Integrating Research and Practice to Transform Cancer Rehabilitation

Catherine M. Alfano, PhD
Vice President, Survivorship
Rose’s Treatment Trajectory

Decision making based on function

Diagnosis
Rose’s Treatment Trajectory

Diagnosis: Decision making based on function

Treatment:
- Lumpectomy
- Refused pain meds due to function
Rose’s Treatment Trajectory

Diagnosis
Decision making based on function

Treatment
• Lumpectomy
• Refused pain meds due to function

Recurrence
• Mastectomy
• Chemo, XRT
• Lymphedema
• No rehab
1,762,450 New US Cancer Cases Diagnosed in 2019

18.1 Million New Cases Globally (GLOBOCAN 2018)
By 2040, 73% will be > 65
Baby Boomer Expectations for Healthcare: What a Difference a Generation Makes

THEN

NEW DEFINITION OF NORMAL FUNCTION...
By 2040, 73% will be ≥ 65
The “Perfect Storm” Problem for Healthcare Delivery

1.7M New patients + 16.7M Survivors

Provider Shortages (ONC, PCP, Nsg, Rehab)

Chronic & Late Effects of Cancer (Physical, Psychosocial, Economic)

Provider Knowledge Deficits

Skyrocketing Cancer Care Costs
Burden of Chronic & Late Effects of Cancer

- Fatigue
- Depression, Anxiety
- Lymphedema
- Neuropathy
- Financial toxicity

- Functional limitations
- Reduced participation in work, life roles
- Reduced QOL

Figure 1  Diagram depicting age-related effects of respective cancer therapies. CHF, congestive heart failure; RT, radiation therapy.
The Perfect Storm

- 1.7M New patients + 15.5M Survivors
- Provider Shortages (ONC, PCP, Nsg, Rehab)
- Provider Knowledge Deficits
- Chronic & Late Effects of Cancer (Physical, Psychosocial, Economic)
- Skyrocketing Cancer Care Costs
Delivering Cancer & Follow-up Care

• Who should be responsible for care?
  
  *Erikson et al., 2007, JOP*

**Doctors needed**

Shortage in primary care physicians is projected to continue to increase in U.S.

2008  |  7,400
2010  |  9,000
2015  |  29,800
2020  |  45,400
2025  |  65,800

Source: AAMC Center for Workforce Studies
The Perfect Storm

Skyrocketing Cancer Care Costs

1.7M New patients + 15.5M Survivors

Chronic & Late Effects of Cancer (Physical, Psychosocial, Economic)

Provider Knowledge Deficits

Provider Shortages (ONC, PCP, Nsg, Rehab)
Problem Delivering Survivorship Care

- Knowledge gaps among PCPs (& oncologists)
- Understanding of Function?

*Potosky et al, JGIM 2011*
The Perfect Storm

Skyrocketing Cancer Care Costs

1.7M New patients + 15.5M Survivors

Provider Knowledge Deficits

Chronic & Late Effects of Cancer (Physical, Psychosocial, Economic)

Provider Shortages (ONC, PCP, Nsg, Rehab)
Costs of Cancer Care (US Delivery Systems & Employers)

• $157.77B by 2020
• Survivorship excess medical costs: $25-48B
• Lost productivity among survivors: $8-16B
Costs of Cancer (US Survivors/Families)

25% Survivors report problems paying medical bills

33% Survivors report worry about medical bills
Ekwueme et al, MMWR, 2019

Survivors 2.65 X more likely to file bankruptcy
Ramsey, Medical Affairs, 2013

Bankruptcy among survivors: 1.79 X higher risk of mortality
Ramsey, JCO, 2016
Health Disparities across Outcomes

• Poorer health outcomes for: low SES, some racial/ethnic minorities, un/underinsured, immigrants, & sexual minority survivors

• Barriers to appropriate & timely treatment; suboptimal pt-provider communication; poor access to supportive resources & comp cancer centers (Lee Smith et al 2015)

• Race/ethnicity mortality gap narrowing for older adults (Medicare access) and in states with health coverage (Siegel et al 2018)
  – Continued disparities: survivors under age 65
WHO IS HOLDING THE SOLUTION?
Solutions to Improve Care & Outcomes

1. Assess survivor needs & function with ePROs
   – Anticipate, assess, & prevent/address patient needs from diagnosis forward

2. Right size Care: Personalized, tailored care referrals from diagnosis forward, shifting care from point-of-care to point-of-need wherever possible
   – Support patient self-management, leverage community resources

3. Disseminate and support the implementation of new care methods or interventions
   – Digital tools; Telemedicine approaches; Clinical care guidelines; quality metrics; payment reform

TOGETHER these should improve pt function & QOL; Decrease provider burden & costs
Comprehensive Cancer Rehabilitation is Part of the Solution

Cheville et al., 2017
Rehabilitation Used to be Part of Cancer Care.... What Happened?

