

1-1-2012

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Bradshaw, V. K., Witney, C. A., Green, L. R., & Costello, L. N. (2012). Embodying knowledge of breast cancer in a disembodied community?. *M/C Journal*, 15(4), n/a. Available [here](#)

This Journal Article is posted at Research Online.

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M/C Journal, Vol 15, No 4 (2012)

Embodying Knowledge of Breast Cancer in a Disembodied Community?

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Abstract

Introduction

Few life experiences have a greater impact upon the sense of self than the diagnosis of a life-challenging illness. Breast cancer is such an illness, and the sudden transition from 'well' to 'ill' is unsettling for a person's sense of knowing who they are in 'their' own body. What you know about your body, what others know about your body and what your biology knows about your body become suddenly problematic. This paper addresses what people know about their bodies before and after experiencing a breast cancer diagnosis by examining relevant theory and empirical data drawn from an online community for people with breast cancer, their families and supporters.

In the [Breast Cancer Click](#) (BCC) online community members are encouraged to blog their breast cancer journey, engage in discussion forums, use a private messaging function to talk in real-time with each other and a breast care nurse, and to participate in live group chat. The records of all these activities have been used in a netnographic study which aims to examine the efficacy of this mutual support community. In this paper we present some of the material which has been created in the community's activities to consider the embodied experience of breast cancer. Evidence from online community members is addressed to consider what a western cultural experience of breast cancer as captured by a disembodied online community can tell us about embodiment and embodied knowledge.

How Do We Know?

In 'Knowing and Being', Polanyi argues that knowing is related to two separate methods of investigation which nonetheless need to be integrated. On the one hand is the detailed knowledge of the particulars, and on the other the grasping of the big-picture conceptualization of the whole. "A medical student," he writes, "deepens his knowledge of a disease by learning a list of its symptoms with all their variations, but only clinical practice can teach him to integrate the clues observed on an individual patient to form a correct diagnosis of his illness, rather than an erroneous diagnosis which is often more plausible" (460). The implication here is that there is more at stake than a formulaic listing of symptoms. The 'knowing' relates to knowledge around the disease of breast cancer; the 'being' relates to the experience of being a breast cancer patient.

The necessary theory underpinning the identification of disease, the progress of symptoms and the side effects of treatment fails to capture the experience of the breast cancer patient, which is mutually recognisable among other patients even where superficial aspects of the disease manifestation diagnosis and progress may differ. Lekkie Hopkins writes of her immediate and bodily experience of hearing the diagnosis of her breast cancer:

Thwack! 'The good news is that you won't die of this. The bad news is that you will have to lose a breast'. Whoosh earthwards. Floor opens to swallow my life force. Body a shell. Head empty, uncomprehending. Within seconds, whoosh again, upwards this time. Blood rushes to head, face blooms red, eyes zoom onto the tiny points of calcification on the x-ray image, ears boom. Lose a breast, lose a breast, lose a breast ricochets off the walls. Kind eyes, gentle hands, steady voice: 'Can I call someone? Your partner?' Kind eyes, gentle hands, steady voice. Lose a breast, Lose a breast, Lose a breast (132).

Such embodied knowledge may not be recognisable within a medical/scientific context. Conflict can arise between a woman's embodied knowledge of her breast cancer and the medical/scientific understanding involved in her treatment (Thomas-McLean, *Memories of Treatment*). Perhaps surprisingly, the body can appear absent in medical discourse and alternative approaches are needed to provide an embodied perspective. Considering poet and feminist scholar Adrienne Rich's invitation to women to learn to think through the body, Lekkie Hopkins wondered "what it must mean to lose part of that body" (134). Thomas-McLean has noted that frameworks of health and illness can fail to capture the "complexities associated with living with an altered body" (*Beyond Dichotomies* 202). She promotes the idea that "women speaking for themselves, about their own experiences" is an important part of the repository of knowledge and understanding about breast cancer (*Memories of Treatment* 629). Our knowledge comes from our physical nature, our embodiment within our world and the meanings attached to the body within our social context.

An online community constructed using community networking technologies may seem an unlikely place for reclaiming the knowledge of the body. However, deep connection between members has been observed in online communities studied in detail (Bonniface et al.). The qualitative richness of complex experiences, missing from the medical discourse, can be found in such communities and constitute an alternative source of data to traditional interview methods. As mentioned, it is not an aim of this paper to address the efficacy of the Breast Cancer Click community, but to use some of the material which has been created in the community's activities to consider the embodied experience of breast cancer. In speaking for themselves in the Breast Cancer Click community, women reveal both their *knowing* and *being* as breast cancer survivors.

