Cancer-related distress among different racial-ethnic groups from a community-based distress screening program

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Background

Cancer patients are at risk for elevated distress. Thus distress screening and referral is now a recommended component of patient care. Although implementation is increasing, very little is known about the unique concerns and unmet-resource needs among diverse racial-ethnic groups to ensure programs are adequately resourced to fulfill gaps in care and support.

Objective

Using CancerSupportSource® (CSS), a validated community-based distress screening instrument, we compared the needs among the largest racial-ethnic groups participating in a distress screening, referral, and follow-up program in the Cancer Support Community's (CSC) national affiliate network (N = 50).

Methods

•English speaking cancer survivors (n=905) attending CSC affiliates nationwide participated in an integrated distress screening, referral and follow-up program.

•Participants rated the level of concern (0 to 4) about 15 items, including a 4-item depression subscale, and identified the type of help they want (talk with a member of their health care team **and/or** written information).

•Overall distress is sum of 15 items. Depression score is sum of 4 items with risk for depression indicated if score ≥6.

•Regression analysis (adjusting for age, income, education) was used to test independent effect of ethnicity (non-white minority vs. white) on distress and depression; type of concerns (rated ≥2); and items selected to talk with the health care team.

•We limited the analysis to the largest racial-ethnic groups in the sample:
  - Non-Hispanic white (n=629)
  - Black or African American (n=79)
  - Latino or Hispanic (n=85)

Key Features of Cancer Support Source® (CSS):

•CSS targets the 7 key areas of psychosocial needs identified in the IOM Report (2008).

•CSS asks survivors to rate their concerns today **and** to identify the type of support they want to receive for addressing their concerns (talk with a member of their health care team, written information, or both).

•Reports are instantly generated including fact sheets and email alerts that can be customized for any institution.

•CSS is HIPAA compliant and can be linked to the EHR using HL7 and web services interface.

•CSS screening can be completed by the patient from home or on-site, using any type of browser.

Table 1. **Sample characteristics** of patients of a community-based cancer support organization completing a web-based distress screening tool by ethnicity.

	White (%)	Latino (%)	Black (%)	p-value*
Female	79	75	84	0.43
Education				
Less than college	41	68	61	
College degree	30	11	29	
Graduate degree	29	21	10	<0.001
Income				
<$40K	23	40	43	
$40-59K	13	19	11	
≥$60K	37	16	16	<0.001
Type of cancer				
Breast	40	45	53	
Lung	5	4	8	
Colorectal	6	6	5	0.89
Time since diagnosis				
<1 year	60	56	62	
≥5 years	13	13	13	0.98
Age, years (mean)	57	51	55	0.0015

