



The Development of a Pilot Registry Focused on Breast Cancer in Women 40 Years of Age and Under.

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Introduction

The Young Survival Coalition (YSC) is the premier international, nonprofit network of breast cancer survivors and supporters solely dedicated to the critical concerns and issues unique to young women (YW) affected by breast cancer. It is a strategic goal of YSC to increase the amount of quality research about young women, to define the greatest research needs for young women with breast cancer and to advocate these needs to doctors and researchers.

Background

There are more than 250,000 women who were diagnosed with breast cancer at the age of 40 or under living in the US.^[1] Among women aged 15-34 years, breast cancer is the number one cause of cancer death.^[2] Breast Cancers that are diagnosed in younger women are generally more aggressive and result in lower survival rates.^[3,4] Although there is cause for optimism regarding advances in the prevention, diagnosis and treatment of breast cancer among the general population, the situation for young women remains less certain and is complicated by a series of special concerns and questions. Lastly, there is a lack of research data about this age group.

Citations

References: [1] extrapolated from US Census Data 2000, [2] National Cancer Institute 2005 Fact Book, p.40 [3] National Institutes of Health Web site; www.nih.gov, [4] American Cancer Society. Cancer Facts and Figures. Atlanta: ACS 2005-2006.

Goals/Objectives

The Young Survival Coalition (YSC) seeks to create the most comprehensive database resource that will gather data from premenopausal women affected by breast cancer and make it available to researchers with important research questions. This pilot study will explore the feasibility of such a resource through the collection of data from the YSC constituency and identify potential barriers and trends that may inform the construction of a larger study cohort in future collaborations with researchers.

Key Steps/Methods

- Work together with a team of advocates, members of YSC's Medical Advisory Board and other specialists to create an internet based survey.
- Test the questions in an anonymous sample of YSC's volunteer constituents using Zoomerang.com.
- Evaluate the responses to measure the ability to retrieve relevant data about premenopausal women from participants.
- Evaluate the method of data collection to better understand the scope of the technical requirements necessary for a successful future registry resource.
- Developed a 90 item online questionnaire designed to gather data on:
 - Characteristics of participants
 - Known risk factors for breast cancer
 - Suspected new risk factors, (e.g. shift work, metabolic index, and genetic polymorphisms)
- Invitations sent to 91 constituents on March 7, 2008 and follow-up communications sent to original 91 on March 24th. Additional initial invitations were sent on March 24th to 110 more constituents.
- Survey closed on April 7 with 54 completions, 2 partial completes.

YSC Medical Advisory Board

Deborah Axelrod, MD, Leslie Bernstein, PhD, Ira Bleiweiss, MD, W. Archie Blyer, MD, Ernie Bodai, MD, Judy Garber, MD, MPH, Aron Goldhirsh, MD, Laurie Goldstein, MD, Clifford Hudis, MD, Kathryn Kash, PhD, Roz Kleban, MSW, Thomas Kolb, MD, Minetta Liu, MD, Susan Love, MD, Edward Luce, MD, Kathy Miller, MD, Anne Moore, MD, Larry Norton, MD, Kutluk Oktay, MD, FACOG, Olufunmilayo Olopade, MD, Ann Partridge, MD, MPH, Edith Perez, MD, Bert Petersen, MD, Irma Russo, MD, Jose Russo, MD, Lillie Shockney, RN, George Sledge, MD, Richard Stevens, PhD, Deborah Toppmeyer, MD, Kimberly van Zee, MD, Eric Winer, MD, Karrie Zampini, CSW.

Expected Outcomes

- Analysis will yield a better understanding of how a pilot survey could be adapted to create an effective registry of all young women affected by breast cancer, and what could yield the best method of understanding of the health history of our sampled population.
- Analysis will provide an indication of the feasibility to accumulate a control group made up of survivors, their mothers and their healthy sisters or peers.
- Analysis will provide an indication of whether mothers and healthy sisters are available to participate in an adjunct study used to confirm in utero and early health history of subjects.
- We hope to inspire the research community to ask important research questions about early onset breast cancer.

Best Practices

- Advocates can work successfully in partnership with a professional advisory board, researchers, and organizational staff to create research that will make a significant impact in the research being done on young women affected by breast cancer.
- Conducting online surveys can be a cost-effective and comprehensive method of gaining a better understanding of the needs of our constituency.
- Teamwork with researchers and medical professionals can reveal methods to and obstacles to creating a registry that could help us understand where research gaps exist.
- Encouraging young women to participate in a broad research opportunity that may grow in the future into many smaller research studies asking vital questions can be done within our organization while recognizing barriers.
- Project LEAD advocates can partner with esteemed members of the research community to develop tools to find answers to important questions about what may or may not cause cancer in all women.

Funding for this project has been provided by the National Breast Cancer Coalition Fund through a generous grant from the Breast Cancer Fund of the National Philanthropic Trust and the Avon Foundation.

Observations

- Sample size: 54 BC survivors completed online survey (27% of contacted); 72% indicated a mother, sister or healthy peer would be willing to participate in a future study.
- Residence: 24 states, 63% lived in state for 5 or more years. 52% lived in state for 20 or more years. 13% were foreign born but live in the US now.
- Age at BC diagnosis: 29% (14/49) in 20-29, 63% (31/49) at 30-39, and 8% (4/49) at 40-49
- Education: 79% completed at least a 4 year college degree. 32 with a bachelors degree, 8 with a Masters, 5 with a Ph.D., M.D. or other advanced degree
- Employment: 56% were management or professionals, 22% had other office jobs
- Race: 91% White, 9% Asian.
- Reproductive history: 35 women have been pregnant, with 2 of 35 pregnant after BC dx, 33 of 35 pregnant before BC dx.
- Weight: 155 lbs (median)
- Height = 5'5" (median)
- Marital status: 89% reported being married or living with a partner.
- History of cancer: Prior lymphoma diagnosis (n=1)
- Comments to survey questions: Not considered too lengthy; several questions considered repetitive, tedious (e.g., career history), or confusing (e.g., exercise patterns, when born).

Conclusions

- Relatively high response rate among current YSC members suggests strong feasibility to develop a cohort registry and to identify best practices in determining health history of young breast cancer survivors. We need to identify if young women outside of YSC's volunteer membership would be as willing to participate in a registry.
- High completion rates of questions and feedback about content indicate that YSC volunteers are very well motivated to share information about their diagnosis, health and treatment history, mother's health history, mother's behavior during her pregnancy with subject.
- Most questions were answerable and length of survey is acceptable among this subset of the population.
- Future directions are to refine the questionnaire per comments made in the pilot study, possibly pilot it to more diverse populations, develop methods to increase response rate, establish the data registry of the full-scale study cohort, expand it to include more diverse populations of young women, and academic collaborations.
- The Registry as planned, and with the current demographic constituency of YSC, may be suitable for some types of research questions (e.g., factors associated with later recurrence) but less so for others (e.g., predictors of outcomes in non-white women). Keen attention will continue to be given to developing research-quality data, effective follow-up methods, and recruitment of participants from diverse backgrounds, so that the Registry will be able to contribute greatly in the future to understanding breast cancer in young women.



Diagnosed at Age 32



Diagnosed at Age 28



Diagnosed at Age 22