Psychosocial health disparity among diverse racial-ethnic groups: Implications for the use of a patient-powered registry

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Background (95). Cancer patients are at risk for elevated distress, and research underscores culture powerfully impacts the type and degree of distress. In 2013, the Cancer Experience Registry (CER) was established to engage patients online to share their experience by completing a web-based survey; through a collective voice their answers will help inform researchers and health care professionals and ultimately improve the QOL for cancer survivors. The present objective was to compare needs among the largest racial-ethnic groups in the registry sample: non-Hispanic white (n=2165), black or African American (n=99), Latino or Hispanic (n=76), and Asian (n=36).

Methods (100): Participants were recruited by outreach across advocacy organizations and through social and traditional media to complete an online survey about QOL including 27 distress items (rated 0-4) and a 4-item depression subscale. We examined differences among racial-ethnic groups in level of distress (sum of 27 items); risk for depression (score≥6); type of concerns (rated≥3); and items about shared decision-making. Multivariate analysis was used to control for age, employment, education, cancer diagnosis, and time since diagnosis. Latino registrants were younger (median age 50 y) than whites (58 y), blacks (58 y), and Asians (59 y). Statistically significant findings are reported ($p<0.05$).

Results (100). Latinos reported greater distress than whites and blacks and higher risk for depression than whites. Latinos reported greater concerns than whites over feeling irritable (29% vs. 17%, respectively), isolated (29%, 18%), worry about future (51%, 35%), nutrition (58%, 38%), sleep (43%, 26%), and CAM (23%, 13%). Blacks reported greater concerns than whites over pain (36%, 23%), making a treatment decision (25%, 15%), and side effects (29%, 18%). Latinos (11%), blacks (11%), and Asians (16%) reported greater concerns than whites (5%) over transportation. Latinos were less likely to receive information about cancer type and treatment choices than whites, blacks, and Asians.

Conclusion (98): Recruitment efforts yielded modest enrollment of ethnic minorities. Greater outreach to these underserved groups is imperative. Latinos were, on average, younger than other registrants providing an opportunity to learn more about their experiences through follow-up survey questions. Latinos reported greater levels of distress even after adjusting for age, employment, education, cancer diagnosis, and time since primary diagnosis suggesting cultural differences may contribute to greater levels of distress. We also observed cultural differences in the types of concerns reported that provides insight into tailored resources and tools to address the social, emotional, and financial challenges of a cancer diagnosis.

Research Implications (48): Future research should examine the interaction between cultural and socioeconomic factors that may influence needs and utilization of psychosocial health care. There were substantial differences observed for Asians but sample size was limited. Research efforts into QOL of cancer survivors require strategic outreach to ethnic minorities.

Clinical Implications (24): Understanding cross-cultural patient experience is essential to integrating culturally competent psychosocial health care into the overall treatment of ethnically diverse cancer survivors.

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Learning Objectives: Compare levels and types of distress among different racial-ethnic groups; Identify strengths and limitations of using a patient-powered registry

