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Fatalism, Medical Mistrust and Pre-Treatment Health-Related Quality of Life in Ethnically Diverse Prostate Cancer Patients

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Abstract

Objective—Few studies have examined the impact of cultural processes prevalent in minority ethnic groups such as cancer fatalism and medical mistrust on health-related quality of life (HRQoL) following a cancer diagnosis. The present study examined relationships among ethnicity, HRQoL and two possible cultural vulnerability factors—fatalistic attitudes and medial mistrust, among an ethnically diverse sample of men with prostate cancer (PC) prior to undergoing active treatment.

Methods—A total of 268 men with localized PC (30% African American, 29% Hispanic & 41% non-Hispanic white) were assessed cross-sectionally prior to active treatment. Path analyses examined relationships among ethnicity, vulnerability factors, and HRQoL.

Results—Ethnicity was not related to HRQoL after controlling for relevant covariates. Hispanic men reported greater cancer fatalism compared to non-Hispanic white men (β= .15, p= .03), and both Hispanics (β= .19, p<.01) and African Americans (β= .20, p<.01) reported greater medical mistrust than non-Hispanic whites. Fatalism demonstrated a trend towards negatively impacting physical well-being (β= −.12, p= .06), but was not significantly related to emotional well-being (β= −.10, p= .11). Greater medical mistrust was associated with poorer physical (β= −.14, p= .03) and emotional well-being (β= −.13, p= .04).

Conclusions—Results indicate that fatalistic attitudes and medical system mistrust were more prevalent among minority men. Less trust in the medical system was associated with poorer physical and emotional well-being. Attention to perceptions of the health care system and its relation to HRQoL may have implications for targeting culturally-driven attitudes that may compromise adjustment to a PC diagnosis.

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Background

Prostate cancer (PC) is the most commonly diagnosed non-skin cancer in American men [1]. Survival rates vary by racial/ethnic group, a difference which persists after controlling for socioeconomic status and access to care [2]. A large number of studies have evaluated health-related quality of life (HRQoL) outcomes following PC treatment [3–4] with some attention to racial/ethnic differences. Penedo and colleagues [5] found lower post-treatment HRQoL among African American (AA), and Hispanic (H) men compared to non-Hispanic white (NHW) men. Furthermore, AAs and Hs reported greater medical comorbidity, lower physical activity, and poorer sleep functioning. These medical and behavioral factors mediated the relationship between ethnic group membership and HRQoL. In a separate study, AA men reported lower levels of general and disease-specific HRQoL relative to NHWs prior to PC treatment even after controlling for age, education, and income [6]. Others demonstrated similar findings, where AA men reported poorer HRQoL at diagnosis prior to PC treatment compared to NHWs [7]. However, none of these studies evaluated attitudinal factors that may explain these racial/ethnic differences.

Few studies addressed the role of sociocultural factors in HRQoL in PC patients across the disease continuum. Prior work, though not conclusive, showed that certain sociocultural characteristics (e.g., acculturation, religiosity, and familism) can benefit HRQoL. Greater acculturation has been related to better HRQoL [8], but the impact of religiosity and familism (an orientation towards a strong family attachment & affiliation) have been mixed. Whereas some studies have found that religiosity did not have a significant effect on physical or emotional well-being, others found that religious activity was associated with fewer depressive symptoms among Black cancer survivors [9–10]. Qualitative studies have shown that familism may impact HRQoL both positively and negatively for ethnic minority patients [11].

Cancer fatalism and medical mistrust are salient constructs for many H and AA individuals and have been shown to negatively impact health by way of influencing health beliefs, assumptions, and behavior [12]. However, no study to date has evaluated the impact of these variables on pre-treatment HRQoL in PC. Cancer fatalism is the belief that a diagnosis of cancer will inevitably result in death [13]. Minority populations, such as AAs and Hs are more likely to endorse higher levels of cancer fatalism compared to NHW individuals [14–16]. Cancer fatalism may act as a barrier to the screening, detection, and treatment of cancer [13] even after controlling for age, education, and income [17]. Although the role of cancer fatalism as it relates to cancer screening has been well developed in the literature, a gap remains in understanding the impact of fatalism on HRQoL outcomes among cancer survivors. Medical mistrust involves a tendency to distrust healthcare systems and health-related providers [18]. It is well documented in the literature that AAs are more likely to report higher levels of medical mistrust than NHWs [19] and some studies suggest that Hs also endorse high levels of medical mistrust [20]. In breast cancer samples, the relationship between race/ethnicity (i.e., AA and H) and poorer HRQoL was partially mediated by medical mistrust [21].

