PERSPECTIVE

Cancer from Both Sides Now: Combining Personal and Research Perspectives on Survivorship

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Cancer survivorship is increasingly a situation of chronic disease management that needs to be integrated with the context of broader health and well-being. This perspective paper combines personal experiences and a professional research program to address the complexities of long-term management of cancer and integrated care and the importance of psychological distress and psychological growth expressed in diverse pathways of survivorship. The role of age is addressed as partially defining the extent and nature of long-term psychological effects. General internists are in a unique position to play a central role in enabling cancer survivors to integrate the cancer experience into their lives and their overall health and well-being.

KEY WORDS: cancer; survivorship; aging; psychology; well-being; chronic illness management.

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I write this perspective paper from a unique vantage point encompassing two very different viewpoints—those of a 12 year+ prostate cancer survivor managing a recurrence for 11 years and a researcher specializing in impacts of cancer survivorship on quality of life and psychological well-being. From this vantage point I want to raise several issues relevant to the critical role of general internists in helping cancer survivors manage their cancer. An essential starting point is that, for many, cancer is now a chronic disease^{1–4} and should be managed as such. Internists already deal with many cancer survivors in their patient populations and will deal with even more in the future.⁵ From the time of diagnosis and, especially, following active treatment, there must be careful ongoing surveillance and management of long-term effects and late effects and/or treatment decisions if cancer recurs. This management is increasingly seen as primarily the personal responsibility of the patient/survivor. However, both general internists and oncology specialists play critically important roles in supporting and facilitating cancer survivors' own choices and responsibilities. To take responsibility and make careful decisions, survivors must weigh information from many sources; to do so, they need the help and guidance of both general medical practitioners and oncologists (and often

other specialists). In turn, to be an effective guide and monitor, the internist needs to combine communication with oncologists with his or her own commitment to high quality, holistic chronic illness care. And these activities occur in the broader context of individual survivors' health and whole lives.

From my dual perspectives, I address two areas derived from the combination of my own experiences as a cancer survivor and my research: (1) coordinated management of follow-up and health behavior choices and (2) the importance of the psychological side of cancer survivorship within one's life experiences, including, especially, age. Both areas require considerable attention from clinicians.

FOLLOWING UP, SURVEILLANCE, AND MANAGEMENT

The goal for long-term care of cancer survivors is to ensure coordinated attention to their long-term cancer-related needs as an integral part of their health care for the rest of their lives. One aspect concerns whether longer term follow-up is best done by oncology specialists or internal medicine practitioners and, if by internists and family practitioners, how to transition to that care provider. The National Action Plan for Cancer Survivorship¹ and the Institute of Medicine report, *Lost in Transition*,² for example, addressed this issue, with no clear conclusion. The movement toward survivorship care plans^{5–8} promises to be a major step toward addressing responsibilities and enhancing communication and clarity of roles. While pediatric cancer care has paid some attention to coordination and transitions to adult care,^{9–11} little attention has been paid to the roles of generalists in continued care of the bulk of cancer survivors, that is, middle-aged and older persons.^{2,4,8,12}

In my case, for almost 12 years I had the good fortune to continue an excellent relationship with my urological oncology surgeon continuing as my primary doctor for surveillance and management of my cancer, while all other care resided with my internist and other specialists. Together, my urologist, my wife, and I have charted a course through treatment, post-treatment care, transition to survivorship, and management of recurrent disease compatible with my overall view of my cancer, my health, and my life. However, when he recently took another position, not only did I feel “abandoned,” but I became faced with the question of whom to see for my cancer-related management—another urologist, an oncologist, or my PCP, an internist. All may be good choices, but each would bring distinctly different training and perspective. I am still struggling with a decision, especially as my recurrence trajectory has taken a turn upward.

My case is somewhat unusual, but it illustrates two crucial points: (1) the “fit” between a particular provider and a particular patient, with his or her own approach to health and well-being, is critical, and (2) the need for coordination of follow-up care and surveillance is evident. A complete, well-formulated survivor care plan could be the foundation for such coordination for the entire period of survivorship.^{1,2,5–8} Despite the good intentions of all providers involved, without such a fully delineated plan, coordination is difficult, and problems can result from focusing too narrowly on one part of health, such as cancer.

