Jennifer Wiernikowski

Maximizing Wellness as a Lymphoma Survivor

Hamilton Health Sciences

Juravinski Cancer Centre
A Cancer Care Ontario regional partner

Maximizing Wellness as a Lymphoma Survivor

Living Well With Lymphoma: Patient and Family Education Day
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Survivorship is unique to each

Objectives

- To explore definitions of cancer survivorship
- To examine the changing trends with respect to cancer survivorship in Canada
- To review the consequences of survivorship and strategies to maximize wellness from the perspective of lymphoma patients

Defining Survivorship

Survivors and their Families

Survivorship

Medical/Health care community

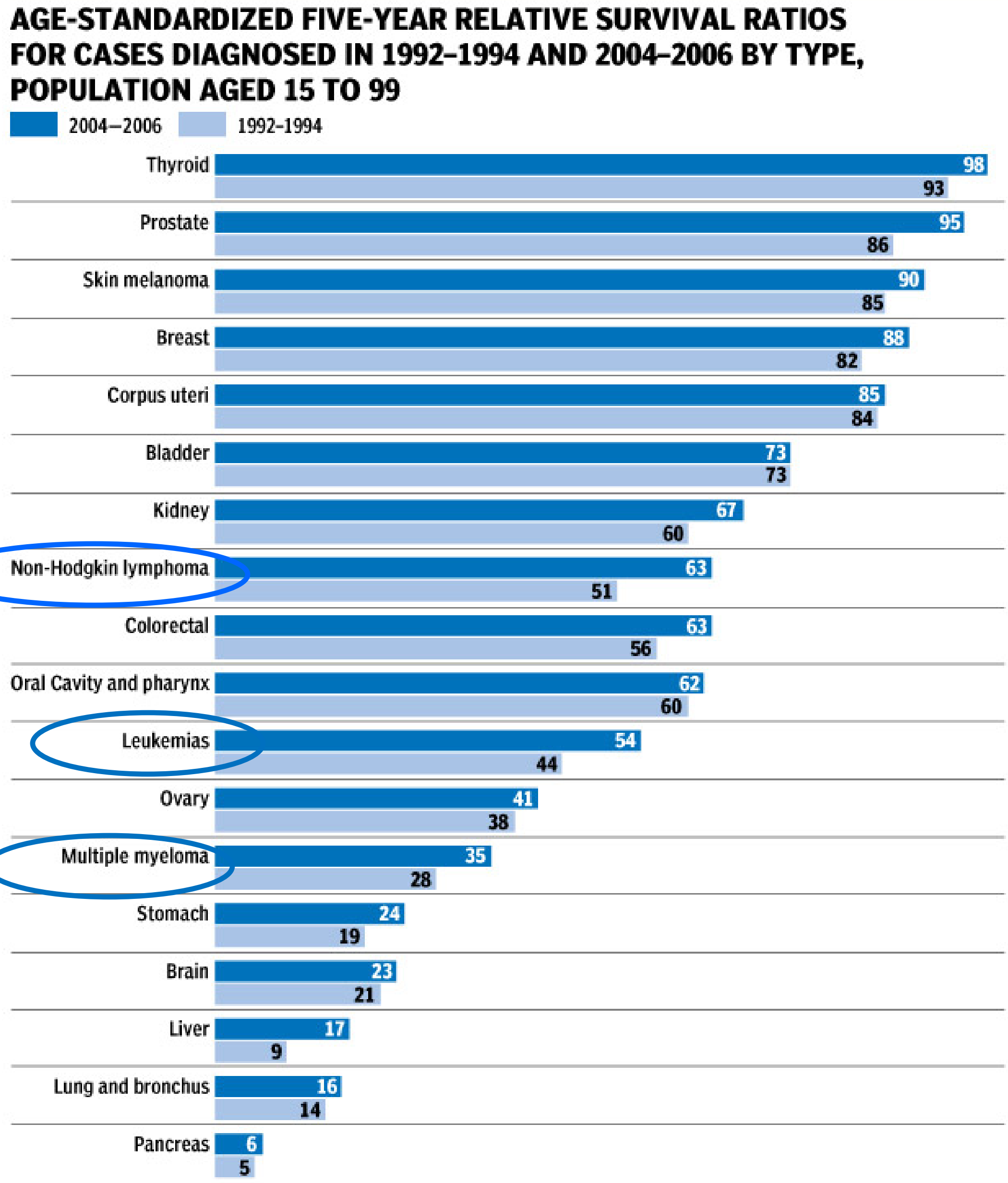
National/International organizations

Defining Cancer Survivorship

- NCCN~ From the time of diagnosis until the end of life, covering physical, psychosocial and economic issues of cancer
- LAF~Survivorship begins at diagnosis & includes physical, emotional, and practical aspects. It describes the many experiences and emotions that are part of living life as a cancer survivor
- NCI~ adds that family members, friends and caregivers are also affected by cancer

Individuals who have been diagnosed with cancer and the people in their lives who are affected by the diagnosis, including family members, friends, and caregivers.

