

What Now? Service Needs at Re-Entry in Adult Leukemia and Lymphoma Survivors

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Process Guidelines for Today

- Ask clarifying questions as we go along
- Please let me know if I am talking too quickly

Overview

- Who I am
 - Evolution of Identity as a Health Services Researcher
 - Approach to Research
- Current Work
 - Context of My Work
 - Presentation of cancer survivorship re-entry/ care transitions work
- Q&A

Evolution of Health Service Researcher Identity

- Indirect evolution
- Background
 - Sociology → Social work (DV)
 - Doctoral work in Social Work & Sociology
 - CU: Division of Health Care Policy & Research
- Result:
 - Multiple interwoven professional identities
 - Multiple professional “languages”

Research Approach

- Mixed-method
- Applied/translational
- Interdisciplinary, Multidisciplinary,
 - Psycho-oncology is informed by gerontology, sociology, psychology, social work, nursing, health care policy, medicine, etc.
- Integrative
 - @ nexus of very different worlds: research, clinical/practice, advocacy/consumer, policy

Current Work: Research

Explores psychosocial aspects of cancer survivorship at re-entry and beyond

- Outcomes & Processes:
 - quality of life, thriving, meaning making, coping, etc.
- Service needs:
 - unmet needs, implications for intervention models/programs (content, timing, etc.).
- Role of service delivery mechanisms and models

Current Work: Dissemination

- Care Transitions Model for chronic illness:
 - Care Transitions Program
- Re-entry Model for Psycho-oncology / cancer survivorship

Social and policy context for current work

- Why is this topic important?
 - Tx efficacy → growing number of survivors
 - Problem of success
- Growing attention
 - Lance Armstrong
 - NCI established Office of Cancer Survivorship
 - IOM reports
 - “Crossing the Quality Chasm” (2001)
 - “Lost in Transition” (2005)
 - “Cancer Care for the Whole Patient” (2008)

IOM Essential Elements of Survivorship Care

- Prevention
- Surveillance
- Intervention
 - for consequences of cancer and its tx
- Coordination
 - b/t specialists and PCPs

● page 2, Lost in Transition (2005)

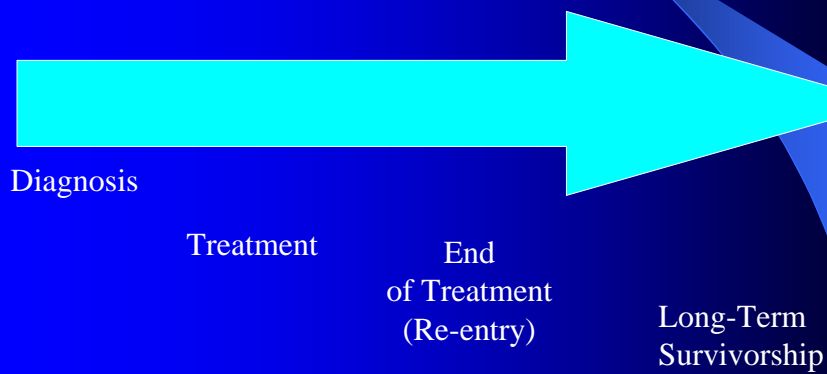
Conceptual context, key terms

- Cancer Survivorship
 - Re-entry
 - Quality of Life

“Cancer Survivor”

- History of term
- Current definitions
 - NCI: Person with cancer: from time of diagnosis through balance of life*
 - NCCS: Adds family members, friends and caregivers
- Evolution of the Concept
 - Disputed identity
 - Relationship to re-entry work

Survivorship Continuum



What is Re-entry?

- Time period between end of treatment and survivorship (Stanton, et al., 2005)
- Transitional Phase
 - Psychologically: Adjustment
 - Service delivery: Care transition
 - Frequency of interaction
 - Type of providers/settings
 - Approach

What is quality of life?

