2017B015
Work experiences and challenges for individuals with cancer:
Current state of research and future directions
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Talk Overview

PART 1
Background and current state of research on cancer and employment  » BANEGAS

PART 2
Real-world examples of employment-related intervention  » AUBEL

PART 3
Future directions for the field and research on cancer and employment  » DE MOOR
1.69 million new cancer cases and 600,920 cancer deaths expected in 2017

15.5 million individuals with a history of cancer were alive in 2016

Breast (female), prostate, lung, and colorectal cancers are the most commonly diagnosed

Overall, cancer mortality is decreasing, about 25% in the past two decades

Phases of Cancer

- **Pre-Diagnosis Phase**: period prior to cancer diagnosis
- **Treatment Phase**: period following cancer diagnosis through end of treatment
- **Continuing Phase**: period between treatment & end-of-life phases
- **End-of-Life Phase**: period prior to death
Phases of Cancer and Associated Events

**DIAGNOSIS**
- Intense medical care related to cancer diagnosis process
- Emotional and mental effects of cancer diagnosis
- Treatment Decision-making

**TREATMENT**
- Intense medical care related to treatment
- Physical, psychological, emotional and social effects of treatment
- Potential fatigue, functional impairment, stress, depression, employment challenges, financial hardship

**SURVIVORSHIP**
- Medical care related to follow-up and recovery
- Late-/long-term physical, mental, emotional, and social effects
- Return to pre-cancer life, (re-)employment and social reintegration

**END-OF-LIFE**
- Intense medical care related to decreasing health condition
- Decreased functional abilities
- Life transition decision-making
Cancer & Work Model

Work-related Issues Important Across All Phases of Cancer

- Support
- Time-off
- Privacy
- Work-schedule
- Finances
- Co-worker
- Family
- Supervisor
- Return-to-work
- Recovery
- Leave
- Accommodations
- Retire
- Sick-time
- Side-effects
- Insurance
- Appointments
- Income
- Treatment
- Self-worth
- Transportation
Effects of Cancer on Work over Time

Source: Zajacova et al. Cancer. 2015 Dec 15;121(24):4425-32. Figure 3. Effects of cancer diagnosis on economic outcomes, based on adults aged 18 yrs and older.
Gradual Increase in Return to Work Following Cancer

Individuals diagnosed with cancer who return to work or who continued working (%)

<table>
<thead>
<tr>
<th>Months since diagnosis</th>
<th>6</th>
<th>12</th>
<th>18</th>
<th>24</th>
</tr>
</thead>
<tbody>
<tr>
<td>Percentage</td>
<td>40%</td>
<td>62%</td>
<td>73%</td>
<td>89%</td>
</tr>
</tbody>
</table>

Select Factors Associated with Return to Work and Employment Following Cancer

<table>
<thead>
<tr>
<th>Cancer Type</th>
<th>Type of treatment(s)</th>
<th>Time-since-treatment</th>
<th>Burden and type of treatment-related side-effects</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>Caregiver support</td>
<td>Marital status</td>
<td>Insurance status</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Income</td>
</tr>
<tr>
<td>Workplace Accommodations</td>
<td>Workplace Flexibility</td>
<td>Employer Benefits</td>
<td>Type of work (e.g., manual labor)</td>
</tr>
</tbody>
</table>
Many Individuals with Cancer Have No Choice but to Continue Working

**44%**
Percentage of employed cancer survivors who reported to have not made any employment changes in 12 months following cancer diagnosis

**Top 3 Reasons** for maintaining employment following cancer diagnosis

- **63%** FINANCIAL REASONS
- **51%** FEEL WELL ENOUGH TO WORK
- **42%** NEED TO KEEP HEALTH INSURANCE

**Sources:**
Indicators of Work Productivity Loss in Cancer Survivors

At any time from when you were first diagnosed with cancer until now, were...

