The Cost of the Cure

Documenting the Collateral Damage of Breast Cancer Treatment

Dr. Susan Love Research Foundation is dedicated to achieving a future without breast cancer by engaging the public and the scientific communities in innovative research on cause and prevention. The importance of prevention is overshadowed by a decades-long focus on early detection and the cure, with those who have gone through treatment being heralded as survivors and surrounded in a celebratory pink cloud, instilling the message that once a person has gone through treatment, the journey is over and life can return to normal. For many patients, though, life does not resume as normal. Rather, they find themselves needing to adjust to a new normal, which includes dealing with the side effects from their treatments. Dr. Susan Love Research Foundation set out to document and report the true cost of a breast cancer diagnosis by capturing the voice of the people with first-hand experience. What we learn from the public may lead to breakthroughs in treatment protocols, better communication between doctors and patients, and improved survivorship.
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While information regarding side effects of various treatments does exist, much of it does not fully reflect the voice of the people affected. With the goal of documenting and reporting the true cost of a breast cancer diagnosis, Dr. Susan Love Research Foundation initiated an effort to crowdsource the side effects that women experience by going directly to the women affected and asking them to share their concerns and questions about life during and after treatment.

Crowdsourcing the Questions

The Collateral Damage project began in August 2013 when Dr. Susan Love Research Foundation emailed its constituents asking about side effects from breast cancer treatment, which resulted in more than 1,100 responses. To augment this database of patient-generated information, Dr. Susan Love Research Foundation reached out to Susan G. Komen and Young Survival Coalition,
and the “Question the Cure” collaboration was announced in October 2013. Other advocacy organizations were approached and recruited, resulting in 17 additional groups agreeing to sign on and help crowdsource input from their constituents. Throughout Breast Cancer Awareness month, these organizations undertook an active media campaign to get the word out and to request responses. To enhance the experience for respondents and to facilitate data collection, Dr. Susan Love Research Foundation developed a project-specific webpage for participants to learn more and provide their treatment related concerns. These efforts resulted in the accumulation of more than 9,000 questions and comments from more than 3,200 people with a history of breast cancer.

Dr. Susan Love Research Foundation created a project-specific web page, Questionthecure.org, for participants to learn more and provide their treatment related concerns.
Even at this early data-gathering stage, there were some striking findings. First, the response was overwhelming, spanning a broad array of topics. Examination of the information received from participants confirmed the hypothesis that those who have received a cancer diagnosis have concerns that are not being met regarding the short- and long-term consequences of their treatments. The most frequently reported side effects included fatigue (18.6%), memory problems (18.0%), anxiety and/or depression (14.1%), sexual problems (13.5%), and numbness or neuropathy (12.8%).

A second theme emerged that respondents felt they had not been told, and were unaware, that they might experience any of several well-known side effects from treatment, including neuropathy and fatigue. A third insight was that women wanted to know how to alleviate their symptoms and if anecdotal remedies actually work.
Verbatim Comments from Respondents

- Why do I feel like I’m out of sync with the rest of the world?
- Will I ever stop worrying about recurrence?
- Is it normal to have anxiety before mammograms and follow up appointments after treatment is over?
- Will motivation to do things ever be what it was before the diagnosis and surgery?
- Is it normal to suffer from depression after prolonged use of Tamoxifen?
- I am constantly tired, regardless of the number of hours of sleep I get. Is this common?
- Will my pre-cancer physical stamina ever return?
- Will I ever have the energy to go a whole day without a nap?
- It has been eight years since my diagnosis and treatment. Will I ever get the energy I had back?
- What has Taxotere done to my hair follicles? Is the hair regrowth just decelerated or are the cells killed by this chemical agent?
- Will my thick, healthy hair ever return?
- Is it normal to grow heavy, coarse black hair on the upper lip and chin while taking Aromasin?
- Why did my hair come in so curly?
- I have issues with word and name recall, is this related?
- Why can’t I remember songs I played on the piano?
- Is there a way I can get back my higher cognitive function and memory?
- Do cognitive difficulties persist as long as ten years following chemotherapy?
- When will I stop forgetting simple things?
- How common is it to forget titles of books, movies, or songs?
- Will my hot flashes ever stop (waiting 17 years now)?
- Why are my toenails curling down?
- How long do toenails and fingernails discolor and fall off?
- Why did I have loose teeth during and after chemo?
- Is gum recession a common occurrence post chemo or radiation or Tamoxifen?
- Will neuropathy ever reverse itself?
- Will cold laser treatments help my ever increasing numbness in both my hands and feet?
- Will my feet ever stop feeling numb?
- Will the feeling ever return in my upper arm?
- Is numbness and continuing pain at breast attachment sites normal after mastectomy?
- Will I feel sexual stimulations from my nipples?
- How do I tell my soul mate that I have no sexual drive anymore?
- Will sex ever be comfortable again?
- Is it normal to experience extreme vaginal dryness after treatment?
- Is my insomnia related to my breast cancer treatment?
- Will it ever be comfortable to sleep on my stomach again?
- Is there a faster way to return to full mobility in my arm?
- Is it normal to not be able to put one of my arms straight above my head when stretching?
- Is it common to drop things easily?
- What if your saliva has a salty taste?
- Does the radiation exacerbate rosacea?
- Is it normal to suffer hearing loss?
Finding and Sharing the Answers

After collecting and tabulating the thousands of responses, Dr. Susan Love Research Foundation identified two phases for completion of the project.