- Quality of Life (QOL) research in psycho-oncology examines the physical and psychosocial effects of cancer on patients, survivors, and their families.
- Applied field, interdisciplinary origins

Quality of Life



Physical

Fatigue

Pain

Appetite and sleep changes

Infertility

Sexual dysfunction

Secondary health issues (osteoporosis, heart failure, second cancers)

Psychological

- Anxiety, depression
 - Worry, uncertainty, distress
- Life outlook
- Identity
- Coping
- Life satisfaction
- Adjustment

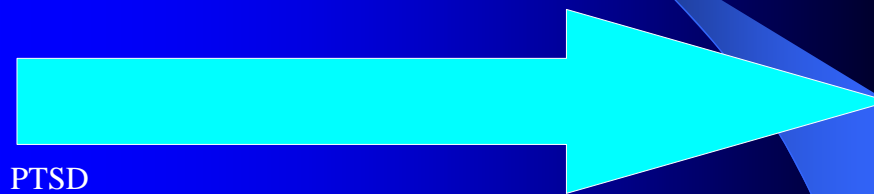
Social

- Relationships
- Career and employment opportunities
- Health and/or life insurance issues
- Social & leisure activities

Spiritual/Existential

- Sense of Meaning
- Purpose
- Appreciation for Life
- Faith
- Relationship to the transcendent

Wide range of QOL outcomes



PTSD

Distress

Severe
impairment

Positive
coping and
adjustment

Thriving
Growth

What do we know about adjustment after treatment?

- Variability
 - Many cancer survivors show positive adjustment within 1-2 years (Stanton, et al. 2005): 25%
 - Estimates of clinical levels of distress in L/L survivors range from 15-20%
 - Geffen, et al.'s (2003) study of cancer survivors at re-entry (2 years post-treatment cessation) found
 - 18% met clinical criteria for PTSD
 - 32% had PTSD symptoms

QOL and Service Needs in Adult Leukemia and Lymphoma Survivors

“THRIVE”

- K07 Career Development Award
- Funded by the National Cancer Institute
- August 2006-July 2011
- Focus: quality of life and service needs of adult leukemia and lymphoma survivors at re-entry

Frameworks guiding this study

- Adult/Lifespan developmental models
- Survivorship continuum model
- Psychosocial frameworks
- Health services delivery frameworks

“THRIVE” Aims

- Aim 1: To assess the quality of life and service needs of adult L/L survivors
 - Lifespan development
 - Meaning making
- Aim 2: Intervention design targeted to support successful adjustment in re-entry.

Eligibility Criteria

- Diagnosis of AML, ALL, CML, CLL, non-Hodgkin's Lymphoma or Hodgkin's Lymphoma
- Age 18-80 at time of diagnosis
- 3-48 months from end of treatment*
 - *CML

THRIVE Study

- Phase I:
 - In-depth interviews (n=21)
 - Pilot-test survey instruments (n=10)
 - Pilot-test mailing protocol (n=100)
- Phase II:
 - Surveys (n=550)
 - Colorado Central Cancer Registry
 - 45% adjusted response rate
 - In-depth interviews (n=19; 40 total Phase I+II)
 - 372 requests

THRIVE Study

- Phase III:
 - Data analysis
 - Independent Qualitative and quantitative analyses
 - Inter-method analyses
- Phase IV-V
 - Intervention design
 - Member validation
 - Pilot testing of new program