*Chi-square test or ANOVA

Results

Table 2. Levels of overall distress and risk for depression by ethnicity

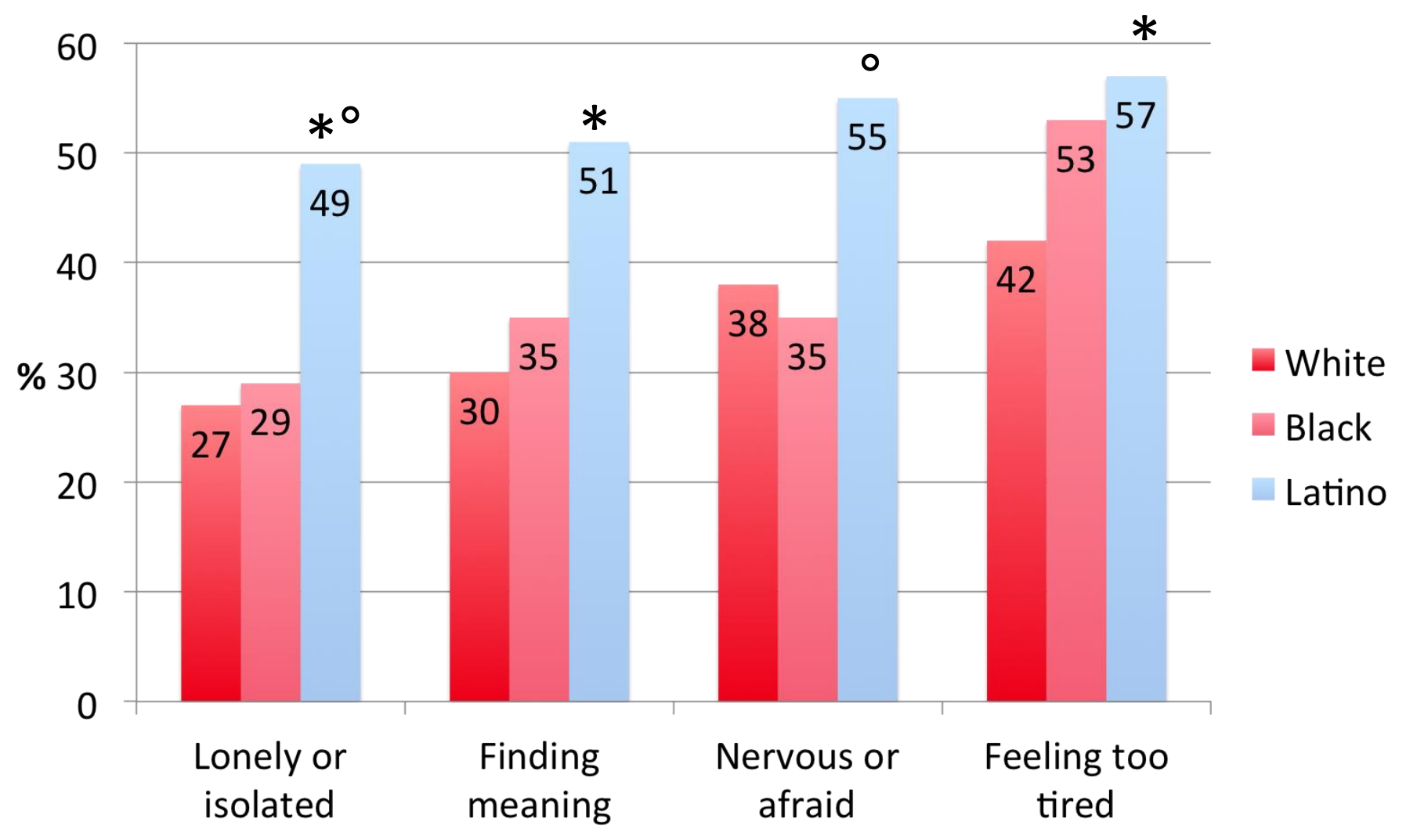
		Overall distress score			At risk for depression		
	n	Mean	SD	p-value*	%	AOR	p-value*
White	629	19.1	(10.8)	ref	38	1.0	ref
Black	79	22.5	(14.7)	0.54	39	0.91	0.73
Latino	85	26.0	(15.0)	0.020	59	2.10	0.004**

Latinos had significantly higher levels of distress than whites and higher risk for depression than whites and blacks, holding age, income and education constant.

AOR=adjusted odds ratio
*Multivariate regression analysis adjusted for age, income and education
**Latinos compared to blacks, (AOR=2.30, p=0.016).

Results

Emotional Concerns



*Reference=white, p<0.05
° Reference=black, p<0.05

Figure 1. Proportion of participants rating concerns moderately to very seriously concerned (2 or above) by ethnicity

Latinos were significantly more concerned than <u>whites and blacks</u> about feeling lonely or isolated; and more concerned than <u>whites</u> about:(1) finding meaning, (2) feeling nervous or afraid or (3) too tired to do the things they need or want to do.

