

Psychosocial Impacts of Radiation Tattooing For Breast Cancer Patients

A Critical Review

BARBARA CLOW AND JANET ALLEN

Cette revue de la littérature rapporte ce que les patientes du cancer du sein ont écrit sur leur connaissance et leur attitude face au tatouage permanent qui définit la surface du corps à irradier. La communauté médicale accepte généralement l'usage des marques permanentes, avançant l'hypothèse que les tatouages favorisent un traitement radiologique plus précis et procurent un dossier permanent de l'exposition aux radiations. Mais il existe de plus en plus de témoignages des femmes qui s'offusquent des marques permanentes sur leur corps, depuis le rejet catégorique jusqu'à l'indifférence ou encore l'acceptation d'emblée des tatouages en dépit des séquelles éventuelles pour leur bien-être psychologique.

The emotional and psychological trauma and distress of breast cancer diagnosis, treatment, and recovery are well-documented. The existing literature attributes this distress to fears about death, recurrence and overall health (Ashing-Giwa et al.), the impact of treatment and recovery on relationships, children or work (Ashing-Giwa et al.; Buick et al.), and concerns about physical changes to the breasts resulting from mastectomy, lumpectomy, and other treatments (Deshields et al.). Other studies explore possible associations between breast cancer diagnosis and treatment and mental health issues, including post-traumatic stress symptoms (PTSS) (Andersen et al.; Andrykowski and Cordova) and depression (Mosher and Danoff-Burg; Roussi et al.). What is unclear from this research, however, is how the use of permanent tattoos in radiotherapy for breast cancer affects women's psychosocial understandings and experiences of the disease. Even research that focuses on patients' experiences of radiotherapy does not directly address the psychological impact of permanent radiation tattooing (Buick et al.; Deshields et al.; Siekkinen et al.).

The current standard of practice for defining the area to be irradiated for breast cancer treatment is by marking the skin with small, permanent blue ink dots or "tattoos" (Griffiths et al.; Winer et al.). For breast cancer patients,

tattooing typically involves anywhere from four to twelve dots—depending on the institution—at points ranging from the collarbone to the fold under the breast and from the breastbone to underneath the underarm (Karmarnicky, Rosenberg, and Betancourt). While health care providers stress the need for tattoos to ensure accuracy and as a permanent record of radiation exposure, a growing body of research and anecdotal evidence points to an interest in alternatives to and removal of permanent medical tattoos used in radiotherapy (Foreman; Probst et al.). This interest seems particularly high among breast cancer patients, which supports the conclusion that some women experience distress in response to this treatment practice (Alam and Arndt; Billingsley; David, Castle and Mossi; Foreman).

This discussion is based on an analysis of traditional peer-reviewed literature and grey literature, defined as information produced by government, academics, business, industry and the public in both electronic and print formats but which is not controlled by commercial publishing (Schoepel and Darace). Web-based information, particularly patient/survivor fora and blogs, represents an important source of evidence for this analysis. Our review of literature reveals that women have diverse responses to medical tattooing for radiation treatment, positive and negative, which may affect their experiences of cancer and care. Yet limited attention is afforded this aspect of cancer treatment, particularly in the peer-reviewed literature.

At the same time, a small body of research suggests that women's experiences of medical tattooing may be affected by social location—race, culture, socio-economic status, geography, etc. Discussion of the social determinants of health is also generally absent in the peer-reviewed literature. This dearth of systematic research on cancer tattooing is disturbing in light of the varied perceptions and experiences of women living with a diagnosis of breast cancer.

