

Racial/ethnic differences of understanding of biospecimen storage/sharing among breast cancer patients and non-cancer age-matched control subjects in a nationwide study



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BACKGROUND

- ❖ Collection of biological samples has become routine in clinical trials.
- ❖ Patients' understanding of biospecimen collections, storage, sharing, and current and future use may enhance cancer patients participation in cancer research that involves biospecimen collection.
- ❖ However, there is a significant knowledge gap in the cancer research community about cancer patients' understanding of biospecimen collection for current and future research.
- ❖ The understanding of biospecimen collection may differ by race but these differences are understudied.

OBJECTIVES

The primary objective is to examine whether white and non-white subjects who consented to a cognitive function study differed in their understanding of the ways their biospecimens could be used by researchers.

The secondary objective is to examine whether cancer patients and non-cancer control subjects who consented to a cognitive function study differed in their understanding of the ways their biospecimens could be used by researchers

METHODS AND MEASURES

- ❖ Breast cancer patients scheduled to receive chemotherapy at NCI Community Oncology Research Program (NCORP) and healthy controls participated in the study.
- ❖ Consent form related to biospecimens was administered to participants during the baseline visit.
- ❖ Approximately two weeks after consenting, participants' understanding of biospecimen use was evaluated:
 - ❖ Four items covered biospecimen sharing (score 0-4);
 - ❖ Three items covered relevance to care (score 0-3);
 - ❖ Nine items covered biospecimen use (score 0-9);
 - ❖ Six items covered research purpose (score 0-6);
 - ❖ Higher scores indicate better understanding in all cases.
- ❖ Sample question: Did you agree for researchers to use your human biological sample to answer specific questions in the current study? Yes/no/unsure.
- ❖ Linear models were used to compare the mean scores between white (Caucasian) and non-white (Black 71% and other 29%) subjects, adjusting for education and baseline reading comprehension (WRAT).

