Creativity in an online community as a response to the chaos of a breast cancer diagnosis

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Creative Arising from Chaos

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 her herself, her family, her friends and her work life into chaos. Other Clickers immediately responded to the diagnosis of breast cancer as a catastrophe to the patient and her family struggling 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)

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 which they can do at home, whereas the next treatment on the horizon. This Clicker uses the blog to help her deal with the next stage of a seemingly interminable round of surgical and chemotherapeutic procedures which have thrown her family, her friends and her work life into chaos. Other Clickers immediately responded to the diagnosis of breast cancer as a catastrophe to the patient and her family struggling 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,

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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 alter [...] 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 her 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 to widen a 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 well-being and control (Bulfone et al. 241).

Blogging and Breast Cancer

The creative pursuit may already be part of women's “normal” pre-diagnosis life, or may be identified and pursued as a result of the diagnosis and used as information to help them 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 gd 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 resilience 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 management and for information sharing.

One Click member, the author of the Paw Paw Salad blog, received a top blog award from the breastcancerblogs.org website. She writes about her life with breast cancer and the stories of not knowing when or if she will ever be free of the disease. She is positive, however, about the future. She women herself 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.

Mammoirs

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 “mammor,” 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’s 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.

References


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