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Cancer Survivorship - A Journey Like No Other!

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Cancer has been called The Emperor of All Maladies".[1,2] Rich or poor, old or young, male or female - there is perhaps no other disease that induces more fear among patients diagnosed with it, and induces all who are touched by it to face their mortality.[1,3,4]

And it is in *that moment, when patients face their mortality, that they are forever altered*. For them and their precious families, cancer can *never be a distant memory now.*

This moment of truth then is the genesis of "the terrible costs of cancer on each life it touches",[1,2] . There is little doubt that, in its throes, patients are reminded constantly of the fallibility of human existence"[3-5] A diagnosis of cancer is undoubtedly a pivotal point in time for patients, family members and their physicians.[6,7]

Estimates suggest that there are more than 18 million cancer survivors in the US currently. Worldwide estimates are imprecise, but suggest a range between 30 and 40 million. An impressive 14% of survivors are those who have survived more than 20 years after the primary cancer.[2,5,6] In general, these numbers of prevalent cancer survivors tend to underestimate the actual prevalence of survivors.[1,2]

This paper introduces the topic of cancer survivorship, describes the impact of cancer on patients, and presents the mandate for empathetic but cutting-edge, high-quality care needed by cancer survivors.[1-4]

Advances in early detection of, and treatment strategies for, cancer have both contributed to increased survival after a diagnosis of cancer. Approximately 66% of adults, and 79% of children, diagnosed with cancer today will survive beyond 5 years of diagnosis. Acute toxicities such as radiation pneumonitis, and chronic organ toxicities such as congestive cardiac failure, neurocognitive deficits, infertility and second malignancies are all now described as the price of cure or prolonged survival after cancer.

Cancer Survivorship is not the same as Survival after cancer. Survival is simply a measure of time elapsed after a cancer diagnosis, and is divided into "disease-free" and "overall" periods. Cancer Survivorship however is a process, an evolution of time since diagnosis, in combination with the impact of cancer as a disease process, and the adverse outcomes on health of the generally multiple cancer treatment modalities.

Similes have been drawn between cancer survivorship and the seasons of the year. The result is the rather fanciful but poignant term known as the "Seasons of Survival" reflecting the interface between the" Survivorship Spectrum" and the" Treatment spectrum". It is divided into "acute, extended, or permanent seasons". An understanding of these phases of survival is important for facilitating an optimal transition into and management of *long term survivorship.*

"*Survivors*" of cancer are defined as individuals diagnosed with cancer from the moment of diagnosis through the balance of their lives.[1,2,3,6] *Long Term Survivors* are those who have survived for 5 years or more after a cancer diagnosis and embody the concept of "the permanent season of survival".

"*Cancer Survivorship Research*" seeks to examine, assess, prevent or control, the impact of cancer & its treatment on the health status of survivors. It includes the study of risks for and development of recurrences and their management, and with time, the risk for and management of long-term and late effects of the cancer or its treatments.[1-3]

The <u>goals</u> of Cancer survivorship *research and care* include the provision of *the Best Possible level of care that will enable cancer patients and survivors to survive and return to their lives*.[1,2] *Cancer survivorship research* has 4 main aims: (a) study and effect decreases in adverse cancer diagnosis and treatment-related outcomes (such as late effects of treatment, second cancers and poor quality of life); (b) assess the new normal health status of survivors after treatment and facilitate better health outcomes over time; (c) provide a knowledge base regarding optimal follow-up care and surveillance of cancer survivors; and (d) optimize health after cancer treatment.[1,2,4]

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At every part of the survivorship journey, we as physicians must always remain mindful of the privilege of helping our patients reach calmer waters after an incredibly difficult diagnosis and treatment period. Cancer exerts a profound impact on our patients, and nothing we have read in books or papers can really prepare us for the impact of the shock patients and physicians feel in that life-altering moment of diagnosis, or the difficult, painful treatment and survivorship journey(s) of the months or years ahead![1,2,4] Because Cancer Survivorship addresses the health and life of persons diagnosed with cancer, it has both physical and emotional impacts. [2,5,6,7]