CANCER EXPERIENCE REGISTRY®

A PROGRAM *of the* CANCER SUPPORT COMMUNITY

Psychosocial health disparity among diverse racial-ethnic groups

Implications for the use of a patient-powered registry

CANCER SUPPORT COMMUNITY

A Global Network of Education and Hope

Setting the Stage

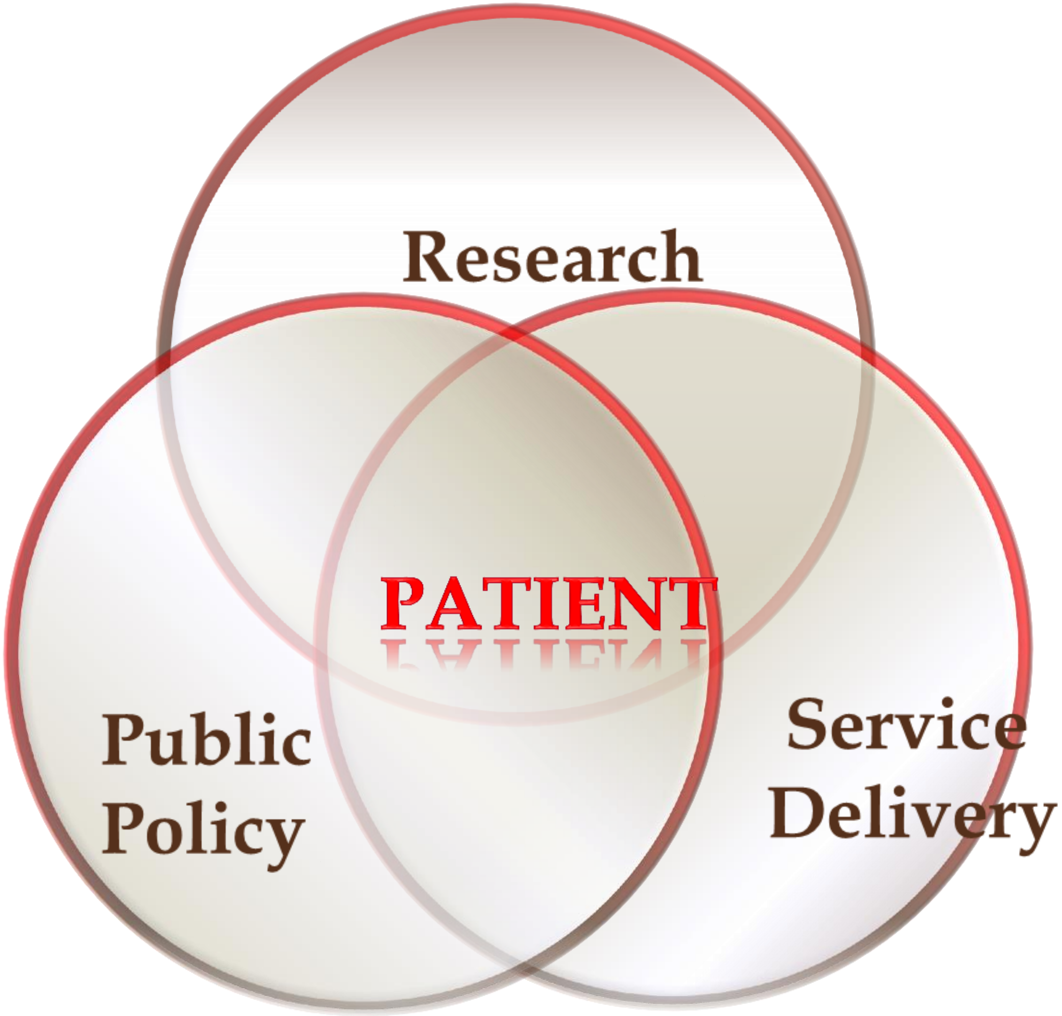
- The way in which we conceive of cancer and treat cancer is changing rapidly
- As precision medicine is becoming more ubiquitous, the old paradigm of outcomes research no longer fits
- There is a demand for patient-centered care
- There is a need for research that sheds light on the patient experience with respect to genomic, bio-molecular and psycho-social/behavioral profiles, and not necessarily within the disease silos as we have traditionally conceived

Cancer Support Community

OUR MISSION:

To ensure that all people impacted by cancer are empowered by knowledge, strengthened by action, and sustained by community.

Cancer Support Community



Research

PATIENT

Public Policy

Service Delivery

What is a Registry?

- An observational study of subjects with certain shared characteristics that collects ongoing and support data over time on well-defined outcomes
- Hypothesis generating
- Non-interventional
- Data collection

Value of a Registry

- Understand real-world
  - prescribing and treatment patterns
  - effectiveness and safety of treatment
- Understand disease epidemiology from initial diagnosis through progression
- Provide insight into regional differences
- Provide data on sub-populations
- Inform design for future research

What is a patient-powered registry?

- What does it meaning to engage patients, survivors and caregivers to share their experience and provide insight?
- What does it mean to be a trusted partner?
  - Full disclosure
  - Contract between the participant and the agency
- What are the opportunities to understand sub – group differences?