- Any change in work because of cancer (extended paid time off, unpaid time...
  - Yes: 58%, No: 42%

- Cancer interfered with ability to perform physical tasks required by job
  - Yes: 25%, No: 75%

- Cancer interfered with mental tasks required by job
  - Yes: 14%, No: 86%

- Ever felt less productive at work
  - Yes: 25%, No: 75%

Age of Individual with Cancer may Affect the Impact on Work

11.4
Average number of work days missed among employed individuals who are age **65 years and older**, recently (≤1 year) diagnosed with cancer

16.9
Average number of work days missed among employed individuals who are **under age 65 years**, recently (≤1 year) diagnosed with cancer

Higher Average Annual Productivity Loss for Cancer Survivors, By Sex

Importance of returning/continuing work following cancer diagnosis

<table>
<thead>
<tr>
<th>Return to normalcy</th>
<th>Recovery</th>
<th>Social support</th>
<th>Self-worth</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mental and social stimulation</td>
<td>Productivity</td>
<td>Retention</td>
<td>Engagement</td>
</tr>
</tbody>
</table>
Cancer and Employment: Real World Application
Continued employment benefits everyone in the workplace after a diagnosis of cancer

1 Framework
A broad overview and few examples will be reviewed.

2 Best Practices
Please share your best practices and ideas during the Q&A session.

3 Resources
CEO Cancer Gold Standard

An example of a framework based in science, adaptable to a wide range of employers
The Gold Standard provides a framework for employers to have a healthier workforce by focusing on cancer risk reduction, early detection, access to clinical trials and high-quality care.

The Gold Standard is a no cost accreditation, for more information visit www.CancerGoldStandard.org
The Gold Standard’s five pillars

1. Prevention
   - Tobacco Cessation
   - Nutrition
   - Exercise
   - Weight Management
   - Vaccinations

2. Screening
   - Health insurance options for early cancer detection

3. Cancer Clinical Trials

4. Quality Treatment and Survivorship

5. Health Education and Health Promotion
**PILLAR 4:** Sustain a workplace culture that recognizes the needs of cancer survivors and their family members/caregivers.

**POLICIES**

- **Clear accommodation policies** – such as a flexible work schedule and/or modified duties for a period of time for transition.

- **Flexible work policies** for employees who are family members/caregivers.

- Information about policies & services in **training programs for all managers**.

- **Designated occupational health or HR advisors** for employees – and their managers – about how policies and appropriate services can be helpful after a cancer diagnosis.

**PROGRAMS**

- **Support programs** for survivors and caregivers – from cancer diagnosis through post-treatment support needs.

- **Mentoring/peer** support programs.

- Assistance in **navigating the cancer clinical trial system** e.g. disease management services, health education seminars.

- **Referral system** to critical navigation and survivorship services.
Gold Standard employers of choice
Best Practices

Examples of workplace initiatives
Gold Standard Employers at a Glance

**VANDERBILT UNIVERSITY**

*Gold Standard Employer: Vanderbilt University Medical Center*

**MD ANDERSON**

*Gold Standard Employer: MD Anderson Cancer Center*

MD Anderson celebrates Survivorship Week for their employees who have been affected by cancer.

**MOFFITT CANCER CENTER**

Moffitt Cancer Center promotes health in prevention and survivorship of cancer.
Novartis’ Survivorship Program

The Cancer Survivorship Program

Ensemble is a supportive community that provides quality guidance and medical, emotional and physical support to associates touched by cancer.

You’re not alone
As a Novartis associate, you have access to a wide range of resources designed to help you cope with the personal and professional stress of a cancer diagnosis.

- What if I cannot come to work or need some time to address health concerns?
- If my physical needs change, can my work environment be adjusted?
- What if I just need someone to talk to?

Contact a Nurse Navigator by calling 855-5NAVIGA (855-562-8442). 8am-5pm EST (Mon-Fri)

Please click here to contact us.

We respect your privacy, and we want you to know that the information you provide will be held strictly confidential. Novartis will not have access to the information you provide. Our email address and call line are linked to separate private and confidential portals which are password protected and accessible by the Ensemble Nurse Navigators only.
Resources

For cancer survivors, occupational health providers, and employers
Cancer Survivor Resources: Cancer and Careers

BE THE BOSS OVER CANCER
Cancer and Careers empowers and educates people with cancer to thrive in their workplace, by providing expert advice, interactive tools and educational events.

