Psychosocial Consequences of Cancer Survivorship

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Purpose

- To discuss a recent article in Cancer that reviewed long term physical and psychological consequences faced by adult cancer survivors.
- To discuss the less studied issues related to transitioning from treatment into survivorship.
- To review areas for future research that can guide interventions for adults who have survived cancer.

Survivorship

- Number of long term cancer survivors is growing, with more than 10 million individuals with a history of cancer living in the US.
- Increased attention being turned to survivors and the physical, as well as psychological, challenges they face.

Survivorship

- While most individuals return to normal after oncology treatment, some difficulties can remain, or new ones can arise over time (late effects).
- These **physical** and **psychological** consequences impact quality of life.
- Long term consequences are defined as problems that persist for at least 5 years post treatment.
- Tonight discuss adult cancer survivors (not children)
- Trend that adult research has been improving over past 10 years

Cancer - Special Issue on Survivorship

Stein, K.D., Syrjala, K.L., & Andrykowski, M.A. (2008). Physical and Psychological Long-Term and Late Effects of Cancer. *Cancer.*[1]

Physical Consequences

- Within the field of psycho-oncology, researchers investigate the impact of cancer and related complications on daily functioning.
- The good news is that the majority of cancer survivors describe good general health 5 years or more after treatment.
- However, for a significant portion of survivors, researchers have found the following physical impairments to be more common than others…

Physical Consequences[1]

1) Fatigue or lack of stamina
2) Musculoskeletal problems
3) Decreased participation in activities
4) Sexual dysfunction

Ness et al., 2006[2]

- Compared cancer patients and non-cancer patients (controls) using 1999–2002 population-based home interview survey from the Centers for Disease Control National Health and Nutrition Examination Survey (NHANES)
- Over 10,000 adults enrolled (279 were recent cancer survivors and 434 were considered long term survivors, using the 5 year mark)
- Found that that long-term adult survivors had a higher likelihood:
  - physical limitations (53% compared with 21% for controls without cancer), particularly for activities that require sustained muscle activity
  - restricted participation in sustained activities such as shopping, sports, and social events (31% vs 13% reported by controls).

Sweeney et al., 2006[3]

- Using data from The Iowa Women's Health Study, they examined 25,719 postmenopausal women (median age = 72 years). 2218 participants had a history of a cancer diagnosis, with 1068 long-term survivors.
- Found that compared with individuals who had not had cancer, the elderly female cancer survivors reported only modest but significant difficulties with ability to do heavy housework (42% vs 31%), walk a half mile (26% vs 19%), or walk up and down stairs (9% vs 6%).
- Again, the activities noted were those requiring muscle strength, stamina, or mobility, whereas there was not a difference in the women's abilities to do less strenuous activities like preparing meals.

Ganz et al., 1998[4] and 2002[5]

- Conducted a large cross sectional study of breast cancer survivors (stages I and II) one to five years post treatment.
- Found long-term breast cancer survivors have increased physical impairment and symptoms, but not consistently poorer psychosocial or work function.
- The most frequent physical symptoms were general aches and pains (70%), muscle stiffness (64%), and joint pain (62%).
- Premature menopause as well as chemotherapy were found to be related to sexual dysfunction.
- Later, in a follow up study, the same women were reassessed – however, now they were 5 to 10 years post-treatment. They found that most of the women continued to do well overall, but that sexual activity declined and cognitive difficulties increased.

Nurses Health Study[6,7]

- Using a prospective design, this study followed women for four years who were, and who were not, diagnosed with breast cancer.
- Compared to women who did not have breast cancer, those diagnosed with breast cancer had:
  - Higher rates of decline in physical functioning (musculoskeletal)
  - Lower ratings of vitality
  - Lower social functioning
  - Higher rates of pain
- These differences were found even when controlling for baseline abilities, other comorbid conditions, age, education, race, and lifestyle factors.
- However, they noted that the problems appeared to lessen as time from diagnosis increased, though for some, the deficits remained up to 4 years later.

Prostate Cancer[8-11]

- For long-term survivors of prostate cancer, general physical function appears to be unaffected by treatment type, with the exception of androgen deprivation.
- Conversely, sexual dysfunction occurs in most men with prostate cancer and can be severe in some cases.
- Urinary obstruction, urinary incontinence, and bowel urgency also occur in survivors at rates greater than individuals who have not had prostate cancer.

Risk Factors for Physical Consequences

- Older in years of age
- Lower income

Psychological Consequences

- Psychological distress is the most commonly studied mental state in individuals living with cancer.
- It encompasses a variety of psychological responses, including depression and anxiety.
- Clearly, distress is the normal response when actively coping with cancer diagnosis and treatment, but for some individuals distress can be a more stable difficulty that lasts for years, or even for a lifetime, after cancer treatment has ended.

How common is it for survivors to continue experiencing significant psychological distress?

- Depression - 10% to 25%[12], 20% to 50%[13], 0% to 58%[14]
- Anxiety disorders - 6% to 23%[15]
- Post-traumatic stress disorder (PTSD) - 0% to 32%[16]
- Clearly, we are still unsure as to the accurate rates of diagnosable psychopathology

Psychological Distress…what we do know…

- Many cancer survivors report positive consequences from their cancer experience.[17]
- Serious psychopathology (major depression or PTSD) is relatively uncommon [18], though compared to individuals without a cancer history, survivors may have a slightly higher risk for depression and PTSD.
- Polsky et al. [19] found that a cancer diagnosis within the past 2 years increased the risk of reporting significant depressive symptoms 3-fold to 4-fold relative to individuals with no cancer diagnosis.
- A nearly 2-fold increase in risk for reporting significant depressive symptoms was found in survivors 4 to 8 years post cancer diagnosis.