Online Support in a (Dis)embodied Community

The research question addressed in this paper is "What embodied knowledge about breast cancer can be shared in the disembodied realm of an online support community?" Women experiencing the betrayal of their bodies seek the authenticating experience of sharing their stories with others whose lives have embodied analogous experiences. [Breast Cancer Click](#) (BCC) was set up to provide a connection between breast cancer patients and their supporters with others who are currently undergoing treatment and those that have completed their treatments wishing to support others. This peer-to-peer support is expanded through interaction with an online Breast Care Nurse, providing education and information and unraveling the medical terminology and diagnosis with each specific patient, where requested.

Through personal messages, forum threads and group online chats regular contact is maintained with newly diagnosed members, those currently involved with treatment, and those considering reconstruction and other post-surgical options. It is through these active members' dialogue that we can appreciate the value provided by this disembodied communicative space. Using the principles of netnography (Kozinets), which applies ethnographic techniques to online communities and environments, the posts, chat, forum contributions and private messages (all de-identified) were archived to provide the raw data for this study. Transcripts were analysed to identify themes arising (Strauss & Corbin) and to select content which illustrates these themes and illuminates the experience of participants and the value or otherwise of the online community. Necessarily, with hundreds of thousands of words posted as part of the ongoing research project, only selected material is presented here. Three major areas of discussion are presented for this paper: development of a *new normal*, breast image and holistic health. We have not 'personalised' the contributions of Breast Cancer Click members, but have indicated verbatim quotes via the attribution to (BCC).

The 'New Normal'

I have silicone implants and swimming now feels VERY wierd. (BCC)

This statement is indicative of a range of language comparing the pre-diagnosis, or pre-cancer, body with the changed circumstances which embody the results of the cancer even while the medical model excises it. Insights and comments on the bodily experience arise in a range of circumstances such as: through the experience of hair loss following on from chemotherapy; questions about authenticity and reconstruction following surgery.

im expecting to shave my head as soon as i see hairloss.

i have already had my hair cut shorter to help my kids adjust etc.

i cut my hair short too before chemo so i get used to the idea havent shaved it yet though. (all BCC)

These comments indicate the intuitive use of simulation strategies as a means of adjusting to the anticipated response of the body to the experience of chemotherapy. This simulation strategy reintroduces a sense of agency for the BCC member, allowing them to feel as though they have chosen to change their appearance.

Sometimes the edge of the new normal can be softened by the experience of social and emotional solidarity conveyed through others embodying their support for the person with a breast cancer diagnosis:

oh when i lost my hair, my boss (at the time) was so lovely, and he shaved his head, and we had our pics taken together :).

Mine too- the school did greatest shave just as I lost my hair. Raised \$900. (Both BCC)

Although the experience of losing hair through chemotherapy is very different from that of being shaved, the embodiment of 'different' can serve to offer consolation and companionship for those who are embarking on a breast cancer journey. A return to the 'old normal' can be a cause for celebration, along with a recognition that the body continues to function as it had pre-cancer:

i remember the feeling when my hair was long enuf to dye back to blonde :) was fabulous when it got long enuf for a bit of a style instead of just fluff! (BCC)

Breast Image, Mastectomy and Reconstruction

Within the breast cancer community, the issue of reconstruction following mastectomy becomes a very personal one, whilst also, for some people, involving wider gender politics. Although it might seem this is an elaboration of the discussion around challenges to the concept of the 'pre-cancer self' and the new normal, women's breasts have such a range of associations in Western culture that it is hard to be objective about the new embodiment of the post-cancer self.

I had a lumpectomy but it's obvious size wise and I lost my nipple completely ... but I won't reconstruct or wear padding.

We all look great (scars are not so lovely) but with swimwear or a bra on we are all OK. I went from a small a cup to a c cup as the plastic surgeon suggested we 'may as well kick a goal as a point'. (Both BCC)

Sometimes the experience of the disease is such that the 'new normal' places the body into an anomalous category. There is an embodiment of strangeness which over-rides the conscious understanding about biology and function. The rational, knowledgeable, self can sometimes be seen to be in conflict with the experiential being of the post-treatment breast cancer patient. This was the case with a 29 year-old BCC member who successfully fell pregnant after her diagnosis. This exchange was via live chat between the breast care nurse (BCN) and the BCC member, so it sometimes reads in a disjointed way as the messengers respond to each other's posts in a semi-synchronous way.

Do you think you will breast-feed? (BCC Breast Care Nurse)

probably not. (BCC)

i feel weird about my boobs now. (BCC)

How do you mean? (BCC Breast Care Nurse)

like i'd make sure baby got first milk etc, and then bottle feed. (BCC)

oh umm its hard to describe, they don't feel like they are for that purpose anymore. (BCC)

i don't like the left one being touched much. (BCC)

Good plan - good for baby to have some breast milk. (BCC Breast Care Nurse)

No - I guess it feels odd - not normal? (BCC Breast Care Nurse)

As in this exchange, the online community operates to validate the experiences of its members, to offer support and understanding. The politics around breast feeding, as with those around a woman's physical appearance, mean that people with a diagnosis of breast cancer often perceive they are subject to a range of social 'shoulds' at a time when they are trying to re-learn (or to learn) an authentic sense of being in communication with, and being in communion with, their body.