Theoretical Framework

Women's voices are all but absent in the literature that addresses radiation tattooing used in breast cancer treatment. Because a feminist framework positions lived experience as a valid source of knowledge (Reinharz and Davidman), it is an important lens through which to view the psychosocial aspects of radiation treatment for breast cancer. Patients' concerns are evident, not so much in formal research, but through anecdotal evidence. For example, online personal weblog or "blog" entries and discussion groups that address

type could sell the war, then it might also promote other products and services" (Jones 17). With this commodification process firmly entrenched in mainstream media and entertainment, women come to see their breasts as objects for others rather than an aspect of their embodied selves (Jones; Millsted and Frith; Young). Currently, there is only one "perfect" breast shape—one that is "round, positioned high on the chest, large and firm" (Jones 18). While these cultural influences exert pressure on women to conform to this ideal, it does not mean that women are merely passive vessels for culturally prescribed norms

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the issue provide a snapshot of attitudes about permanent radiation tattoos. Inclusion of these informal sources of information is not intended to replace evidence obtained through systematic, peer-reviewed research, but simply to provide a preliminary starting point for discussions about how radiation tattooing is currently being defined—or not defined—as a challenge for breast cancer patients. Clearly, further research is needed to explore the themes raised in this review of the literature from a feminist perspective that accounts for women's experiential knowing.

It is understandable that both aesthetics and emotional significance factor into women's medical decision-making about their breasts considering the complex, and often contradictory, meanings of women's breasts in modern Western culture. Rachel Millsted and Hannah Frith state that "women's breasts are invested with social, cultural and political meanings which shape the ways in which we make sense of and experience our embodied selves" (455). They are simultaneously sites of maternal nurturing, femininity, and sexual desirability (Jones; Millsted and Frith; Young). Early representations of the female breast in art and mythology valued voluptuous, prominent breasts as symbols of abundance, fertility, and nurturance (Jones). Standards of beauty shifted in the middle-ages in Europe to a preference for small, round, firm, and widely-spaced breasts and their role in male sexual pleasure and desire overshadowed any maternal meaning (Jones). With colonization came nude images of African women in photographs and art in nineteenth century Europe and these images clearly depicted African women's bodies and breasts as sagging and used-up—in stark visual contrast to the perky, eroticized, white aesthetic ideal (Jones).

The commercial potential of women's breasts was first realized during World War II when "filmmakers and advertisers realized that if the prominent-breasted female

regarding the "perfect" breast: "women actively negotiate their position in relation to a complex web of discourses, gazes, audiences, identities and visibilities" (Millsted and Frith 463).

Psychosocial Impact

The role of permanent radiation tattooing in breast cancer treatment is neglected in the literature, in part because the marks are sometimes seen—by both patients and practitioners—as a relatively minor issue in the context of managing a disease that is potentially life threatening (Alam and Arndt; Harris). In support of this view, some women living with permanent radiation marks have reported ready acceptance of the tattoos while others view them as a minor nuisance or inconvenience (Foreman). However, there is also evidence to suggest that permanent radiation tattoos pose a significant psychosocial challenge for some women living with breast cancer. For instance, many of those reporting distress see the tattoos as compounding the trials of dealing with significant physical changes to their breasts and bodies arising from diagnosis and treatment (Langellier). Clearly, women experience a wide range of reactions to radiation tattooing for breast cancer and the depth of their reactions as well as the reasons for them vary.

Breast cancer patients may also object to tattoos for cultural and/or religious reasons. One example of this potential conflict involves women who observe Orthodox Judaism because tattooing is explicitly forbidden by the Torah. A website dedicated to Jewish women's health advises readers that temporary markings should be used if at all possible and if not, that the tattooing should be performed by a non-Jew (Jewish Women's Health). Similarly, Langellier documents a case in which a devout Catholic

breast cancer patient—who understood tattooing to be inconsistent with her faith—expressed fears associated with tattooing. “So a religious thing,” she said, “would be that I had to get over the fact of I had four little dots of tattoo and when I grew up the thing is that people who had marked their bodies were children of the devil and that you were to go to Hell” (Langellier 153). Anecdotal evidence suggests that the religious or cultural significance of tattooing may not be validated by medical professionals. For example, an online blog entry describes a woman’s experience in which she raised a religious objection to the use of permanent tattoos but was told by the doctors and technicians that she had to have them (Eva). As mentioned earlier, medical tattoos are regarded as the gold standard for marking the field of radiation treatment, but there is evidence that alternatives to tattoos, semi-permanent or temporary marks using henna and other products, have been offered by medical professionals when religious objections are raised (Gitlin). Further research is needed that considers the role of faith and culture in patients’ meaning-making and decision-making processes about this treatment practice and the potential inconsistencies in provision of care.