- Cancer treatment shifts (improvements)
- Community-based care delivery
- Fragmented Care without central EHR
- Limited cancer rehab workforce

Alfano et al., 2012

Cancer Survivorship and Cancer Rehabilitation: Revitalizing the Link

Catherine M. Alfano, Office of Cancer Survivorship, National Cancer Institute/National Institutes of Health/Department of Health and Human Services, Bethesda, MD
Patricia A. Ganz, School of Medicine, School of Public Health, and Jonsson Comprehensive Cancer Center, University of California, Los Angeles, Los Angeles, CA
Julia H. Rowland, Office of Cancer Survivorship, National Cancer Institute/National Institutes of Health/Department of Health and Human Services, Bethesda, MD
Erin E. Hahn, School of Public Health and Jonsson Comprehensive Cancer Center, University of California, Los Angeles, Los Angeles, CA
Results of Fragmented System

• 60%+ of cancer survivors need rehabilitation
  (Thorsen et al., 2011)
  – 90% of those with metastatic dx (Cheville et al., 2008)
• No routine assessment of symptoms, functional problems; patients don’t report them either
• 9% older adults with functional limitations identified in Geriatric Assessment received OT or PT (Pergolotti et al., 2015)
• Impairments & symptoms: ↓QOL, functioning, work; ↑healthcare utilization
More Results of Fragmented System

- Rehab disconnected from oncology, follow-up care
- Providers & patients are unaware of what rehabilitation could offer
- Little info on NCI CCC websites about cancer rehab (Silver et al, 2017)
- Little training in function/rehab for oncology, primary care providers
- Cancer rehab workforce shortages
Capitalizing on Oncology Care Paradigm Shifts

• Precision Medicine (Immunotherapy)
  – Right treatment, right patient, right time
  – Risk-stratified care (UK, Australia)

• Technology to detect impairments & aid referrals (ePROs, sensors)

• Big Data and AI analytics

• Value-based reimbursement, novel payment models
Where our Research Goes

Bench to Bedside?

JCO
NEJM
JAMA
The Great Divide

Science

Health Policy

Patients
Building Next-Generation Cancer Rehabilitation

Integrate 5 Agendas:

1. Implement the Prospective Surveillance Model
2. Expand the Cancer Rehabilitation Team
3. Develop “Precision Medicine” Rehabilitation
4. Demonstrate the VALUE of cancer rehabilitation
5. Disseminate and support implementation of care changes
Next-Generation Cancer Rehabilitation: A Giant Step Forward for Patient Care
Catherine M. Alfano¹, PhD & Mackenzi Pergolotti², PhD, OTR/L

Abstract
Purpose: The aim of the study was to review the current state of cancer rehabilitation evidence and practice and delineate an agenda for building the future of cancer rehabilitation care.
Findings: Despite the benefits of cancer rehabilitation interventions and the unmet needs among patients with cancer, very few patients receive these services.
Conclusions: Interdisciplinary cancer rehabilitation should be implemented from diagnosis forward. Building this care involves coordinating efforts in four critical areas: innovating cancer rehabilitation care delivery, expanding the team of providers, creating precision medicine cancer rehabilitation, and demonstrating the value of cancer rehabilitation to drive referrals and reimbursement.
Clinical Relevance: Creating next-generation cancer rehabilitation care has the potential to improve the lives of the growing population of cancer survivors.

