

Cancer Survivorship and Programmatic Approaches to Developing Effective Coping Strategies

Penny Damaskos, PhD, LCSW, OSW-C
Resources for Life After Cancer

Goals of Talk

- Review psychosocial characteristics of survivorship
- Review some research
 - Incidence of long standing symptoms
 - Efficacy of group interventions
- Review programmatic approaches to assist individuals in coping with transition in survivorship

NCI Definition of Survivor

- **Survivor**

An individual is considered a cancer survivor from the time of diagnosis, through the balance of his or her life. Family members, friends, and caregivers are also impacted by the survivorship experience and are therefore included in this definition.

(NCI Office of Cancer Survivorship <http://dccps.nci.nih.gov/ocs/definitions.html>)

Survivorship is a Unique Time

- Now recognize that post-treatment is a discrete phase in the cancer continuum
- Define this as a time when individuals make a transition from “patient” to “survivor”
- Multiple issues at the end of treatment with the sense of relief is rarely simple with unexpected emotions/reactions

Rowland 2008, Stanton et al 2005

Survivorship is a Unique Time

- End of scrutiny by health care team
- Individuals are no longer absorbed by immediate health care needs or the “crisis of treatment”
- Engaged in re-evaluation and assessment of life goals/roles
- Motivation provided by a new urgency regarding life goals and meaning

Rowland 2008; Ganz, 1998; Stanton 2005

Survivorship is a Unique Time

- Transition from patient to survivor is complicated by:
 - multiple losses
 - sense of abandonment by medical team
 - heightened vulnerability
 - fear of recurrence
 - increased anxiety
- Individuals struggle to maintain a balance between their internal anxieties and external voices “aren’t you happy to be alive!”

Rowland, 2008; Stanton 2005

Survivorship is a Unique Clinical Time

- People have emotional energy to address multiple issues vs. business of treatment
- Clinically very rich time where people can develop insights into their experiences
 - What just happened?!
 - Existential concerns
 - Re-evaluation of life can be very productive
 - Foundation for internal solidification of new identity and awareness

Case 1--Nancy

- 24 year old, recently married
- Diagnosed with node positive, breast cancer
- Rapid decisions regarding future
 - Embryo preservation?
 - Reconstructive surgery right away
 - Quickly decided against delaying treatment
 - Facilitated discussion with husband

Nancy--- continued

- In therapy for during treatment and into survivorship
 - Multiple losses
 - anxiety about fertility
 - complete disruption of life “ I was on a path”
 - changed relationship with friends who “just didn’t get it”
 - disturbance in faith—inability to find comfort there
 - Relationship shifts
 - parents—relied on her more than before
 - husband—stressors in relationship
 - job—inability to find meaning in her work

Nancy--continued

- Began to make major changes in life
- Re-evaluation of meaning in life and purpose
 - This became more significant as she experienced inconsistencies in her usual supports
 - friends, family, faith
 - Decided to leave job s he had been doing for many years
 - Returned to school and became an elementary teacher
 - Gradually relied less on mother/parents, regained sense of adult self
 - Stabilized relationship with husband

Nancy --continued

- Able to take the crisis and challenge of diagnosis and make successful transition into new phase of life
- Able to reestablish old relationships and forge new ones
- Able to create new meaning in her life
 - Connected to service of teaching
 - Connected to personal values
 - Filled the gaps—spiritual and children

Nancy--continued

- Continued to see her on a “check in basis”
- Anxiety around appointments and life events such as:
 - when father diagnosed with cancer
 - as she tried to have a baby
- With each life event she managed well and applied “lessons learned”
 - called on her resources, relationships and strong sense of self

Survivorship Research

- Over 11 million cancer survivors in the US today
- Researchers have been looking at the long-term adaptation of survivors including the impact on
 - families
 - memory
 - sexual functioning
 - financial issues
 - Infertility