The adverse sequelae of cancer or cancer treatment contribute to a high burden of illness, greater risk of premature mortality, escalating morbidity, rising health costs, and decreased length and quality of survival. Ways to address (manage or treat) the long-term or late effects of cancer have yet to be examined rigorously, with few studies even comparing survivor outcomes pre-and post-diagnosis.[1,2,4,5,6]

In general, *long-term adverse effects arise during the acute cancer treatment phase and do not subside after cancer treatments have ended*. Examples include Lymphedema after breast cancer surgery, or the painful escalating neuropathies after Taxol for a given cancer. *Late Effects are those adverse outcomes that arise months or years after all cancer treatment has ended*. Examples include cardiomyopathy after Adriamycin for breast cancer or ovarian failure after Cytoxan for breast cancer.[2-4,6]

Late effects refer specifically to unrecognized toxicities that are absent or sub-clinical at the end of therapy and become manifest later with the unmasking of hitherto unseen injury due to failure of compensatory mechanisms over time or organ senescence. *Long-term effects* include any side effects or complications of treatment for which patients must compensate. They are also known as persistent or chronic effects because they do not go away after treatment ends, Late effects, in contrast, appear months to years after the completion of acute cancer treatment.

Cancer survivors in the USA, Europe & the developed world consist of a highly motivated group committed to effecting positive changes in the realms of cancer prevention & control, treatment(s) & cure, and importantly, the prevention or management of serious long-term and late effects.1,2 Such adverse impacts of the cancer treatment and survivorship journey include health challenges such as organ senescence or failure, debilitating pain and fatigue, declines in function and activity. and the emotional or physical scars of living constantly with health challenges and an uncertain future.[2,3,5,6]

Cancer Survivorship is still a fledgling research area in developing countries such as Pakistan. We need to examine ways to jumpstart this field in developing countries and assess cultural issues and other possible barriers that must be overcome in order to bring this field to life in multiple emerging countries .[1-4]

Together, survivors and their families constitute a profound and courageous pantheon of individuals who share not only the many heartbreaking moments of diagnosis and treatment, but also the irreplaceable moments of joy during the cancer survivorship journey. Moments that come just in time and usually unbidden to show patients and physicians that light will come and soon![2,4,6]

This journey, encompassing the seasons of survival, can only be traversed a step at a time, even though longer periods of disease-free survival are thought to be commensurate with greater or better overall survival. Each season of survival is unique, with its specific impacts on health status. But, at every phase of survivorship patients must fight and overcome the unique challenges of long term or late health effects, the side effects of cancer and its treatment, the pain and fatigue caused by the cancer or the grueling disfiguring gut wrenching cancer treatments, and their impact over time on health and on emotions.[1,2,4] Truly apt to the concept of "seasons of survival" is the notion of taking the cancer journey a step at a time, and to "carry on", as patients know they must, but often with an Altered body image and grief for all that has been lost.[1,5] All along this journey are memories and aversive experiences that act as constant reminders of a painful struggle for life.[2,3,6]
These are important contextual points we as doctors must include in our assessment of cancer survivors.

Cancer Survivors may never again be who and what they once were. And yet, despite these negatives, studies show that most survivors continue to soldier on, striving for dignity, for strength, even as they struggle to find their "*new normal" health indicators, so that they, and their doctors, can understand the depths of their toxicities or injuries and effect management strategies that will lift them out of a downward trend*.[3,4]

Addressing the myriad challenges of long-term and late effects of cancer and its treatment is synonymous with the irreversible Journey of Cancer Survivorship! It is a journey marked by battles and struggles. The battles that must be faced may be related to diagnostic tests and/or the varied treatments (surgeries, radiation, Chemotherapy), and even the impact of growth factors (eg GCSF)) that force the bone marrow to create and release red and white blood cells - enough so that the very same treatments, or new therapies (chemo, radiation, others), can continue to be administered on time and with dose intensity, a vicious cycle that exhausts but is necessary.[2-4]

Yes, the treatments kill the cancer cells - but they also exert impacts physiologically and /or visibly on the healthy parts of bodies and even on the brave, beautiful faces of our patients! And they also may exert profound reactions among patients who need to now accept the new version of themselves that will be their "new normal" selves that they have become.

Survivorship entails a journey for survival during which we do our best to prevent premature mortality and preclude morbidity. It is distressing, however, that the research/knowledge gaps described years ago by this. Author are still unaddressed![1-4] Research and practice knowledge gaps in cancer survivorship science require rigorous work so that we can find ways to protect survivors against health challenges and Multimorbidity. We have found that survivors suffer from a median of 5-6 health conditions over the extended post-treatment period. The mechanisms underlying why this is happening need to be examined, and interventions developed and tested to facilitate for cancer survivors their return to health and vitality.

Interestingly, in the transition of patients from oncology to primary care settings, we also have found that primary care physicians need to be educated about the late effects of cancer treatment![4] They (PCPs) also need to be better prepared to recognise and address negative outcomes during their post-treatment care.[1-3,6]

Future follow-up care models & practices grounded in rigorous research methodology are needed since follow-up "guidelines" today are nothing but conjecture and opinion and not based on evidence.[4,5] This must change. Sadly, the lack of methodological rigour among adult cancer survivors is a huge criticism of extramural research to date and must be addressed.

We need research on cancer survivorship that will:
1) permit the timely diagnosis and treatment of adverse outcomes
2) enable the timely diagnosis and treatment of recurrences
3) facilitate screening and early detection of second cancer(s)
4) allow for detection and management of co-morbidities;
5) Provide the opportunity to initiate timely preventive strategies such as lifestyle changes
6) develop and use treatment summaries and follow up care plans
6) Find ways to initiate palliative care early and provide effective pain management
7) Examine ways to jumpstart this field in developing countries and assess cultural issues that must be overcome relating to this research.1-4

Continued cancer survivorship research must also:
a) inform our understanding of the mechanisms underlying adverse sequelae
b) lead to the design of less toxic treatments
c) test the effectiveness of interventions
d) test models of post-treatment follow-up care
e) develop an evidence base for optimal follow-up care practices that address barriers; and
f) Inform survivor and provider decision-making.[1-4]

Sadly, these issues, first articulated by this author 18 years ago, continue to persist.

We must always remember that the battle for survival is not an ordinary journey! It leaves in its wake multiple painful, emotional, and dehumanizing aspects of a life-altering journey patients have been travelling so bravely, and also its aftermath - the negative sequelae of diagnosis or treatment(s) that leave Survivors-patients battle scarred, weary, vulnerable, but always so profoundly grateful to be alive!

As physicians, we must treat our patients. But we must also make it a point to honour the courage of all Survivors who came to those fateful moments of diagnosis and won inordinately difficult battles for healing - These are poignant and extraordinary journeys to be sure, journeys involving treatments that disfigure, change, and leave patients/ survivors so deeply exhausted and so vulnerable, but always with at least a tiny kernel of additional strength that carries them through life-saving battle(s), and then also the ensuing ones that arise as a result of living with compromised health as an aftermath of the cancer, now to be treated as a chronic illness! [1,2,3,5,6]

Our research has found that Survivors join these battles and undergo everything they must so that they can return to their homes, families, and lives!

In sum, we should be proud to acknowledge the courage and strength of our cancer patients, nay, survivors! These are the qualities that allow them to win the battles and put up with the struggle to stay alive - so that they can return to their past lives, and most importantly so that they may pick up once more the reins of nurturing their families and continuing the
care and protection of their precious loved ones!

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