Keywords: Cancer survivors; disease management; rehabilitation; survivorship; toxicity.
1. Implement the Prospective Surveillance Model

Stout et al, Cancer. 2012

Functional tests
Clinical exam
ePRO symptoms
Exercise
Diet
Evidence For This Approach

ASCO 2017 plenary: ePROs improve QOL, reduce ED visits, increase time on chemo, improve survival
(Basch 2016; Basch 2017)

N=27 RCTs

A systematic review of the impact of routine collection of patient reported outcome measures on patients, providers and health organisations in an oncologic setting

Jack Chen, Lixin Ou, and Stephanie J Hollis

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# Evidence For This Approach

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A systematic review of the impact of routine collection of patient reported outcome measures on patients, providers and health organisations in an oncologic setting

*BMCHSR, 2013; 13: 211.*

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Implement PSM Step 1: Digital “Easy button” for Oncology Referrals


- Aid practice, do NOT add to “to do list” for clinical encounter
- We are in this together: coordinate care across providers, to rehab, psych, palliative care, exercise, etc
- 2-part solution: comprehensive assessment of patient symptoms/needs & treatment algorithms to aid referrals
Implement PSM Step 2: Address Provider Shortages

- Concern re: not enough providers
- Go beyond asking about symptoms: Include function and participation in risk-stratified referral pathways to efficiently use the healthcare system (Newman et al, *OTJR*, 2019)

Fatigue:
- ✓ YES
- □ NO

Participation thermometer

- Referrals to multi-disciplinary team
- Materials and info supporting self-management
Figure 1. Prospective Surveillance Model Incorporating Multiple Assessments of Impairments, Activity Limitations, and Participation in Work and Leisure Roles
2. Expand the Cancer Rehabilitation Team

- More players on the team…
- Playing as one team
- Coordinating across disciplines/services to be the easy button for oncology
  - 2015 NIH rehab meeting (Stout et al 2016, Archives PM&R)
Figure 2. Components of Comprehensive Cancer Rehabilitation Care

Alfano & Pergolotti 2018. Rehab Nursing 43(4), 186-94
Perspective

A New Initiative on Precision Medicine

Ferenc F. Cools, M.D., Ph.D., and Harold Varmus, M.D.


Comments open through March 4, 2015

“This evening, I'm launching a new Precision Medicine Initiative to bring us closer to curing diseases like cancer and diabetes — and to give all of us access to the personalized information we need to keep ourselves and our families healthier.”

— President Barack Obama, State of the Union Address, January 20, 2015

President Obama has long expressed a strong conviction that science offers great potential for improving health. Now, the President has announced a research initiative that aims to accelerate progress toward a new era of precision medicine (www.whitehouse.gov/precisionmedicine). We believe that the time is right for this visionary initiative, and the National Institutes of Health (NIH) and other partners will work to achieve this vision.

The concept of precision medicine — prevention and treatment strategies that take individual variability into account — is not new: blood typing, for instance, has been used to guide blood transfusions for more than a century. But the prospect of applying this concept broadly has been dramatically improved by the recent development of large-scale biologic databases (such as the human genome sequence), powerful methods for characterizing patients (such as proteomics, metabolomics, genomics, diverse cellular assays, and even mobile health technology), and computational tools for analyzing large sets of data. What is needed now is a broad research program to encourage creative approaches to precision medicine, test them rigorously, and ultimately use them to build the evidence base needed to guide clinical practice.

The proposed initiative has two main components: a near-term focus on cancers and a longer-term aim to generate knowledge applicable to the whole range of health and disease. Both components are now within our reach because of advances in basic research, including molecular biology, genomics, and bioinformatics. Furthermore, the initiative taps into converging trends of increased connectivity, through social media and mobile devices, and Americans’ growing desire to be active partners in medical research.

Oncology is the clear choice for enhancing the near-term impact of precision medicine. Cancers are common diseases; in the aggregate, they are among the leading causes of death nationally and worldwide, and their incidence is increasing as the population ages. They are also especially feared, because of their lethality, their symptoms, and the often toxic or disfiguring therapies used to treat them. Research has already revealed many of the molecular lesions that drive cancers, showing that each cancer has its own genomic signature, with some tumor-specific features and some features common to multiple types. Although cancers are largely a consequence of accumulating genomic damage during life, inherited genetic variations contribute to cancer risk, sometimes profoundly. This new understanding of oncogenic mechanisms has begun to influence risk...
3. Develop “Precision Medicine” Rehabilitation

- Understand drivers/pathways of impairment, disability and better predict RISK
- Use ePROs, other data to determine who needs what and what level of intervention (ACS/ONS Roundtable 2018)
  - Who needs clinical care vs. who can get community or self-management interventions
- Develop tailored Rx for prevention or early mitigation
  - Based on –omic and other clinical, physiological, psychosocial, and patient-generated data
  - Depending on outcome-- restoring function (cardiorespiratory function), enhancing participation (a specific type of work role) and/or preventing a late effect (bone loss)
  - Ex: can exercise disrupt cardiotoxicity? How much, what dose?
3. Develop “Precision Medicine” Rehabilitation

