


When Breast Cancer Survivorship Discourse Doesn't Work: Reflections From a Patient

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Abstract

Within this narrative, I document my experiences with breast cancer. On 2 separate occasions, diagnoses did not qualify me for survivor identity within the current interpretation of breast cancer survivorship discourse. Yet each time, I underwent treatments that were necessary, but physically and emotionally difficult. I briefly discuss how breast cancer survivorship discourse is interpreted, including how this discourse has benefitted women, but also, the challenges in survivorship discourse adoption (including how the current survivorship definition differs). I then discuss my struggles in feeling like I could not assume breast cancer survivorship discourse, including the confusion and despair, as well as feeling ineligible for support groups. Briefly, one suggestion for change is made.

Keywords

breast cancer, survivorship discourse, benefits, challenges

Introduction to the Issue

As a nurse academic, I am well aware of illnesses such as breast cancer, and important lifestyle factors to lessen the risks for developing this dreaded disease. Despite being health conscious, at 42 years of age I was diagnosed with ductal carcinoma in situ (Stage 0). Fourteen years later, cancer returned, and I was diagnosed with metastatic breast cancer (Stage 4). As will be described below, it felt like the discourse of breast cancer survivorship never applied to me. This has impacted how I view my situation, introduced confusion and despair, and impacted what supports I access. In order to illustrate this, I first describe how survivorship discourse is interpreted, as well as problems with this interpretation, and then describe my circumstances.

Key Factors for Consideration

Since the late 1980s, women's experiences with breast cancer have been reconceptualized. Prior to this time, breast cancer was viewed with fear and stigma (1). In 1985, Dr Fitzhugh Mullan, himself having experienced cancer, suggested the use of the word "survivor" for those diagnosed with cancer rather than "cure"; his rationale was that this term better described the experience of cancer (2). The label survivor—in relation to breast cancer—was taken up by the media

and advocacy groups—leading to changes in how breast cancer was/is conceptualized, talked about, and experienced (3).

The adoption of breast cancer survivorship—where women claim the label of survivor—has had a positive impact on some women with breast cancer. For example, some women find the term "survivor" empowering and linked with bravery and strength (the warrior), and readily assume this identity (4–7). Other benefits of incorporating this identity include better psychological health, greater post-traumatic growth, and increased life satisfaction as compared to those who identify with the patient or victim identity (5).

Even though survivorship is defined as from diagnosis to end of life (eg, National Cancer Institute, n.d.) (8), how patients understand survivorship is different. Interpretation includes the element of time (when and how long does one need to have had breast cancer treatment to be considered a survivor?), severity of the illness in relation to the breast cancer experiences of others, what constitutes end of

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treatment, and what stages of breast cancer are considered survivable. Some women do not feel they fit the label of survivorship, and others, do not like this term.

I have experienced both ends of the breast cancer diagnosis spectrum. Each time, I have not felt part of the breast cancer survivor group. When first diagnosed with breast cancer, my stage was labelled Stage 0. Despite being diagnosed early, I underwent 2 surgeries, as well as 5 weeks of radiation. Treatment was completed 6 months after the diagnosis. I wanted to adopt the label of cancer survivor but felt embarrassed. My cancer was Stage 0, so how could others take my cancer seriously (After all, what does Stage 0 mean?) How could I dare compare myself to others who experienced ongoing chemotherapy treatments, loss of hair, and full mastectomies? I didn't think of attending support groups for women with breast cancer because of the fear that others would perceive my cancer as trivial. Even though this was truly a life changing experience, my situation did not stack up to those with Stages 2 and 3. I did not feel I could state that I was a breast cancer survivor.

The feeling of not fitting into the breast cancer group returned in 2019. Despite eating healthier after the first diagnosis and continuing my lifetime pattern of extensive exercising, I was again diagnosed with breast cancer. Initially, it was thought that this was Stage 1, but when a bone scan revealed a metastasis in the neck of my right femur, I was catapulted into Stage 4. How could this happen?