Schnoll, Knowles & Harlow, 2002

Survivorship Research

- More than 40 % of survivors struggle with longstanding side effects from treatment and psychological distress
- More than 48% of survivors reported symptoms of PTSD and continued grief responses
- 40% to 80% of cancer survivors report a persistent fear of recurrence
- 50% of breast cancer survivors reported disturbance in body image and distaste of scars and other body changes
- Many researchers have noted a diminished interest in sex and worsening sexual functioning as one of the most significant long term consequences of cancer

Schnoll, Knowles & Harlow, 2002

Impact of Group Therapy

- Spiegel (1978) conducted a support group for women with metastatic breast cancer ---those that participated in lived twice as long as those that did not
- Fawzy and Fawzy (1993) Melanoma survivors who participated in educational programs and learned adaptive coping mechanisms coped better and reported less anxiety than those that did not
- Goodwin (2001) While psycho-educational support groups do not extend life, they do help attendees cope better during treatment and afterwards

Kissane, 2009

Impact of group therapy

- Group therapy has been more effective than individual therapy in relieving anxiety and depression
 - Normalizes the experience
 - Reduces anxiety
- Groups experience can help people to increase quality of life
 - develop appreciation for deeper meaning and value in life

Kissane, 2009

How Can We Help?

- Research points to the importance of problem solving strategies to help facilitate adaptation among survivors such as:
 - Changing lifestyle
 - Fostering acceptance
 - Finding meaning
 - Expanding/fostering social support
 - Supporting adaptive coping mechanisms

What have we learned?

Most survivors can experience reactions/adjustments along three major areas:

Physical

Practical

Emotional

Rowland 2008; Ganz, 1998; Stanton 2005

Physical Adjustments

- Physical losses
- Many long standing side effects
 - Fatigue/stamina
 - Cognitive changes
 - Sexual functioning
 - Infertility
- Can cause barriers to usual level of functioning

Practical Adjustments

- Relationships can go through role changes
 - family, friends, on the job
- Financial stressors
- Medical Insurance
- Education
- Career
 - Gaps job history--new job or change careers

Emotional Adjustments

- Changes to the “healthy self”
 - Adjustment of self image/self-esteem
- Fear of recurrence
- Increased sense of vulnerability
 - Hypervigilance—constantly watching
 - Awareness of mortality
- Belief systems (spiritual/cultural)
 - finding meaning from the experience
- Social isolation/loneliness
- Overall sense of anxiety

Complexities of Follow Up

- An individual's ability to adjust and cope is fluid not static
- Individuals can experience repeated adjustments over time
 - triggered by tests
 - life changes and milestones
 - anniversaries of treatment
 - losses

Long-Standing Side Effects— “Back to the Future”

- We encourage our survivors to be diligent about screenings and follow up but:
 - Confusion about where to follow up
 - Reluctance to do so because of fear of recurrence
 - Re-traumatizing
 - Repeat the same patterns of coping which can be adaptive or maladaptive
- Mindful of the impact follow up can have on survivors and coping

Long –Standing Side Effects

- Can lead to:
 - Intermittent follow up and fear of recurrence
 - Anger at healthcare team
 - not being told about longstanding effects
 - Depression
 - Time of renewed vulnerability
 - Isolation
 - Inability to cope

How Can We Help?

- Through programmatic/group approaches
 - Normalize concerns
 - Decrease isolation
 - Empower through education
 - Focus on communication
 - family, friends, medical team
 - Address living with uncertainty
 - Encourage continue development of support and adaptive coping mechanisms

How do we help?

- Recognize that people navigate the survivorship phase in multiple ways
- Recognize that survivorship has multiple phases with repeated phases of coping
- There is not one way to understand and make sense of a cancer experience
- Aim to reduce isolation and increase knowledge by connecting people to peers and educational opportunities

RLAC Mission

- Post-Treatment Resource Program (PTRP) est. in 1988 renamed Resources for life After Cancer (RLAC) in 2011
- Survivorship Initiative established in 2003
 - Psychosocial support arm of initiative and for all patients at MSKCC and community
- To help adult cancer survivors (childhood cancer survivors) with adjustment after cancer
- Use a multi-modality approach including:
 - educational programs, support groups, individual counseling