Method

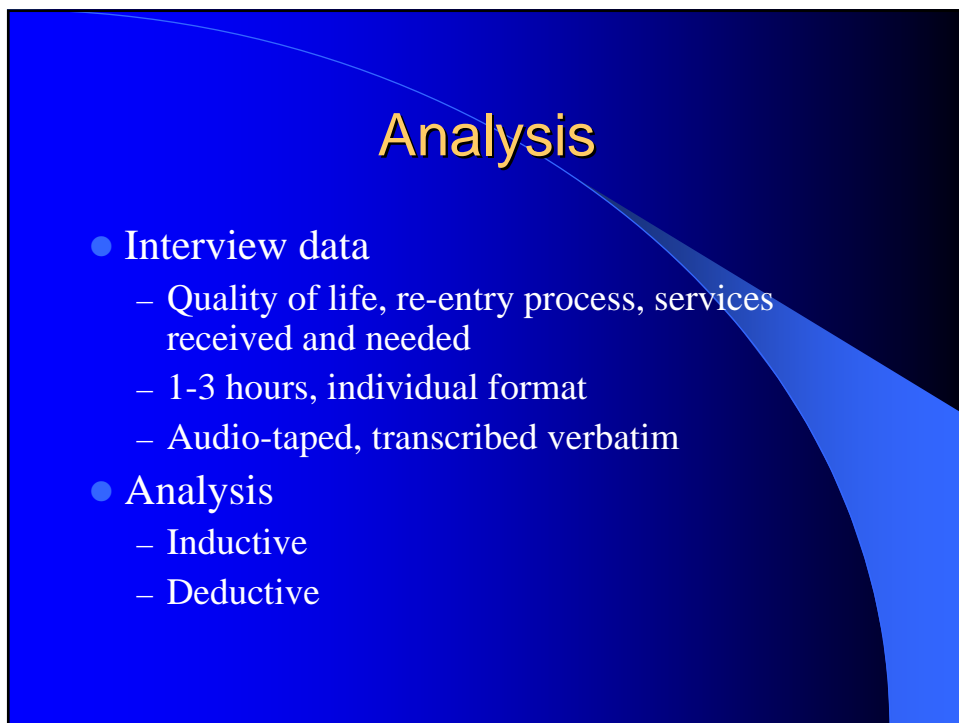
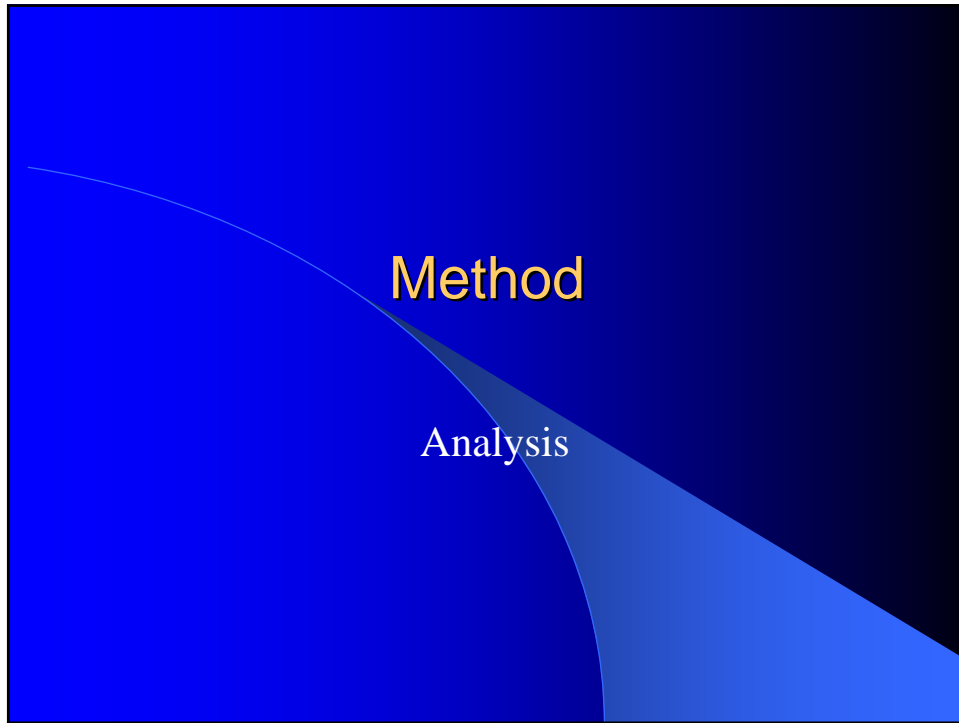
Participants

Participants (n=40)

- Gender:
 - 25 women
 - 15 men
- Time since end of treatment
 - Range: 3-48 months*
 - Mean: 25 months
- Relapsed: 4
 - *CML
- Age @ dx
 - Range: 20-80
 - Mean: 47
- Age Distribution
 - <35: 10
 - 36-45: 8
 - 46-55: 9
 - 56-65: 8
 - >65: 5

Participants: diagnoses

Non-Hodgkin's lymphoma	16
Hodgkin's lymphoma	9
Other lymphomas	5
ALL	2
CLL	2
CML	3
AML	2
Other Leukemias	1
Total	40



Results

Results: Overview

- Survivor descriptions of re-entry process
- Re-entry difficulties
- Role of Time and Timing
- Survivor service needs recommendations

Re-entry: survivors' descriptions

- Characterized by powerful imagery and emotional descriptors.

