

Defining cancer survivorship

Michael Feuerstein

Published online: 20 January 2007
© Springer Science + Business Media, LLC 2007

Abstract This paper reviews the major definitions of cancer survivorship. The current definition of a cancer survivor used in this new journal will consider many of the elements of cancer survivorship as described in these earlier definitions. It is expected that the details of the definition of cancer survivor will evolve as knowledge in the area increases... *The Journal of Cancer Survivorship: Research and Practice* will focus on research, academic discourse, and policy-related to adults living with a cancer diagnosis following primary treatment for cancer through the end of life.

Keywords Cancer survivor · Evidence based · Research · Policy · Health · Quality of life

Introduction

When I was discussing the plans for this journal with researchers involved in cancer control, a number of thoughtful questions emerged. The most common question was, “How are you going to define ‘survivorship?’” As I began to talk with potential contributors, the same question came up as they were determining whether their research fell within the scope of this new journal. I thought about the

consequences of various definitions as I was contemplating titles for the journal. New definitions of what constitutes a cancer survivor have emerged over the years. Survivors have been variously defined as those first diagnosed with cancer to those living with a cancer diagnosis for 5 years or longer.

The family has also been considered as survivors in definitions. Also in many countries, cancer is viewed as simply “another chronic illness” and the term cancer survivor is not often used. While many of the challenges are similar to various chronic illnesses, there are unique aspects of living with cancer. It may be informative to contrast how different cultures and nations address these challenges. This is something the new journal can hopefully facilitate. Each of the existing definitions of and perspectives on cancer survivorship has their purpose (e.g., policy related, disease statistics accounting, adjustment /coping, and advocacy). However, none of them, including the one this journal will use, provide an evidence-based definition of survivor or survivorship. These will emerge as the field does.

For example, some research and clinical observation indicate family members are affected by cancer and in turn can impact many aspects of survivorship. But are family members really survivors? Certainly, they are not survivors in the same way (biologically, functionally, socially, emotionally) as those who have the illness. I am not taking issue with this definition. It serves a number of very important purposes (e.g., expanding the number of individuals affected by cancer, developing better ways to help families, broadening the advocacy base). There are many needs of the survivor and his or her family and it is the intent of this journal to consider them. Yet such a broad definition at this point may divert scientific attention away from the need to better understand the epidemiology, mechanisms, and improved management of the many

M. Feuerstein (✉)
Departments of Medical and Clinical Psychology and Preventive
Medicine and Biometrics,
Uniformed Services University of the Health Sciences,
Bethesda, MD, USA
e-mail: mfeuerstein@usuhhs.edu

M. Feuerstein
Georgetown University School of Medicine,
Washington, DC, USA

challenges the survivor with the illness experiences. These areas are not mutually exclusive and efforts should be allocated to both, however, there is a critical need for an evidence-based definition using population health data related to those living following a diagnosis of and treatment for cancer. The evolution of an evidence-based definition should consider earlier definitions of the construct. This not only provides an historical perspective but can inform future attempts to refine the definition.

Historical perspective

In 1985, Mullan, a physician and survivor of cancer himself, wrote a very thought-provoking paper in the *New England Journal of Medicine* in an effort to define the course of cancer [3]. One aspect of cancer that he commented on was the widespread belief that once diagnosed with and treated for cancer that the patient was either “cured” or “living with overt or covert disease.” Based on his experience and discussions with other cancer patients, Mullan proposed that this binary concept of ‘cure,’ while appealing, did not realistically capture the cancer experience as it truly unfolds for many. He proposed the use of the term “survival” because it seemed more applicable to both those who were “cured” and those with continuous disease.

Mullan went on to write that “the vagaries, phases, and syndromes of survivors are far more complex than the simple idea of cure suggests.” He proposed that while the concept of a cure suggests patients follow two separate courses; one for those cured and one for those not cured, this is not consistent with what actually occurs. He argued that there are many more commonalities in residual problems in those diagnosed with various cancers, despite whether someone declared them as “cured” or not. These commonalties place all survivors of cancer in a separate group from those who have not experienced cancer. It is clear that there are some cancers with poorer prognoses and greater morbidities than others. Also, all survivors of a certain cancer type do not necessarily experience the same pattern of problems (i.e., not a homogeneous group as with any biological phenomenon). Despite these differences, Mullan emphasized the commonalities. In this groundbreaking paper, Mullan also proposed “stages of survival” including: acute, extended, and permanent. He also enumerated many of the challenges faced by those living with a cancer diagnosis. However, while a useful source of information, his conceptualization was based on personal and clinical experience. It is now time to develop an evidence-based concept of survivorship. Survivors need this as the basis for new approaches.