BACK TO WORK AFTER CANCER

Setting Professional Boundaries
Although it can be difficult to say “no,” learning how can help you become a better employee.

Recasting Yourself After Cancer
A common fear for people returning to their same job/company following a diagnosis or treatment is that people will see them differently. Learning how to move past this can help you feel more confident during the job search.

Men, Cancer & Work: Coming to Terms with the “New Normal”
A diagnosis of cancer can affect the identity often attached with one’s work—especially if you see yourself as a “provider.” Learning how to reconnect with your career path can make you feel more whole.

Back to Work
Find out what you need to know about how your cancer history may affect you on the job and how to take control of your career.

INFORMATION
365,000+
Individuals access expert information, support and resources online, in print and in person annually.

EDUCATION
99%
99% of 2016 program participants said they can use what they learned in their day-to-day activities.
Provider Resources

NIH NATIONAL CANCER INSTITUTE
Division of Cancer Control & Population Sciences

Office of Cancer Survivorship

For Health Care Professionals
This page provides numerous cancer-related resources for health care professionals:
clinical trials and links to other National Cancer Institute resources, please go to the

- Guidelines
- Collection of Helpful Resources
- Publications and Newsletters
- Searchable Database and Newsletters
- Cancer Survivorship Telephone Workshop Series
- Past Biennial Cancer Survivorship Research Conferences

For Health Professionals and Researchers

- Improving Emotional Health, Quality of Life, and Healthy Behaviors
- Treatment and Follow-up Care
- Preventing Infections in Cancer Patients, Survivors, and Caregivers
- Family History and Genomics
- Web Plus Survivorship Module
- CDC’s Programs and Research
- Data Resources
- Resources by Cancer Type
- Caregiving Resources and Research
- Support Programs and Services
- Survivorship Fact Sheets
  - Cancer Survivorship: Version 1 (with family photos) [PDF-433KB]
  - Cancer Survivorship: Version 2 (with individual photos) [PDF-401KB]
Employer Resources: Workplace Transitions

PREPARE
Understand your role as a manager. Know the law and learn about accommodations.

SUPPORT
Get help managing diagnosed and caregiving employees.

ACT
Get help creating a transition plan for your employee.

Workplace Transitions is a free resource created to help you and your company (whether small or large) manage cancer in the workplace. It was designed to enhance the quality of life for people facing cancer and to improve employee retention, morale, and productivity. It offers guidance for managers, free resources for employees and managers, and support for companies of all sizes.

This eToolkit is designed to complement your company’s existing policies and procedures. Knowing what your company already provides is important to your success.
FOR MANAGERS:

GET STARTED

WORKPLACE TRANSITIONS
for people touched by cancer

WorkplaceTransitions.org
Conclusions

» All employers can support employees affected by cancer whether they are a cancer survivor, caregiver/family member, or manager.

» There are a range of resources available to provide a culture of wellness for this growing population.

» This niche of the employee will become increasingly important to focus on holistic wellness in the development, improvement, and research of clinical employee health/occupational health initiatives.
Employment after a Cancer Diagnosis: Research Gaps and Opportunities

Janet S. de Moor, PhD, MPH, Program Director
Healthcare Assessment Research Branch, Healthcare Delivery Research Program
Division of Cancer Control and Population Sciences
National Cancer Institute, National Institutes of Health
Agenda

1. Review state of the science about cancer-related work limitations and employment outcomes.

2. Summarize the gaps in the science that should be addressed with future research.

3. Provide a research agenda for optimizing employment outcomes following a cancer diagnosis and treatment.
Cancer and its treatment

46 out of 100 people will be diagnosed with cancer at a working age (i.e., between the ages of 20-64)

Fatigue, pain, sleep disturbances, functional limitations, anxiety, depression, cognitive changes, hair loss, sexual dysfunction, anemia, appetite loss, constipation, diarrhea, incontinence, bleeding, bruising, nausea, vomiting, lymphedema, infections, heart problems, endocrine system problems, osteoporosis, peripheral neuropathy, hearing loss, second cancers...
Cancer and work

~64% of cancer survivors return to work at some point after diagnosis.

