

Intervening on Reproductive Health in Young Survivors

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Research Program

California Breast Cancer Research Program

Research Priority

Community Impact of Breast Cancer

Award Type

Translational Research Award

Application ID

200B-0144

Award Amount

\$968,782

Start Date

6/1/2014

Abstract

Non-technical overview of the research topic and relevance to breast cancer: The study proposes to generate and test the efficacy of the Reproductive Health Survivorship Care Plan (SCP-R), a novel survivorship care tool to meet the reproductive health needs of young breast cancer survivors (YBCS). Ten percent of the 2.8 million breast cancer survivors in the U.S. were diagnosed with cancer when they were younger than 45 years old. Most young patients undergo chemotherapy and/or endocrine therapy, treatments that impair ovarian function and result in significant reproductive health late effects. These late effects include symptoms of estrogen deprivation such as hot flashes, fertility concerns, limited contraception options and sexual problems. Together they have a major, negative impact on quality of life. Despite substantial research, treatment guidelines and clinical expertise on these issues, most YBCS and their healthcare providers (HCPs) have limited guidance on how best to manage these reproductive health late effects. Consequently, YBCS's informational and clinical care needs are not met by currently available resources. In 2006, the Institute of Medicine recommended development of survivorship care plans to improve patient knowledge about the effects of cancer and guide follow up care. However, these plans lack adequate guidance on reproductive health. Therefore, we propose to translate available knowledge on managing reproductive health issues in YBCS

into a practical, accessible, evidence-based tool (the SCP-R) to address this deficit in survivorship care. The proposal responds to the CBCRP research priority on the community impact of breast cancer by focusing on delivery of reproductive healthcare to YBCS, a medically underserved population. The long-term goal is to incorporate the SCP-R into existing survivorship care plans for dissemination and sustainability. The question(s) or central hypotheses of the research: The study will determine if the Reproductive Health Survivorship Care Plan tailored to individual survivor needs will improve estrogen deprivation symptoms, fertility concerns, contraceptive practices and sexual function in YBCS. In addition, healthcare providers who receive the tailored SCP-R will have improved preparedness on managing reproductive health issues in YBCS and more discussion of these issues with their patients, compared to HCPs who do not receive the SCP-R. The general methodology: The goal of the project is to generate the web-based SCP-R and test its impact on YBCS and their HCPs. The study will focus on YBCS who were age 45 and younger at diagnosis and within five years of diagnosis because of the unique reproductive health needs in this population. As HCPs are a key source of cancer-related information and decisions, the SCP-R will also target providers. The research team is comprised of patient advocates and seasoned investigators in reproductive health, breast oncology, primary care, cancer survivorship, health behavior and clinical trials. This dedicated team will translate the large body of knowledge on estrogen deprivation symptoms, fertility concerns, contraception, sexual health from research, professional societies and clinical expertise into practical, evidence-based screening and management strategies for YBCS and HCPs. These strategies will be incorporated into the SCP-R. In the clinical trial, 157 YBCS will be randomized in equal numbers to receive the SCP-R and biweekly reproductive health prompts that are tailored to their reproductive needs (intervention group), or usual care (waitlist control group). Over six months of follow up, YBCS will be asked to track hot flashes daily and undergo periodic assessments of fertility concerns, contraceptive practices and sexual function. Each YBCS will be asked to identify a HCP who will receive the same information as their patient. Providers will be asked about their preparedness to manage reproductive health issues. HCP discussions of reproductive health issues with their patient will be determined. We will compare outcomes by intervention group. Innovative elements of the project: The project will be the first to address a gap in research on translating knowledge on reproductive health into health services delivery to improve everyday outcomes in YBCS. While multiple general survivorship care plans have been developed and are widely available on the Internet, none have been tested to improve reproductive health outcomes. Among ongoing trials reported in large research and grant funding databases, none aim to improve reproductive health issues that figure so prominently in quality of life of young breast cancer survivors. The proposed SCP-R intervention is novel in its focus on reproductive health, design to impact multiple levels (YBCS and HCPs) and tailoring to individual need. These innovations will change the current approach to survivorship care planning by integrating specialty care outside of oncology, emphasizing the multi-disciplinary approach to caring for cancer survivors. The attributes will result in high likelihood of delivering an impactful survivorship tool to improve long-term reproductive health in young breast cancer survivors. Publications: The Race for Beauty: Examining the Social Drivers of Personal Care Product Use and the Impacts of Exposure on Black Women Developing a post-treatment survivorship care plan to help breast cancer survivors understand their fertility Perception of fertility potential is associated with contraceptive behavior in female young adult

cancer survivors Screening anti-tumor drugs to identify candidates for development into novel non-hormonal contraceptives Contraceptive choices and menstrual patterns in high level female athletes Contraceptive choice among young cancer survivors: what do patients value?