It was made clear that there is no cure for Stage 4 breast cancer—what became clearer over time was that there are no *survivors* with Stage 4. I was told that I was palliative. It was suggested my husband and I attend a class on breast cancer; early in this class, I realized that this was a mistake. All participants were diagnosed as Stages 1 and 2. There was no one in this class that had a Stage 4 diagnosis. I was upset that the leader of the class clearly did not know about Stage 4 medications. When my husband and I slipped out of the class early (rather, in sheer grief, I partially staggered out of class), I sobbed. Very little of the information applied to me. This time my prognosis was not too miniscule, but rather, *too far gone*. I had tried so hard to follow all protocols around regular checks and living well, but all my efforts seemed for naught.

Over time, the shock thankfully dissipated. Although being reminded of my Stage 4 diagnosis through a total hip replacement because of a metastasis, as well as 2 new small bone metastases (my sternum and T9—thoracic vertebra), I am doing well. I have had radiation to my right leg, as well as to the sternum and T9. I continue with medications that address the cancer cells (targeted therapy) and lower estrogen levels (aromatase inhibitors). The medications have strong side effects, like bone, muscle and joint pain and brain fog (9). I am keenly aware that once again, I do not fit within the common understanding of the survivorship group. I won't survive this time; the emphasis is on buying time, as well as enjoying quality of life. While I could attend a support group for women with Stage 4 cancer, I

am too scared of the impact of others dying upon my mental health. Will I lose hope too early?

The challenges for me now involve living with the side effects of the medications. I will take these medications until they stop working or I pass away. Now I also deal with the existential questions. What do I do when I don't feel strong or like a warrior? The ontological insecurity (10) is heightened; now death is no longer a possibility, but a reality—the question becomes when and the goal becomes delaying death for as long as possible. Ironically, even though survivorship is no longer an option, re-negotiating an identity is crucial for me. Who am I, now that I need to retire early to handle the side effects of the medications? What will I do to meaningfully fill my days when I am officially retired? I want to continue to contribute to society but recognize that at some point, this privilege of helping others will diminish. My prayer is that I will have grace to accept the benevolent help of others when I cannot reciprocate their support.

Recommendations and Conclusion

Survivorship discourse, including the common understanding of women about survivorship, has been beneficial for many women. However, some women feel excluded. How breast cancer survivorship discourse is interpreted needs to celebrate individuals like myself, who do not “fit” the understanding of survivorship. Health care professionals, support organizations, and the general public need to be more aware of the actual definition of survivorship, and celebrate everyone who has cancer as survivors, including those with Stage 4 cancer.

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References

1. Gibson AF, Lee C, Crabb S. 'If you grow them, know them': discursive constructions of the pink ribbon culture of breast cancer in the Australian context. *Fem Psychol*. 2014;24(4):521-41. doi: 10.1177/0959353514548100
2. Mullan F. Seasons of survival: reflections of a physician with cancer. *N Engl J Med*. 1985;313(4):270-3.
3. Barbor M. Silent patients find their voices through an advocate's journey. *Oncol Nurse*. 2018;11(1):11.
4. Bell K. The breast-cancer-ization of cancer survivorship: implications for experiences of the disease. *Soc Sci Med*. 2014;110:56-63. doi: 10.1016/j.socscimed.2014.03.031

5. Cheung S, Delfabbro P. Are you a cancer survivor? A review on cancer identity. *J Cancer Surviv.* 2016;10(4):759-71. doi: 10.1007/s11764-016-0521-z
6. Kelly KM, Shah N, Shedlosky-Shoemaker R, Porter K, Agnese D. Living post-treatment – definitions of those with history and no history of cancer. *J Cancer Surviv.* 2011;5(2):158-66. doi: 10.1007/s11764-010-0167-1
7. Sherman DW, Rosedale M, Haber J. Reclaiming life on one's own terms: a grounded theory of study of the process of breast cancer survivorship. *ONF.* 2012;39(3):E258-68. doi: 10.1188/12.ONF.E258-E268
8. National Cancer Institute. Survivorship. n.d. <https://www.cancer.gov/publications/dictionaries/cancer-terms/def/survivorship>.
9. Breast Cancer Now. *Aromatase inhibitors*. Accessed October 24, 2022. <https://breastcancer.org/information-support/facing-breast-cancer/going-through-breast-cancer-treatment/hormone-therapy/aromatase-inhibitors-anastrozole-exemestane-letrozole>.
10. Wilson E. Social work, cancer survivorship and liminality: meeting the needs of young women diagnosed with early stage breast cancer. *J Soc Work Pract.* 2020;34(1):95-111. doi: 10.1080/02650533.2019.1604497