

# Rethinking assumptions about cancer survivorship

by Svetlana Ristovski-Slijepcevic and Kirsten Bell

## Abstract

*A growing body of research informed by theories and methods in the social sciences and humanities indicates that certain problematic messages are commonly embedded in popular and oncological representations of cancer. Becoming more aware of these underlying messages has the potential to improve the ways clinicians think about and manage cancer. (Note: A written response to this article appears in Truant, Kohli, & Stephens (2014), Response to "Rethinking Assumptions about Cancer Survivorship": A Nursing Disciplinary Perspective, Canadian Oncology Nursing Journal, Vol. 24, Issue 3, p. 169)*

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## Introduction

For much of the twentieth century, the diagnosis of cancer was effectively a "death sentence". However, during the last 30 years cancer has been transformed from a largely fatal disease to one in which the majority of those diagnosed receive treatments that result in long-term, disease-free survivorship (Ganz, 2007). This improvement in survival rates has been accompanied by a shift in focus from cancer *victims* to cancer *survivors*.

Although the "cancer survivor" label has today become widely used, the term itself is relatively recent, and is generally attributed to Fitzhugh Mullan. In an influential commentary published in the *New England Journal of Medicine* in 1985 (Mullan, 1985), Mullan, who was both a physician and cancer survivor, argued against the dominant view that there were two different paths for people diagnosed with cancer: either death or cure. Instead, he suggested that there was one path for people diagnosed with cancer, the path of survival, dominated by dealing with the physical, psychological, and social effects of diagnosis and treatment.

Mullan's landmark piece had a snowball effect, as his call for a consumer network led to the creation of the National Coalition of Cancer Survivorship in 1986, which, in turn, was instrumental in the development of an Office of Cancer Survivorship within the National Cancer Institute a decade later (Rowland, 2007). This move served to dramatically increase the profile of cancer survivorship and the allocation of earmarked research funding, which increased exponentially from \$2 million in 1998 to \$22 million in 2004 (Geiger, Strom, Demark-Wahnefried, & Buist, 2008). The growing body of research on cancer survivorship culminated in the publication of

*From Cancer Patient to Cancer Survivor: Lost in Transition* in 2006 (IMNRC, 2006), a comprehensive report that highlighted the ongoing issues cancer survivors face post treatment and the need to develop better models of care to respond to their distinctive needs.

Today, the topic of cancer survivorship features prominently in oncology journals in all of the major subfields (oncology nursing, clinical oncology, psychosocial oncology, etc.), and is a key focus of dedicated research, conferences, and even a specialist journal. Although there is ongoing concern about its lack of conceptual clarity (Farmer & Smith, 2002; Khan, Rose, & Evans, 2012), for the most part "survivorship" has become a standard way of talking about the experience of life after cancer treatment in the oncological literature.

The growing prominence of cancer survivorship within the oncology community has been echoed in increased popular attention to the topic, with celebrity survivors featuring prominently in the media, and films and television shows poignantly highlighting the experience of life with—and after—cancer (e.g., *The Big C*, *The Bucket List*, *One Week, 50/50*, etc.). The entry of corporate sponsors has also served to dramatically increase the profile of cancer. Today, it is virtually impossible to go shopping without bumping into "pink" products—product lines where a small portion of the proceeds go to breast cancer research. Thus, if cancer was a disease that was unspeakable a few decades ago, so feared it was discussed only through euphemism, today it has officially come out of the closet and into mainstream culture.

However, amidst these varied oncological and popular representations of cancer survivorship, a growing number of voices can be heard speaking out against mainstream conceptions of life with and beyond cancer. Mostly cancer "survivors" themselves, critics have railed against the relentlessly upbeat tone of representations of cancer survivorship (Ehrenreich, 2001; Segal, 2010). As the documentary *Pink Ribbons, Inc.* (Pool, 2011) attests, concerns have also been raised about the corporatization and "pinkification" of breast cancer, and its impact on research and practice. Although these concerns might appear to be very far removed from the day-to-day work of oncology professionals, the broader critique of current conceptualizations of cancer survivorship they entail *also* implicates the oncology community—at times via both personal and professional experience (Astrow, 2012). As Delvecchio Good et al. (1990) note, "A nation's practice of oncology is shaped not only by medical technology and therapeutics, but by local popular and medical cultures as well" (p. 55–56).