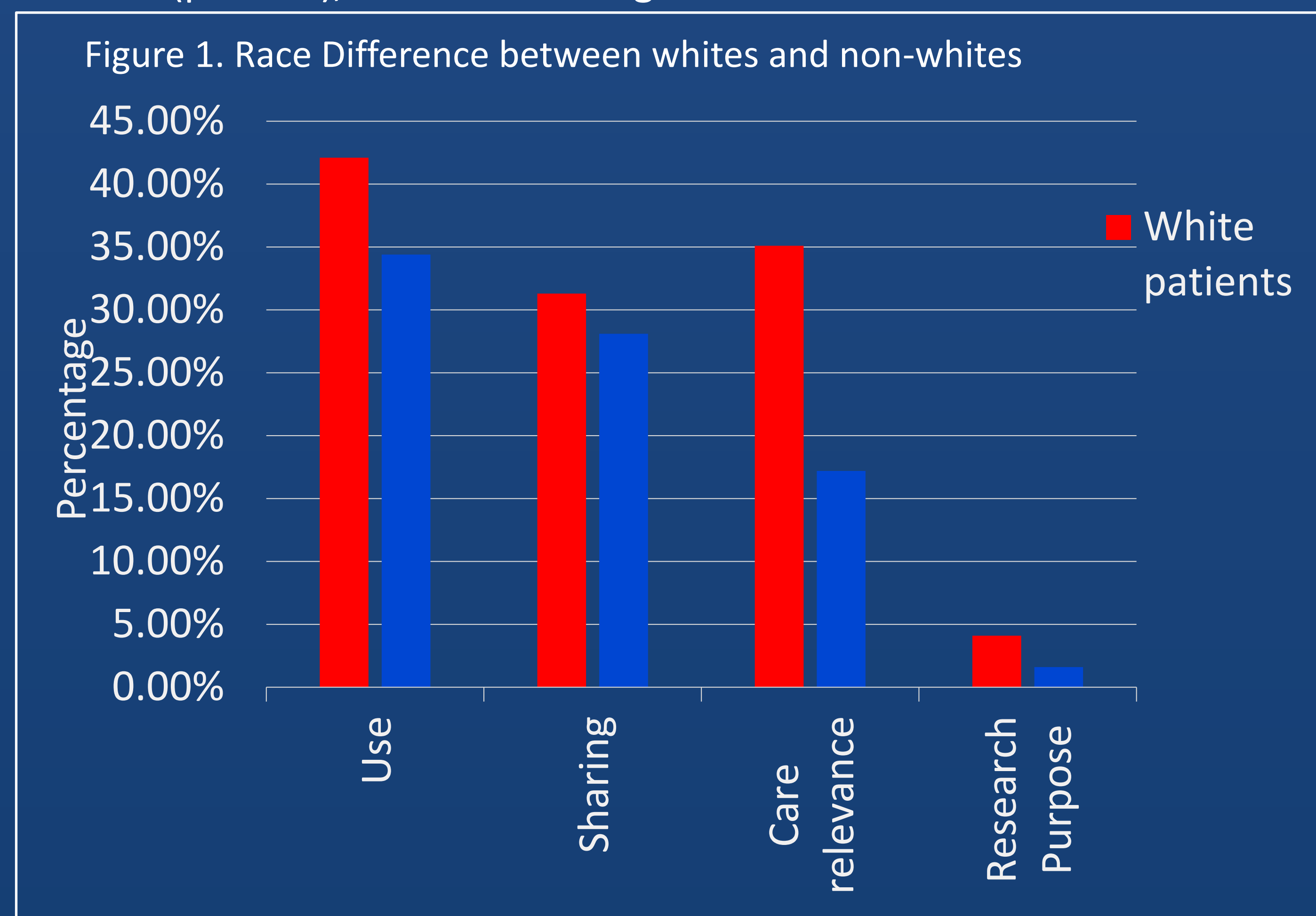
RESULTS

Demographic Characteristics		White (n=592)	Non-white (n=58)
Age	Mean	53.11	50.69
	SE	1.52	9.22
	Range	22-81	33 - 70
Education	Some High School	1.1%	3.1%
	High School	16.7%	18.8%
	Part College	36.4%	37.5%
	College	27.6%	26.6%
	Graduate	17.8%	12.5%
Marital Status	Widowed	5%	9.4%
	Divorced	11%	15.6%
	Separated	1.9%	3.1%
	Single	7.6%	20.3%
	Relationship	4.8%	7.5%
	Married	69.8%	42.2%

❖ The mean scores for distance matching analyses between white (n=58) and non-white (n=58) subjects were not different from the actual mean scores for white(n=592) and non-white (n=58) subjects. We therefore reported the actual results

RESULTS Cont'd

- ❖ The adjusted linear models showed that white subjects scored higher than non-whites (mean scores 14.43 vs. 13.43) on the survey questions overall ($p < 0.05$), after accounting for education and WRAT.



- ❖ White subjects were more likely than non-whites to correctly answer all the questions for the
 - ❖ biospecimen use (42.1% vs. 34.4%, $p < 0.22$),
 - ❖ biospecimen sharing (31.3% vs. 28.1%, $p < 0.74$),
 - ❖ relevance to care (35.1% vs. 17.2%, $p < 0.01$),
 - ❖ research purpose (4.1% vs. 1.4%, $p < 0.97$).

Mean scores of the patient and control groups (all race) for outcome variables (n=650)

Variables	Treatment (n=461)			Control (n=241)			95% CI
	n	M	SD	n	M	SD	
Handling†	428	7.55	1.97	223	7.84	1.71	-0.02 – 0.57
Sharing†	427	2.36	1.46	223	2.34	1.45	-0.26 – 0.21
Relevance to care†	427	1.43	1.25	223	2.09	1.12	0.47 – 0.85*
Research Purpose†	427	2.78	1.69	222	2.60	1.60	-0.43 – 0.09

* $p < 0.01$

- ❖ Cancer patients were less likely than non-cancer control group to understand biospecimen's relevance to care (1.43% vs. 2.09%, $p < 0.01$).
- ❖ There was a significant difference between non-white cancer patients and non-white control group in understanding biospecimen handling ($p < 0.04$), but there was no difference between white cancer patients and white control group.
- ❖ White and non-white control group had better understanding about biospecimen's relevance to care and biospecimen use for research purpose than white and non-white cancer patients ($p < 0.01$).

CONCLUSIONS

- ❖ Our research suggests that the subjects comprehension related to biospecimens is low overall across all racial/ethnic backgrounds, but non-white subjects' scores remained lower than whites even after adjusting for education and WRAT.
- ❖ Cancer patients may have difficulties in understanding biospecimen collection and its current and future use.
- ❖ Efforts should be made by researchers to make it easier for all study subjects, especially non-white subjects and cancer patients, to understand biospecimen collection and use.

SELECTED REFERENCES

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MEDICINE of THE HIGHEST ORDER

