The Survivorship Movement: Yesterday, Today and Tomorrow

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Objectives

- Review history of survivorship movement
- Explore semantics & stages of survival
- Identify multiple dimensions of advocacy
Trading Places 1971-1972
The Evolution of Cancer Care Awareness

- **American Cancer Society**
  - 1913 American Society for the Control of Cancer
  - 1936 Women’s Field Army (educate, raise $)
  - 1945 Changed name to ACS
  - **1952 Reach to Recovery**

- **The Leukemia Society**
  - 1949 Robert Roesler de Villiers Foundation
  - 1960 The Leukemia Society (included lymphoma, multiple myeloma)
  - 2000 The Leukemia & Lymphoma Society

- **Clinical trials 1960’s**
  - Radiation therapy, combination chemotherapy
Why Survivorship?

Dr. Elizabeth Kubler Ross & Death & Dying

1960-1970’s  Learning to die from cancer

1970-1980’s  Learning to live with, through, and beyond cancer
The War on Cancer

President Richard Nixon signs National Cancer Act on December 23, 1971

“Make the Conquest of Cancer a National Crusade”
Breast Cancer

- 1970’s War on Cancer, advocates speak out (Shirley Temple Black, Happy Rockefeller, Betty Ford)
- 1976 SHARE: Self help for women with breast cancer
- 1977 Why Me? By Rose Kuschner
1970’s Birth of Oncology

- Oncology as new sub-specialty
- Only in academic centers
- Physicians gave chemotherapy
- Oncology nursing begins
1980’s New Needs

- Support groups
- Wellness
- Community
- Surviving
- QOL as focus
- Networking
- LTC (PLTC)
“Despite the success on the treatment front, we have done very little in a concerted and well-planned fashion to investigate and address the problems of survivors. It is as if we have invented sophisticated techniques to save people from drowning, but once they have been pulled from the water, we leave them on the dock to cough and splutter on their own in the belief that we have done all that we can.”

Fitzhugh Mullan  NEJM: 313:270-273 (July 25), 1985
Birth of a Movement

1986 National Coalition for Cancer Survivorship (NCCS) founded in Albuquerque NM

Network
Raise Awareness
Support
Stimulate Research

For ALL Cancers! All Phases!
Breast Cancer in the 80’s

- NABCO
- Y-ME (Chicago)
- Susan G. Komen BC Foundation (Dallas)
- Women’s Community Cancer Project (Boston)
- Women’s Cancer Resource Center (Oakland)
- Breast Cancer Action (San Francisco)
- Mautner Project for Lesbians with Cancer (Washington, DC)
- Susan Love, MD, as unifying voice
New Decade – 1990’s

Proliferation of Disease-Specific (BODY-PART) Advocacy Organizations
GYN Advocacy

- 1991 Gynecologic Cancer Foundation (GCF) founded
- 1993 Conversations! Newsletter started
- 1995 (GCF) awarded 1st research grants
- 1995 SHARE became Self-Help for Women with Breast or Ovarian Cancer
- 1997 Ovarian Cancer National Alliance formed (response to DOD research program)
Into the 1990’s

- **1991** National Breast Cancer Coalition
  - Do the Write Thing
  - National Action Plan
  - DOD $$$

- **1993** Cancer Leadership Council
  Develop consensus on health care policies from perspective of patients/survivors
Survivorship Takes Off....

- 1995  Imperatives for Quality Cancer Care (NCCS)
- 1996  Office of Cancer Survivorship
- 1997  Lance Armstrong Foundation
March on Washington DC in 1998
The goal – “No More Cancer”

Results:
- 16% increase in funding for NIH
- opened the door to discussing access to care issues
2000 New Century

A National Action Plan for Cancer Survivorship: Advancing Public Health Strategies

Living Beyond Cancer: Finding a New Balance

Managing Late and Long-Term Sequelae of Cancer and Cancer Treatment

Childhood Cancer Survivorship

From Cancer Patient to Cancer Survivor

Lost in Transition

CDC

IMPROVING CARE AND QUALITY OF LIFE

INSTITUTE OF MEDICINE
NATIONAL RESEARCH COUNCIL
2005-2006 The Big Bang
IOM Report Shows

- Cancer is often a chronic condition, but is not treated as one.
- When treatment ends, most cancer survivors do not have a follow-up care plan or treatment summary.
- Surviving cancer is something to celebrate, but it is not the end of the road.
- Cancer changes your life forever, and it also changes your healthcare needs forever.
Who is a Survivor???
Luxury of Labeling

- Patients
- Survivors
- Thrivers
- Victors
- Sufferers
- Activists
- Warriors
- Veterans
- Advocates
- “The Blessed”
- Cancer Fighters
- Cancer Conquerors
- Cancer “Killers”
What is Survivorship?
“Survivorship is not some club you join after several months of treatment – or after five years or ten years. Rather, survivorship is life-long, beginning with the diagnosis of cancer and continuing for the balance of life – through the medical studies and treatments, the financial and vocational trials, the ups and the down.”
A Cancer Survivor’s Almanac: Charting Your Journey

“Cancer survivorship is the challenge faced daily by millions of Americans who are engaged in defiance of disease and in affirmation of life. The disease-free return to active life and terminal care and palliative treatments are all part of the continuum of survivorship.”