Attentive to the social context of cancer and its complex cultural meanings, a growing number of social scientists and humanities scholars are conducting research into the disease, along with nursing scholars influenced by social science theories and methods. Yet, for the most part, the oncology community remains unaware of this literature, much of which is published in books and journals that are not cited in the standard health sciences indexes. We therefore seek to offer oncology care professionals some thoughts about the sorts of messages that might be unintentionally conveyed to patients, drawing on insights from scholarship informed by social science and humanities perspectives.

## What messages might care professionals be unintentionally conveying?

### Getting cancer is a choice

Evident within the oncological literature is a growing focus on lifestyle in relation to both secondary and tertiary cancer prevention. In this literature, lifestyle factors such as diet, weight, and

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physical activity are seen to have a key role to play in preventing cancer and disease recurrence. To date, this research is still in its infancy, and the evidence regarding the impact of lifestyle modification on cancer survivorship is much clearer for treatment-related morbidities than cancer-related mortality (Demark-Wahnefried, Pinto, & Gritz, 2006). However, despite the inadequacies in the evidence base, there is a tendency to oversell the role of lifestyle in tertiary prevention (Bell, 2010).

While encouraging cancer survivors to improve their diet, physical activity levels and weight might seem beneficial to promote regardless of the state of the evidence base, without care to attenuate these messages, cancer all too readily becomes framed as a choice. In other words, it is seen to be a disease that can be prevented if people make the 'right' choices in terms of their lifestyle, i.e. their diet, weight and level of physical activity. Social science research suggests that cancer survivors are often well aware of these lifestyle messages and may feel implicitly blamed for their cancer (Bell, 2010). Evidence also suggests they may experience a need for vigilance around lifestyle (Sinding & Gray, 2005), and a sense of blame and self-recrimination in the context of a recurrence (Bell, 2010).

### Surviving cancer is an accomplishment

Scholars have long pointed out the emphasis on the 'heroic cancer patient' in popular representations of cancer (Doan & Gray, 1992; Bell & Ristovski-Slijepcevic, 2013). However, traces of this emphasis on the role of optimism and a fighting attitude in cancer survival can also be found in the various subfields of oncology (Delvecchio Good et al., 1990; Doan & Gray, 1992). Indeed, the very terminology we use—e.g., the term 'survivor' itself—is part of the problem. This label, which has been around for centuries, has picked up various connotations over time. For example, with the rise of social Darwinism, 'survival' gained connotations of fitness, competitiveness and superiority (Bell & Ristovski-Slijepcevic, 2013). Since the 1970s, a survivor has been understood to be a person who exists despite adversity, one who continues to live after, or one who is always able to come through, last and persist (Bell & Ristovski-Slijepcevic, 2013).

As a result of these larger meanings, the term 'survivor' itself is loaded—something those so labelled are often well aware of. As Ehrenreich (2001) observes, "once the treatments are over, one achieves the status of 'survivor'... the mindless triumphalism of 'survivorhood' denigrates the dead and the dying" (p. 48). Moreover, by situating cancer in the past (as something 'survived'), the term tends to obscure the ongoing presence of cancer in many so-called survivors' lives. It also makes invisible the experiences of people with metastatic disease, many of whom are living for longer periods with cancer, as a chronic but essentially controlled disease. They have not 'beaten cancer' or 'survived it' in the sense of being declared disease-free, but nor are they terminal.

### Cancer makes you a better person

In recent years, the field of psychosocial oncology has witnessed a great deal of interest in concepts like 'benefit finding' and 'post-traumatic growth', which suggest that trauma may lead to "a greater appreciation of life and changed sense of priorities; warmer, more intimate relationships with others; a greater sense of personal strength; recognition of new possibilities or paths for one's life; and spiritual development" (Tedeschi & Calhoun, 2004, p. 6). Although intended as *descriptions* of the potentially positive changes wrought by cancer, there is a danger that such concepts can become *prescriptive*—a state to which all survivors are expected to aspire (Bell, 2012; Segal, 2010; Segal, 2012). This is evident in some of the language used to talk about post-traumatic growth, where it is framed as a 'healthy' response to cancer, implying that other responses are less than healthy (Bell, 2012).

