International Collaboration on Cancer Survivorship Research and Care: Opportunities and Challenges

Kevin D. Stein, PhD
Managing Director, ACS Behavioral Research Center (BRC)
Director, Survivorship & Quality of Life Research
American Cancer Society
National Home Office
Atlanta, Georgia
Cancer Survivorship – A Global Issue
The whole is *greater* than the sum of it’s parts

Aristotle (384-322 BC)
5-year prevalence, all cancers, both sexes. Globocan 2012 estimates.
International Prevalence of Cancer

All cancers excl. non-melanoma skin cancer: both sexes
Estimated 5-year prevalent cancer cases (x1000), adult population

- Europe: 9,168 (28.2%)
- Asia: 13,192 (40.5%)
- Oceania: 447 (1.4%)
- Africa: 1,780 (5.5%)
- Latin America and Caribbean: 2,643 (8.1%)
- Northern America: 5,315 (16.3%)
Definitional Issue: Who is a Cancer Survivor? (NCCS, 1986)

NCCS, ACS, and NCI definition: Anyone who has been diagnosed with cancer is a survivor— from the time of diagnosis and for the balance of life.

Differentiate types of survivors:

• In active treatment
• Disease-free long-term survivors (≥5 yrs post-dx);
• Those living with cancer as a chronic disease

NCCS = National Coalition for Cancer Survivors
Why focus on Cancer Survivors?
Trends in Cancer Survival in Developed vs Developing (LMI) Countries

Figure 4. Localized and regional extent of disease among more and less developed health services, large bowel cancer

Figure 4a. 5-year absolute survival

![Bar chart showing 5-year absolute survival for localized and regional stages.

Localized:
- Less developed health services (e.g., Thailand, India, Philippines) - 32.0%
- More developed health services (e.g., Singapore, Turkey) - 49.8%

Regional:
- Less developed health services (e.g., Thailand, India, Philippines) - 45.7%
- More developed health services (e.g., Singapore, Turkey) - 64.1%

Figure 4b. Absolute survival

![Survival graph showing differences between more and less developed health services.]

More developed
- Localized: 26.0%
- Regional: 27.0%

Less developed
- Localized: 29.0%
- Regional: 34.0%

http://survcan.iarc.fr
The absolute number of cancer survivors is predicted to increase nearly threefold over the next few decades, while the number of cancer deaths is expected to double.
Cancer Survivors are at risk: **Chronic & Late** Effects of Cancer

- Recurrence/new cancers
- CVD
- Diabetes
- Osteoporosis
- Obesity
- Functional limitations
- Disability
- Neuropathy
- Pain
- Sexual Impairment
- Lymphedema
- Incontinence
- Poor Quality of Life
- Fatigue
- Depression, Anxiety
- Uncertainty
- Poor body image
- Relationship changes
- Job & Insurance problems
- Financial burden
- Endocrine dysregulation
- Obesity
- Diabetes
- Osteoporosis
- Recurrence/new cancers
- CVD
- Endocrine dysregulation
- Financial burden
Trends in Obesity in the US: It’s headed your way!!!
Why Focus on Cancer Survivors?

• Population of cancer survivors is growing...

• Yet, high level of unmet needs
  – For information
  – For emotional support and symptom management
  – For post-treatment care

• And, still much to be learned regarding:
  – Prevalence and management of late effects
  – Ongoing post-treatment care needs
  – Optimizing health and health behaviors
The Current State of Affairs, Internationally…

• Great differences across nations with respect to survivorship research, care, and policies
• Limited, but growing, recognition of survivorship as a distinct phase along the cancer continuum
• Little current international coordination, but there are signs of hope…
1st EORTC Cancer Survivorship Summit
30-31 January 2014
Square Meeting Centre (Brussels, Belgium)

Cancer Survivorship: a need for international collaboration
1st EORTC Cancer Survivorship Summit

30-31 January 2014
Square Meeting Centre (Brussels, Belgium)

Special Issue: European Journal of Cancer

Format:
5 original articles, based on pre-summit working groups:

1. second malignancies
2. cardiovascular disease
3. infertility/sexuality
4. cognitive dysfunction
5. psychological/social impact of cancer
This supplement was sponsored by the National Cancer Research Centre Istituto Tumori “Giovanni Paolo II” Bari (Italy) through the Italian Ministry of Health-funded research project “Multidimensional assessment of long-term cancer survivors including discovery of genetic bases of susceptibility, depressive stage, prevention of affective disorders”, and through intramural funding of the American Cancer Society’s Behavioral Research Center.
European-American Dialogues on Cancer Survivorship: Current Perspectives and Emerging Issues

Format:

- 10 original articles, 1 introduction, 2 forewords, 1 preface, 1 afterword
- Jointly written by a mixed team of 55 US and European researchers
- Reporting on similarities, disparities and problems from point of view of each author’s respective continent.