- Tailor intensity of care based on need
- Need to shift care to point-of-need wherever possible,
  - Improve access (telemedicine, digital health), decrease costs, make rehab care more feasible

4. Demonstrate the VALUE of cancer rehab

- Expand science base: outcomes beyond impairment:
  - pt employment (NCI meeting) and participation (AOTF);
  - oncology tx efficacy; oncology clinic flow; prevention of late effects; ED visits, survival?
4. Demonstrate the VALUE of cancer rehab

- Don’t wait 17 years –NOW: Use the science base to conduct simulation models, anticipating the effects of earlier/broader access to cancer rehab on outcomes
  - ACS/ASCO Summit; ACS/ONS Roundtable
- Test models of coordinated care delivery – optimize pt outcomes, address workforce constraints, control costs to patient and healthcare system
  - Publish these results!
Building Next-Generation Cancer Rehabilitation

4. Demonstrate the VALUE of cancer rehab

Commentary

A Health Services Research Agenda to Fully Integrate Cancer Rehabilitation Into Oncology Care

Mackenzi Pergolotti, PhD, OTR/L; Catherine M. Alfano, PhD; Alison N. Cernich, PhD, ABPP-CN; K. Robin Yabroff, PhD; Peter R. Manning, MBA; Janet S. de Moor, PhD, MPH; Erin E. Hahn, PhD, MPH; Andrea L. Cheville, MD; and Supriya G. Mohile, MD, MS

TABLE 1. Ten Suggested Areas of Targeted HSR Demonstrate the Value of Cancer Rehabilitation

<table>
<thead>
<tr>
<th>HSR to Achieve the Triple Aim of Better Care, Health, and Value in Health Care (Berwick 2015)</th>
<th>HSR for Rehabilitation and Disability (Graham 2018)</th>
<th>HSR to Better Demonstrate Cancer Rehabilitation Value (Current Study)</th>
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<td>Molding the beliefs and expectations of patients, families, and communities</td>
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<td>1) Increase understanding of beliefs and expectations of patients and families, clinicians, and policymakers regarding cancer rehabilitation care, delivery, cost, and value</td>
</tr>
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<td>Better ways to involve physicians in care</td>
<td>Better ways to involve rehabilitation services and professionals in care</td>
<td>• What are key stakeholder perspectives and understanding of the value of cancer rehabilitation?</td>
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<td></td>
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<td>• What are the innovative program models with which to address stakeholder needs?</td>
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5. Disseminate & support implementation of care changes

- Write clinical practice guideline (ACRM)
  Request endorsement from ASCO, others
  - Work out triage issues (new ACRM-ACSM collaboration on self vs supervised exercise vs rehab)

- With guideline: develop digital tools for patient assessment & referral
  - Deliver content at point-of-need where possible

- From guideline, develop quality metrics for accountability (Dec 2918 NCI meeting)
  - Rehab metric for delivery; onc/PCP metric for assessment/referral; accompanied by payment reform
Congressional Cancer Survivors Caucus (2017-)

- Forum for conversation between members of congress & cancer experts
- But WHAT IS OUR ASK?
- Tell the right story with the right data
Cancer Rehabilitation Needs Better Marketing

- We KNOW we optimize function and QOL
- We KNOW we can get patients back to work
- .... Are you TELLING these stories to the right people?
  - Oncology team
  - Cancer center/hospital leadership
  - Payers, donors
• **Researchers**: outcome data re value of cancer rehab; best practices

• **Clinicians**: market what you do. Speak & write pieces for patients, oncology, your leadership, your payers, donors

• **Educators**: teach students and continuing ed curricula

• **All**: work with digital health companies to create tools

• **All**: Work on cancer rehab guideline, quality metrics
Rose’s Treatment Trajectory

**Diagnosis**: Decision making based on function

**Treatment**: • Lumpectomy • Refused pain meds due to function

**Recurrence**: • Mastectomy • Chemo, XRT • Lymphedema • No rehab

**Dx: HF**

**Prevention?**
The Great Divide...Bridged

Big Hairy Audacious Goal

Science

Health Policy

Patients
“It’s better to shoot for the stars and hit the moon than shoot for the fence …and hit the dirt”