As Segal (2010) observes, this dominant cancer narrative of the 'new and improved' cancer survivor has a certain coercive potential. In her words, "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." Social science research with survivors affirms the coercive dimensions of these narratives—with participants highlighting the pressure they experience to maintain a positive demeanor and disguise the ongoing effects of cancer (Sinding & Gray, 2005; Kaiser, 2008; Segal, 2012). While cancer often engenders transformation, these transformations are diverse. This has led some to suggest that post-traumatic transformation may be a more appropriate term than ones focusing on either stress or growth (Kahana, Kahana, Deimling, Sterns, & VanGunten, 2011).

### Life with and after cancer is a narrow set of experiences

During the past few decades, 'quality of life' has emerged as an increasingly important concept in the cancer community (Velikova, Stark, & Selby, 1999; Ashing-Giwa, 2005) where it is seen as "the ultimate goal of oncology practice" (Ferrell, 2008, p. 231). However, the way quality of life is defined and measured offers only a limited framework through which life can be described and experienced. Quality of life—what it is and what it means to people—is an extraordinarily complex phenomenon. Any simple conversation with a person with cancer illustrates its fluid and multifaceted nature, defying current attempts at quantification and measurement (Gasper, 2010).

Therefore, it is debatable whether quality-of-life assessments aid in providing a better understanding of the experiences of people who have lived through cancer; instead, they may be limiting the expression of experiences by forcing them to "deal with a model of health and illness that is the product of the medical point of view" (Apolone, 1998, p. 431; Skinner, 2012). As Astrow (2012), a medical oncologist, put it "[o]ur medical care system has the best of intentions, but may hold a narrow view of what constitutes a meaningful life" (p. 1640).

## Implications for clinical practice and research

We highlight the above-mentioned thoughts not only to raise awareness of the different connotations of cancer survivorship outside the oncology field, but also to emphasize the need for deeper reflection on the ways in which clinical practices may serve to inadvertently perpetuate some of these more insidious messages about cancer survivorship. This may be a time ripe for a cultural shift in the public cancer discourse and medical practice (Surbone, Annunziata, Santoro, Tirelli, & Tralongo, 2013).

Social scientists have taught us that language and terminology are not neutral and descriptive, but actively construct the ways we think about phenomena. Unfortunately, here our terminology works against us. As many observers have noted, oncological language is pervaded by metaphors of war and battle—it is virtually impossible to talk about cancer in a non-metaphorical fashion. While we are not advocating an attempt to de-metaphorize cancer (an impossible task given the metaphoric nature of human thought), being more aware of the language and terminologies we use and their potential for alienating those we interact with is a good place to start. How do we talk about cancer with patients and their families in routine daily practice regarding their expectations of care and what is to happen? What outcomes do we project as important to achieve? How do we suggest they continue living the rest of their lives?

It is also important to consider the language and messages used in patient education materials and support services, along with marketing and fundraising campaigns, which are often particularly guilty of reinforcing insidious messages about cancer. As specialist clinics and programs for people with a history of cancer emerge

(as they have already begun to across North America), attention also needs to be paid to how such programs are labelled. Survivor clinics? Wellness clinics? Transition clinics? The labels used are likely to have a substantial impact on who attends the programs, why, and what expectations are placed on those attendees.

Close consideration should be given to the expected outcomes of support services, especially dominant categories such as (active) coping, adjustment, adaptation, etc., and, of course, 'quality of life'. What do these categories actually mean? Used unquestioningly, such classifications can become self-perpetuating, naturalizing particular ways of understanding the experience of life with and after cancer. Interdisciplinary exchanges between clinicians and scholars influenced by insights from the social sciences and humanities have the potential to dramatically transform how clinicians think about and manage cancer and its consequences, and that can only be good for those affected by the disease. ❧

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