CANADIAN* CANCER SURVIVAL RATES IMPROVE



***Excluding Quebec**

SOURCE: CANADIAN CANCER REGISTRY, STATISTICS CANADA AND PROVINCIAL/TERRITORIAL CANCER REGISTRIES

ANDREW BARR / NATIONAL POST

National Post Sept 15, 2010

Maximizing Wellness

- As a survivor of lymphoma it is important to understand the impact of the illness experience and the longer term effects of treatment in order to find ways to achieve the best possible state of wellbeing
- Speakers today cover
  - Information about the disease
  - Fatigue
  - Exercise
  - Nutrition
- I am challenged to answer the question, “What is left to talk about?”

Consequences of Surviving Cancer: *A Delightful Dilemma*

- Up to 75% have ongoing problems with their health related to their treatment, not the cancer
- Fatigue
- Over 50% of cancer survivors experience chronic pain
- 70% experience depression, fear of cancer coming back, uncertainly
- Infertility
- Struggles with sex/sexuality
- Loss of income/financial worries
- Changes in self esteem
- Cognitive changes (chemo brain, chemo fog)

Haylock, P. 2006. AJN, 106(3): 6-11

Fatigue

- Contributors can be anemia, pain, lack of sleep, medication side effects, impaired nutritional intake, depression, disease
- The Energy Bank
  - Deposit
    - Physical activity (unless not recommended)
    - Eating well, may need a dietician to help
    - Stress reduction
    - Energy conservation
  - Withdraw
    - Consider your spending carefully!

Sex and Sexuality

- Previous struggles with sexuality and intimacy with your partner will likely not be improved with cancer diagnosis and treatment
- Changes in body image
  - Scars from surgery
  - Weight changes
  - Loss of hair
  - Loss of strength, looking pale
- Fertility trouble
- Women may undergo early menopause as a result of chemotherapy leading to vaginal dryness, painful intercourse, & hot flashes

Talking About Sex

- What used to be spontaneous, fun and easy may now need some work and conversation.
- There is no right or wrong way to deal with sexual changes after treatment for cancer. The team is there to help and referrals for consultation can be made when needed.

Emotional Challenges

- Living with uncertainty
- Depression & distress/anxiety/guilt/grief & loss
  - May need to explore past strategies for coping
- Change in roles
- Change in relationships
- Maximizing wellness depends on working through the emotional changes and challenges. We can help!
- Loved ones and friends may be anxious for you to get back to normal but ‘normal’ may have shifted. Many people find adjusting to life as a survivor challenging which can be a surprise

Depression and Distress

- Sadness beyond what might be considered normal and permeates all aspects of the person’s life
- Depressed mood, lack of interest or pleasure in activities you usually enjoy, difficulty sleeping, feeling guilty or worthless, decreased energy, inability to concentrate, appetite changes
- It is a spectrum, over 50% of cancer survivors will find themselves somewhere on the spectrum at some point on the journey
- Very treatable! Please let your team or family doctor know if you are struggling

A Survivor Story

- Jeff
  - Diagnosed in 2010 at age 45 with Diffuse Large B Cell Lymphoma
  - He embarked on CHOP-R chemotherapy and radiation.
  - Treatment completed in September of 2010, he continues to do well
- Social Hx
  - Married, 2 children now 17 and 19, he was a self employed contractor at the time of diagnosis.
- Treatment Course Complicated By
  - Peripheral neuropathy, diffuse muscle pains, insomnia, fatigue, depression, weight loss, reduced heart function

- What was Jeff’s Primary Concern in the 6 months following completion of treatment?

1. Lack of sexual desire and arousal
2. Depression
3. Need to return to work
4. Risk to his heart related to weakened heart muscle
5. Fear of recurrence

3. Need to Return to Work

Returning to work

- His return to being a self employed contractor will be affected by
  - Fatigue
  - Poor heart function makes him tire easily, less stamina
  - Peripheral neuropathy
  - Ongoing insomnia/depression
- He is motivated to return to work because
  - He seeks meaning and wants to feel normal
  - He wants to contribute within the family, to support his children as they begin to plan for post secondary school
  - He misses the social aspect of his work, joking with his friends and the opportunity to think about normal everyday things apart from his cancer diagnosis.
- Jeff returned to work in March 2011, 13 months after diagnosis.

