The Imperative of Happiness for Women Living with Breast Cancer

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Les discours publics et privés façonnent la manière dont les femmes font l'expérience du cancer du sein y compris leurs façons d'appréhender les pensées négatives et de comprendre la maladie. Le discours biomédical dominant présente les sentiments dépressifs comme une maladie grave qui a besoin d'être traitée médicalement. A l'inverse, le discours "existentiel" reconnaît les pensées négatives comme un processus normal et les considère même nécessaires à la traversée de l'épreuve du cancer et au développement personnel. La médicalisation de la douleur et la prominence de la pensée positive comme norme sociale peuvent ôter du pouvoir aux femmes et prévenir la planification d'interventions cohérentes au niveau des sphères sociale, culturelle et communautaire.

"I think you are depressed. It's understandable as 50 percent of women with breast cancer may become depressed." Many Australian women who have breast cancer may be given this diagnosis when consulting their general practitioner or a psychiatrist. In the dominant expert biomedical and psychological discourses, sadness and depressive feelings have been conceptualised as a mental illness that should be diagnosed early and treated.

Everybody would agree that great attention needs to be paid to the emotional well-being of women with breast cancer. However, there are different and conflicting discourses on how to interpret and deal with the emotional experiences of living with breast cancer.

The biomedical framework views illness mainly as a biological disease that needs to be identified and treated. Interpreting emotional experiences as mental illness is a relatively recent phenomenon. In their book, *The Loss of Sadness: How Psychiatry Transformed Normal Sorrow into Depressive Disorder*, Allan Horwitz and Jerome Wakefield argue that, with the exception of bereavement, the Diagnostic and Statistical Manual of Mental Disorders (DSM) recognised no contextual events that might qualify the depressive syndrome as a normal response to serious life events. Moreover, the growing biomedical literature focusing on the links between depression, disease progression and cancer recurrence, reinforces the notion that depression is fundamentally biological (Spiegel and Giese-Davis; Clarke and Gawley). Cancer has been conceptualised as a factor increasing the risk of clinical depression, with depression in turn leading to poorer cancer outcomes. A patient information document published by the U.S. National Institute of Mental Health describes depression in people with cancer as the result of "abnormal functioning of the brain" and warns that people may "misinterpret depression's warning signs, mistaking them for inevitable accompaniments to cancer" (National Institute of Mental Health). In Australia, the psychosocial clinical practice guidelines for women with breast cancer published by the National Health and Medical Research Council recognises a degree of anxiety and depression as normal but emphasizes that a large proportion of women with cancer will develop a depressive disorder that can interfere with their sleep, diet, relationships, and ability to work and that ultimately can compromise the success of cancer treatment (National Health and Medical Research Council; The Health Report). The Beyondblue fact sheet on "Depression and Breast Cancer" states that "depression is more than just a low mood, it is a serious illness" and that "up to 50 per cent of women with early breast cancer may experience depression and/or anxiety in the year after diagnosis." Identifying and treating depression is a major target of the Australian mental health policy (Commonwealth Department of Health and Aged Care). Health professionals are urged to take action and to identify and treat people with cancer who are at risk of depression. Treatment of depression increasingly involves the use of pharmacological treatment with antidepressant drugs. Biomedical explanations of depression are fully supported by pharmaceutical companies through the promotion of antidepressant drugs to health professionals and consumers. Prescriptions for antidepressants in Australia increased almost fivefold between 1990 and 2002 (Mant et al.). In 2006, government expenditure on antidepressants was more than 476 million Australian dollars (Australian Government and Department of Health and Ageing).

In parallel with the biomedical discourse on depression, there is an abundant psycho-oncology literature on coping with cancer which claims that positive thinking is related to a better health status and better chances of recovery (Wilkinson; McGrath, Jordens, Montgomery and Kerrige), and may boost the immune system to fight cancer (Ehrenreich 2009). In the breast cancer culture, cheerfulness has become mandatory (Ehrenreich 2001). "Positive" narratives of patients are chosen over "negative" experiences to inform patients (Swift and Dieppe).

Other discourses are being used to describe the feelings experienced by people living with cancer. In his work on the illness narratives of people living with cancer, Arthur Frank argues that illness such as cancer is not a disease but an essential part of the human experience which needs to be lived fully to become meaningful (1991, 1995, 2004). He says that "we fail to console ourselves with the recognition that illness may be necessary to realize all we can become as humans" (Frank 2004: 9). He wants to emphasize mourning as an affirmation rather than a state of mind which should be "treated" quickly and stated that "to adjust too rapidly is to treat the loss as simply as an incident from which one can bounce back, it devalues whom or what has been lost" and considers that even fairly deep depression must be accepted as the experience of illness (Frank 2002: 40). In Australia Miles Little et al. stressed that insights into the nature of the subjective experiences of people with cancer could be gained from the existentialist philosophers and from the history of attitudes to death. Catherine McGrath argues that positive thinking may have adverse consequences as it could lead to a sense of failure and guilt if things go not well (McGrath et al.). In the United States, Barbara Ehrenreich demonstrated that there was no valid evidence linking positive thinking and cancer recovery. She wondered if the repression of understandable feelings of anger and fear was itself harmful and "weigh on a cancer patient like a second disease" (2009: 43).