Return-to-work rates range from 24% to 94%.

There are nascent efforts to understand and address cancer-related work limitations.

Availability ≠ Access.
Almost one-fifth of people (18%) diagnosed with cancer face discrimination from employers or colleagues on return to work, research by the charity Macmillan suggests.

The survey of 1,000 patients, all in work when diagnosed, indicated that 15% returned to work before feeling ready.

Others said they felt guilty for taking time off work for medical appointments.

Liz Egan, from the charity, said: “It’s appalling... so many employees are not offering the right support.”

Sacked for having cancer

For Cancer Survivors, a Job Hunt Can Be the Next Big Obstacle

By Alexandra Peers | Sept 17, 2016

AFTER battling ovarian cancer, Sherry Salway Black returned to her job as second in command of a Washington nonprofit group to find “a lot of turmoil,” she says, and altered friendships, questions about her leadership and surprise that she was fine.

When, on top of dealing with “instant menopause,” Ms. Black found out that she and someone else had both been promised the president’s job, she thought it was time to move on. “After cancer,” Ms. Black said, “I had a changed role.”

Nationwide, the cancer survival rate is climbing, with the number of survivors now at about 70 million. With early detection of the disease on the rise, more and more of those people are in their prime working years.
Essential ingredients for optimizing employment outcomes among cancer survivors

• Robust data about how cancer and its treatment impact survivors’ work lives.

• Evidence-based interventions to prevent cancer-related work limitations or to address work limitations and concerns after they occur.

Let’s get Cooking!
Over the last 20 years there have been a growing number of studies that have documented:

- Scope and severity of cancer-related work limitations, in particular for well-studied survivor populations.
- Risk/protective factors for work functioning.
- Patient’s perspective on cancer-related work limitations and the response of their health care providers and employers.
- There are many unanswered questions about impact of cancer on employment and effective strategies for improving work outcomes.
Gaps in the science

1. What are the long-term impacts of cancer on employment?

2. How do work limitations/concerns about employment and associated financial burden affect cancer survivors’ adherence to treatment?

3. How (and by whom) are employment limitations and concerns addressed during cancer treatment? What strategies and approaches designed to restore physical and/or psychosocial functioning have an impact on employment outcomes?

4. How do employers meet the needs of survivors during treatment and recovery?
   - What is the impact of employer-level policies and accommodations on work functioning?

5. What strategies and approaches should be included in interventions to optimize employment outcomes among cancer survivors.
The primary goal of the meeting was to help NCI develop a research agenda for understanding and addressing the many ways that cancer impacts employment.

A select group of 21 practitioners, researchers, and other professionals were convened to examine the problem of cancer-related work limitations from multiple perspectives.

https://healthcaredelivery.cancer.gov/employment/approaches.html
The way forward

1. Implement a multi-level suite of approaches to understand and address cancer-related work limitations.

2. Enhance partnerships and stakeholder engagement.

3. Expand the focus and locus of data collection.

4. Improve referral systems and care coordination.
A multi-dimensional problem requires multi-dimensional and multi-level solutions.

Coordination across levels is key.

Enhance partnerships and stakeholder engagement

- Treatment-decision making
- Survivorship care planning
- Work accommodations
- Research
- Policy-making
Capitalize on enhanced partnerships to strengthen research and practice

Knowledge Generation

Application

Health care providers

Patients and their families

Employers

Researchers
Expand Focus and Locus of Data Collection
Improve screening and referral systems and care coordination
Conclusions

Cancer treatment precipitations functional limitations that can interfere with survivors’ work lives.

Employment is central to quality of life and should be considered during treatment decision making and survivorship care planning.

It’s complicated: work outcomes are influenced by a range of factors operating at different levels of influence.
Conclusions

Research is needed to inform a more comprehensive understanding of how cancer impact a person’s work life and to identify and implement strategies to mitigate the impact of cancer on employment.

Enhanced partnerships and stakeholder engagement as well as a suite of multi-level strategies are needed to optimize employment outcomes after cancer.
Thank you!