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Cancer Survivorship: A Dynamic Paradigm

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Introduction: Epidemiology of Cancer Survivorship

Psycho-oncology is an emerging field within behavioral science that aims to meet the needs of the growing number of individuals with a history of cancer. The number of cancer survivors in the United States has quadrupled since the passage of the National Cancer Act in 1971; this is largely due to advances in cancer treatment and early detection coupled with the aging of the population (Horner, 2009; Institute of Medicine, 2005). In contemporary use, the term *cancer survivor* refers to any person who has received a cancer diagnosis, irrespective of whether that individual is currently undergoing treatment or has a hopeful prognosis. By 2020, the number of cancer survivors in the United States is anticipated to rise from nearly 12 million individuals (roughly 4% of the population) to 20 million (Erikson, Salsberg, Forte, Bruinooge, & Goldstein, 2007). The sheer number of cancer survivors coupled with the medical, social and psychological sequelae they face constitutes an issue of public health significance.

*Figure 1 - Number of Cancer Survivors in the United States Actual (1971-2010) and Projected (2011-2020)*

Once considered a death sentence, cancer has become widely recognized as curable in many cases. Resulting from continuous scientific breakthroughs, this shift constitutes the new guiding framework in psycho-oncology. I employ Thomas Kuhn’s definition of paradigm as “universally recognized scientific achievements that for a time provide model problems and solutions to a community of practitioners” (1962, p. x). The need to define and articulate the emergent paradigm grows in intensity as the duration of cancer survivorship increases in concert with the increasing number of cancer survivors, demanding the attention of public health practitioners.

**Overview of the Paper**

In this paper, I aim to describe the dynamic paradigm shift in the field of psycho-oncology in concert with the epidemiologic shift from cancer death to survivorship. I will compare the old paradigm—“pre-survivorship” or “pre-term” view of cancer as incurable—to the development and maturation of psycho-oncology as a field characterized by a new worldview—the reality of cancer survival as an increasingly common occurrence. The new cancer survivorship paradigm consists of three distinct iterations: cancer survivorship in its 1) infancy (as proposed by physician and cancer survivor Fitzhugh Mullan in 1985), 2) childhood (as proposed by Noreen Aziz in 2007) and 3) adolescence (proposed in this paper). A historical perspective will illuminate the issues and breakthroughs at each stage, tying the context to the development of the new paradigm and its emerging changes. Lastly, I suggest and describe the new iteration of the paradigm (adolescence) that builds upon and expands the ideas of its predecessors. In order to accomplish this aim, I will outline the paradigm evolution, making specific additions to the most recent paradigm articulated in the literature, detailed in Figure 2.
Described as “entering its adolescence,” the field of psycho-oncology continues to adapt and expand along with its guiding paradigm (Rowland & Bellizzi, 2008). Definition of the iterations in the new yet rapidly developing framework demonstrates maturity of the field and enables enhanced sophistication of research (Kuhn, 1962). Psycho-oncology is a young yet rapidly growing field with significant public health implications. Thus, it needs a clear and up-to-date paradigm. In this paper, I propose an enhanced version of Aziz’s “evolving paradigm” with increased emphasis on the Institute of Medicine recommendations detailed in the 2005 report “From Cancer Patient to Cancer Survivor: Lost in Transition.”

**Old Paradigm: Cancer as Incurable - “Pre-Term”**

Prior to the recent, rapid advances in treatment and early detection, cancer frequently proved to be a terminal illness. The prevailing framework assumed that the trajectory of cancer
consisted of only two phases: diagnosis and treatment (Miller, Merry, & Miller, 2008). The term “cancer survivor” was not defined or commonly used in the oncology lexicon until the mid-1980’s (Miller, et al., 2008). Few cancer patients received an encouraging prognosis until the last few decades of the 20th century (Bellizzi, 2004). The National Cancer Act of 1971 declared war on the “dread disease” of cancer and did not include the word “survive” or “survivor,” indicative of public perception of cancer at the time (National Cancer Act, 1971).

Americans’ views of cancer likely reflected the state of the science since most cancer patients were not expected to survive for more than a short period of time. Given this reality, early therapies tended to be aggressive, with little attention to or recognition of issues of toxicity and long term side effects that threatened quality of life (Miller, et al., 2008). In fact, cancer treatments were rarely curative, but merely palliative (Ganz, Casillas, & Hahn, 2008). Thus, the cancer paradigm had not yet accounted for survival but merely diagnosis and treatment.