The current study examined disparities in HRQoL among AA, H, and NHW PC patients prior to treatment initiation. We hypothesized that cultural vulnerability factors (defined as cultural beliefs, including cancer fatalism and medical mistrust, previously associated with poorer patient outcomes) would be related to HRQoL and partially mediate any relationship between ethnic group membership and HRQoL. We also expected that AA and H men would report both poorer HRQoL and more cancer fatalism and medical mistrust than NHW men.

Methods

Participants

Participants were enrolled in a larger study examining the association between ethnic group membership and HRQoL in men diagnosed with PC prior to initiating treatment. Participants were required to be age 21 or older and have a diagnosis of PC. Exclusion criteria included: history of cancer other than skin or prostate, completion or initiation of active PC-related treatment (e.g., radical prostatectomy, radiation therapy, cryotherapy, and/or androgen deprivation therapy), severe psychiatric disorder (e.g., psychotic disorder), and severe cognitive impairments as evaluated by the Mini Mental State Exam (MMSE) [22]. Self-reported ethnicity was used to categorize patients into ethnic groups (i.e., NHW, H, or AA). Participants who self-identified as belonging to multiple ethnic groups or who identified as Asian/Asian American or American Indian/Native American were not included in the analyses due to small sample sizes for these other groups.

Measures

All study measures were available in English and Spanish. A study staff member fluent in Spanish was available to meet with participants who chose to complete assessments in Spanish. An IRB-approved translation company translated the measures not available in Spanish which then underwent further review by bilingual and translation certified study staff that had experience working with H populations.

Covariates—The study assessed several self-reported covariates such as age and subjective social status (MacArthur Scale of Subjective Social Status) [23], sociocultural covariates such as language preference as a proxy for acculturation, familism and religious behaviors. The Perceived Support from the Family subscale of the revised Bardis Familism Scale [24] was used as an indicator of familism. The Perceived Support from the Family subscale demonstrated adequate psychometric properties and internal consistency in the current study for English and Spanish versions combined (Cronbach's $\alpha = .83$) as well as for the Spanish version alone ($\alpha = .84$). The Religious Behavior subscale of the Ironson-Woods Spirituality/Religiousness (SR) Index short form was used to assess religiosity [25]. Psychometric properties for the Religious Behavior subscale were adequate when testing the English and Spanish versions combined ($\alpha = .88$) as well as the Spanish version alone ($\alpha = .88$). The following medical variables were also included in the analyses: PSA level at diagnosis, time since diagnosis, and comorbid medical conditions. Medical chart reviews were conducted to extract PSA level and diagnostic information. The Charlson Comorbidities Index was used to assess medical comorbidity [26].

Ethnicity—Ethnic group membership was self-reported using a standard racial/ethnic background item [27]. H ethnicity took precedence over race in the categorization schema, so the H ethnic group was racially diverse.

Cultural Vulnerability—The composite score of the Powe Fatalism Inventory (PFI) [17] was used to measure participants' level of cancer fatalism. An adapted version of the PFI [12] was administered using "prostate cancer" rather than the general term "cancer". The internal reliability for the PFI was adequate when testing English and Spanish versions combined (i.e., Cronbach's α = .85) as well as the Spanish version alone (i.e., α = .89). The Group-Based Medical Mistrust Scale (GBMMS) [18] total score was used to assess medical mistrust. In the current study, the internal consistency of the GBMMS English and Spanish versions combined (α = .89) and Spanish version alone (α = .86) were adequate.

HRQoL—The Functional Assessment of Cancer Therapy-General (FACT-G) [28] was used to assess HRQoL. The FACT-G yields four subscale scores and a composite score; only the Physical Well-being and Emotional Well-being subscales of the FACT-G were used. Previous studies have also examined these individual subscales [29–30]. The internal reliability for the FACT-G Physical Well-being and Emotional Well-being subscales were adequate when testing English and Spanish versions combined (Cronbach's α = .79 and .75, respectively) and Spanish version alone (α = .88 and .70, respectively).

Procedure

Participants were recruited from multiple urology clinics in South Florida. Recruitment was conducted by either having a study staff member present at each urology clinic to recruit and conduct initial eligibility screening or a study staff member contacted the potential participants via phone. The complete assessment battery consisted of a set of questionnaires designed to be completed in a face-to-face interview format and an additional set of questionnaires that were mailed and completed by participants prior to the interview. All participants, irrespective of whether they attended in-person visits or participated via mail, were compensated $50. The study procedures were approved by the Institutional Review Boards (IRB) at both the University of Miami and Miami VA Healthcare System.

Statistical Analyses—Several analyses were conducted to determine whether the covariates in the current model varied by ethnic group membership. Multiple one-way analysis of variance (ANOVA) tests were conducted with ethnic group as the between subjects factor. Similar comparisons were also made for the cultural vulnerability and HRQoL variables. All descriptive analyses were conducted using SPSS Statistics for Windows, Version 21.0.

Path analyses were conducted using Mplus statistical software version 6 [31] to test specific study hypotheses. Full information maximum likelihood (FIML) was used to estimate model parameters with missing data. Because there is no single gold standard, several indices were used to assess goodness of model fit [32] including the model chi-square (p-value > .05), the comparative fit index (CFI > 0.90), root mean square error of approximation (RMSEA < 0.06), and standardized root mean squared residual (SRMR < 0.08) [33]. Suggested

modification indexes were used to improve model fit. A significant relationship between variables was determined by a *p*-level <.05 of the standardized beta coefficient of interest.

Because ethnic group membership was categorical, the variable was dummy-coded by selecting a reference group and creating two new dummy-coded variables. When NHW men served as the reference group, H and AA men were separately compared to NHW men. Additional analyses were conducted where H men served as the reference group and allowed for separate comparisons to be made between H and AA men. All analyses that included ethnic group membership as a variable of interest were run twice in order to make comparisons among all three groups.

Path analyses were conducted to examine the relationship between ethnic group membership and pre-treatment HRQoL, ethnic group and cultural vulnerability factors, and the relationship between cultural vulnerability factors and pre-treatment HRQoL. These analyses included the same set of covariates with HRQoL and evaluated ethnic group differences in HRQoL and cultural vulnerability factors, and whether cultural vulnerability factors were related to HRQoL. A final set of path analyses assessed whether the relationship between ethnic group membership and pre-treatment HRQoL was mediated by cultural vulnerability factors. Similar to the more simplified path models, separate paths were run for both physical and emotional well-being as well as for each ethnic group comparison.

Results

Descriptive Statistics

A total of 897 men were screened to participate; 370 were deemed ineligible. Of the 527 eligible men, 147 refused (e.g., too busy or experiencing comorbid medical conditions). A total of 273 men completed the assessment and data were excluded for two participants that had invalid data and for three participants who could not be categorized into one of the three ethnic groups of interest. Therefore, analyses were conducted with a sample of 268 men diagnosed with PC who had not initiated active treatment.

Characteristics for the total sample and by ethnic group are presented in Table 1. The most commonly reported comorbid medical conditions were: connective tissue disease, lupus, or arthritis (28%); diabetes (20%); and circulatory problems in the legs or arms (peripheral vascular disease; 18%). PSA levels were significantly positively skewed, so log transformed values were used in all subsequent analyses. Multiple one-way ANOVAs were conducted to determine whether the conceptually relevant covariates, cultural vulnerability factors, and HRQoL variables differed among ethnic groups (see Table 1). Of note, there were no significant differences in cultural vulnerability factors between men seeking active treatment versus surveillance.

Ethnicity & HRQoL—A series of path analyses were conducted to test the first hypothesis that AA and H men will each report poorer physical and emotional well-being compared to NHW men and that there will be no differences between minority ethnic groups. To improve model fit per modification indices, the H dummy-coded variable was covaried with language

preference and the AA dummy-coded variable was covaried with religious behavior in all analyses that included a NHW reference group. As for models with H as the reference group, the NHW and AA dummy-coded variables were each covaried with language preference. As expected, there were no significant differences in physical and emotional well-being between Hs and AAs (physical well-being: $\beta = .07$, $p = .45$; emotional well-being: $\beta = .11$, $p = .23$). Contrary to our hypotheses, H and AA men did not report poorer physical and emotional well-being relative to NHWs (physical well-being: $\beta = -.09$ to $-.16$, $ps > .05$; emotional well-being: $\beta = -.01$ to .11, $ps > .10$). Of the examined covariates, only familism was significantly related to emotional well-being (emotional well-being: $\beta = .18$, $p = .01$); no covariates were significantly related to physical well-being.

Ethnicity & Cultural Vulnerability Factors—The second set of path analyses evaluated the relationship between ethnic group membership, and cancer fatalism and medical mistrust. Results indicated that H men reported greater levels of cancer fatalism compared to NHW men, but levels of cancer fatalism did not differ between AA and NHW men. Both H and AA men each reported greater levels of medical mistrust compared to NHW men. There were no significant differences between levels of cultural vulnerability factors between H and AA men (see Table 2).

Cultural Vulnerability Factors & HRQoL—Additional path analyses examined whether greater levels of cancer fatalism and medical mistrust were associated with poorer physical and emotional well-being after controlling for relevant covariates. Cancer fatalism was not related to physical well-being ($\beta = -.12$, $p = .06$) or emotional well-being ($\beta = -.10$, $p = .11$), although a trend was observed where greater levels of cancer fatalism were related to poorer physical well-being. As hypothesized, greater levels of medical mistrust were significantly associated with poorer physical and emotional well-being for all participants (see Table 3). Assessment language preference (Spanish) was a significant covariate in all the path models examined and was related to poorer HRQoL (physical well-being: $\beta = -.12$ to $-.13$, $ps \leq .05$; emotional well-being: $\beta = -.15$ to $-.15$, $ps < .05$) for path models testing the relationship between both medical mistrust and HRQoL, and for cancer fatalism and HRQoL. Familism was positively related to emotional well-being only (see Table 3). As ethnic group membership was not significantly associated with either physical or emotional well-being, the full path model evaluating whether cultural vulnerability factors mediated the relationship between ethnic group and HRQoL was not evaluated.

Conclusions

This study examined relationships among ethnic group membership, cultural vulnerability factors, and HRQoL (i.e., physical and emotional well-being) among men diagnosed with PC who had not initiated active treatment. Our findings showed that greater medical mistrust among all participants was associated with poorer physical and emotional well-being above and beyond relevant covariates. In contrast, cancer fatalism was not related to levels of physical or emotional well-being. Cancer fatalism and medical mistrust have been examined in cancer populations as they relate to poorer screening behavior, less satisfaction with care, lower adherence to treatment, and likelihood of having a physician [17,19,34–35]. But to date, no studies have assessed how these two constructs related to physical and emotional

well-being in ethnically diverse men diagnosed with PC who have not received active treatment. These results provide novel information about culturally specific correlates of HRQoL for men with PC. Although previous studies have explored sociodemographic correlates of HRQoL outcomes [36], none have looked at fatalism and medical mistrust. This is the first study to identify a significant relationship between medical mistrust and poorer pre-treatment HRQoL in men with PC and the results were consistent with those from a similar study in women with breast cancer [21]. These findings have important clinical implications as greater levels of cultural vulnerability factors may place men at risk for experiencing poorer physical and emotional adjustment following PC diagnosis. Clinicians should be aware that culture may interact with pre-treatment physical and emotional well-being, which can have implications for post-treatment outcomes.

Ethnic group differences in HRQoL were only identified when covariates were not included in the analyses. Specifically, NHW men reported better physical well-being than H and AA men, and contrary to study hypotheses, AA men reported significantly better emotional well-being than H men. After controlling for relevant sociodemographic, medical, and sociocultural covariates, ethnic group membership was no longer significantly associated with physical or emotional well-being. In the current study, physical well-being for each ethnic group was higher than that of general older US adult male population [37]. These higher scores may account for the lack of differences in HRQoL. Moreover, sociodemographic and medical factors were not related to pre-treatment physical well-being. It is possible that sociodemographic and medical characteristics play a more significant role in the presence of treatment-related dysfunctions. For example, work by Dahn et al. [38] showed that in the post-treatment phase, education and income are related to disease specific HRQoL. Our results also showed that greater familism was significantly associated with better emotional well-being. To our knowledge, this is the first study to document a positive and possibly protective function for familial attitudes among men diagnosed with PC who have not initiated active treatment.

As expected, H men reported greater levels of cancer fatalism compared to NHW men. However, AA men in our sample had similar levels of cancer fatalism compared to both NHW and H men contrary to hypotheses. Previous research has found that lack of health insurance is related to greater cancer fatalism in AAs. In our sample, the vast majority of AA participants were VA patients with access to health care. Results also showed that H and AA men reported greater levels of medical mistrust compared to NHW men. As predicted, levels of both cultural vulnerability factors did not differ between H and AA men. The findings support previous studies that show cultural vulnerability factors are more prominent in ethnic minorities [39] and therefore, particularly important to consider when working with H and AA individuals.

Limitations

Despite the novel findings, several limitations should be taken into account. First, the generalizability of the current study's findings is limited to AA, H, or NHW men only. The ethnic group membership categories utilized were further limited in that ethnic minority subgroups may have been heterogeneous, especially within the H group. Second, study

findings for HRQoL are limited to physical and emotional well-being outcomes only. A major limitation is that findings were based on cross-sectional data, so the direction between observed relationships or any causal inferences cannot be determined. Finally, although all the men in the study shared the experience of being diagnosed and living with active PC, the participants varied by those who had initiated active surveillance, were undecided about treatment type (active treatment or active surveillance), or were waiting to receive scheduled prostate cancer treatment(s). Future studies should obtain information related to the treatment decision process (e.g., the treatments men are offered after receiving a PC diagnosis and factors that impact treatment decision) as well as the treatment type selected by participants. Additional longitudinal research is needed to determine the possible causal direction of the role of cultural factors to help inform clinicians if these factors, and particularly medical system mistrust, are placing patients at greater risk or if those at greater risk are more likely to display these characteristics.

Future Directions

Future studies should prospectively evaluate associations among cultural vulnerability factors and HRQoL trajectories to gain a better understanding of how these factors may impact adjustment over the PC disease trajectory especially for those complete active treatment, as well as the extent to which educational and psychosocial programs can address perceptions about chronic diseases and the health care system. While this study focused on cultural vulnerability, future studies should address how cultural resiliency processes (e.g., family interdependence) may prospectively impact HRQoL in ethnic minorities. Furthermore, additional research is needed to clarify the role of religiosity on cancer fatalism and HRQoL, especially for H patients pre-treatment given that religiosity has been shown to both facilitate and impede adjustment.

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Table 1

Mean (SD) for Sociodemographic, Medical, Cultural Vulnerability, and Quality of Life Variables

	Total Sample (*N* = 268)		Non-Hispanic White (*n* = 111)		Hispanic (*n* = 77)		African American (*n* = 80)	
Covariates								
Age[a,b]	63.42	7.83	65.37	8.23	61.77	7.78	62.30	6.74
Subjective Social Status[a]	6.71	1.81	7.10	1.65	6.26	1.93	6.59	1.80
Time since Diagnosis (months)[b]	11.64	19.74	16.00	24.97	10.10	16.18	7.08	12.21
PSA Level at Diagnosis (ng/mL)	8.38	14.13	8.44	19.15	6.76	7.73	9.82	9.91
Medical Comorbidity Index Score	2.11	2.51	1.99	2.37	2.02	2.32	2.35	2.87
Acculturation (% Spanish, *n*)	15.3%	*n* = 41	–	–	53.2%	*n* = 41	–	–
Familism[a,c]	11.12	2.51	10.77	2.29	11.86	2.71	10.95	2.51
Religious Behavior[a,b]	14.83	5.98	13.16	5.87	15.30	5.84	16.87	5.64
Cultural Vulnerability Factors								
Cancer Fatalism[a]	34.47	9.53	33.42	8.63	36.63	10.51	34.05	9.69
Medical Mistrust[a,b]	23.80	7.61	21.95	7.45	25.11	7.49	25.26	7.48
Quality of Life								
Physical Well-Being[a,b]	25.26	3.90	26.05	2.87	24.28	5.24	25.08	3.43
Emotional Well-Being[c]	19.56	4.28	19.48	4.14	18.85	4.99	20.36	3.60

[a]Significant difference between Non-Hispanic White and Hispanic men, $p < .05$.

[b]Significant difference between Non-Hispanic White and African American men, $p < .05$.

[c]Significant difference between Hispanic and African American men, $p < .05$.

Table 2

Path Coefficients for Ethnic Group Membership and Cultural Vulnerability Factors

	β	***p*-value**
Cancer Fatalism		
H > NHW	.15	.03*
AA = NHW	.03	.66
AA = H	−.12	.10
Medical Mistrust		
H > NHW	.19	.00**
AA > NHW	.20	.00**
AA = H	.01	.90

*p<.05

**p<.01

H: Hispanic

AA: African American

NHW: Non-Hispanic White

Table 3

Path Coefficients for Medical Mistrust and Pre-Treatment HRQoL

	β	*p*-value
	Physical Well-Being	
Covariates		
Acculturation	−.12	.05
Age	.06	.39
Subjective Social Status	.04	.49
Time since Diagnosis	.02	.74
PSA at Diagnosis	−.01	.99
Medical Comorbidities	−.10	.12
Familism	.06	.41
Religious Behavior	−.05	.52
Medical Mistrust	−.14	.03*
	Emotional Well-Being	
Covariates		
Acculturation	−.15	.02*
Age	.08	.21
Subjective Social Status	.03	.68
Time since Diagnosis	.02	.80
PSA at Diagnosis	−.03	.64
Medical Comorbidities	−.01	.86
Familism	.18	.00**
Religious Behavior	.07	.32
Medical Mistrust	−.13	.04*

* p<.05

** p<.01