Objective:

To stimulate an international dialogue among researchers, create a springboard for increased collaboration, and aid in the development of a shared care model to improve the quality of life of cancer survivors worldwide.
Introduction: Dialogues on Cancer Survivorship: A New Model of International Cooperation

Kevin Stein and Vittorio Mattioli

Foreword I: The European Perspective
John Dalli

Foreword II: The American Perspective
John R. Seffrin

Preface: Francesco de Lorenzo and Pamela J. Haylock

Original Articles

Cancer Survivorship Research in Europe and the United States: Where Have We Been, Where Are We Going, and What Can We Learn From Each Other?
Julia H. Rowland, Erin E. Kent, Laura Forsythe, Jon Havard Loge, Lars Hjorth, Adam Glaser, Vittorio Mattioli, and Sophie D. Fossa

Population-Based Cancer Registries for Quality-of-Life Research
Melissa S. Y. Thong, Floortje Mols, Kevin D. Stein, Tenbroeck Smith, Jan-Willem W. Coebergh, and Loneke V. van de Poll-Franse

Cancer-Related Fatigue and Its Impact on Functioning
Ollie Minton, Ann Berger, Andrea Barsevick, Fiona Cramp, Martine Goedendorp, Sandra A. Mitchell, and Patrick C. Stone

Cardiac Toxicity in Cancer Survivors
Daniel J. Lenihan, Stefano Oliva, Eric J. Chow, and Daniela Cardinale

Interventions to Promote Energy Balance and Cancer Survivorship
Catherine M. Alfano, Alessio Molfino, and Maurizio Muscaritoli

Employment Challenges for Cancer Survivors
Anja Mehnert, Angela de Boer, and Michael Feuerstein

Informal Caregiving for Cancer Patients
Francesca Romito, Gil Goldzweig, Claudia Cormio, Mariet Hagedoorn, and Barbara L. Andersen

Current Perspectives and Emerging Issues on Cancer Rehabilitation
Michael D. Stubblefield, Gill Hubbard, Andrea Cheville, Uwe Koch, Kathryn H. Schmitz, and Susanne Oksbjerg Dalton

Survivorship Programs and Care Planning
Mary S. McCabe, Sara Faithfull, Wendy Makin, and Yvonne Wengstrom

Health Care Policy and Cancer Survivorship
Katherine S. Virgo, Julia L. Bromberek, Adam Glaser, Denis Horgan, Jane Maher, and Otis Brawley

Afterword: The Role of Comprehensive Cancer Centers in Survivorship Care
Wim H. Van Harten, Angelo Paradiso, and Michelle M. Le Beau
The Challenges of coordinating the issue:

- 55 Authors from different continents, with different time zones, and primary language
- "day job" workloads and commitments
- Larger writing groups of essentially strangers
- Differences across countries in policies/practice
- Differences in research and practice
- Social and cultural factors that influence and shape the unique survivorship care scenarios for every country
European Collaborative Group on Cancer Survivorship (ECGCS)

The European Collaborative Group on Cancer Survivorship was founded on Friday, April 27th 2012 in Bari, Italy, by a group of researchers with many years’ experience in the field of cancer survivorship to unite their efforts in a new initiative to improve research and meet the needs of cancer survivors.
The ECGCS Website

www.ecgcs.eu
Proposed Focus Areas of the ECGCS

- Current knowledge status
- Gaps in knowledge
- Barriers (policy, access to care, ethical, etc)
- Development of research programs & guidelines
- Study planning and comparison
- Educational and training projects
- Dissemination of findings
- Specific health policies
- Future directions and strategies
Current ECGCS Membership

Current Membership includes 120 individuals from 22 countries:

**EU States (17):** Italy 22; United Kingdom 16; Netherlands 9; Sweden 5; Norway 4; Germany 4; Belgium 3; France 3; Denmark 2; Finland 2; Ireland 2; Portugal 2; Spain 2; Switzerland 2; Romania 1; Russia 1; Slovakia, 1

**Other States (5):** United States 31; Australia 2; Canada 2; Israel 2; Turkey 1
International Survivorship Efforts: 3 “Tiers” of Development

• Tier 1: The United States, Canada, Australia, and Western and Northern Europe + Italy
  – Extensive research infrastructure, emerging policies, practices and guidelines

• Tier 2: Eastern/southern Europe, Asia (primarily Japan & Korea), parts of Latin America (e.g. Brazil)
  – Limited research infrastructure, few survivorship oriented policies or practice, no guidelines

• Tier 3: Low-to-middle income (LMI) countries: Africa, the Caribbean, Central America
  – Very limited research, almost no focus on survivorship, focus on treatment and pain management
International Organizations and Societies

- American Cancer Society®
- National Cancer Institute
- Livestrong Foundation
- We Are Macmillan Cancer Support
- International Agency for Research on Cancer
- World Health Organization
- ISOQOL
- UICC
IPOS Federation Editorial in
Psycho-Oncology

Psycho-Oncology 21: 1027–1033 (2012)
Published online in Wiley Online Library (wileyonlinelibrary.com). DOI: 10.1002/pon.3154

Editorial

Psychosocial care in cancer: an overview of psychosocial programmes and national cancer plans of countries within the International Federation of Psycho-Oncology Societies

Luigi Grassi1*, Maggie Watson2 and on behalf of the IPOS Federation of Psycho-Oncology Societies’ co-authors†

1Section of Psychiatry, Department of Biomedical and Specialty Surgical Sciences, University of Ferrara, Ferrara, Italy
2Royal Marsden Hospital and Institute of Cancer Research, University College London, London, UK

*Correspondence to: Section of Psychiatry, Department of Biomedical and Specialty Surgical Sciences, University of Ferrara, Ferrara, Italy. Email: Luigi.Grassi@unife.it

Abstract

We report data from representatives of national professional psycho-oncology societies on the integration of psychosocial care into national cancer programmes or cancer plans. To date information on how, or whether, psychosocial care has been recognized and integrated into com
So, what do we need to do now???

• Look for international, cross-cultural opportunities for collaboration
• Build on existing efforts while also developing new infrastructure
• Identify leadership and future directions
• Seek the “low hanging fruit”
Potential Impact of International Collaboration

1. Conducting Survivorship Research
2. Developing and Enhancing Infrastructure
3. Providing Optimal Care to Survivors
4. Policy and Advocacy Efforts
Potential Impact of International Collaboration

1. In Conducting Survivorship Research....

   • Increase statistical power from pooled data
   • Improve the generalizability of findings
   • Improve upon opportunities for mentorship and research capacity building
   • Ability to compare and contrast various models of survivorship care
Potential Impact of International Collaboration

2. Developing & Enhancing Infrastructure

• Establish and enhance cancer registries
• Encourage use of common data elements in clinical trials and survivorship research
• Establish and coordinate INTERNATIONAL COHORT STUDIES of cancer survivors (with appropriate control groups)
Potential Impact of International Collaboration

3. In Providing Optimal Care to Survivors

- Identify BEST PRACTICES from various countries and share that information internationally to improve care of survivors
- Compare/contrast various models of survivorship care
- Identify best methods for screening, assessment, and management for issues that affect QoL
Potential Impact of International Collaboration

4. In Policy and Advocacy Efforts

• Create international “think tanks” to share best practices in policy and advocacy efforts
• Identify optimal communication strategies
• Leverage the voice of cancer survivors & advocates to increase attention and funding on survivorship issues
How do we do this???