While much of the evidence found from a search of online support forums suggests that women’s experiences with permanent radiation tattooing are largely negative, it is possible that these views do not reflect the majority of women, given that those who are most dissatisfied with their experiences are more likely to voice their concerns. Certainly other evidence suggests a significantly different interpretation of tattooing. For some breast cancer patients, the blue dots themselves come to represent bonding and sisterhood—they are perceived as badges of honour for having survived the disease. One example of defining the permanent tattoos in this way is Schwan’s book, *The Blue Tattoo Club: A Breast Cancer Sisterhood*. The book—and associated online support forum—consists of personal stories from breast cancer survivors about diagnosis, treatment, and recovery. The blue tattoos indicate membership in this club, membership that women do not choose but which nevertheless connects them in their healing struggles and victories. Sheryl Crow, a prominent music artist and member of the blue tattoo club has been quoted as saying, “I’ve kept my tattoo because it is a reminder for me. It’s a reminder of that time. It’s a reminder of how I want to look at my life. I want to remember” (Entenmann).

Similarly, some women seem to embrace tattooing after treatment as an opportunity for self-expression. While much of the support for breast cancer survivors focuses on aesthetic aspects of healing such as breast reconstruction, nipple and areolar tattooing, and prosthetics (See El-Ali, Dalal and Kat; Hang-Fu and Snyderman; Henseler et al.; Spear and Arias), some survivors are eschewing efforts to match their pre-treatment appearance in favour of expressing the nuances of their cancer

experiences and consequent shifts in personal identity through non-medical tattooing. A growing number of breast cancer survivors are actively transforming their medical tattoos and scars into works of art by incorporating them into permanent decorative designs that have personal significance. Women are redefining their experiences of breast cancer by becoming walking works of art and redefining the meaning of “disease” and “illness” in the process (Radley and Bell). Radley and Bell maintain that the creation of visual images depicting breast cancer increases the visibility of the disease thereby challenging the “cultural cloak that has lain over both cancer generally and breast cancer in particular” (368). Such forms of artistic expression can also represent a type of personal narrative—a way for survivors to share a “story of the body *through* the body” (Langellier 146). For many women, cancer has meant a loss of control (Thomas-MacLean) and the act of redefining the marks and/or scars associated with cancer treatment constitutes an act of re-embodiment and empowerment.

Once the body is permanently marked for treatment, some women choose re-marking on their own terms as a form of resistance and an act of reclaiming their bodies (Langellier). This act of resistance is consistent with feminist critiques of how the medical establishment views patient autonomy, which is currently defined largely in terms of rational choice and informed consent (Dodds). According to feminist theories of bioethics, this understanding of autonomy is limited as it fails to account for the social circumstances and power relations that shape the context in which the choice is made (Dodds). Autonomy is also conceived of as an all-or-nothing proposition—either one is deemed competent to give informed consent or not. According to Dodds, “this lack of middle ground, of an awareness that the capacity to make health care decisions may admit by degrees, is one effect of the identification of autonomy with informed consent, which can be particularly harmful to women’s interests” (217). She notes that a patriarchal system, the kinds of medical decisions women are required to make, and the cultural perception of women as irrational and overly emotional all contribute to the construction of health care options that limit women’s autonomy (Dodds). While informed consent and the capacity to choose are of course important, Dodds argues that “respect for autonomy is not restricted to respect for choices of a certain kind but also requires the development of autonomous selves” (226-7).

A review of online support forums and personal blog narratives also suggests that many breast cancer patients feel they have little or no choice about permanent tattoos. BrandonMom stated:

Whether you are someone that enjoys seeing your battle scars, or someone that prefer [sic] to minimize the permanent marks, the choice should be yours

and you should be informed of the pros/cons of each method [temporary or permanent marks]. Not just told “you will get tattoos.” From most women I have spoken to, they are not aware there is another choice. That seems wrong to me. The choice should be the patient’s to make, as the patient has to live with the decision.

