Discourses and experiences of cancer survivorship

The population of patients living with, or recovered from, cancer is increasing. In North America, they are commonly designated as *cancer survivors*. Cancer survivor, however, is not only a label. It was claimed as a new status, in contrast to *cancer victims*, by what was initially a grassroots movement in the early 1980s (Mullan, 1985). It has now become institutionalized in North America, with public and private agencies, scientific conferences, and medical journals, all dedicated to the physical and psychosocial issues facing cancer survivors (Bell & Ristovski-Slijepcevic, 2013; Institute of Medicine and National Research Council, 2006).

The redefinition of cancer victims as cancer survivors is linked to a wider discursive shift characterized by a more positive, optimistic attitude to the experience of cancer. In the survivorship framework, the patient is portrayed as an active, empowered participant in the fight against disease. Treatment is a battlefield and the survivor is celebrated as the triumphant, heroic victor. Most strikingly, cancer is presented as a “makeover opportunity” (Ehrenreich, 2001). In “countless personal stories of self-improvement” (Segal, 2010), the survivor is a hero transformed by the experience, growing stronger and wiser (Segal, 2008; Stacey, 1997). A telling example is Lance Armstrong, who was cured of a testicular cancer, then went on to win the Tour de France, and wrote in his autobiography (2006): “I prefer the title of cancer winner to that of Tour winner, because of all that this experience has brought me as a human being, as a man, husband, son, father.”

Such a dominant discourse has an impact on patients (Bell, 2012; Sinding & Gray, 2005), who live in a social world with explicit and implicit norms and expectations regarding their experience of and attitude toward cancer. As Segal (2010) wrote in a provocative editorial entitled *Cancer isn’t the best thing that ever happened to me*: “If, as a person with cancer, you violate the code of optimism, or if cancer somehow failed to improve you, you’d better be quiet.” Research has also shown that, while some patients are keen to embrace the survivor identity, many others resist the label (Kaiser, 2008; Rees, 2018).

The terms cancer *survivor* and *survivorship* are also becoming more common in Europe (Reuben, 2004). However, terms, concepts, and discourses may change as they cross an ocean and their impact may vary in different cultural contexts. In order to investigate the hypothesis that they may find alternative expressions in Europe, we conducted an exploratory study of cancer experience in French-speaking Switzerland. We recruited 13 women in sustained remission (5-10 years) from breast cancer. We conducted two focus groups (6 or 7 participants), in which we discussed materials selected to illustrate the three core aspects of the survivorship discourse: 1) encouraging a positive, active attitude in patients; 2) celebrating the patient as a heroic victor; 3) envisioning cancer as an opportunity of self-improvement. Our participants identified this discourse as distinctly American, with a ‘just do it’ flavor, and rather alien to their own experiences, which they mostly described as traumatic, characterized by silent and painful isolation.

Silent experiences, hidden trauma

Cancer is commonly considered an existential disruption (Hubbard & Forbat, 2012). Our participants described the moment of diagnosis and the following months of treatment as a traumatic experience, characterized by intense emotions but also a sense of detachment. Such detachment is similar to the dissociative state typical of acute stress reaction (American Psychiatric Association, 2013): they were living "in a stand-by mode," "in a bubble," and "without really touching the ground." They said they experienced, in this initial phase, a "loss of control" over their lives, being "unable to do anything, only being ill," surrendering to the health care "machine" and its "whirlwind of treatments."

The physical and psychosocial impact of cancer extends well beyond the acute phase. The prior trauma and future prognostic uncertainty induce a sense of existential vulnerability that can at times challenge or even disrupt one's self-identity (Smit, Coetzee, Roomaney, Bradshaw, & Swartz, 2019). Our participants described their intense efforts to try to forget, move on, and reclaim a normal life; however, they also insisted that "they were not the same persons before and after cancer." This change in their sense of identity was experienced as an existential wound, very far from the self-improvement highlighted in the survivorship framework.

In the stories of our participants, the initial, traumatic existential breach required an immediate, protective reaction of dissociation and repression, in great part because of the demands of treatment. Unearthing and sharing these experiences with other participants was painfully intense, revealing thereby a deep and still fresh wound, a trauma that had remained mostly unarticulated. The participants did not speak about their experience, for complex, and in part contradictory, reasons. First, silence is intrinsically linked to their defensive urge to try to forget and move on. Moreover, they feared to be "a burden" for their relatives. They also dreaded evoking feelings of "pity" or "embarrassment." This sense of being compelled to silence seems related to a criticism of 'complainers' grounded in an individual and collective ethos of stoicism. Finally, they remained silent because they believed that no one could understand them. They feared being hurt by insensitive, "clumsy," and "incoherent and stupid" comments. In the groups, participants were sometimes vehement about people claiming to understand the experience of patienthood without having actually suffered from breast cancer:

> *To know someone who has had cancer doesn't give these people the right to talk as if they had lived this experience in the first person … Everyone thinks they know exactly what we have been through … but, I mean, they don't know anything … you don't know, shut up!*

The pain expressed here is one of radical isolation, echoing Arthur Frank's statement (1995) that those who are ill are "wounded not just in body but in voice."

Virtues of the collective

This sense of isolation was also perceptible in the relief participants found in telling their stories within the group. They expressed a deep surprise that they were in fact able to speak about their experiences, sharing their thoughts, fears and emotions with their peers. They reflected that giving room to the experience might be more helpful than desperate attempts to forget and move on. At the end of the study, the participants insisted on an additional meeting to discuss the possibility of creating a continuing support group stemming from the focus groups. Their project, however, has not been realized to this day. It is also notable that, in our region, a number of programs for cancer patients include some form of group support, but most of the participants had not found their way to them. In other words, our participants, like many patients, seemed ambivalent about the prospect of sharing their experiences. Repression is likely one major reason at play here.