Holistic Health

We went for a brisk walk around west-end with heart rate monitors on to check our pulse rates. It was great to do the exercise in a group situation. I am looking forward to getting in touch with my pre-diagnosis body again. I gently stretched my 'bad' arm which was OK.

I am very happy to say that my energy levels have already improved and have just been for a walk. My unused muscles are waking up and I feel excited now I realize it is possible for me to return to my pre-diagnosis fitness levels and activities. (Both BCC)

The physicality of the experience of cancer and its treatment can act as a spur to people who wish to reassert control over their bodies and bring their body back into a positive relationship with health and fitness. Sometimes this impetus can provoke an almost super-human response on the part of the person with breast cancer:

I had been attending Body Pump 2 or 3 times a week for 10 years prior to my diagnosis and made casual acquaintances with other regular attendees. [...] I returned to the classes myself while still on

chemo, I was having a weekly light dose for 3 months so felt OK. While my energy levels were a bit low I managed to do about 75% of the class with light weights and just stopped when I became tired. The instructor and other class members were so supportive. It helped me to feel like I was getting back to normal just being able to participate in the classes. (BCC)

On occasions, BCC members will post in a way that invites support from those who have developed successful strategies or responses to similar challenges. Here the mind is sometimes seen as determining the response of the body:

[I'm] finding it hard to get motivated enough to go out. This is made worse because I have put on lots of weight and am so unfit compared to my pre-cancer body. So doing exercise just isn't as much fun anymore. Hopefully it will get better. (BCC)

When a person with a breast cancer diagnosis seeks strategies to move beyond a place in which they feel stuck, it is often through harnessing a sensory image. The means of moving through a challenge, or towards an acceptable new normal, might be via the use of senses, simulation and experiential movement:

I feel like I'd like to have someone gently hold my hand and lead me to do all the cardio, exercises and stretching. Having been through so much I feel like being nurtured but instead I have to be strict and a bit tough to take steps to go forward. [...] Often I pop outside and if the sky is clear and it's not too cold I walk around the block. (BCC)

Communication and the Body

What is clear from these communications between members is that an experience of breast cancer can trigger particular responses associated with physical embodiment. Even as the person with a new diagnosis of breast cancer tries to rationalise the diagnosis, the treatment and the prognosis, so they are assaulted by a range of highly physical sensations, from feeling sick, to feeling crushed, to feeling as if even the certainties of gravity have been challenged by this embodiment of change (Walker, Plant, Hopkins).

For those working through their response, initial analysis of the data from the disembodied BCC community indicates that accommodating the post-cancer self often takes a physical form, an acceptance of the revised self and its engagement in sensory and simulated ways with the wider world. For example it is often aspects of the post-surgery body that BCC members use to highlight the possibility of a lighter, more humorous, response to the challenges of their experience:

haha XX [friend who has had a breast cancer diagnosis] and [I] still go to lift the boob when washing in the shower haha.

a friend of mine had [a] double reconstruction a few years back and needed 'replacement nipples' that were imported from the US - we all laughed when she announced they have arrived in the post for her! (Both BCC)

In terms of the research question, "What embodied knowledge about breast cancer can be shared in the disembodied realm of an online support community?", the data presented indicates that experience of the life-changing disease of breast cancer can trigger a new appreciation of the physicality of the human condition. This can be shared with others in a similar situation, seeking confirmation of shared experience. The disembodied community allows the member-self to move from the cognitive realm into an experiential one. It foregrounds the strangeness of the revised body through temporary but highly visible indicators, such as the loss of hair following chemotherapy, and permanent but less visible changes, such as the removal of a breast. It allows these changes to be recontextualised as the *new normal*, and provides a safe space in which to explore and imagine further responses to these embodied challenges such as whether to use a prosthesis, or to embark upon a reconstruction. The physically disembodied community of the BCC may constitute a lived space where the daily experience of breast cancer is addressed; "simultaneously part of bodily forms and their social constructions" (Moss and Dyck 49).

This initial analysis of BCC community posts indicates that one way through the maelstrom of diagnosis, treatment and living with an altered body is a renewed focus upon experiential data and the sensory life. Simulation is often used and described as a means of coming to terms with the new normal. Theoretical discussions around embodied knowledge, may yet prove to have practical outcomes by contributing to a composite and shared understanding of the disease and in supporting people whose lives have triggered a radical re-appraisal of what it is to be an embodied being.

Acknowledgements

The research project upon which this paper is based is funded jointly by Breast Cancer Care WA and the Australian Research Council with in-kind contributions from Edith Cowan University and utilizes a social network site linked to [Breast Cancer Care WA](#) and [Steel Blue's Purple Boot Brigade](#).

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