CANCER EXPERIENCE REGISTRY℠

- Tracks the immediate, ongoing and changing **social and emotional experience** of cancer survivors throughout the cancer continuum
- Reaches survivors and caregivers across the country, engages them to **share their voices** about issues that matter to them
- Provides education and support resources that speak to their needs

Goals of the Registry

- Promotes self-advocacy
- Encourages active participation in the cancer community
- Provides critical data to educate the medical community
- Provides evidence for policy makers
- Guides program/service development
- Helps improve quality of care

The Capacity of the Cancer Experience Registry

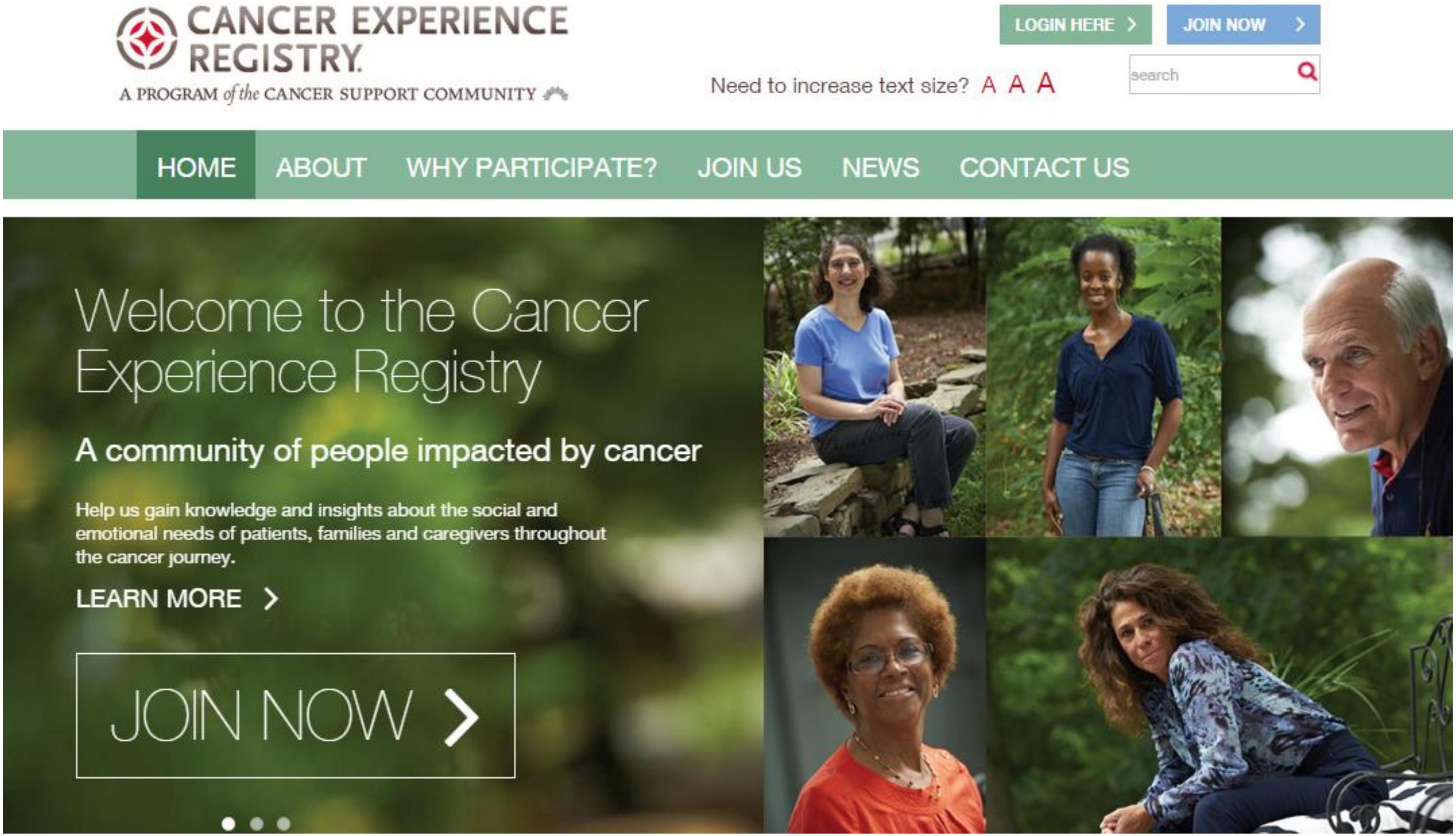
- Built on a process of inter-disciplinary research collaboration in which we integrally engage patients and caregivers as experts

