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Creativity in an Online Community as a Response to the Chaos of a Breast Cancer Diagnosis

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Abstract

Introduction

A catastrophe is often considered to be a final decisive event, resulting in a disastrous end. Two recent examples of catastrophes satisfying this definition were the 2012 super storm Sandy in the United States of America and the 2011 floods in Brisbane, Australia. The progress of these disasters was reported worldwide, yet coverage soon disappeared from the headlines, leaving people to deal with the aftermath of rebuilding homes, businesses and lives. The diagnosis of breast cancer is an individual's catastrophic event. While not on the community-wide scale of the disasters mentioned previously, it can have disastrous effects on the individual as well as their family and friends. At the moment 1 in 8 women can expect to have a breast cancer diagnosis. In Australia alone this means approximately 1,375,000 people are likely to receive this diagnosis in the course of their lifetime. This article addresses how breast cancer can and does prompt women and their supportive friends, families and partners to become more creative as a result of the breast cancer (BC) diagnosis.

In these cases, creativity—defined as doing something a little differently or thinking outside the square—can offer some remedy for catastrophe. Becoming totally involved in the creative moment, so as to lose all track of time and forget the trials and worries of BC, is referred to as flow. Flow is an "optimal experience" in which "people become so involved in what they are doing that the activity becomes spontaneous, almost automatic; they stop being aware of themselves as separate from the actions they are performing" (Csikszentmihalyi 53). This is one fruit of the creative process.

This article refers to women as having breast cancer because the majority of people diagnosed with BC are women. However it is acknowledged that men constitute 0.8% of the total number of people diagnosed with BC (Breast Cancer in Australia). Responding to public concern, a range of charities has been formed to support people with breast cancer. One such charity is Breast Cancer Care WA (BCCWA). Together with the Australian Research Council (ARC) and Edith Cowan University (ECU), BCCWA supports an online community for people with breast cancer, Breast Cancer Click (Click). The membership of Click includes several male Clickers who are partners and supporters of Click members with BC.

The Click online community consists of people with BC and their supporters, as well as health care practitioners and researchers. Those members with breast cancer are very interested in learning more about BC and supporting others in a similar situation whereas the health care practitioners and researchers are both supporting those with breast cancer and exploring the possibilities offered by online communities, to enhance their professional skills. Members of Click could be described as a community of practice, "groups of people informally bound together by shared expertise and passion for a joint enterprise" (Wenger and Snyder 139), in this case a passion for responding positively to a BC diagnosis. Wenger and Snyder go on to say: "People in communities of practice share their experiences and knowledge in free-flowing, creative ways that foster new approaches to problems" (140). The Click community helps foster creativity.

Many of the verbatim quotes used in this article are taken from the www.breastcancerclick.com.au (Click) website. Instead of identifying a speaker with a personal attribution the term "Clicker" is used, and then qualified as a Clicker with breast cancer (BC) to differentiate the author from a Clicker who supports someone with breast cancer (Supporter). The Click website provides every member with an opportunity to express themselves and they often respond creatively to the challenges that confront them.

The Chaos and Catastrophe of a Breast Cancer Diagnosis

When a woman is first diagnosed with breast cancer, it is often as a result of her bi-annual mammogram. She expects a routine visit but is advised instead that she requires further investigation because abnormalities have been detected. This is not what she expected. Probably all previous mammograms have been normal. The personal catastrophe occurs when the woman receives a definitive diagnosis of breast cancer. Chaos is added to catastrophe as the patient and her family struggle to grasp the meaning of the diagnosis and the multiplicity of treatment options. For some, the diagnosis is quickly followed by another catastrophic event, the removal of one or both breasts. For others the catastrophe occurs by increments. This is evident in a member's blog on the Click website,

More surgery [...] dammit!!!!!!! I just want this over NOW. The whole lot. I want my hair back, I want my working life back, I want the smile back on my man's face. I want ME back. I want to dance again. I want to have a conversation with friends that doesn't include my diagnosis or prognosis [...] short term, long term [...] any bloody term!!!! (Clicker BC)

People with a breast cancer diagnosis do not always have an endpoint in sight, or an acceptable endpoint at all, and the chaos of treatment and recovery is focused on coping with the present and the next treatment on the horizon. This Clicker uses her blog to help her deal with the next stage of a seemingly interminable round of surgical and chemotherapeutic procedures which have thrown herself, her family, her friends and her work life into chaos. Other Clickers immediately responded to her angst with messages of support and understanding. Had this clicker not written a blog, she would not have received this support and consequently she may have coped less successfully with her treatment. Given the chaos and catastrophe inherent in a breast cancer diagnosis, what else can individuals do that makes a positive difference to their lives as they deal with the "treatment, wait, check" cycle that is the medical response to breast cancer?