What is particularly important when trying to make choices and trying to manage long-term survivorship is the need to recognize and include in care the context of one’s broader health. Many survivors have other conditions that are managed with their general internists. The typical “fragmentation” of cancer care from other care can lead to complications from focal attention on cancer, on the one hand, or focal attention to other medical conditions, on the other.

In my case, I focused too intently on being a cancer survivor and on what seemed best for my cancer care. Like many cancer survivors, I was highly motivated to make healthy lifestyle choices regarding my cancer based on available advice about nutrition and prostate cancer. I eliminated red meat (and other sources of fat, such as nuts). Doing so, without a coordinated nutritional plan, I negatively affected other facets of my health. I continued to eat many calories, which inevitably came primarily from carbohydrates. In essence, I became a “super-carber,” chronically over-taxing my insulin system.

In 2007, a routine physical exam revealed diabetic-range blood glucose. I immediately realized the connection to how I had been eating, and felt that if I were to change from my “super-carb” levels and re-calibrate my eating habits, I could make a large difference in my blood sugar. My internist at the time, however, perhaps not appreciating the extent to which I had modified my diet to manage my cancer, wanted to prescribe insulin. I had to fight to try self-management; when I insisted, eating according to guidelines for my “new” disease resulted in weight loss and, within several months, lowered my glucose to non-diabetic levels, which I have maintained. Now, however, since part of the solution to dramatically reducing carbohydrate intake has been to increase fat and protein intake, I am worrying about prostate cancer impacts again, potentially warranted due to my jump in PSA. The point is that there is value—and danger—both in cancer-specific care *and* general care (or care focused only on another disease, such as diabetes). Management of cancer survivorship is often in the context of multiple diseases, especially as survivors age. It is essential for all involved care providers, oncologists and internists alike, to recognize this broader context and to treat cancer as *part* of the individual’s physical health, not either as the *only* important part or, alternatively, as something to be monitored by other providers.

Trajectories, Psychological Impacts—Negative and Positive, and the Role of Age

A second critically important issue also arises from both my own experience as a prostate cancer survivor and my research. This is the importance of the “personal” side of health—one’s psychological well-being—and the complex factors that make up well-being. In particular, I note two aspects of psychological well-being. The first is the variety of impacts and trajectories of

psychological responses to cancer, both initially and into survivorship. The second is how cancer fits in the dynamics and totality of one’s life and, relatedly, the age-related nature of the psychological impact of cancer.

Of course, psychological aspects of cancer survivorship have received considerable attention, usually framed as health-related quality of life^{13–16} (HRQOL), often essentially using a functional approach defining high HRQOL as low levels of mental or physical *dysfunction*. An alternative, complementary approach broadens “well-being” to give equal attention to optimal health, which includes the potential for or reality of positive aspects, such as increased social relations and personal growth^{17–22} and the “life well-lived.”

After my diagnosis at 49, my life changed dramatically. I suddenly realized that my lifespan could be quite limited. Interestingly, as a lifespan developmentalist, I had talked for years in classes and writing about the course of lifespan development^{23,24} and a life course model,^{25–28} both of which stress the importance of major life events (including illness) as influencing trajectories of lives and the subsequent need for people to feel in control and make sense of their lives^{29,30}. Now I experienced personally the need to make sense of a threat to my life. I had to make decisions I did not want to make, about treatments that I and my wife knew had no guarantees of success even as they had “guarantees” of potentially significant permanent side effects. I became a different person in many ways.

I decided to shift my professional attention. I had been researching social psychological aspects of aging and people’s reactions to early retirement. A week after my surgery, with catheter in tow, I sat down with my new laptop to map out research on how people deal with cancer survivorship. That is the research area I have focused on since (e.g.,^{28,31–33}).

In the process, I came to appreciate the opportunity to grow psychologically and to alter my relationship to my life, my mortality, and other persons as well as continuing to experience a certain overall distress, specific negative side effects, and concerns about how to deal with my recurrence. This, too, fits within an essential dictum of lifespan developmental models, that *every* life event presents to the individual *both* loss *and* growth, a challenge and an opportunity to develop.^{21,23–25,34} Also, in my research, my support group, survivorship events, and online interactions with other survivors, I have seen the vast diversity of patterns of impact on cancer survivors.