Defining Survivor vs. Survivorship

- Is it a time frame?
- Is it a process?
- Is it a stage of survival?
Differences in Defining

- **Time Frame**: Pediatric oncology first defined survivor as any patient living 5 years free of disease after diagnosis.

- **Process**: NCCS created term “survivorship” as process of survival and labeled anyone with cancer as survivor going through stages.

- **Stage**: Oncology (medical) community defines survivor as patient who is no longer in active treatment.
“Seasons of Survival”


- Acute Stage
  - Diagnosis
  - Treatment

- Extended Stage
  - Remission
  - Maintenance

- Permanent Stage
  - Long-term survival
  - “Cure”
Stages Intertwined

- Acute
- Transition
- Extended
- Permanent
- End of Life
Survivorship Pathways

Living cancer-free for the remainder of life
Living cancer-free for many years but experiencing one or more serious, late complications of treatment
Living cancer-free for many years, but dying after a late recurrence
Living cancer-free after the first cancer is treated, but developing a second cancer
Living with intermittent periods of active disease requiring treatment
Living with cancer continuously without a disease-free period

(ACS Survivorship Facts & Figures 2013)
Impacts of Long Term Survival

- Social/Financial
- Psychological/Emotional
- Spiritual/Existential
- Physical/Biomedical
Quality of Life Model Applied to Cancer Survivors

Physical Well Being and Symptoms
- Functional Activities
- Strength/Fatigue
- Sleep and Rest
- Overall Physical Health
- Fertility
- Pain

Social Well Being
- Family Distress
- Roles and Relationships
- Affection/Sexual Function
- Appearance
- Enjoyment
- Isolation
- Finances
- Work

Psychological Well Being
- Control
- Anxiety
- Depression
- Enjoyment/Leisure
- Fear of Recurrence
- Cognition/Attention
- Distress of Diagnosis and Control of Treatment

Spiritual Well Being
- Meaning of Illness
- Religiosity
- Transcendence
- Hope
- Uncertainty
- Inner Strength

Cancer Survivorship

Ferrell, BR and Grant, M. City of Hope Beckman Research Institute (2004)
Social Impacts

- Isolation
- Appearance
- Changes social roles & relationships
- Distress within family unit
- Sexuality issues (physical, emotional, social)
- Employment discrimination/problems
- Insurance and financial concerns
- Inequalities in minority populations
Psychological Impacts

- Fear of recurrence or death
- Chronic anxiety
- Uncertain future, control
- Fear of dependency
- Survivor guilt
- PTSD or depression
- Chemobrain (cognition)
Spiritual/Existential Impacts

- New sense of “normal”
- Who am I now?
- Meaning of illness and life after cancer
- Changing sense of hope and future
- Relationship with organized religion and God
- Transcendence – going beyond, surpass, exceed
- PTG (post traumatic growth)
Physical Impacts

**Long-term or lingering effects**
Continue after treatment ends
May be chronic
Example: Peripheral neuropathy, fatigue, pain

**Late or delayed effects**
Surface months to years later
Example: Recurrence, osteoporosis, vaginal atrophy, lymphedema
No Guarantees

Illness doesn’t make life uncertain. It simply exposes the uncertainty of life.

(Wendy Harpham, MD, author, lecturer, cancer survivor)
It doesn’t matter if the glass is half empty or half full. Be thankful that you have a glass and grateful that there’s something in it.

www.inspirationalpicturequotes.net
Advocacy

- IS NOT:
  - Just about political activism or legislative advocacy
Advocacy IS:

- Multi-dimensional
- Meant to affect change and thereby improve the quality of people’s lives.
NCCS Model of Advocacy

- For SELF
  - Personal Advocacy

- For OTHERS
  - Groups & Organizations

- For COMMUNITY
  - National & public interest, including research and politics
Dimensions of Advocacy As A Consumer Issue

- Self-Advocacy (Personal)
- Community Advocacy (Groups and Organizations)
- National and Public Interest
- Research Advocacy
- Legislative Advocacy
Self-Advocacy

- Personal level/Empowerment
- Basic foundation of all advocacy
- Using skills that are included in Cancer Survival Toolbox
- Identifying someone to advocate for you
Community Advocacy

- Interpersonal
- Advocate with and for each other
- Finding Resources
- Giving Back
National Advocacy

- Professional advocacy
- General or disease-specific advocacy organizations
- National committee representation
- Raise awareness through writing, publishing, public speaking
- Collaborations
- Raise money for research
Research Advocacy

- Patient/consumer advocates
- Sit on medical research boards
  - NCI
  - ASCO
  - AACR
- Review & give input for grant proposals from survivor perspective
Legislative Advocacy

- Activists
- Develop & pass cancer-related initiatives
- Testify before government bodies
Deborah Collyar Model of Advocacy

- Fund-raising (Komen, LAF)
- Support and education (Y-ME, LLS)
- Watchdog (Breast Cancer Action Fund)
- Research (IMF, PanCan)
- Legislative (NCCS, NBCC)
To be continued…….