• Build awareness of survivorship issues
• Build capacity for survivorship care, research, and policy work in survivorship
• Develop, implement, and share guidelines for survivorship care
• Develop governmental policy support for international collaborations

From grass-roots to grass-tops (Policy makers)
Global collaboration is the way forward

*If you want to go fast, go alone*

*If you want to go far, go together*
Synergy

Synergy, from the Greek word Synergia, meaning “to work together”
June 18-20, 2014
Atlanta, Georgia
Early bird registration until April 30
More info:
www.cancer.org/survivorshipconference2014
QUESTIONS
ACS Educational Publications (Facts & Figures)
Integration of Survivorship Activities

- Discover and Knowledge Gain
- Information and Program Development
- Policy and Advocacy Efforts
- Information and Program Delivery
ACS Educational Publications (Facts & Figures)

- Cancer Treatment & Survivorship Facts & Figures 2012-2013
- Global Cancer Facts & Figures 2nd Edition
American Cancer Society’s International Research Collaborations
CANCON

Future Joint Action on the Development of the European Guide on Quality Improvement in Comprehensive Cancer Control

Starting Date: February 2014
Ending Date: February 2017
TO PUBLISH The ‘European Guide on Quality Improvement in Comprehensive Cancer Control’

The Guide will act as a European benchmark, providing a roadmap or strategy to optimize cancer control.
WORK PACKAGE STRUCTURE

WP 1, COORDINATION
- WP 4, GUIDE COORDINATION
- WP 5, PLATFORM FOR MEMBER STATE COOPERATION

WP 2, DISSEMINATION
- WP 6, INTEGRATED CANCER CARE
- WP 7, COMMUNITY-LEVEL CANCER CONTROL

WP 3, EVALUATION
- WP 8, SURVIVORSHIP & REHABILITATION
- WP 9, SCREENING

future projects
WP 8, SURVIVORSHIP & REHABILITATION

OBJECTIVE:
• to develop a rehabilitation and survivorship plan. Proposed structure based on "patient categorization (fully cured/ not cured (chronic cancer) /advanced phase)

NEEDS TO ADDRESS:
• For cured patients: surveillance, sequels (late side effects), permanent or temporary disabilities, need (late) side-effects, prevention of recurrence, psycho – social needs (distress mgt scale), return to work- reintegration to productive life
• For chronic patients: mgt of cancer as chronic disease, disability, return to work while being treated, etc;
• For advanced stage patients: supportive and palliative care
Work Package Details

Number: 8 - Rehabilitation and Survivorship
Leader: French National Cancer Institute (INCa)
Total budget of WP: 800k€ (estimate)

Names of Associated Partners:
- Catalan Institute of Oncology (ICO), Spain
- Institute of Public Health, Slovenia
- National Cancer Research Centre "Giovanni Paolo II", Italy
- Trondheim University Hospital, Norway
- Cancer Society of Finland, Finland

Names of Collaborating Partners:
- Scientific Institute of Public Health, Belgium
- Ministry for Health, the Elderly and Community Care, Malta
- European Collaborative Group on Cancer Survivorship
- International Psycho-Oncology Society
- Direccao-General da Saúde, Ministerio da Saúde, Portugal
ERA-NET on Translational Cancer Research (TRANSCAN)
Joint Transnational Call for Proposals 2013 (JTC 2013) on:

"Translational research on tertiary prevention in cancer patients"
Low Hanging Fruit...
Low Hanging Fruit...
THE BIG question

- How do we create a system of cancer survivorship care that meets the needs of all our survivors?

To answer this, we need GLOBAL COLLABORATION
It takes a village...
Trends in Cancer Mortality Worldwide over Last 35 years
International Prevalence of Cancer

World: Both sexes
Estimated 5-year prevalent cancer cases, adult population (total: 3,254,463)

- Breast: 6,255,391 (19.2%)
- Prostate: 3,923,668 (12.1%)
- Colorectum: 3,543,582 (10.9%)
- Lung: 1,893,078 (5.8%)
- Cervix uteri: 1,547,161 (4.8%)
- Stomach: 1,538,127 (4.7%)
- Bladder: 1,319,749 (4.1%)
- Corpus uteri: 1,216,504 (3.7%)
- Thyroid: 1,206,075 (3.7%)
- Other: 10,101,298 (31.0%)
Causes of Comorbidities and Late Effects: Is it a Cancer effect or is it simply Aging?

- AIDS
- Myocardial Infarction
- Congestive Heart Failure
- Peripheral Vascular Disease
- Cerebrovasc. Disease
- Dementia
- Chronic Pulmonary Disease
- Rheumatol. Disease
- Septic Ulcer
- Diabetes
- Diabetes w/ Complication
- Renal Disease
- Hemiplegia or Paraplegia
- Moderate/Severe Liver Disease

Weight:
- 1
- 2
- 3
- 6

Dementia (1) + Severe Liver Disease (3) = 4