- An interconnected series of patient registries with the capacity to link them to each other providing data that heretofore would not be meaningfully to other available databases

- Responsive and evolving

The Cancer Experience Registry

- Open to anyone impacted by cancer and their caregivers
- Totally confidential
- Include sub-registries for specific cancer diagnoses:
  - Breast Cancer
  - Metastatic breast cancer
  - Multiple myeloma
  - Chronic myeloid leukemia
  - Chronic lymphocytic leukemia
  - Lung cancer
  - Melanoma
  - Prostate cancer
  - Caregivers
  - Gastric cancer
  - Others being added
- Identifies issues specific to the cancer experience
- Shares findings with participants and provides real-time updates



Welcome to the Cancer Experience Registry

A community of people impacted by cancer

Help us gain knowledge and insights about the social and emotional needs of patients, families and caregivers throughout the cancer journey.

Background

- As the number of cancer survivors grows exponentially, there is an increased emphasis on a multi-modal understanding of quality of life.
- Cancer patients are at risk for elevated distress, and research underscores that culture powerfully impacts the type and degree of distress.
- Our objective in the present study was to compare the needs among the largest racial-ethnic groups in the registry sample:
  - Non-Hispanic White (2156)
  - Black or African American (99)
  - Latino or Hispanic (76)
  - Asian (36).

Patient Reported Outcomes

- Participants rated the level of concern about 27 items (0 “not at all” to 4 “very seriously” concerned)
  - Overall distress is sum of 27 items (range 0 – 108)
  - Individual concerns (rated ≥3, seriously or very seriously)
- 4-item depression subscale
  - Risk for depression if score ≥6
- Questions related to treatment decision making

Statistical Analysis

- Regression analysis used to test independent effect of ethnicity (non-white minority groups vs. white) on distress and depression
- Multivariate analysis used to control for imbalances across ethnic groups in:
  - Age
  - Employment
  - Education
  - Cancer diagnosis
  - Time since primary diagnosis

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Results

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Sample Characteristics

	White (n=2156)	Black (n=99)	Latino (n=76)	Asian (n=36)
Median age (years)	58	58	50	59
	%			
Income <$40K	29	52	43	28
Employed full-time	36	35	47	37
< College degree	31	44	45	26
Cancer diagnosis				
Breast	45	28	39	47
MM	14	34	22	22
CML	13	8	9	3
Time since dx <2 yrs	28	29	32	45