North American critics have argued that some stories remain untold because “people don’t want to listen about the most horrible fears of cancer patients” (Segal, 2010). The hero narrative has thus become “the preferred paradigm for understanding the experience of breast cancer” (Goldenberg, 2010). Our participants’ stories were untold stories, and indeed stories of horrible fears, enduring tragedies and non-heroic journeys through the experience of cancer. However, they were not silenced by some dominant survivorship discourse. These women remained silent because they believed no one was able, or even willing, to understand their pain.

The survivorship discourse has been justifiably criticized as coercive. Nevertheless, it invites patients to speak up and tell their stories. Even though such testimonies are expected to adhere to a “positive” frame, there is a degree of freedom offered here, an invitation to share and to break the radical isolation experienced by our participants. The survivorship movement has been true to its commitment to “break the silence” (Lorde, 1980). By contrast, rather than being compelled to speak up, our participants felt condemned to silence. Yet, they eagerly seized the opportunity to engage in a collective, narrative work with their peers. This was actually a serendipitous effect of our research project. Our findings, clinical wisdom, and even common sense suggest that patients need to find someone willing to listen to their stories without attempting to shape them according to a pre-existing framework of optimism and positivity. Under the appropriate circumstances, support groups can offer such an opportunity; our participants insisted only their peers could understand them. However, stories can be shared, to a significant extent, even between people with differing experiences. In this regard, it may be worth reminding that clinical practice is about helping patients in their singular predicament. Therefore, we believe that clinicians, if they are willing to engage authentically with their patients’ painful experiences, can offer relief to the terrible isolation.

References

American Psychiatric Association. (2013). *Diagnostic and Statistical Manual of Mental Disorders* (Fifth Edition). Arlington: American Psychiatric Publishing.

Armstrong L. (2006). It’s not about the bike: My journey back to life. New York: Berkley Books.

Bell, K. (2012). Remaking the self: Trauma, teachable moments, and the biopolitics of cancer survivorship. *Culture, Medicine, and Psychiatry*, *36*, 584–600. https://doi.org/10.1007/s11013-012-9276-9

Bell, K., & Ristovski-Slijepcevic, S. (2013). Cancer survivorship: Why labels matter. *Journal of Clinical Oncology*, *31*), 409–411. https://doi.org/10.1200/JCO.2012.43.5891

Ehrenreich, B. (2001). Welcome to cancerland: A mammogram leads to a cult of pink kitsch. *Harper’s Magazine*, November issue, 43–53.

Frank, A. W. (1995). *The wounded storyteller: Body, illness, and ethics*. Chicago : University of Chicago Press.

Goldenberg, M. (2010). Working for the cure: Challenging pink ribbon activism. In R. Harris, N. Wathen, & S. Wyatt (Eds.), *Configuring health consumers: Health work and the imperative of personal responsibility* (pp. 140–159). Houndmills, Basingstoke, Hampshire ; New York : Palgrave Macmillan.

Hubbard, G., & Forbat, L. (2012). Cancer as biographical disruption: Constructions of living with cancer. *Supportive Care in Cancer*, *20*, 2033–2040. https://doi.org/10.1007/s00520-011-1311-9

Institute of Medicine and National Research Council. (2006). *From cancer patient to cancer survivor: Lost in transition*. Washington, DC: The National Academies Press.

Kaiser, K. (2008). The meaning of the survivor identity for women with breast cancer. *Social Science & Medicine*, *67*, 79–87. https://doi.org/10.1016/j.socscimed.2008.03.036

Lorde, A. (1980). *The cancer journals*. San Francisco: Aunt Lute Books.

Mullan, F. (1985). Seasons of survival: Reflections of a physician with cancer. *New England Journal of Medicine*, *313*, 270–273. https://doi.org/10.1056/NEJM198507253130421

Rees, S. (2018). A qualitative exploration of the meaning of the term “survivor” to young women living with a history of breast cancer. *European Journal of Cancer Care*, *27*, e12847. https://doi.org/10.1111/ecc.12847

Reuben, S. (2004). *Living beyond cancer: A European dialogue*. Bethesda: Department of Health and Human Services, NIH, NCI.

Segal, J. Z. (2008). Breast cancer narratives as public rhetoric: Genre Itself and the maintenance of ignorance. *Linguistics and the Human Science**s**, 3*, 3–23. https://doi.org/10.1558/lhs.v3i1.3

Segal, J. Z. (2010). Cancer isn’t the best thing ever happened to me. *Vancouver Sun*, April 1. Retrieved from https://www.pressreader.com/canada/vancouver-sun/20100401/281805690115355

Sinding, C., & Gray, R. (2005). Active aging—spunky survivorship? Discourses and experiences of the years beyond breast cancer. *Journal of Aging Studies*, *19*, 147–161. https://doi.org/10.1016/j.jaging.2004.05.001

Smit, A., Coetzee, B. J., Roomaney, R., Bradshaw, M., & Swartz, L. (2019). Women’s stories of living with breast cancer: A systematic review and meta-synthesis of qualitative evidence. *Social Science & Medicine*, *222*, 231–245. https://doi.org/10.1016/j.socscimed.2019.01.020

Stacey, J. (1997). *Teratologies: A cultural study of cancer*. London ; New York: Routledge.