This perceived lack of autonomy is highly problematic given the wealth of research that confirms the psychological benefit of women’s active involvement in

a previous study on cancer support services in Atlantic Canada showed that women made treatment choices based on social rather than medical imperatives. Faced with the choice of a mastectomy or extended absences from home to have radiation treatment following a lumpectomy, many women opted for the more invasive surgery because it allowed them to remain with their families and friends (Clow et al.). We not only need more research on women’s choices in relation to breast cancer tattooing, but also research that addresses the impact of social location on women’s choices.

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treatment (Deadman et al.; Fallowfield et al.; Pozo et al.; Till, Sutherland, and Meslin). While some sources identify the patient’s right to choose between temporary or permanent tattoos (Probst et al.; “Use of Tattoos”), often this information is presented to emphasize the inferiority of temporary marks. Opportunities for choice regarding treatment are particularly significant for women marginalized by socioeconomic status. For example, Clark notes that working class women with breast cancer are less likely to advocate for themselves or challenge physicians’ recommendations than middle-class women who have greater access to resources and information. As permanent marks are considered standard practice, little is known about women’s preferences, resistance, or autonomy in this regard.

It is important to note that choice can be a problematic element for female breast cancer patients. Thomas-MacLean notes that women may struggle with making breast cancer treatment decisions and be uncomfortable as well as unfamiliar with the autonomy afforded them in this regard. She identifies the important dilemma that “given the uncertainty of many cancer treatments, one must ask what choices are really being presented” (Thomas-MacLean 634). A feminist analysis of this phenomenon suggests that women, in contrast to men, often lack a frame of reference for egalitarian approaches to health care. Without experience being treated as respected partners in health care, women may be unaccustomed to assuming a proactive stance on their own behalf (Thomas-MacLean). Of course this analysis is not meant to imply that women are incapable of exercising autonomy, but rather that gender—the behaviours, roles, attitudes and expectations attributed to women and men by society on a differential basis—will affect how women understand and exercise “choice” (Clow et al. 2009). For example,

Medical Standards

The medical justifications for using any kind of tattoos to define the radiation field are precision and consistency (David, Castle, and Mossi; Harris; “Use of Tattoos”; Uyeda). Typically, radiation treatment is administered in a series of daily consecutive doses over a period of several weeks and it is crucial that these doses are applied to the exact same area each time (David, Castle, and Mossi). Another frequent argument for permanent tattoos, as opposed to temporary markings, is based on the need for long-term consistency: should additional radiation be required—due to cancer recurrence or the development of a new cancer—it is critical to know the exact site of treatment because the tissue cannot withstand a second full-dose course of radiation treatment (Kraus-Tiefenbacher et al.). Physicians often discourage patients from having tattoos removed on these grounds, arguing that the marks aid in follow-up examinations and serve to identify the irradiated area should the cancer re-occur and further radiation is needed (Hampshire; Harris; “Use of Tattoos”). According to some researchers, marks in the centre of the torso are most important years later should a breast cancer patient require future radiation treatment to an adjacent area (Probst et al.) or access additional treatment at a different facility (“Use of Tattoos”).

While the medical rationale for permanent tattooing has been clearly articulated, David, Castle, and Mossi have identified three main concerns about the practice and its medical justification: mobility, visibility, and emotional impact on the patient. First, mobility refers to the tendency of marks to shift over time. In other words, permanent tattoos do not necessarily provide an accurate record of radiation treatment because their location can change over time, particularly for overweight and elderly

patients, due to stretching or shrinking of the skin and changes in elasticity (David, Castle, and Mossi; Probst et al.). Second, visibility concerns include locating and identifying the dots on darker-skinned patients and distinguishing the radiation marks from hair follicles. While educational materials often emphasize the smallness of radiation tattoos, the size itself can create challenges for accurately locating the marks from one treatment to the next. Moreover, it is sometimes necessary to use temporary markings because the permanent ones are not universally effective for all breast cancer patients. For instance, standard blue-ink tattoos may not show up well on patients with darker skin tones (David, Castle, and Mossi), which suggests the ineffectiveness of using permanent tattoos for treating African Canadian women and other women of colour with breast cancer. Third, emotional impact refers to the fact that “permanent tattoos remind cancer survivors daily of their disease and treatment” (David, Castle, and Mossi 1), experiences that many patients may prefer to forget.