**New Paradigm: Cancer as Treatable, Increasingly Curable**

The passage of the National Cancer Act in 1971 led to an influx of funding into cancer research, which, in turn, yielded scientific breakthroughs that increased the likelihood of cancer survival. In the following sections, I detail three evolutions of the new cancer survivorship paradigm. First, “infancy” describes the inception of the term “cancer survivor” and the three stages of survivorship: acute survival, extended survival, and permanent survival as described by Fitzhugh Mullan (1985). Second, “childhood” builds upon Mullan’s foundation of the new paradigm by adding the complex challenges of lingering physical effects of cancer and its differential impact on individuals and families of various socioeconomic statuses as defined by
Noreen Aziz. This paper proposes a third version of the paradigm, “adolescence,” building on Julia Rowland’s description of the field of psycho-oncology in 2008. The proposed paradigm iteration builds upon the Mullan and Aziz models by incorporating the Institute of Medicine recommendations highlighting the importance of psychosocial considerations including social, psychological, financial and interpersonal factors. The three versions of the new cancer survivorship paradigm demonstrate the rapid growth and development of psycho-oncology as a field with public health significance.

**First Iteration - Infancy**

Physician and cancer survivor Fitzhugh Mullan’s definition of the term *cancer survivorship* and articulation of its stages led to the creation of the new paradigm. In its infancy, the paradigm encompassed the concept that cancer had the potential for remission, extending the cancer trajectory to include a survivorship phase beyond the previous model of diagnosis and treatment. Mullan described the new cancer continuum by comparing the phases experienced by survivors to seasons of the year (Mullan, 1985). By definition, those with cancer no longer had to wait five years after treatment to describe themselves as “survivors” but could use the term upon diagnosis (2008; 1985). The term *survivor* applies regardless of whether an individual is currently engaged in active treatment or has a poor prognosis. Some definitions extend the term *cancer survivor* to caregivers and family members of the individual with cancer, who likely feel deep psychosocial impacts of cancer in their own lives (2008).

The cancer survivorship paradigm described by Mullan incorporates three distinct phases. The first stage, “acute survival,” encompassed the diagnosis and treatment of cancer (Miller, et
Next came “extended survival,” a time of recovery, “watchful waiting” and ongoing monitoring (2008; 1985). “Permanent survival,” the final stage of Mullan’s paradigm, signified a decreased emphasis on the experience of cancer as well as a lower perceived risk of recurrence (2008; 1985). The paradigm shift from pre-survivorship to survivorship in its infancy hinged upon increased survival rates as a result of biomedical breakthroughs.

Second Iteration - Childhood

In its developmental years, the cancer survivorship paradigm built upon the previous iteration described by Mullan, adding the recognition that cancer often involves long-term impacts. Moving beyond Mullan’s focus on the improved treatments and longer life expectancy for survivors, the new paradigm begins to acknowledge scientific advances in understanding the long term effects of cancer, clearly defining and updating the phases of cancer survivorship (Aziz, 2007). The new iteration of the paradigm calls for an interdisciplinary focus that:

(a) Seeks to identify, examine, prevent and control adverse sequelae of cancer and its treatment;
(b) Manages, treats and prevents comorbidities;
(c) Incorporates health promotion and lifestyle interventions to optimize health after cancer treatment;
(d) Defines optimal follow-up care and surveillance strategies and guidelines for all survivors;
(e) Pays special attention to disparities in survivorship outcomes by age, income, ethnicity, geography or cancer site; and
(f) Explores the impact of the survivorship experience on the family (and vice versa).

Aziz’s paradigm remains primarily focused upon biomedical sequelae of cancer, extending Mullan’s model by adding the importance of long-term effects such as fatigue and sexual dysfunction as well as late effects or symptoms that may arise months to years after treatment. In addition, the Aziz model addresses the challenges presented by comorbidities such as diabetes, heart disease, or other existing chronic conditions a survivor may have. As described by Aziz, the survivorship paradigm in its childhood addressed the shift from a “primarily seek and-destroy mindset toward one reflecting the importance of both curing the disease and controlling its attendant adverse sequelae” (Aziz, 2007, p. 419).