Thus, I have focused my research on the patterns of psychological impacts of survivorship. Among important aspects of survivorship, I, and many other researchers, have noted that cancer survivorship can proceed along a range of psychological pathways.^{15,22,28,31,34} For some, cancer initiates a persistent pathway into distress, reducing well-being and health. For others, cancer can introduce a pathway to thriving, to a sense of personal growth and stronger self-identity that moves them to what they feel is a new, better way of being.^{17–19,22,28} Still others, after initial distress, re-establish a level of well-being that, in most respects, is like that prior to having cancer, reporting minimal long-term psychological impact.^{13,15,31} In essence, for them cancer was an acute disease that received a successful treatment. I admit to great surprise when, as a survivor whose life, both personally and professionally, was greatly changed, I saw in my data that two-thirds of prostate cancer survivors reported that they “seldom or never” think about having had prostate

cancer.³¹ But I realized that I shouldn't have been surprised, because rich and varied experiences and reactions are the essence of lifespan development and the life course.

Further, my and other research (and my personal experience of being diagnosed at age 49) indicates that the likelihood of fitting into one or another pathway is consistently related to age.^{28,31–37} Middle-aged and older survivors are experiencing their survivorship in combination with normative age-related changes, both physiological and psychological, and increasing levels of chronic disease.^{38–42} We find that while older survivors report more co-morbidities, younger cancer survivors like me often report more psychological impact (especially positive impacts) than those who are older. In other words, my own experience as a “young” prostate cancer survivor was not unique, but I should not have expected that all men with prostate cancer—or certainly all cancer survivors—would share my pattern of impact. In many, especially older, survivors, other life events and the context of other health conditions frame the lived experience of cancer. So much depends on age. Yet so much depends on prior and concurrent experience with illness and other life events. That is, while age appears to be important, it is essential to ascertain the trajectories or pathways of specific individuals, since every generalization (younger are more likely to experience sustained psychological impact; older are less likely to benefit from treatment) can serve as a starting point, but does not apply to every individual.

Therefore, my colleagues and I^{28,31–32} emphasize research that (1) is based in lifespan developmental and life course models, (2) reflects the lived experiences of survivors following diverse trajectories, (3) recognizes the positive, psychological growth-oriented opportunities of cancer while never forgetting the negative impacts, and (4) emphasizes that effective surveillance, management, and treatment all require recognition of the whole, complex person. My own experiences as I age and negotiate my cancer and my broader health concerns in the overall contexts of my life (professional career, personal relationships) parallels, confirms, and illustrates the validity of these emphases and the challenge presented to general internal medicine clinicians (and others) to incorporate the fullness and complexity of life and health in caring for their patients who are cancer survivors.

Implications

The ramifications of this depiction of my experience and the broader issues of cancer survivorship for general internists are profound. It is essential that all medical providers, certainly including those in general internal medicine, realize and recognize both the potential psychological impacts and the diverse pathways among cancer survivors. In clinical practice, they can clarify the pathways of their individual patients and personalize their care to reflect the individual aspects of well-being that “fit” with each cancer survivor's experience and perspective.

As primary care providers for persons across the adult age spectrum, they are in a unique position to interact with their patients as they age and as they may integrate cancer into their aging processes. As “generalists” they are in a unique position to deal with the whole person, and the whole lived experience of having and surviving cancer, in diverse patients with diverse personal, social, and health trajectories. They can

emphasize with their patients the integration of physiological, psychological, social, and spiritual facets of health and well-being. They can help cancer survivors focus on the “teachable moments”^{43,44} that cancer can provide to facilitate health behavior change and self-change (that is, growth) in their patient populations.

I believe the end result of attending to factors such as these is an improved set of outcomes for both cancer survivors and their primary health care providers. General medicine internists can—and inevitably will—be the care providers who can help cancer survivors place their ongoing cancer management in the context of their broader health concerns. They can work with cancer survivors as they age and as they cope with their cancer in the broad context of their illness and health processes. By being fully informed about the choices survivors are making, the trajectories on which their cancer journeys may be proceeding, and the potential for enhanced health care and enhanced living at least sometimes afforded to their patients by their cancer survivorship, general internists can provide cancer survivors with the foundation to face continuing fears, continuing surveillance, and sometimes recurrent disease and/or late effects in the most effective and successful way.

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