Perceptions of Cancer Clinical Trials Among Racial and Ethnic Minority Cancer Survivors

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Background
- There are significant challenges with recruiting racial/ethnic minority patients, who are often underrepresented in this research, into cancer clinical trials (CCTs).

Aims
- The objective of this study was to compare perceptions about CCTs among the largest racial and ethnic groups in a US-based cancer registry sample.

Methods
- 3,167 individuals diagnosed with cancer, enrolled in the Cancer Support Community’s Cancer Experience Registry, answered questions about their experiences with and views on CCTs. Participants provide sociodemographic information and rated their level of agreement (0 = strongly disagree to 4 = strongly agree) with eight statements related to CCTs.
- Individuals that endorsed Hispanic or Latino ethnicity were coded as such regardless of race. Black or African American, Asian, and White racial groups consist of non-Hispanic or Latino individuals only.
- Bivariate associations between sociodemographic and CCT item ratings were examined. MANCOVA was used to determine associations between race and ethnicity and beliefs about CCTs after controlling for significant covariates, as well as age and gender. Statistical significance was adjusted for multiple comparisons with Bonferroni corrections.

Participants

<table>
<thead>
<tr>
<th>N = 3167</th>
<th>Mean/ n SD / %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (years)</td>
<td>57 (Range: 20 – 91)</td>
</tr>
<tr>
<td>Female</td>
<td>2379 79%</td>
</tr>
<tr>
<td>College degree or higher</td>
<td>2048 68%</td>
</tr>
<tr>
<td>Non-Hispanic or Latino Ethnicity</td>
<td>3073 97%</td>
</tr>
<tr>
<td>White</td>
<td>2766 87%</td>
</tr>
<tr>
<td>Black or African American</td>
<td>1083 3%</td>
</tr>
<tr>
<td>Asian</td>
<td>44 1%</td>
</tr>
<tr>
<td>Multiple races</td>
<td>32 1%</td>
</tr>
<tr>
<td>Hispanic or Latino Ethnicity</td>
<td>94 3%</td>
</tr>
<tr>
<td>White</td>
<td>52 2%</td>
</tr>
<tr>
<td>Black</td>
<td>3 1%</td>
</tr>
<tr>
<td>Asian</td>
<td>1 1%</td>
</tr>
<tr>
<td>American Indian or Alaska Native</td>
<td>7 1%</td>
</tr>
<tr>
<td>Other</td>
<td>20 2%</td>
</tr>
<tr>
<td>Multiple races</td>
<td>8 1%</td>
</tr>
<tr>
<td>Time since diagnosis (years)</td>
<td>5 (Range: 0 – 17)</td>
</tr>
<tr>
<td>Ever experienced recurrence</td>
<td>692 22%</td>
</tr>
<tr>
<td>History of metastatic disease</td>
<td>445 14%</td>
</tr>
<tr>
<td>Treatment history</td>
<td>1943 61%</td>
</tr>
<tr>
<td>Surgery</td>
<td>1858 59%</td>
</tr>
<tr>
<td>Chemotherapy (past)</td>
<td>265 8%</td>
</tr>
<tr>
<td>Radiation therapy (past)</td>
<td>1369 43%</td>
</tr>
<tr>
<td>Radiation therapy (current)</td>
<td>65 2%</td>
</tr>
</tbody>
</table>

Results

Beliefs and Perceptions about Cancer Clinical Trials

- Fewer than half (41%) of registrants reported that a member of their health care team spoke to them about participating in a CCT.
- 17% reported that they took part in a CCT.
- The proportion of registrants that reported a member of their health care team spoke to them about participating in CCTs did not differ by race or ethnicity (p > .05).

Association between Race and Ethnicity and Beliefs about Clinical Trials

<table>
<thead>
<tr>
<th>Factor</th>
<th>Wilks’ Lambda</th>
<th>F(18,6693)</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Race and Ethnicity</td>
<td>.970</td>
<td>4.026</td>
<td>&lt; .001</td>
</tr>
</tbody>
</table>

- The effects of race and ethnicity on the beliefs and perceptions of CCTs are significant, even after controlling for the effects of age, gender, education, and income.

Implications and Conclusions

- While the proportion of cancer survivors reporting that their health care team discussed CCTs did not differ by race, there is elevated mistrust among ethnic and racial minorities about the medical establishment and fear of being used as a “guinea pig” in CCTs, as well as perceived poorer understanding of CCTs. Fear of receiving a placebo was consistently high across racial and ethnic groups.
- Race and ethnicity play a small yet statistically significant role in beliefs and perceptions about CCTs; future research needs to explore other factors contributing to differences in CCT perceptions.
- These findings highlight important outreach and educational opportunities for healthcare providers and patient advocacy organizations, including comprehensive treatment decision counseling that is sensitive to survivors’ diverse needs and concerns.

Acknowledgments
This work is supported by AbbV, Amgen Corporation, Bayer, Boehringer Ingelheim, Bristol-Myers Squibb, Celgene Corporation, Eli Lilly and Company, Genentech, Inc., Janssen Biotech, Inc., Novartis, Pfizer Oncology, Pharmacyconnect, Inc., and Teva Oncology.

References

The Cancer Experience Registry is an online research initiative that captures the immediate and ongoing social and emotional experiences of cancer survivors and their caregivers.

The Registry is for all cancer survivors and caregivers, but also includes 10 disease-specific surveys.

Findings contribute toward advancing research, health care and policy.

Over 12,000 cancer survivors and caregivers are registered in the Cancer Experience Registry.

Learn more or join the Registry at www.CancerExperienceRegistry.org

American Psychological Association Annual Convention, Washington, DC – August 3 – 6, 2017