There is a sharp contrast between the biomedical discourse on the psychological effects of breast cancer and the "existential" discourse that would acknowledge negative feelings as a "normal" and even needed process in the cancer journey. The limitations of the biomedical framework were first shown by Ivan Illich, 50 years ago (1976). His argument is in some ways simple. Death, pain, and sickness are part of being human. Irvin Yalom argues that confronting death need not result in despair that strips away all purpose in life and that it can be an awakening experience to a fuller life. All cultures have developed means to help people cope with all three. Modern medicine has unfortunately destroyed these cultural and individual capacities, launching instead a biological approach to defeat death, pain, and sickness. More recently, Nikolas Rose argues that doctors and psychotherapists are now positioned as experts on people's subjective experiences who reduce existential questions about the meaning of life and illness to technical questions about the most effective ways of coping or managing one's emotional life and malfunction (Rose).

Women are encouraged to express their feelings, but only in a certain way: cheerfulness is required and dissent a kind of treason. Confronting mortality and painful feelings is not on the agenda even if empathy for women with breast cancer has become the norm.

Public and private discourses shape the manners in which women experience breast cancer, including their strategies for coping with negative feelings and making sense of breast cancer illness (Stoppard). A study of the media portrayal of depression in high circulating magazines in Canada and the U.S. from 1980 to 2005 showed a trend over time towards a reductionistic and bio-medicalized notion of depression (Clarke and Gawley). In their analysis of print media articles on depression in Australia, Rob Rowe et al. showed how three key discourses—the biomedical, the psycho-social and the administrative/managerial—worked together "to produce unhappiness as individualised pathology in need of management through biological, psychological or social structural controls" (680). Discourses influence the cancer patients' experiences, with cancer patients knowing they must tell everyone they are "thinking positive" even if they do not feel that way and are not sure what "thinking positive" means (Wilkinson and Kitzinger). With the "expert" advice of health professionals, women are often guided to think about their emotional distress in pharmacological and psychotherapeutic terms. Patients presenting at medical surgeries know that "there is an illness called depression, that it seems widespread, and that doctors are there to treat it" (Shaw and Kauppinen 131). In 1994, in her famous book *Patient No More: The Politics of Breast Cancer*, Sharon Batt hoped that the increasing participation of women with breast cancer in the public sphere would mean that their private grief would be acknowledged. She wrote "Can a woman truly confront her mortality when her lipstick is just right?"(312). Fifteen years later, women are encouraged to express their feelings, but only in a certain way: cheerfulness is required and dissent a kind of treason (Ehrenreich 2009). Confronting mortality and painful feelings is not on the agenda even if empathy for women with breast cancer has become the norm.

Discourses are used in a dialectic way. Women with breast cancer may find the medicalization of breast cancer to be problematic, but may also be reluctant to leave the realm of acute care (Thomas-MacLean). The medicalization of their feelings may allow them to gain moral sympathy and recognition (Shaw). Investigation of cultural models of illness and recovery in breast cancer support groups showed evidence of a shared model of breast cancer and recovery, but also that certain aspects of this model, in particular the importance of maintaining a positive attitude and "fighting spirit" were contested among members (Coreil, Wilke and Pintado). In a discourse analysis of breast cancer self-help groups, Linda Bayers showed that survivors faced a major challenge to cope with dominant discourses and to affirm themselves as authoritative and legitimate "knowers." The current proliferation of personal accounts of grief may represent an attempt by patients to recover their voice in the face of the medicalization of grief (Walter).

"There is no cure for being alive," says one of the heroes of Salley Vickers' last novel (20). This is not to say that emotional feelings of women living with breast cancer should not be properly acknowledged. However, it can be argued that the medicalization of human suffering and the promotion of positive thinking as the moral normality may disempower women and ignore the individual personal growth through the facing of life challenges. A focus on individual treatments may impair the planning of coherent interventions that take into account the broader social, cultural and community context. We need to switch the current paradigm from representing depressive feelings mainly as a medical illness to a broader existential understanding of sadness and unhappiness in the face of life events in our communities. Barbara Ehrenreich (2009) relates the positive thinking dogma in the breast cancer world to the prominent cult of positive thinking in the United States. She argues that the American infatuation with positive thinking had not made American people happier but that the refusal to consider negative outcomes obscures judgment and may have contributed to major failures such as the recent economic disaster. She advises to confront problems openly and defends a vigilant realism and "critical thinking" rather than "positive thinking" as the best ways forward. Questioning social norms on how women should experience breast cancer and fighting the medicalization of normal human emotions remain ongoing challenges for women living with breast cancer.

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Red Taffeta

The dress I didn't wear to your wedding,
a red taffeta frock
the cranberry red I didn't buy:
it was not practical.

My sister would know how to dress:
silk taffeta strapless gown,
posing beside her husband.

She knows how to be feminine:
she always got the boyfriends,

she knows.

I was molested by my fourth grade teacher.
I would know how to be a woman
at nine, at ten.
A girl in a black and white school photo:
I would be beautiful,
I know

I would not have this secret:

I want to be my sister.

Silk taffeta strapless gown,
posing beside her husband.
Erna's surgery scars,
cancer-free,
fifteen years on.

Ilona Martonf's first book of poems, Blue Poppy*, was published in 2009 (Coracle Press) and her chapbook,* Visiting the Ridge *in 2004 (Coracle). Martonfi's poems have appeared in* Vallum, Carte Blanche, The Fiddlehead, Poetry Quebec, Serai, Poets Against War. *Poet, activist, teacher, editor; Founder/Producer/Host of* The Yellow Door and Visual Arts Centre Readings; *co-founder* Lovers and Others.