Mullan also proposed, “that survivorship should be studied as a phenomenon in itself rather than a byproduct or afterthought of basic research on cancer treatment.” This journal will facilitate such an effort. As operational definitions of survivorship evolve based on evidence, it is important to remember Mullan’s view of survivorship as a “phenomenon” or “experience” with phases. He proposed the need for a new paradigm or way of viewing “surviving with cancer.” Survivorship, he argued, needed to be seen as a concept that can be used to help describe, explain, better manage, or prevent the many challenges that now face those living with a diagnosis of cancer. Survivorship is a working concept in transition; a way to organize a body of knowledge that will improve over time and ideally impact the health and well being of those diagnosed with and treated for cancer.

Aziz [1] and Aziz and Roland [2], have recently elaborated on the definition of survivorship. Aziz [1], while providing an initial descriptive epidemiology of survivorship in the United States and highlighting new research areas, indicated that any consideration of survivorship needs to account for the phenomena of late and long term effects of cancer, referring to the effects of primary treatment on the health and well being of survivors. Late effects, which can occur months to years post-treatment, are unrecognized toxicities that are absent or sub-clinical at the end of primary treatment for cancer. Long term effects often persistent over time and are side effects of either the cancer or its treatment “for which a cancer patient must compensate” (e.g., peripheral neuropathy, other pain conditions, prolonged or recurrent fatigue, cognitive problems, depression).

Another point highlighted by Mullan as well as Aziz and Rowland is that the many challenges that confront the cancer survivor are not simply a continuation of problems experienced during treatment but represent unique problems in the trajectory of the experience with this illness as the survivor transitions from the acute to the chronic dimensions of illness. The problems experienced are multifaceted (i.e., medical, functional, economic, social, emotional, health systems, etc.) [1] and dynamic (fluctuate over time). Therefore, the advancement of knowledge will require many diverse disciplines using several types of research methodologies.

Working definition

There are several cancer related journals that cover many aspects of the acute phase or primary treatment of cancer. This journal will not be added to that list. The *Journal of Cancer Survivorship: Research and Practice* will focus on populations and individuals with a diagnosis of cancer who

have completed primary treatment for cancer. It is well recognized that there are survivors who continue with “treatment” or management and that it may be unclear when primary treatment ends. This journal will consider these cases as survivors as well. These survivors have completed primary treatment or the major aspects of treatment and either desire or need to “get on with their lives.” This journal will consider the survivor as the individual with the cancer diagnosis, not the family. However, the support systems of cancer survivors are important elements of survivorship and as such they are targets for research. Also, methodologically sound comparisons of cancer survivors and non-cancer comparison groups are especially needed at this point to provide a better understanding of the natural history of cancer survivorship. Contributors to this journal will need to carefully provide case definitions or complete descriptions of study populations so readers will have a clear picture of who the work was targeting. While providing data regarding time between diagnosis and study onset maybe less complicated, it is preferable for authors to provide data on the duration from termination of primary treatment to study onset.

As evidence accumulates regarding *adult cancer patients following primary treatment until end of life*, a more

complete definition of cancer survivorship will emerge. This journal will help facilitate this more comprehensive understanding, one that is based upon sound epidemiological, etiological, and clinical research. While Mullan argued for the need for improved knowledge regarding cancer survivors over 20 years ago and certain aspects have improved, as more evidence-based descriptions and understanding of the challenges facing cancer survivors emerge, many of the problems faced can hopefully be prevented or, at least, more effectively managed than at present. There is much work to be done and this journal will help disseminate it.

References

1. Aziz, N. M. (2002). Cancer survivorship research: Challenge and opportunity. *Journal of Nutrition*, *132*, 3494S–3503S.
2. Aziz, N. M., & Rowland, J. H. (2003). Trends and advances in cancer survivorship research: Challenge and opportunity. *Seminars in Radiation Oncology*, *13*(3), 248–266, (Jul).
3. Mullan, F. (1985). Seasons of survival: reflections of a physician with cancer. *New England Journal of Medicine*, *313*, 270–273, Jul.