One assumption of the childhood version of the paradigm as defined by Aziz is that cancer is increasingly viewed as a chronic disease for many survivors (Avis & Deimling, 2008; Aziz, 2007; Doyle et al., 2006; Miller, et al., 2008; Rao & Demark-Wahnefried, 2006; Rowland & Bellizzi, 2008). While an individual may become cancer free after treatment, the risk of recurrence persists, which can lead to the perception of cancer as a chronic disease. An increased recognition of the need for research across the phases of cancer survivorship serves as the backdrop of the paradigm shift described by Aziz. Similar to the “seasons of survivorship” described by Mullan, these phases are now widely conceptualized as a continuum or trajectory, ranging from diagnosis and active treatment to re-entry into everyday life after treatment to long-term survivorship (Aziz, 2007; Doyle, et al., 2006; Stanton, 2006). Seemingly similar, the cancer continuum representing the Aziz paradigm adds enhanced knowledge to Mullan’s paradigm. It takes into account scientific evidence about long-term effects of cancer that has emerged over the past several decades (Aziz, 2007). The major differences between the two models of survivorship include the increased recognition of cancer as a chronic disease and the larger body of
knowledge of negative biomedical sequelae of cancer that may emerge in long-term survivorship.

**Proposed New Paradigm - Adolescence**

Building on the work of Aziz, I posit that increased recognition of cancer survivors’ psychosocial needs constitutes another iteration of the survivorship paradigm. Two major factors serve as the driving force for the paradigm shift: 1) a call for better psychosocial care issued by the Institute of Medicine, and 2) an emerging sub-discipline in the field that challenges the primary emphasis on negative psychosocial sequelae and late effects of cancer as hallmarks of survivorship. While the Aziz paradigm included a basic introduction of the psychosocial dimensions of life impacted by cancer, the proposed new iteration promotes development of a more complete understanding of the psychosocial factors that deeply impact the lives of cancer survivors. The conceptualization of the cancer continuum, ranging from diagnosis and active treatment to re-entry and ultimately to long-term survivorship, remains relevant but the new iteration places greater emphasis on psychosocial care. In the following section, I will detail the major changes that justify the new cancer survivorship paradigm with particular emphasis on the Institute of Medicine recommendations including the need to expand research beyond active treatment to the re-entry and long-term survivorship phases.

**Impetus for the New Cancer Survivorship Paradigm**

Widely recognized as the nation’s expert advising body on topics related to health, the Institute of Medicine (IOM) issued an extensive report in 2008 entitled “Cancer Care for the Whole Patient.” The report classified psychosocial services as integral components of quality
care for individuals with cancer. Coupled with the IOM’s call, the rise of post-traumatic growth as a major research area within psycho-oncology demonstrates significant progression of the field, as the development of subfields signifies a level of maturity in any given field (Kuhn, 1962).

As the number of cancer survivors and the duration of survivorship increase correspondingly, the body of literature dedicated to the psychosocial aspects of cancer continues to grow, necessitating an examination of the conceptual frameworks. Until quite recently, the literature has focused largely on biomedical perspectives, often neglecting the psychosocial aspects of survivorship (Stanton, 2006). The new paradigm addresses the need for integration of psychosocial aspects of cancer into existing and future research across the cancer continuum.

 Importance of the Re-Entry Phase: Public Health Implications for Research and Practice

Research has typically concentrated on the earliest stages of cancer survivorship, particularly diagnosis and active treatment (Stanton, 2006). A potential explanation includes the ease of access to cancer survivors currently undergoing treatment. These survivors likely spend significant amounts of time at cancer centers engaged in a process of accepting, adjusting to and treating their cancer. The subsequent state, re-entry after treatment, is the topic of the Institute of Medicine report “From Cancer Patient to Cancer Survivor: Lost in Transition” (Hewitt, Greenfield, Stovall, & National Cancer Policy Board (U.S.). Committee on Cancer Survivorship: Improving Care and Quality of Life., 2006). The report “focuses on survivors of adult cancer during the phase of care that follows primary treatment” (2006, p. 2). The focus on the re-entry phase stems from the recognition by the IOM of the “unmet needs of the large and growing
number of cancer survivors during this phase of care” (2006, p. 2). The final state, long-term survivorship, remains understudied despite wide recognition (Stanton, 2006).

**New Paradigm: Increased Recognition of Psychosocial Aspects of Survivorship**

Building explicitly on the Aziz paradigm, the proposed new iteration incorporates attention to psychosocial health. In order to illuminate the paradigm shift, the following section quotes the Aziz paradigm item by item with new contributions in bold.