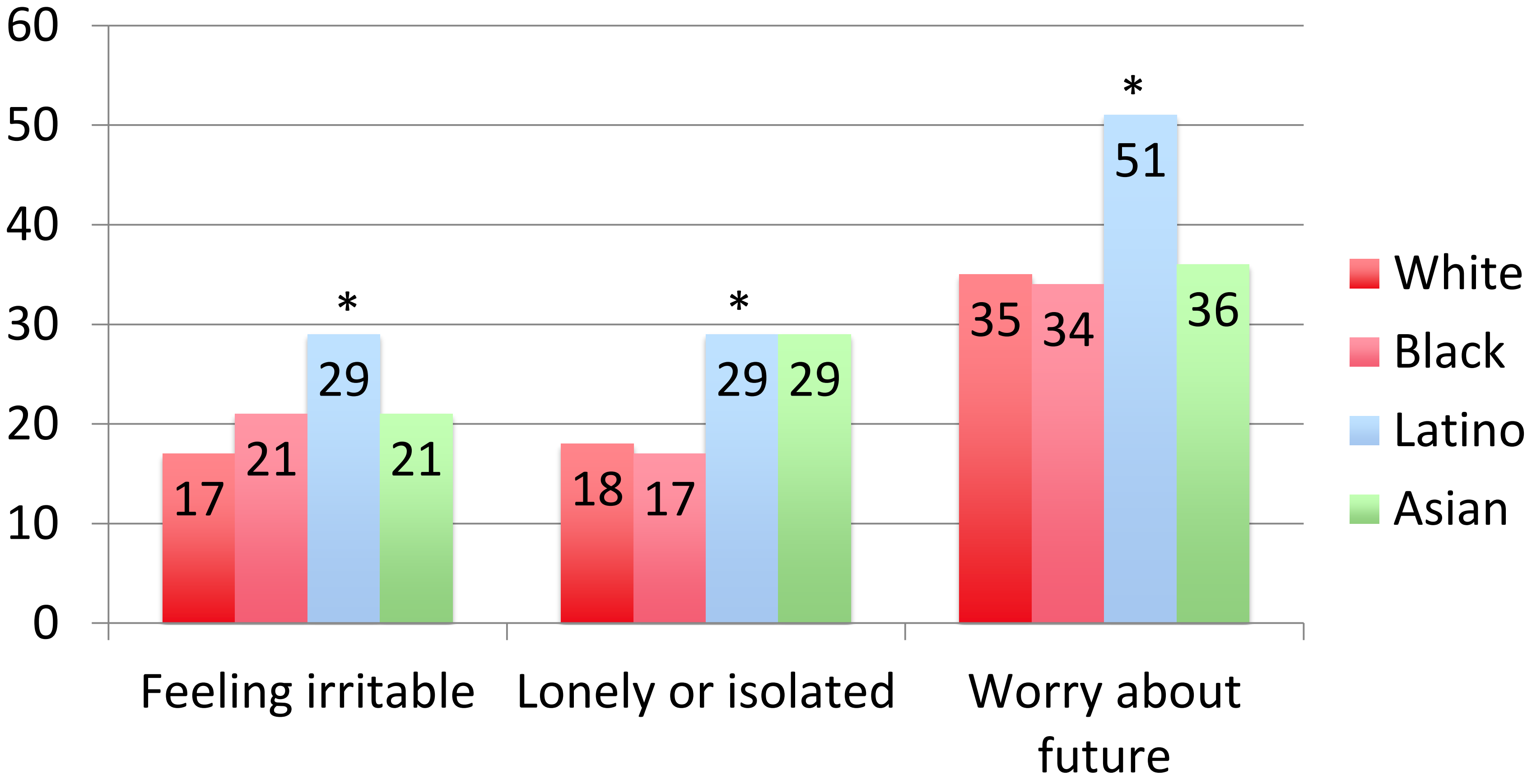
Distress and Depression

	Overall distress score (range 0-108)		At risk for depression	
	Mean	95% CI	%	Adjusted odds ratio
White	36.6	35.6, 37.6	47	Reference
Black	37.7	32.3, 43.1	55	1.3 (0.8, 2.1)
Latino	44.9*	39.1, 50.6	66	2.0 (1.1, 3.4)*
Asian	39.9	29.8, 49.9	52	1.1 (0.5, 2.5)