Phase I) Formal data collection

Phase II) Developing educational resources

Phase I: Formal data collection

The objectives for Phase I are twofold:

1. to compare the crowdsourced responses to existing data collection instruments focused on quality of life and to use these validated instruments for formal data collection; and

2. to develop a new validated questionnaire to study the issues not covered by existing data collection instruments.

In Phase I, Dr. Susan Love Research Foundation plans to build upon the existing resource of the Health of Women [HOW] Study™, an online cohort study open to anyone aged 18 or older which has the goals of identifying risk factors for breast cancer and factors related to survival. The online study follows participants over time and is questionnaire-based, asking about a variety of different factors and exposures including exercise, lifestyle, medical history, and environment, among others. New questionnaires are released every few months. Since the study launched in October 2012, more than 50,000 participants have registered, of whom approximately 10,000 have a previous diagnosis of breast cancer.

In order to collect information related to the side effects from treatment in a systematic manner, Dr. Susan Love Research Foundation will compare the responses from the crowdsourced cohort to existing quality of life questionnaires that are based on small sample reports from patients in a clinical setting. Many such instruments exist, including the FACIT measures, Center for Epidemiologic Studies Depression Scale, Fatigue Symptom Inventory, Memorial Symptom Assessment Scale, the Medical Outcomes Study measures, and others.
To accomplish the first Phase I objective, Dr. Susan Love Research Foundation will work with experts in cancer survivorship and quality of life research to determine the best available questionnaires for capturing side effect information. These validated questionnaires will be released to [HOW] Study participants in October 2014 (once again during Breast Cancer Awareness month to enhance participation) to document their experiences with the commonly reported side effects. Using existing, validated questionnaires will provide the added benefit of allowing us to compare our population to others who have used the same instruments.

However, the existing validated questionnaires have certain limitations: they do not go into depth regarding length of suffering and the side effects collected are relatively general. In addition, they cannot answer some of the additional concerns that arose during the original call for input, including if remedies exist for certain symptoms, and how well physicians are communicating with their patients. Because of these limitations and the desire to learn and report more information about collateral damage, the second objective for Phase I is to fill this void by developing and validating a new questionnaire that covers these unexplored areas.

To accomplish this objective, Dr. Susan Love Research Foundation will collaborate with researchers who have undertaken the development and validation of previous quality of life questionnaires to develop a new validated data collection instrument. This new questionnaire will include questions on specific side effects experienced, the length and severity of suffering, remedies that provided benefit and those that did not, and the quality of information patients received from their treating physician(s). To create a scientifically sound instrument, the questionnaire will undergo rigorous validation testing before implementation. Upon successful validation, the questionnaire will be distributed to [HOW] Study participants with a history of breast cancer for data collection.

Using these previously validated and newly created/validated questionnaires within a study that follows a large group of people over a long period of time will also allow for deeper investigation. For example, it will be possible to examine if time since diagnosis is related to side effects or severity, and to compare symptom information between similarly aged women with and without a history of breast cancer. This also has the potential to provide information about whether certain side effects fade over time, and if the general population is more or less likely to suffer from the same complaints. In addition, because of the extensive health and exposure information already being collected through the [HOW] Study, correlations of particular side effects and other medical problems or patient characteristics will be examined, which may help to better predict the likelihood of developing side effects. For example, it may
be possible to understand if restless leg syndrome is a risk factor for peripheral neuropathy, or if chemobrain is more common when one has a family history of dementia.

**Phase II: Developing an Educational Resource**

To address the second goal of reporting the true cost of the cure, Dr. Susan Love Research Foundation will compile results from both waves of questionnaires and distribute them widely. Reports and infographics will be made available to [HOW] Study participants and collaborating partners to share with their constituents. Social and traditional media channels will be used to disseminate the information. In an effort to add to the scientific literature and educate physicians and researchers of the findings, scientific articles will be written and published in peer-reviewed journals, and results will be presented at various scientific meetings. Dr. Susan Love Research Foundation’s website will feature a dedicated section on Breast Cancer Treatments that will contain educational resources for patients, caregivers, and the public, as well as providing a forum for capturing feedback and stimulating dialogue.

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**Dr. Susan Love Research Foundation**
2811 Wilshire Blvd., Suite 500
Santa Monica, CA 90403
310.828.0060 / 866.569.0388

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