Resources for Life After Cancer

```
graph TD; A[Resources for Life After Cancer] --> B[Education]; A --> C[Psychosocial Counseling & Education]; A --> D[Advocacy Peer Support]; B --> E[Support groups<br/>Individual counseling<br/>Locus of Information]; C --> E; D --> E;
```

Education

Psychosocial
Counseling &
Education

Advocacy
Peer Support

Support groups
Individual counseling
Locus of Information

RLAC – Program Rationale

- Program developed along the clinical principles of group work
 - Reduce isolation
 - Empower through education
 - Reduce anxiety
 - Build coping mechanisms
- To facilitate adjustments along three domains:
 - physical, practical, emotional

Quality of Life Programs

- Multiple quality of life programming
 - Cross diagnostic borders
 - Specific populations: young adults, men
 - Groups/lecture/workshops
- Relevant for the adult survivor population and childhood cancer survivors
- Programs address recent survivorship issues as well as long standing side effects
- Collaborate with staff from all over MSKCC

General Quality of Life Programs

- Physical quality of life:
 - fatigue, lymphedema, peripheral neuropathy, sexual health, urinary incontinence, cognitive functioning etc.
- Practical quality of life:
 - nutrition, managing relationships, exercise, career, communication w/ medical team, cognitive functioning etc.
- Emotional quality of life:
 - All of the above and fear of recurrence, finding meaning, managing uncertainty, coping with longstanding symptoms

Diagnosis-Specific Groups

- Head and Neck
- Brain
- Lung
- Bladder
- Esophageal
- Colorectal
- Stem Cell Transplant
- Hematologic cancers

Diagnosis-Specific Groups

- Co-led by social workers with nurses, psychiatrists, physical therapists or other medical staff
 - Psycho-educational groups
 - Open enrollment, ongoing groups
 - Caregivers included
 - Pt 2 Pt volunteers--mentoring

RLAC Statistics

- Offer approximately 140 groups/programs
- Over 1,700 people attend our groups from MSKCC and community
- Groups and program are both in-person and on-line
- See over 200 people for individual counseling
- Ongoing program evaluation
- Have many programs on the MSKCC Living Beyond Cancer Website : www.mskcc.org/livingbeyondcancer
 - Have survivors speaking about their experiences
 - Calendar with up to date listings of our programs

Case 2 --Liz

- Diagnosed with colon cancer
- Last weeks of pregnancy
- Age 34
- Immediately started chemotherapy
- Supportive spouse, friends
- Used individual therapy to grieve current cancer and past losses

Case 2 --Liz

- Persistent extreme anxiety
- Marked hyper-vigilance about recurrence
- Could not envision the future
- Felt out of sync with friends and family
- Feelings of guilt for not being able to care for her child when she was an infant
- Intermittent existential crises and alienation

Case 2 --Liz

- Marked persistent grief response to diagnosis
 - Based on her past experiences with cancer—mother died when she was young
 - Exacerbated by diagnosis at the point of birth of her first child
 - Restimulated by life milestones
 - Had to develop trust that she was going to live at the same time that she grieved past losses

Case 2 --Liz

- Was not depressed
 - functioned well
 - connected to family and friends
 - excellent communication/relationship with spouse
 - remained satisfied/productive at work
 - developed coping mechanisms to help with anxiety associated with scans and milestones

Case 2 --Liz

- Individual counseling addressed the grief – past and present
- Liz attended a young adult group at RLAC and there she was able to connect with a group of peers
- Achieved the ability to envision the future
- Developed insights into her feelings
- The group experiences normalized her reactions and reduced her existential isolation

Case 2 --Emily

- The group process gave her the words to describe what she was feeling
- Helped to reduce her anxiety and to normalize feelings
- The group process helped her to be able to trust in a future where she could envision herself living and thriving

Our Goals

- Normalize feelings—recognize that post-treatment adjustment is not simple nor time limited
- Give people the language to better understand their feelings
- Provide support through many venues that work for the individual his/her unique ways of coping
- Facilitate adaptation to survivorship phase
- Help people to recognize that they can go through multiple phases in survivorship
- Help individuals to internalize what they have learned and develop lasting, adaptive coping mechanism
- Help people return to their lives