Progress Report Abstract

Ten percent of the 2.8 million breast cancer survivors in the United States were diagnosed with cancer when they were younger than 45 years old. Most young patients undergo chemotherapy and/or endocrine therapy, treatments that impair ovarian function and result in significant reproductive health late effects. These late effects include symptoms of estrogen deprivation such as hot flashes, fertility concerns, limited contraception options and sexual problems. Together they have a major, negative impact on quality of life. Despite substantial research, treatment guidelines and clinical expertise on these issues, most young breast cancer survivors (YBCS) and their healthcare providers (HCPs) have limited guidance on how best to manage these reproductive health late effects. To meet the informational and clinical care needs of YBCS, the goal of the project is to generate a web-based survivorship care plan on these reproductive late effects and test its impact on YBCS and their HCPs. In the first year of the project, we accomplished the first aim to develop a prototype for the tailored reproductive health survivorship care plan (SCP-R). We conducted systematic reviews of scientific studies and professional society guidelines on four reproductive health areas: hot flashes, fertility concerns, contraception and sexual problems. Findings of our systematic reviews were then converted into written materials for YBCS and HCPs. These written drafts of the SCP-R were reviewed and revised by our multi-disciplinary expert panel, which includes breast cancer advocates, researchers, and HCPs in reproductive health, primary care, breast oncology, and cancer survivorship. The SCP-R prototype was then ready for pilot testing. In the second year of the project, we completed the second aim of the study by pilot-testing the SCP-R prototype with YBCS and HCPs. We conducted 5 focus groups with 37 YBCS and structured interviews with 9 HCPs. These activities have been invaluable in assessing the survivorship care plan, website content, messages and structure in terms of ease of comprehension, credibility and persuasiveness. In addition, based on YBCS feedback, we removed tailoring access to content, as overwhelmingly, our participants wished to access content on all 4 late effect areas (hot flashes, fertility concerns, contraception and sexual health). Following refining the content of the SCP-R, we have developed the study web-site to support the clinical trial. In March, 2016, we have initiated recruitment for the randomized controlled trial to test the efficacy of the SCP-R on improving estrogen deprivation symptoms, fertility concerns, contraception and sexual function.

Publications

Title	Authors	Year
Contraceptive practices among female cancer survivors of reproductive age	Dominick SA, McLean MR, Whitcomb BW, Gorman JG, Mersereau JE, Bouknight JM, Su HI	
Nativity Differences in Stress among Asian and Pacific Islander American Women	Morey BN, Gee GC, Shariff-Marco S, et al.	2018
Use of emergency contraception among female young adult cancer survivors	Medica ACO, Stark SS, Hadnott TN, et al.	2018
Randomized controlled trial of the effect of a reproductive health survivorship care plan on fertility and pregnancy concerns, vasomotor symptoms, sexual health, and contraception in young breast cancer survivors	Stark SS, Kwan B, Myers E, Natarajan L, Su H	2018
Ethical considerations for informed consent in infertility research: The use of electronic health records	Wells KJ, Gordon JR, Su HI, Plosker S, Quinn GP.	2015
Drug metabolising enzyme polymorphisms and chemotherapy-related ovarian failure in young breast cancer survivors	Lindsey M. Charo, Michael V. Homer, Loki Natarajan, Carolyn Haunschild, Karine Chung, Jun	2020
Ovarian stimulation in young adult cancer survivors on targeted cancer therapies	Su HI, Connell MW, Bazhenova LA.	2016
In Vitro Fertilization, Interpregnancy Interval, and Risk for Adverse Perinatal Outcomes	Palmsten K, Homer MV, Zhang Y, et al.	2018
Perceived Infertility and Contraceptive Use in the Female, Reproductive Age Cancer Survivor	Hadnott TN, Stark SS, Medica A, et al. Perceived infertility and contraceptive use in the	2019

Title	Authors	Year
Genetic variants of age at menopause are not related to timing of ovarian failure in breast cancer survivors	Homer MV, Charo LM, Natarajan L, et al.	2017
Best Practices in Counseling Young Female Cancer Survivors on Reproductive Health	Shliakhtsitsava K, Suresh D, Hadnott T, Su HI.	2017
Design of a randomized controlled trial on the efficacy of a reproductive health survivorship care plan in young breast cancer survivors	Stark SS, Natarajan L, Chingos D, et al.	2019
Efficacy of a web-based womens health survivorship care plan for young breast cancer survivors: a randomized controlled trial	Irene Su, H., Stark, S., Kwan, B. et al.	2019