Underserved Breast Cancer Survivors’ Needs: A report from the *Breast Cancer Survivorship Project Collaborative*

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BACKGROUND: When survivorship care plans (SCPs) emerged as a topic at cancer-related meetings, San Francisco Bay Area (SFBA) breast cancer advocates and community-based service providers began discussing concerns that proposed written SCPs might not be useful to underserved cancer patients. In 2015, a small group successfully applied for pilot funding from the Patient Centered Outcomes Research Initiatives (PCORI) Pipeline to Proposal program to address this.

The Breast Cancer Survivorship Project (BCSP) team was formed using a snowball method to identify and recruit diverse cancer survivors, patient navigators, clinicians, advocates and researchers in the SFBA and rural areas. Members represent organizations serving/advocating for cancer patients and survivors of lower income, limited English proficiency, and from racial/ethnic and gender/sexual minorities.

The collaborative established group guidelines and defined key terms. Following a literature review and discussions, we changed our focus from SCPs to patient navigation as the most promising approach to address the needs of underserved survivors. We explored different navigation models and sought to better understand local underserved survivors’ priority needs.

METHODS: The BCSP team collaboratively created a survey to assess regional survivors’ needs. Categories of cancer survivor needs were adapted from existing sources. Colleagues in member organizations translated the survey from English to Spanish and Chinese (Mandarin). It was administered through seven organizations across the San Francisco Bay area and one in rural Northern California, on paper or verbally by support group leaders, patient navigators and advocates with whom the respondents had an established relationship. An online version was also made available in QuestionPro, which was used for analysis in addition to Excel.

Results were shared with participants, survey administrators and other stakeholders meeting. Their feedback was incorporated into narrative responses and suggestions for further actions.

Fig 1. Respondents by Race/Ethnicity

RESULTS: Of the 63 completed surveys, 62 met eligibility criteria. Respondents were racially/ethnically diverse (Figure 1). They lived in San Francisco (44%), East Bay (31%), North Bay (13%), Mendocino (3%) and San Mateo (2%) counties. The majority of respondents were 60-79 years of age (61%); followed by 40-59 years (34%) with a few younger and older. All identified as female and 4 as LGBTQ. We calculated that more than 60% of respondents lived below the poverty line.

The majority of participants (68%) completed treatment in the past 4 years; 21% finished 5 or more years before. Most (70%) had attended a breast cancer support group at some point.

Fig. 2. Unmet Needs Reported by Respondents

Respondents were asked to identify their needs that were not met during the year after treatment. They were offered a list and could select as many answers as they wanted. Figure 2 shows unmet needs in order of frequency selected. Memory, physical and mental health effects were the most commonly reported among the diverse respondents.

Survivors were also asked what services or information topics they would most have wanted as they finished treatment. Access to treatment education, complementary care and access to support group were the most requested (Table 1).

CONCLUSIONS: Underserved cancer survivors need more mental health services—Memory/thinking problems and Mental health effects (44%, 39%) were common unmet needs. Routine medical follow-up appears to be addressed better than treatment side effects. All BCSP findings are being discussed by patient navigation programs and are being used to inform the development of educational materials for cancer survivors. This collaboration has also resulted in efforts to develop Spanish-language patient navigation training materials and guidelines.

Table 1. Services/Information Desired (in order of frequency)
Treatment education
Complementary care
Support group
Mental health/therapy
Recurrence fear reduction
Financial assistance
Side effects
Transportation assistance
Body Image

Table 2. Suggested Follow-up Actions (respondents, team, stakeholders)
Build forum for cancer patient navigators to share across organizations
Test survivorship patient navigation programs in community based organizations
Organize a speaker series for cancer survivors in in harder to reach communities (e.g., rural, non-English speaking)
Create a digital repository for survivors & volunteers to share their talents across organizations providing services for those affected by cancer
Provide a list of relevant resources for areas where they are less readily available (e.g., support groups, complementary medicine, etc.)
Identify and promote affordable training for cancer patient navigators & community health workers