

Engaging Latina Breast Cancer Survivors in Research: Building a Social Network Research Registry

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Background

Latinos are underrepresented in research. The aim of this study is to develop an innovative Social Network Research Registry to enhance Latina breast cancer survivor's research engagement.

Methods

We recruited 29 Latina breast cancer survivors from two community organizations (the seeds). Using cascade recruitment we asked the seeds to identify other Latina breast cancer survivors. Using social network measures we captured the structural (e.g. size) and functional characteristics (e.g. social support) of the network of Latina survivors. We invited participants to be part of the Registry to be contacted for future studies and to specify the types of research and engagement.

Results

We recruited 50 participants in four months (29 seeds, 21 through snowballing). All agreed to be part of the Registry. Participants listed a range of 0-11 Latina survivors ($Mdn=3$). The total network size is 107 and it is formed by six components. We have identified four very highly connected survivors (hubs). The most available type of perceived support was companionship ($Mdn =3$) and provision of information about breast cancer ($Mdn =3$). All were interested in participating in surveys or interviews and most in behavioral interventions (95%), providing biological samples (88%), and lastly drug trials (33%). Most were interested in being engaged in research as health promoters (81%) or members of the community advisory board (67%).

Conclusions

Social network analysis can be useful to identify isolated participants and members that occupy key positions in the network that can be engaged to inform future research and disseminate health information.