Growing recognition of the potential psychological meanings attached to permanent marks has led some researchers to explore techniques for temporarily outlining the radiation area. For instance, David, Castle, and Mossi proposed the use of invisible fluorescent ink that is black light reactive, however, their study was not conducted on patients and further research is needed to assess the viability of this option. Alternatives such as semi-permanent or temporary markings made using markers or surgical pens have been shown to be equally effective as permanent markings (Probst et al.). Probst et al. conducted randomized trials with early stage breast cancer patients comparing the effectiveness of a combination of semi-permanent and permanent markings with the use of semi-permanent markings alone and found no significant difference between the two groups. They concluded that, for the majority of patients, “the choice not to have permanent tattoos will not interfere with the accuracy of the treatment application” (Probst et al. 188).

A review of breast cancer information and education websites demonstrates that information about permanent and semi-permanent or temporary markings is available, but there is little guidance about when or why different types of markings should be used. Despite the generally agreed upon standards of radiation tattooing for breast cancer patients, practices differ from country to country and even between jurisdictions and institutions. It is also interesting to note that standards are changing, although it is often not clear how or why these changes to policy and practice are being made. For instance, the Nova Scotia Cancer Centre (NSCC) in Halifax specifies using four to six permanent markings “about the size of the tip of a pen” located on the chest or breast area. Recently, NSCC reviewed its marking practices for breast cancer radiation treatment and determined that the mark on the upper breast bone—the most visible mark—was

not critical and it has since been eliminated. Because temporary marks are time consuming—they take longer to apply and need to be refreshed—it may be impractical for treatment facilities with high patient volume to consider options other than permanent marks. But more research is needed to understand why some health systems or centres regard permanent markings as the standard of care while others do not, particularly in light of patient reactions to tattoos.

Conclusion

This review highlights gaps in the literature about the use of permanent tattoos to specify the radiation treatment area for breast cancer patients and the meanings this treatment practice may have for the women affected. We are also ill-informed as to the possible significance the tattoos may have in the ways women construct meaning and establish community around their experience of breast cancer treatment and recovery. Meaning-making and support-building are part of the multi-layered emotional and psychosocial processes of managing disease experiences, including the various aspects of cancer diagnosis and treatment. Furthermore, formal research on breast cancer patients' autonomy in medical decision-making respecting the use of permanent tattoos should be undertaken using feminist and sex- and gender-based lenses. Currently, there is no comprehensive analysis of the potential psychosocial impacts of using permanent tattoos to specify the radiation area for breast cancer patients.

Barbara Clow is Executive Director of the Atlantic Centre of Excellence for Women's Health, Halifax, and Associate Professor Research in the Faculty of Health Professions at Dalhousie University, Halifax. She has a Ph.D. in the history of medicine from the University of Toronto and has presented and published on various dimensions of the history of health and healing, including the history of cancer, alternative medicine and thalidomide. In the past ten years, Dr. Clow has pursued a program of research and publication on diverse aspects of women's health, including work in the area of cancer, obesity, the gendered dimensions of health care reform in Canada, lone mother's experiences of inclusion and exclusion, the social determinants of African Canadian women's health, the role of gender in the HIV/AIDS pandemic, and the impact of women's unpaid caregiving work.

Janet Allen is a registered social worker and sessional instructor at dalhousie university's school of social work. Prior to here work as a social work educator, Ms. Allen worked as a researcher in the field of women's health and as a clinical social worker with women survivors of sexual health trauma .

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MALCA LITOVITZ

Whimsy

Take me back to white curtains
blowing in a fresh wind —
a Flower Power poster
with coils of snakes around its head.

Autumn leaves hang brown now on
branches,
but traces of white whimsy live in my
soul.

Malca Litovitz was an award-winning Canadian poet, highly respected professor of English literature and creative writing, editor and critic. Though no longer with us, her indomitable spirit, energy and courage live on in the memories of the many people who knew her — Malca's inner, reflective soul residing forever in her calm, lyrical poems.