may be able to address determinants of distress such as low self-efficacy for

decision-making or unrealistic expectations about prognosis that should be addressed prior to, or as men are making their treatment decision.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1

Mean scores on predictor variables as a function of being above or below the cutoff for significant distress (N=1425)

Predictor (range)	Mean (SD) for participants with distress < 5	Mean (SD) for participants with distress ≥ 5
Decision making self-efficacy (3–9)	8.36 (1.01) *	8.02 (1.31)
Confidence about cancer control (5–100)	62.38 (19.15) *	51.62 (18.24)
Masculine identity (1–5)	4.34 (0.82) *	4.05 (0.87)
Resilience (1–5)	4.03 (0.57) *	3.69 (0.67)
Optimism (8–30)	23.75 (3.68) *	21.89 (4.12)

*
p<.001

Table 2

Results of hierarchical linear regression predicting distress (N=1425)

Predictor variable	Model 1		Model 2		Model 3		Model 4	
	B	SE	B	SE	B	SE	B	SE
Gleason								
7	0.10	0.15	0.21	0.15	0.12	0.14	0.15	0.14
8–10	0.44	0.26	0.72 ^{**}	0.25	0.58 [*]	0.24	0.58 [*]	0.23
Don't know	−0.03	0.24	0.06	0.24	−0.21	0.22	−0.11	0.21
Education								
High school			−0.13	0.22	−0.14	0.20	−0.11	0.19
Some college			−0.38 [*]	0.19	−0.12	0.18	0.07	0.17
College			−0.17	0.18	0.06	0.17	0.25	0.17
Employment status			0.36 [*]	0.16	−0.26	0.14	−0.22	0.14
Marital status			−0.13	0.19	0.05	0.17	0.12	0.17
Age			−0.07 ^{***}	0.01	−0.06 ^{***}	0.01	−0.06 ^{***}	0.01
Race/Ethnicity								
Black Non-Hispanic			−0.10	0.23	0.23	0.22	0.43 ⁺	0.22
Hispanic			−0.02	0.25	−0.01	0.24	0.05	0.24
Other			0.31	0.40	0.02	0.36	−0.10	0.34
Decision making self-efficacy					−0.18 ^{***}	0.05	−0.11 [*]	0.05
Confidence about cancer control					−0.04 ^{***}	0.00	−0.03 ^{***}	0.00
Masculine identity					−0.42 ^{***}	0.08	−0.26 ^{**}	0.08
Resilience							−0.83 ^{***}	0.13
Optimism							−0.04 ⁺	0.02
<i>R</i> ²	0.00		0.04 ^{***}		0.18 ^{***}		0.23 ^{***}	

⁺ p<.05;^{*} p<.05,

100>d

'10>d
**

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