Returning to work

- More than 50% of cancer survivors are under age 65
- Returning to work may fill a financial need, a social need or both (or neither!)
- Getting back to work may take careful planning and a gradual timeline.
- Consider the possible physical, emotional, cognitive pressures that work might bring and what accommodations might be needed at first.

Returning to Work

- Some may not return to work by choice or because of ongoing limitations due to cancer and treatment
- Those who are self employed may find this a very high stress issue, early discussions with the team social worker are important
- When returning to work is not possible it is important to find other ways to build social connections, a feeling of belonging and purpose. Strategies need to be flexible.

Lymphoma Survivors Say…

- “I revel in the beauty and the power of the moment”
- *When treatment was done I just wanted to fast forward 5 years, take a pill and be done. My mom reminded me that if I were to do that I would miss my son’s first day of kindergarten and my daughter’s first steps. It upsets me even now to remember my response was ‘I just don’t care’*
  - Jennifer Rogers, on-line financial journalist Reuters
  - Diagnosed at age 34 with DLBCL in 2007
  - From an address to the audience of MSK Survivorship Celebration June 2011

Lymphoma Survivors Say…

- *After... After is one of the most challenging times because there is too much time to think, to 'survey the damage'*
- *Who you were may not be who you are, and that's a loss you may have to grieve*
- *You may have to deal with late effects of treatment like chemotherapy induced menopause or cognitive impairment. You just can't multitask like you used to. Your memory may be changed. My friend calls it*

  C.R.A.F.T ☺

Dr. Laura Liberman, MSK

Tips to Tolerate the Neutral Zone

- Accept it is ok to feel this way
- Find support (formal programs at your institution, integrative medicine, friends and family)
- Focus on the moment
- Put joy in every day
- Find humour
- Share your experience to help others

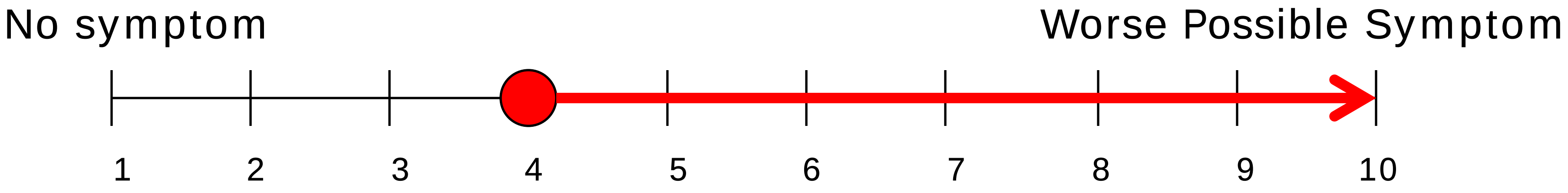
Dr. Laura Liberman MSK

The Role of Survivorship Care

- Disease surveillance
- Research, following outcomes
- Monitoring and management of late effects
- Health promotion activities (risk reduction)
- Health teaching
- Assessment and intervention of psychosocial consequences of survivorship after life threatening illness
- Some may need special services: rehab, PT, OT, genetic counseling
- Patients may fall into low, moderate and high risk for future health problems and may require different intensities of care

ESAS Symptom Assessment Scale

- Pain
- Tiredness (decreased energy)
- Nausea
- Depression (sad or blue)
- Anxiety (nervous or restless)
- Drowsiness (sleepy)
- Appetite
- Wellbeing (how are you overall?)
- Shortness of Breath



Supportive Care

- Your hematology team
- Pain and Symptom Management Team
- Supportive Care Practitioners
  - Psychiatrist
  - Psychologist
  - Nurses
  - Social Worker
  - Registered Dietician
  - Chaplain
  - Physiotherapy
  - Occupational Therapy

Questions

Artist Gay Walker:

"This mandala was drawn as a healing symbol and includes the rich colors of my life. The black shape is the cancer that moved around my center but did not extinguished the brightness of the colors of my life."

References

- CANO/ACIO (2009) Adult Cancer Survivorship: A Self Learning Resource for Nurses. www.cano-acio.ca
- Farley-Short, P et al (2005). Employment Pathways in a Large Cohort of Adult Cancer Survivors. Cancer. 103(6). 1292-1301
- Institute of Medicine National Cancer Policy Board. (2005). From Cancer Patient to Cancer Survivor: Lost in Transition. National Academies Press: Washington, D.C.