**Overarching Framework: The new paradigm employs a whole patient approach to research and patient care across the cancer trajectory, as prescribed by the Institute of Medicine.**

Authored by the nation’s foremost experts in cancer care, the IOM panel incorporated perspectives from a diversity of fields including oncology, social work, nursing, psychology, communication, public health, public policy, and health services research. The 2008 report concluded that:

Attending to psychosocial health needs should be an integral part of quality cancer care. All components of the health care system that are involved in cancer care should explicitly incorporate attention to psychosocial needs into their policies, practices, and standards addressing clinical health care. These policies, practices, and standards should be aimed at ensuring the provision of psychosocial health services to all patients who need them (Adler, Page, & National Institute of Medicine (U.S.). Committee on Psychosocial Services to Cancer Patients / Families in a Community Setting., 2008, p. 69).

In accordance with the IOM conclusion, the following emphases expand the Aziz paradigm to formulate the proposed new paradigm:

Seeks to identify, examine, prevent and control adverse sequelae of cancer and its treatment **including psychosocial sequelae such as anxiety, depression and distress; fear of recurrence, employment issues, and interpersonal relationship challenges.**
Manages, treats and prevents comorbidities with attention to the influence of anxiety and depression that often accompanies comorbidities.

Incorporates health promotion and lifestyle interventions to optimize health after cancer treatment, including counseling interventions to optimize psychological health, an integral component of physical health and effective biomedical care.

Defines optimal follow-up care including psychosocial health services and surveillance strategies and guidelines for all survivors, incorporating screening for depression and anxiety when appropriate (Aziz, 2007, p. 419).

The IOM panel undertook the process of defining “psychosocial health services,” laying the groundwork for future research. This foundation serves as evidence of a paradigm in the field and leads to increased efficiency (Kuhn, 1962). Thus, individual researchers no longer need to establish a definition but can use the existing one as a starting point for their own research. The IOM definition of psychosocial health services follows below:

Psychological and social services and interventions that enable patients, their families, and health care providers to optimize biomedical health care and to manage the psychological/behavioral and social aspects of illness and its consequences so as to promote better health (Adler, et al., 2008, p. 69).

Along with a definition of psychosocial services comes the need to understand the extent of their provision in current practice. Therefore, the next component of the paradigm,

Pays special attention to disparities in survivorship outcomes by age, income, ethnicity, geography or cancer site (Aziz, 2007, p. 419), as well as disparities in access to psychosocial services.

Widespread disparities in cancer diagnosis, stage at diagnosis and anticipated length of survival persist (Byers et al., 2008). Access to psychosocial services also varies, with most survivors failing to receive needed psychological care (Alter, 2009). According to the IOM,
researchers need to identify better and more effective psychosocial health services with attention to understanding which populations respond most readily to services (Adler, et al., 2008). Conversely, IOM also calls for development of interventions that prove highly effective in specific populations including a variety of vulnerable populations (2008).

In addition to developing a deeper understanding of the psychosocial health services, disparities and interventions, psycho-oncology needs to develop broader perspectives on the intra- and interpersonal facets of the cancer survivorship experience. Incorporating the study of psycho-oncology, a new subset of the field, the final component of the paradigm iteration:

Explores the impact of the survivorship experience on the family (and vice versa) (Aziz, 2007, p. 419) and all of its facets. In particular, psycho-oncology research should incorporate ways to understand the survivorship experience in a positive light; acknowledging the challenges while recognizing potential positive impacts such as benefit finding and personal growth.