* $p<0.05$, compared to white

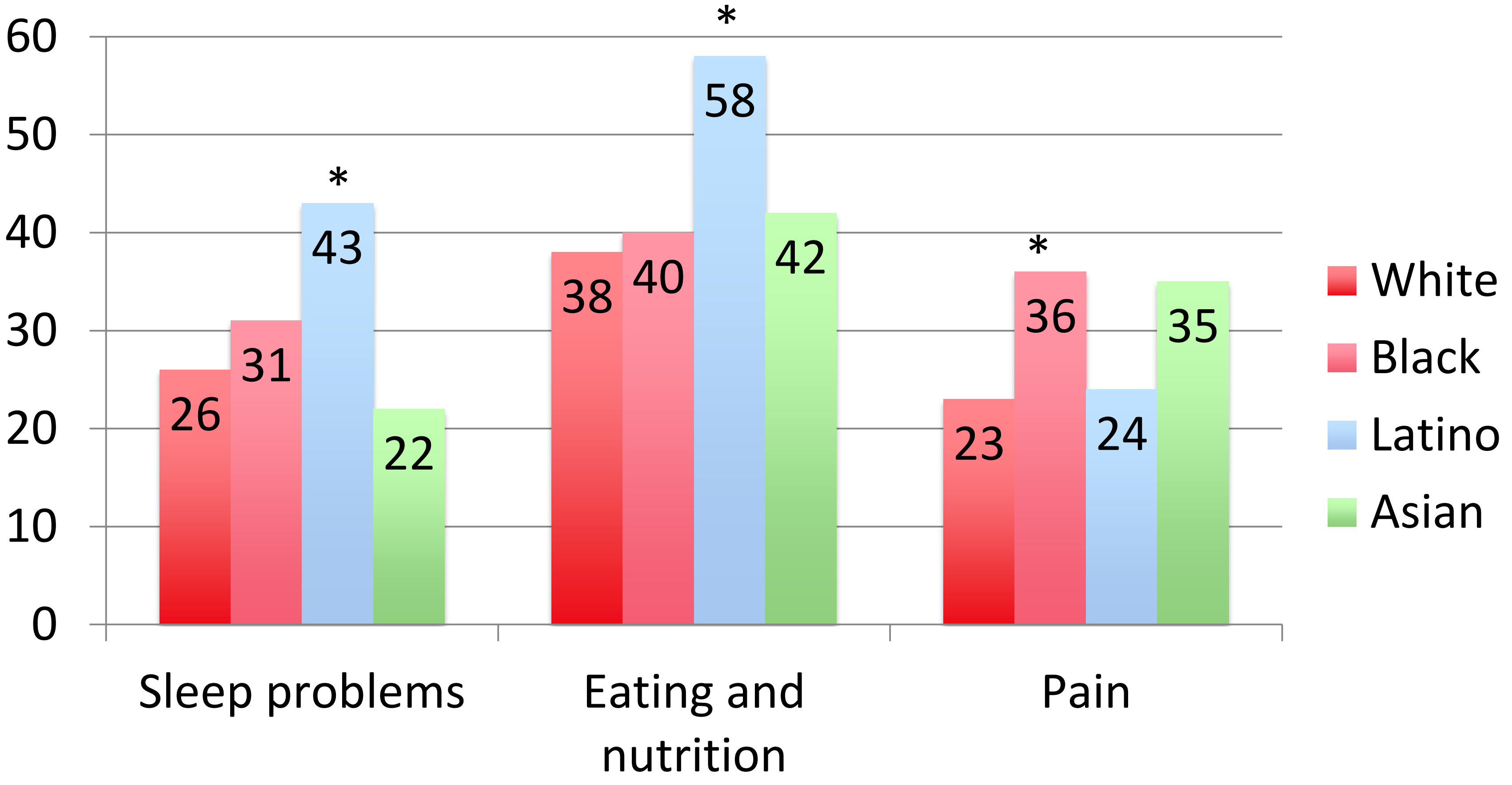
Note: Analysis adjusted for age, education, employment, cancer diagnosis, time since diagnosis

Emotional Concerns



* p<0.05, compared to white

Physical Concerns



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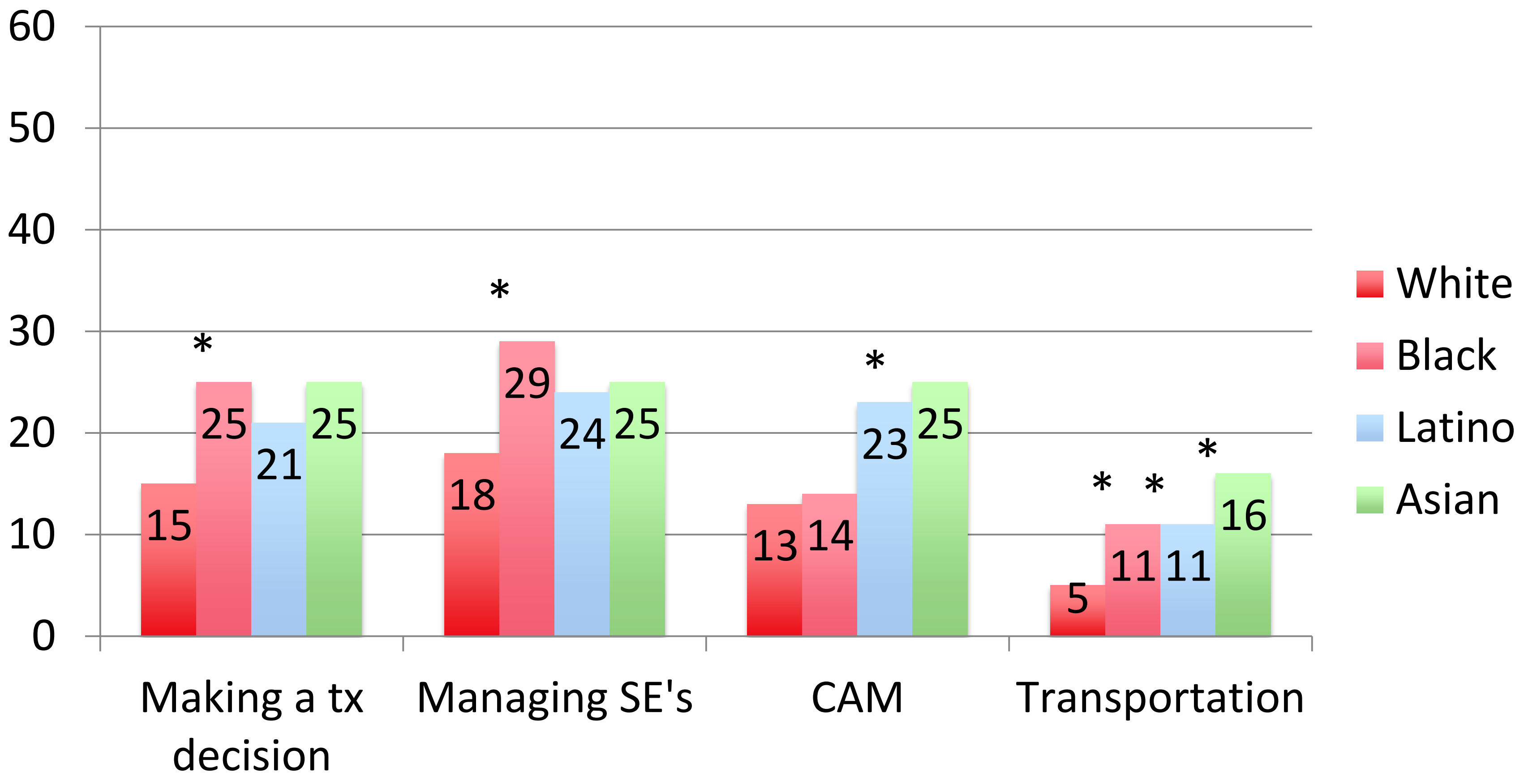
Concerns about Treatment and Care



* p<0.05, compared to white

Shared Decision Making

Prior to making a treatment decision, received information about…

	Cancer type		Treatment choices	
	%	Adjusted odds ratio	%	Adjusted odds ratio
White	91	Reference	78	Reference
Black	92	1.1 (0.4, 2.9)	85	1.6 (0.8, 3.3)
Latino	79	0.3 (0.2, 0.7)*	60	0.4 (0.2, 0.7)*
Asian	96	2.4 (0.3, 17.7)	75	0.8 (0.3, 2.2)

* $p<0.05$, compared to white

Note: Analysis adjusted for age, education, employment, cancer diagnosis, time since diagnosis

In sum

- Even after adjusting for age, employment, education, cancer diagnosis, and time since primary diagnosis, Latinos reported
  - greater levels of distress
  - yet were less likely to receive information about their cancer diagnosis and treatment options
- We also observed cultural differences in the types of concerns reported that provides insight into targeting resources and tools

Strengths and Limitations

- Results reflect a relatively educated, activated population of cancer survivors
- Recruitment efforts yielded modest enrollment of ethnic minorities
  - Sample size was limited, especially for Asian population
- Latinos were, on average, younger than other registrants

Research Implications

- Examine the interaction between cultural and SES factors
- Research efforts into quality of life of cancer survivors require strategic outreach to ethnic minorities

Clinical Implications

- Understanding cross-cultural patient experience is essential to integrating culturally competent psychosocial health care into the overall treatment of ethnically diverse cancer survivors.

Elevating the Patient Voice

At the first meeting I attended, in what seemed like quite a small voice, I asked if I could be heard. In the document and reflected in the key findings, it truly feels like my voice and the voices of all the other folks who spoke have been heard. Thank you.

--Kay Johnson, Patient Advisor, Cancer Experience Registry