



XRAYS (eXamining Relevance of Articles to Young Survivors) Program Survey of Information Needs and Media Use by Young Breast Cancer Survivors and Young Women at High Risk for Breast Cancer

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Abstract

Women age 45 or under with breast cancer, or who are at high risk for breast cancer, have distinct health risks and needs when compared to their older counterparts. Interpreting media reports on research findings, including determining the study implications for younger women is often challenging. To help women better understand media coverage of new research, Facing Our Risk of Cancer Empowered (FORCE) developed the CDC-funded XRAYS (eXamining Relevance of Articles to Young Survivors) program. To assure that the XRAYS program is responsive to the community's needs, FORCE launched a survey to assess where young women turn for information about breast cancer and to identify their information needs. We report results from 1,178 women, age 45 or younger, including: women currently in treatment for, women who have previously been diagnosed with, or those who are at high risk for breast cancer. These results will ensure XRAYS materials and dissemination efforts are responsive to the young breast cancer population's needs, and will inform the broader medical, media and patient advocacy communities about the distinct information needs of this group.

Background

To help younger women better understand media coverage about new research, Facing Our Risk of Cancer Empowered (FORCE) developed the CDC-funded XRAYS (eXamining Relevance of Articles to Young Survivors) program. To assure that the XRAYS program is responsive to the community's needs, FORCE launched a web-based survey to assess where young women turn for information about breast cancer, and to identify their unmet information needs. The survey examined:
 •How frequently women visit various media sources and health- or cancer-related websites for information on breast cancer related information;
 •How much the women trust these information sources;
 •Whether respondents have ever tried to share media reports with their health care team and how the team received the information;
 •When during the process of screening, diagnosis, treatment, survivorship and/or risk management respondents actively seek out information.

Methods

FORCE launched the survey nationally through a network of 50 FORCE outreach groups, partner organizations that serve young breast cancer survivors, and via a social media campaign targeting women age 45. The survey was administered from March 15 through June 30, 2015. A total of 1,178 eligible women responded. Analysts generated crosstabs and conducted chi-square analyses to assess whether patterns in seeking information varied by demographic variables. Omnibus chi-square values are presented. Analysts identified particular cell differences within significant crosstabs that had practical significance for program planning.

Results

Age	Count	Percentage
18-25	44	(3.7%)
26-30	84	(7.1%)
31-35	216	(18.5%)
36-40	353	(30.0%)
41-45	479	(40.7%)

Race/Ethnicity (respondents can select multiple items)	Count	Percentage
Black/African American	53	(4.5%)
Caribbean/West Indian	9	(0.8%)
White/Non-Hispanic	989	(84.0%)
Asian/Pacific Islander	26	(2.2%)
Native American	18	(1.5%)
Spanish/Hispanic	81	(6.9%)
Eastern European Jewish	64	(5.4%)
Prefer not to share	7	(0.6%)
Other	16	(1.4%)
Missing	7	(0.6%)

Breast Cancer Diagnosis	Count	Percentage
Yes	454	(38.5%)
No	397	(32.9%)
Prefer not to share	6	(0.5%)
Missing	331	(28.1%)

Stage of Initial Diagnosis (for respondents who answered "yes")	Count	Percentage
Stage 0 (DCIS or in situ cancer)	47	(10.3%)
Stage 1	103	(22.7%)
Stage 2	156	(34.4%)
Stage 3	87	(19.2%)
Stage 4	26	(5.7%)
I do not know the stage	13	(2.9%)
Prefer not to share	1	(0.2%)
Missing	21	(4.6%)

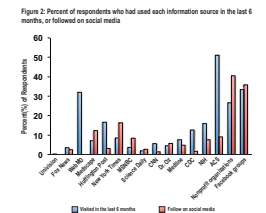
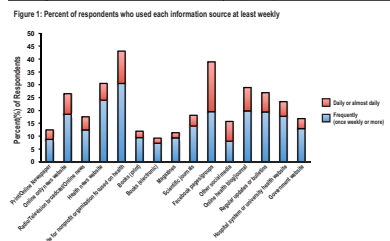


Figure 2: Percent of respondents who had used each information source in the last 6 months, or followed on social media

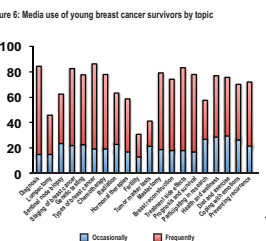
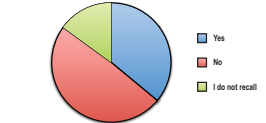


Figure 6: Media use of young breast cancer survivors by topic

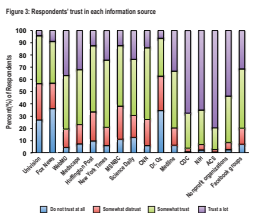


Figure 3: Respondents' trust in each information source

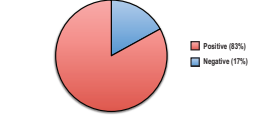


Figure 5: How the information the respondent shared was received by their healthcare team

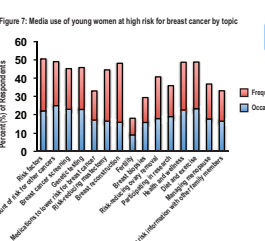


Figure 7: Media use of young women at high risk for breast cancer by topic

Summary

Key relationships of interest for program planning:
 • Women with high school education or less were less likely to seek information.
 • Media use of young breast cancer survivors was not significantly different from young high-risk women.
 • 12% of women with a high school education or less reported sharing information they had learned from media with health care providers, compared with 25-30% of women with at least some college education (chi-square=18.96, d.f.=9, p=.026).
 • Sharing of information learned from media with family and friends increased with education. About one-third (32%) of women with high school education or less reported doing so. About half of those with at least some college (46%) or a BA (52%) shared information with family and friends. More than half (58%) of women with a graduate degree shared breast cancer-related information they had learned from the media with family and friends (chi-square=30.22, d.f.=9, p<.001).

Discussion

High-risk women between ages 18-45 years are using multiple media sources to seek information about breast cancer risk, prevention, screening, and treatment. They are likely to share this information with care providers and their social support networks. XRAYS is addressing a key need for health information. It will be useful for XRAYS to offer reviews of articles on a broad range of topics that can inform decisions at each stage of risk assessment and treatment.

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