The growing body of knowledge of psychosocial aspects of cancer survivorship continues to delve into new intrapersonal and interpersonal realms. Areas of study include the family’s experience of cancer and post-traumatic growth. Post-traumatic growth, an integral area of inquiry within psycho-oncology, refers to personal development that occurs as a result of the cancer experience (Gotay, Ransom, & Pagano, 2007, p. 2103). Addressing this aspect of the Aziz paradigm, significant efforts have contributed to the understanding of the impact of the cancer experience on families (Bellizzi, Miller, Arora, & Rowland, 2007; Bellizzi et al., 2010; Bishop, Curbow, Springer, Lee, & Wingard, 2010; Damber & Aus, 2008; Given, Given, & Stommel, 1994; Schroevers, Helgeson, Sanderman, & Ranchor, 2010; Zwahlen, Hagenbuch, Carley, Jenewein, & Buchi, 2010).
In addition, a new sub-discipline of psycho-oncology has emerged, challenging the extensive study of biomedically-based negative sequelae. Past research “has been based on biomedical models of disease and deficit models of coping and adjustment and thus has primarily documented the negative psychosocial sequelae of cancer” (Parry and Chesler, 2005, p. 1055). A growing body of literature suggests that this myopic view of late effects and long-term negative sequelae has given way to new models of growth and benefit finding that encompass positive change and growth (Bellizzi, et al., 2007; Bellizzi, et al., 2010; Parry & Chesler, 2005; Schroevers, et al., 2010; Stanton, 2006; Zwahlen, et al., 2010). It is widely accepted that a cancer diagnosis can cause substantial psychological distress and disruption to life (Institute of Medicine, 2005; Stanton, 2006). However, psycho-oncology researchers argue that some aspects of the cancer experience create lasting positive changes in some survivors (Parry & Chesler, 2005). Without discounting or ignoring the challenges of cancer, the field of post-traumatic growth explores the deep interpersonal change that occurs in some (though certainly not all) cancer survivors.

Post-traumatic growth manifests as a form of lasting growth that extends beyond the individual’s baseline, pre-cancer level of maturity. According to Parry and Chesler, “the experience of cancer can shatter one’s assumptive reality…that the survivor not only has to cope but might attempt to rebuild his or her life and understanding of life,”(2005, p. 1056). This process can result in “broad and positive changes in one’s life outlook and identity, sense of self, and sense of meaning in the world” (2005, p.1057).

Post-traumatic growth measures change in five areas of life. The Posttraumatic Growth Inventory (PTGI) is a valid scale consisting of 21 measures eliciting results from five domains:
1) increased appreciation of life and different sense of priorities, 2) warmer and closer relationships with others, 3) increased sense of personal strength, 4) recognition of new opportunities for one's life, and 5) spiritual growth and development (Tedeschi & Calhoun, 2004). Each domain “tends to have a paradoxical element to it that represents a special case of the general paradox of this field: that out of loss there is gain” (2004, p. 5). This area of psycho-oncology shows promise in understanding the needs of cancer survivors through a new lens. The emerging body of literature “urges us to consider cancer not only as a traumatic event that requires recovery but also as a potential catalyst for growth” (2005, p. 1056). Instead of focusing purely upon negative sequelae, research is beginning to follow the IOM’s call to view the survivor as a whole person rather than a series of diagnoses.

This new iteration of the cancer survivorship paradigm arises from a model focused on long term and late effects (negative biomedical sequelae) to one fully incorporating psychosocial dimensions that explore potential growth after the cancer experience. New research endeavors to understand the positive aspects of the cancer experience without discounting or obscuring the challenges and long-term impacts of cancer and its treatment. Developments in psycho-oncology, coupled with the IOM call to integrate psychosocial health care into clinical care, demonstrate the centrality of the psychosocial aspects of oncology to improving the lives of survivors.

**Conclusion**

The field of psycho-oncology is in the midst of a paradigm shift that will substantially impact the way research is conducted. This, in turn, will impact the lives of cancer survivors for years to come. In the above pages, I provided a historical overview of the dynamic paradigm
shift in cancer survivorship from pre-survivorship to the cancer survivorship paradigm in its infancy, childhood, and adolescence. The pre-survivorship paradigm, characterized by perceptions of cancer as a terminal disease, persisted until the treatments became increasingly effective after the breakthroughs that resulted from the 1971 National Cancer Act that prioritized cancer as a threat to public health. The survivorship paradigm in its infancy saw the definition of the term “cancer survivorship” by Fitzhugh Mullan. Subsequently, the cancer trajectory expanded from diagnosis and treatment to include phases of recovery and ongoing surveillance. Growing into childhood, the paradigm proposed by Aziz acknowledged the new scientific developments that led to further understanding of long-term and late effects of cancer. Reflecting this knowledge, the cancer continuum changed to three different stages: diagnosis and treatment, re-entry, and long-term survivorship. Finally, the new iteration of the paradigm in its adolescence builds on Aziz’s iteration with an increased emphasis on psychosocial health as prescribed by the Institute of Medicine. Increased attention to psychosocial concerns in the clinical setting, as well as the study post-traumatic growth constitute the new research paradigm which brings hope for our nation’s growing population of cancer survivors.
References:


