

Abstract

An Exploration of the Unique Experience of Survivors of Gynecological Cancer: Sexuality and Body Image

by

Rebecca Skye Caldwell

Gynecological cancers kill many women each year. Those women who survive are often left with the residual effects of surgery and various treatments, and they endure significant and potentially detrimental changes to their sexuality and body image. As a result, while technological advances have increased the likelihood of surviving gynecological cancer, the quality of life issues, such as sexual health and the rehabilitative aspects of treatment, are becoming increasingly important. Unfortunately, the majority of research has focused on sexual functioning and physiological changes that accompany gynecological cancer. Thus, our current knowledge about how changes to sexuality and body image impact gynecological cancer survivors and their quality of life as sexual beings is quite elementary. For this reason, this study was a quantitative and qualitative study designed to explore gynecological cancer survivors' unique experiences surrounding their sexuality and body image.

Quantitative instruments assessed the baseline sexual functioning and distress of 21 gynecological cancer survivors with a mean age of 47 years. Ovarian cancer was the most widespread diagnosis (67%), and chemotherapy was the most prevalent treatment (62%). The quantitative results showed that the gynecological cancer survivors experienced significant mood disturbance and a host of sexual problems surrounding interest in sexual desire, frequency of sexual desire, pleasure, arousal, and orgasm.

A qualitative instrument, an in-depth, open-ended interview, explored the range of residual issues surrounding sexuality and body image experienced by 9 of the 21

gynecological cancer survivors with a mean age of 44 years. The results of these interviews were evaluated thematically, then compared and contrasted with the in-depth, open-ended interviews of 7 women in a cancer-free control group with a mean age of 43 years.

All 9 of the gynecological cancer survivors who were interviewed spoke of significant residual issues with regard to sexuality and/or body image. When asked to reflect on their experience of sexuality and body image as gynecological cancer survivors, the most prevalent themes that emerged were loss of potential maternal opportunities (33%), loss of pleasure (33%), feelings of isolation (44%), loss of wholeness (56%), loss of desire (67%), a dramatic/abrupt shift in self-identity due to loss of physical integrity (67%), a reluctance to initiate discussions about sexual concerns (67%), a negative impact on body image (89%), a negative impact on intimate relationships (100%), and heightened emotions (100%).

All 7 women in the cancer-free control group (100%) spoke of feeling awkward or insecure at some point during adolescence. Thus, while the cancer-free control group members defined their experience historically, the gynecological cancer survivors defined their experience in terms of pre- and post-cancer. Diagnosis and treatment of gynecological cancer was the defining moment in their sexual history, and it dramatically changed their experience of sexuality and body.

Most of the women in the cancer-free control group (86%) spoke of a positive and gradually maturing body image and sexuality that evolved over time, whereas the interviews with the gynecological cancer survivors revealed a theme of a negative, dramatic, and abrupt shift in sexuality and body image triggered by their gynecological

cancer diagnosis and treatment. These survivors were not only faced with the physical side effects of treatment, such as scars, lack of libido, loss of fertility, and changes in body shape, but also with the emotional impact of premature menopause. One woman eloquently summarized: “Yes, I am grateful, but what kind of existence is it? If you lose the core of what drives you, your sexuality, that is what makes you human.” This woman continued her interview by stating that she felt “robbed” of her youth.

All 7 members of the cancer-free control group (100%) mentioned their intimate relationships. The majority of them reported the positive impact of their intimate relationship on their experience of sexuality and body image. Only one mentioned a feeling of self-consciousness that inhibited her in her relationship. In sharp contrast, all 9 gynecological cancer survivors (100%) indicated that their diagnosis and treatment of gynecological cancer had negatively impacted their intimate relationships. Women who had partners reported a distancing, both emotionally and physically. Women who were not currently in relationships spoke of a level of fear or doubt that inhibited them in forming relationships.

Finally, the cancer-free control group members revealed feelings of inadequacy regarding their sexuality and body relative to cultural ideals. This is not surprising given that much of female sexuality is based on social and cultural norms of age, appearance, and child-bearing ability, and any deviation from these norms may cause women anxiety about their appearance. In contrast, all of the gynecological cancer survivors (100%) felt awkward in the sense of being maimed, damaged, asymmetrical, freakish and/or incomplete due to the negative impact of treatment. These findings suggest that the

residual effects of gynecological cancer treatment augment the ever-present unrealistic standards of our society and culture.

This study revealed a two-fold health concern: (a) a need for the consideration of sexuality and body image issues as a component of a gynecological cancer survivor's treatment and rehabilitation and (b) a reluctance on the part of these women to initiate discussions about sexual concerns. Diagnosis of and treatment for gynecological cancer is a major defining moment in a woman's life. It may radically and permanently change her experience of her sexuality and body. Without information provided by a team of health care professionals, there is no reason to assume that a woman would know that symptoms she was experiencing, such as decreased libido or discomfort during sex, were related to cancer treatment. Working together, all health care professionals are in a unique position to aid a woman diagnosed with gynecological cancer in her journey toward physical and psychological rehabilitation.