Psychological Distress…What we do know about fear of recurrence…

- Most survivors experience at least some anxiety or fear about recurrence [20]
- However, not a well studied area of research and much that we still need to know about how that fear impacts daily living, relationships, major life choices, medical utilization, and overall quality of life.

Psychological Distress…What we do know about PTSD…

- Fear of the future can also be related to PTSD
- There have been a growing number of reports of PTSD among cancer survivors and their relatives.
- Most studies deal with survivors of breast cancer, and cancer in children and their parents.

PTSD in Cancer Patients

- Patients have reported experiencing intrusive thoughts about death, traumatic memories of diagnosis and treatment, and fear of shortened future.
- There is disagreement on whether cancer traumas are the same as more ‘classic’ traumas that cause PTSD.
- What researchers have found is that being diagnosed and treated for cancer includes multiple events that can cause distress. It is similar to combat in that it is often ongoing stress and at each step can cause a feeling that your life is being threatened.

PTSD Prevalence is questionable

- Prevalence is somewhere between five and 20%.
- A study employing formal PTSD criteria in women who were a mean of 3 years after breast cancer diagnosis demonstrated prevalence rates of 6% and 10% for current and lifetime cancer-related PTSD, respectively [21]
- A similar study of head and neck cancer survivors 1 year after diagnosis demonstrated a PTSD prevalence rate of 14% [22]
- Although this is a new area of inquiry, clinical experience suggests that cancer survivors can clearly evidence a constellation of distressing symptoms that are quite similar to classic PTSD long after cancer diagnosis and treatment.

Risk Factors for Psychological Consequences[1]

- Researchers have diligently tried to determine risk factors (demographic, clinical, dispositional, psychosocial, and health system variables) to long term psychological outcomes in individuals with cancer.
- Most of this research has focused on negative risk factors, while only a small amount of research has examined positive, protective factors.
- Results have been inconsistent, but suggests that risk for long term psychological difficulties in patients with cancer is probably related to the interaction of a number of factors.
- In particular, the balance between cancer stress/burden and the resources available to cope with that stress is important. However, please note that this finding is not novel to cancer. In fact, research conducted by the eminent stress researchers in our country (i.e., Arnold Lazarus, Susan Fokman, etc.) has documented this relationship between stress/burden and coping resources for decades.

Clinical and Research Implications

Developing a Survivorship Plan

- The Institute of Medicine (IOM) report, *From Cancer Patient to Cancer Survivor: Lost in Transition,* calls for the development of better research to understand the transition from patient to survivor. [1]

Clinical Implications: From Patient to Survivor

This is a difficult time for many of our patients

- Financial burdens/job loss
- Going from high contact health care to feeling like they are ‘flying without a net’
- Social isolation from friends/family members who were once very active during cancer
- Trying to put the pieces back together
- Finding a new normal
- Restructuring relationships and roles
- Sexual dysfunction/diminished intimacy with partner/body image disturbances

Psychosocial Aspects in Developing a Survivorship Plan

- In developing a survivorship plan, psychosocial issues, those physical and psychological, must be addressed.
- Psychologists can be part of this survivorship plan as they are trained in empirically supported therapies that can assist patients in dealing with both the physical and psychological consequences discussed tonight.

Psychosocial Aspects in Developing a Survivorship Plan

- Interventions to improve fatigue/stamina, sexual dysfunction, muscular difficulties, and social engagement.
- Better assessment and identification of psychological difficulties as patients finish their cancer treatment and enter survivorship.
- Referrals for treatment for those who have persistent distress at the end of treatment.
- Education to help patients and family members to recognize depression, anxiety, PTSD, as well as a tailored plan for patients to implement if symptoms occur or worsen.

Psychosocial Aspects in Developing a Survivorship Plan

- We must also assist family members to learn how to cope and adjust to new life with their loved one post cancer.
- Assist patients in understanding what their medical regimen and follow up plan will be post cancer.
- Transitioning care, and a comprehensive plan, from oncologist to primary care provider.

Future Research Physical Consequences[1]

- Does the rapid physical function decline in cancer survivors (compared to non-cancer populations) reflect an accelerated aging process?
- What are the mechanisms for physical impairments that could improve targeted interventions to enhance long-term function in survivors?

Future Research Psychological Consequences

- Interventions have already been devised that can help patients with cancer cope during treatment as well as during survivorship. Future research needs to test these interventions for effectiveness and efficiency in the field.
- Randomized controlled trials to determined which interventions work best for which populations.
- Tailored interventions for patients based on different stages of the cancer experience.
- Tailored interventions based on disease specificity.

Final Note

- Understanding the physical and psychosocial processes that interact during the transition from patient to survivor will take a large research effort. And even more research will then be needed to devise thoughtful interventions to then address the processes and ease the transition.
- The first step is bringing the issue of survivorship into the limelight. This can be accomplished by special issues on survivorship in journals like *Cancer*, increased funding by foundations and NIH to fund survivorship research, and conferences like this one tonight.

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