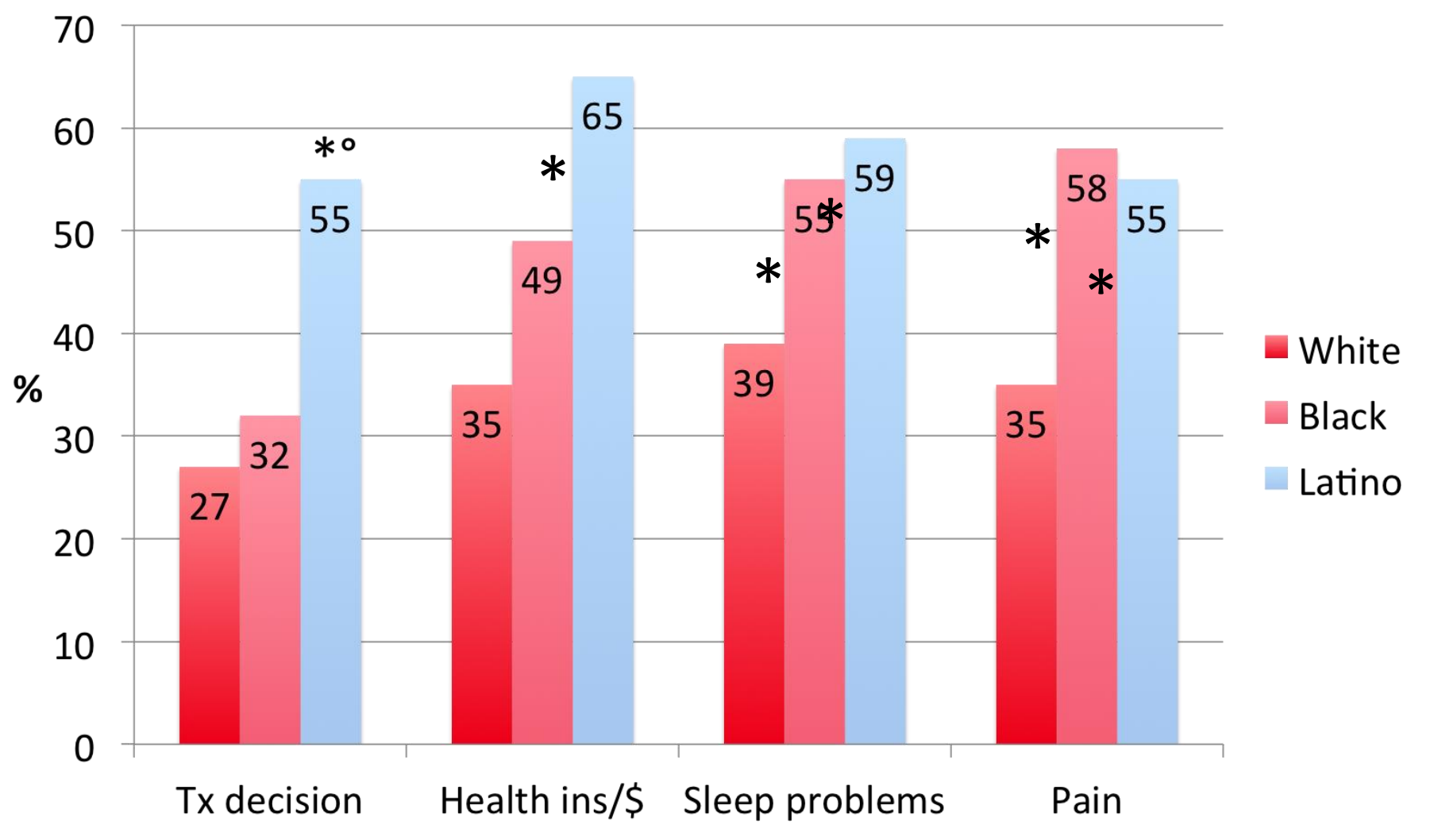
Among those concerned about feeling lonely or isolated, 47% of whites, 73% of blacks, and 58% of Latinos requested to talk with a member of their health care team about their concern.

<u>Latinos</u> were significantly more concerned about making a treatment decision (compared to blacks and whites) and health insurance or money worries (compared to whites).

<u>Latinos and blacks</u> were more concerned than whites about sleep and pain.

Among those concerned about making a treatment decision, 47% of whites, 58% of blacks, and 51% of Latinos requested to talk with a member of their health care team about their concern.

Concerns about Care and Symptoms



*Reference=white, p<0.05
° Reference=black, p<0.05

Figure 2. Proportion of participants rating concerns moderately to very seriously concerned (2 or above) by ethnicity

Implications and Future Directions

- Consistently across racial ethnic groups, cancer survivors report high levels of distress. In particular, Latinos reported even greater levels of distress after adjusting for age, income, and education. We also observed racial-ethnic differences in the types of concerns reported especially around spiritual concerns, worry, fatigue, and isolation.
- While we found racial-ethnic differences, these findings do not account for cultural and other defining community factors that may require different quantitative and qualitative methodologies that are culturally sensitive. Further, these findings are limited and reflective of an already activated sample of the cancer population that is seeking support and education. Sample size was limited for non-white minority groups.
- Future research should investigate factors that impact distress and explore the interaction between cultural and SES factors, including zip code and place. Research efforts into QoL of cancer survivors require strategic outreach to culturally specific communities, elevating the potential for reducing health disparities and recognizing that certain populations might be more receptive to specific forms of help.

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