Creativity Arising from Chaos

When people receive a life threatening diagnosis such as breast cancer, they sometimes choose to think outside the square, to do things a little differently, to change the way they relate to others, to learn a new art or craft or to take up a musical instrument. Being creative seems to provide distraction from the treatment, and may be something to look forward to when the treatment is over. Some choose to participate in a formal creative therapy program, others seek out a creative pursuit which they can do at home. For some women with a breast cancer diagnosis, joining the Click website is itself a creative act. Contributing to an online community with a common interest in BC which gives them unconditional support, such as Click, also provides them with new skills and allows other people to benefit from their advice and experience:

Hi everyone. I know we all have different ways of dealing with our cancer. Mine has been to be more mindful of the wonders around me and savour every possible moment of joy. I have decided to start my own Blog to give myself a creative outlet and share my experiences. (Clicker BC)

There may be a number of reasons for participating in an online community of people with breast cancer and their supporters. Whatever the motivation, it requires a person to think laterally and learn new skills in how to navigate and post to a website. A newbie member enters a relationship with people she hasn't met. She can choose to create a new persona using an avatar, or simply devise a username which represents her online.

Creativity, Click and Flow

Susan Nesbit, an Associate Professor in the University of Manitoba's occupational therapy department, was diagnosed with BC in 2000. She used "everyday creativity to maintain a good attitude and positive spirits" and refers to Csikszentmihalyi's concept of "flow" to explain the gratifying experience which occurs when someone fully participates in an activity:

that I am doing it for its own sake, and when I become so involved [...] that I become spontaneous and almost automatic, I am experiencing flow. My energy flows smoothly, I feel relaxed, comfortable, energetic and totally absorbed, losing track of time. (Nesbit 63)

Richards (489) describes creativity as having two conditions: one is originality and the other is meaningfulness. She argues that everyday creativity "in the multitudinous activities of day-to-day life [...] has been conceptualised as a survival capability" (489). Click allows members to share this everyday creativity, inspiring a creative response in others. One Clicker (BC), who produces handmade cards at home, was inspired to hold a Skype card-making education session for rural and remote people (with and without BC).

Today is a day of craft for me. I held my first remote workshop [...] and it was a huge success. Just made a couple of Father's Day cards for a customer and decided to share some of my work with you all. I'd love you to take a peek at my album [...] doing what I love to do was and is my therapy to get me through each new crisis xxx. (Clicker BC)

It seems this Clicker first achieved flow through the act of making cards for her own pleasure and then maintained that flow through the planning and execution of an online card making class, which was a great success. She found something that helped her to take control of her life and to live more fully and at the same time gave others the opportunity to do the same. The success of this session might inspire this Clicker to conduct more sessions for others, while those attending the session who may be battling a serious illness, might also achieve flow through absorption in the card-making process, then maintain flow through the positive responses they receive from recipients of these cards. Ripples in this online creative space reach out towards a widening pool of card makers, assisting them to cope with chaotic occurrences.

Creative Therapy and Breast Cancer

Some women may choose to participate in formal creative therapy programmes such as art therapy to help them deal with their cancer treatment. In general more women than men with cancer choose to use this creative response to help them cope (Geue et al. 168). This intervention when used with breast cancer patients has been shown to enhance psychological well-being by decreasing negative emotional states and enhancing positive ones (Puig et al. 224). For example, music therapy with a group of BC patients waiting for a chemotherapy cycle appeared to directly reduce patients' anxiety and physiological arousal, while enhancing their sense of wellbeing and control (Bulfone et al. 241).

Blogging and Breast Cancer

The creative pursuit may already be part of woman's "normal" or pre-diagnosis life, or may be identified and pursued as a result of the diagnosis and used as informal therapy to keep the chaos at bay, for example through joining a support website and blogging. Orgad's research shows that when women write about their breast cancer story, "storytelling" online, it helps them cope with their disease. "The act of writing is seen as a crucial affirmation of living, a statement against fearfulness, invisibility and silence" (Lord qtd in. Orgad 67). The new ideas and direction for these women's creativity may also be used to vent their feelings and to gain perspective on their breast cancer journey, or the story may be written to help others facing a similar journey.

As evidenced by the collection of blogs at breastcancerblogs.org it seems a number of women find blogs offer a creative response to their breast cancer journey. The BC blogosphere is a vibrant record of resistance to the disease. Click members are encouraged to blog, and are given space on the site to do so, with full privacy if they choose. A study conducted by Chung and Kim (304) showed those cancer patients and their companions found blogging activity to be helpful in emotion management and for information sharing.

The Clickers are also encouraged to complete a SWEE in their blog. SWEE stands for "structured written emotional expression" where a person writes about their breast cancer journey for 10-15 minutes each day for three to five days in a row. The Clicker has the opportunity to creatively express their positive and negative feelings about their breast cancer diagnosis. Research shows that writing a SWEE can be good for both physical and emotional health (Pennebaker 540; Lieberman, Morton and Goldstein 859; Butcher and Buckwalter 114; Stanton et al. 4165; Low, Stanton and Danoff-Burg 187).

One Click member, the author of the [Paw Paw Salad](#) blog, received a top blog award from the [breastcancerblogs](http://breastcancerblogs.org) website. She writes about her life with breast cancer and the stress of not knowing when or if she will ever be free of the disease. She is positive, however, about the Tamoxifen tablet she must take for another five years or more. She tries to only let the word "cancer" briefly enter her mind, once a day, when she takes her pill and to carry on as normal the rest of the time. On returning home from a camping trip, which she also described in her blog, she noted that her cancer medication bottle was looking battered and dirty.

And for the first time, the sight of it made me smile. I've decided that this is just the way my Tamoxifen bottle *should* look. It's not a bottle to be kept pristine in a medicine cabinet—I want it to be tossed into suitcases, kept cold in dust-covered eskies, dropped on the floor in the morning flurry. I'm hoping that my daily reminder of cancer will, as often as possible, be washed down with camp-stove coffee. And I'm thinking that the last pill of each year's prescription demands a champagne and strawberry chaser (Paw Paw Salad).

This post demonstrates the blogger's ability to perceive and describe BC paraphernalia differently, and she uses this perspective to bolster her resilience in the face of the ongoing BC chaos in her life. Some Clickers express ambivalence towards taking Tamoxifen, a hormone based chemotherapeutic agent, because of its potentially deleterious side effects on their everyday sense of wellbeing. This blog entry may give them a new perspective on life, in spite of the possible side effects of the drug, and encourage them to celebrate the end of each year of taking the pill as one step towards being free of cancer. The fact that the writer can go camping while taking the Tamoxifen pill also demonstrates to others that life doesn't have to stop.

Memoirs

Some people with a BC diagnosis (non-Click members) have gone on to write what is affectionately called a "mammoir" a book which recounts their breast cancer journey or provides advice and information for those newly diagnosed with breast cancer. This is the term applied by Clickers even to established works of literature, such as Professor Brenda Walker's award-winning "mammoir," *Reading by Moonlight: How Books Saved a Life*. The book describes how Walker took refuge from the chaos of her breast cancer diagnosis in the books she'd always loved. Her experience of chaos prompted her to turn towards the creativity of others, which in turn triggered renewed creativity in the form of her memoir.

Conclusion

A diagnosis of breast cancer is for most women, a catastrophe. The newly diagnosed person is aware that this diagnosis may well be followed quite quickly by a mastectomy. Together with adjunct treatments, such as chemotherapy and/or radiotherapy, this causes chaos within the woman's life, family and friendship networks. Each woman and her supporters deal with the catastrophe and ensuing chaos in their own individual creative way.

Creative expressions include blogs, where women can tell their story; poetry, such as haikus and free verse; and simple venting of feelings about diagnosis and treatment. The SWEE technique seems to indicate that written engagement helps people cope with their diagnosis and illness. Attendance at art or music therapy sessions has been shown to be therapeutic and "mammoirs" have been written to help others to avoid the pitfalls of the health system or to deal with treatment and its side-effects.

Both informal and formal or organised creative therapy appears to have positive psychological effects on the woman with breast cancer. Whether each individual with BC achieved flow, as described by Csikszentmihalyi, is not known, but it appears from the Click community that many do use everyday creative acts to help them deal with the ongoing chaos of their diagnosis and treatment.

The Click was created to provide a blank canvas for those with breast cancer and their supporters to reach out to others in a similar situation. Through allowing people to respond creatively and to have those creative responses validated, this reaching out often also involves reaching in—and harnessing creativity.

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