Survivorship

EXPLORING CANCER IDENTITIES: DOES THE LABEL “PATIENT” OR “SURVIVOR” MATTER?

Gilla K. Shapiro, MPA/MPP, PhD(c), Department of Psychology, McGill University

TRIAL SUMMARY: Cancer survivorship: challenges and threats


This study empirically evaluated whether there is an important distinction between the labels “cancer survivor” and “cancer patient.” Conducted at the Princess Margaret Cancer Centre in Toronto, this study examined whether these labels were associated with distinct correlates, including an individual’s identity, sense of self, stressor experiences, subjective wellbeing and health-related quality of life. The authors found that identifying as a “cancer patient” and “cancer survivor” correlated moderately with each other. Although both identities correlated significantly with stressor experiences, subjective wellbeing and health-related quality of life, the associations were small in magnitude. Overall, identifying with the label of “cancer survivor” consistently correlated with a number of more positive outcomes than identifying with the “cancer patient” label. The authors concluded that despite subtle psychosocial differences that favour the “survivor” label, the difference in whether individuals identify as a cancer “survivor” or “patient” is less distinct and meaningful than previously believed. The authors stressed that emphasis in psychosocial oncology should be on facilitating effective adaptation to the coping demands and challenges associated with cancer and its treatment.

COMMENTARY: Due to improvements in cancer diagnosis and treatment, individuals who have been diagnosed with cancer are living longer.

Almost 33 million individuals worldwide have lived 5 or more years after a diagnosis of cancer (2012 statistics). Over 810 000 Canadians were diagnosed with cancer in the past 10 years (2.4% of the population; 2009 statistics). These individuals are often called “cancer survivors” and this terminology has been embraced by the American Cancer Society, the National Coalition for Cancer Survivorship, the National Cancer Institute’s Office of Cancer Survivorship, and the Canadian Cancer Survivor Network among others. However, as outlined in Devins et al.’s presentation, the label “cancer survivor” has a short history and has become the source of contentious debate.

The term was introduced by physician Fitzhugh Mullan in his 1985 publication in the New England Medical Journal as a replacement for existing labels such as “cured.” Mullan’s intention was to recognize that cancer patients not only need support after diagnosis and treatment (what he coined the “acute survival” phase), but during remission and recovery from treatment (i.e. the “extended survival” phase) as well as during a later stage when the likelihood of cancer’s return is sufficiently small that cancer is no longer considered a risk (i.e. the “permanent survival” phase). Mullan’s publication advocated using the terminology of “cancer survivor” along with attending to the biomedical and psychosocial aspects of survivorship. Subsequently, the label has been widely adopted, however, while some definitions refer to individuals who live even one day after diagnosis, others definitions have been more restrictive and refer to individuals who are cancer-free for a number of years. It has diverse significance for patients, is more frequently used by some (i.e. breast cancer) groups than others, may alienate some individuals, and downplays the possibility of recurrence.

Recently, researchers have begun reporting that the adoption of the label “cancer survivor” (rather than ‘cancer patient’ and other identities) has positive consequences for individuals’ physical and mental wellbeing. A recent literature review of 23 studies on cancer identity concluded that “[s]elf-identifying as a cancer survivor was related to...
better quality of life and mental wellbeing, with those having a childhood diagnosis more likely to transition successfully into adult care. However, many of the included studies have small sample sizes, most are qualitative, and the few quantitative studies do not consistently discuss effect sizes. Studies have been predominantly conducted in the United States, and many known confounding variables (including type and stage of cancer, or changes in identification with labels over time) were not examined. Devins et al.’s empirical study in a large Canadian sample (N=326) therefore adds meaningfully to the existing literature by examining whether individuals with cancer distinguish between the labels of “cancer patient” and “cancer survivor” and by testing whether these alternative identities are differentially associated with psychosocial advantages or disadvantages.

First, this study found that identifying as a “cancer patient” and a “cancer survivor” were significantly correlated (r=0.50, p<0.001). Using a Semantic Differential Task, both labels were also closely located in the method’s three-dimensional affective-meaning space, which implies perceived similarity. These findings support other studies that showed that, when given the opportunity, individuals simultaneously endorse multiple cancer identities. It is possible that different identities may be used concurrently to help individuals make sense of different aspects of their cancer experience; however, it is also possible that for some patients the label “cancer survivor” might have become so ubiquitous that they do not perceive a difference. In addition, it is notable that endorsement of different identities may change over time. As data were collected while patients were awaiting an appointment with their oncologist (i.e. the ‘extended survival’ phase), future research may profitably investigate whether the relationship between these two labels is similar 10 years after patients are considered cancer-free (i.e. the “permanent survival” phase).

Secondly, Devins et al. found that both labels were correlated with the sense of self, stressor experiences, subjective wellbeing and health-related quality of life. Similar to other studies, the authors found that identifying with the label of “cancer survivor” was correlated with a number of more positive outcomes than identifying with the label of “cancer patient.” However, an important strength of this study is that the authors report the magnitudes of these associations, which were small (r<0.30). It is also notable that these effects may be accounted for by confounding (self-selecting) variables that are not taken into account in these bivariate correlations. For example, there is a growing field of research indicating that choosing to identify as a cancer survivor is associated with a positive personal orientation (e.g. optimism), religious faith and feeling cancer treatment was successful. It is therefore important not to overestimate the implication of the observed relationship between cancer identity and wellbeing.

Quoting Shakespeare’s celebrated Juliet, Devins and colleagues therefore conclude: “[w]hat’s in a name? That which we call a rose/ by any other name would smell as sweet.” The authors explain that the difference in whether individuals identify as a cancer “survivor” or “patient” is less distinct and meaningful than previously contended. These findings may not be generalizable to other populations. In this study, researchers recruited a heterogeneous group of patients who were undergoing head and neck (40%), prostate (29%), hematologic (28%), breast (3%) or gastrointestinal (1%) cancer treatments in a single treatment setting. Their sample was also mostly male (68%) and of older average age (M=62.97; SD=13.25). As research indicates that identification with, and implications of, the label of ‘cancer survivor’ may vary by gender, age, culture and type of cancer (i.e. particularly in breast cancer), future research should replicate this study in other more homogenous groups.

It is important for researchers, healthcare providers and policymakers to be aware of the ongoing debate regarding cancer identities. The label “cancer survivor” may have diverse meanings, alienate some individuals, downplay recurrences and may not be especially advantageous relative to other labels. Going forward, it may be best practice to use the labels that people use to refer to themselves when they are affected by cancer. When no such label appears to be especially meaningful to a person, it may be preferable simply to employ factual labels such as “treated for cancer” or “has had cancer.”

References

already known
• Many people with cancer are living longer, and the term ‘cancer survivor’ has gained currency.

what this study showed
• Identification with the label “cancer survivor” correlated with a number of more positive outcomes than identification with the “cancer patient” label.
• Despite these small differences, patients consider the difference less meaningful than previously believed.

Next steps
• Efforts should focus on facilitating coping and adaptation and be less concerned with which label is used.