Sense of Abandonment

- “You’re deposited on the outside of the hospital and [they’ve] said, well, you are on your own now. We didn’t take care of you before you had cancer and we’re not going to take care of you now.”

Re-entry: survivors' descriptions

- *Feeling Unsupported / Unsafe*
 - “All of a sudden you’re working without a net. You’re on a high wire and there’s nothing below to catch you”
 - “It was an experience of picking your way through a minefield of trying to deal with life’s daily problems and concerns both physically and emotionally. So there was a sense of being without crutches, so to speak”

Re-entry: survivors' descriptions

- *Unprepared: practical level (what to do)*
 - “Now what? How will I know what I need and when to seek help?”
- *Unprepared: paradigm level*
 - “You’ve grown somewhat dependent on these caregivers and all of a sudden it’s like, okay we’ll see you in three months”

Survivors relate re-entry difficulties to:

- Lack of knowledge about / access to appropriate services & information
- Unmet needs: lack of specific resources
- Incongruence between experience and expectations (self and others) for recovery process and timeline

Problems re: Services

- Services underutilized / not accessed:
 - Barriers:
 - Lack of knowledge about services
 - Didn't know about the service
 - Unaware they needed the service
 - Didn't understand the service
 - Not presented at an optimal time
 - Not explained in a meaningful way

Problems re: Access to Information

- Information Inaccessible
 - Not provided
 - Did not know who to ask (no targeted source)
 - Targeted source not knowledgeable
 - Unable to get information from targeted source.
 - “So I didn't feel I could call him back up and say I'm still having a problem when I knew they weren't going to help me. Even though it was something they deal with all the time & it's something so common from cancer treatments that you would think they would have the highway as to what to do. Instead they are telling me to figure out what bus stop to stand at.”

Problems re: Information

- Tools and/or information provided were not helpful
 - Format not patient-centered
 - Timing
 - Content/approach
 - “it told you how to eat right—no, it said you *should* eat right, it said you *should* exercise. It said you *should* keep a record of all your appointments, you should do this, you should do that, but it didn't tell you how to do it.”

End-of-Treatment Transition

- Care Transition
 - Non-existent
 - Inadequate
 - Lack of communication:
 - Inadequate preparation
 - Unhelpful preparation
 - “The oncologist said that obviously you've got our full attention while you're going through treatment, but once you leave you will be on your own”

Unmet Needs

- Specific resources
 - For Survivors (vs. patients)
 - For those with Leukemia and Lymphoma (vs. other cancers)
 - “I wish there were more financial support. I’ve called and there are a lot of organizations who give assistance for cancer, but most are for breast or cervical or ovarian cancer”

Incongruence between experience and expectations

- Unexpected reactions to end of treatment
 - Disappointment at end of treatment:
 - Feeling unprepared:
 - “I felt prepared in a certain way that I knew what was coming up and I felt that I had doctors if I had any questions or problems after treatment, I could call them up and talk about that. But that was absolutely the opposite of what happened.”

Incongruence between experience and expectations

- Physical after-effects
 - Longer re-entry time than expected
 - Fatigue: “if I hadn’t been to the support group where I heard other people talk about the fatigue, I would really wonder what’s the matter with me?...I’ve been told by other cancer survivors that it takes 1-3 years”
 - Persistence and late appearance of after-effects
- Identity Changes
 - “You don’t expect that you’re going to come out and have some basic parts of you be really different”

Interpersonal Difficulties

- Invisibility/Lack of Understanding
 - Lack of understanding of chronicity (CML)
 - Others do not understand the length of time required for recovery generally
 - Lack of understanding of fatigue and its impact
 - I try to be patient when someone says ‘you’re not back to work yet, isn’t there something you can do?...I try to educate them”

Time and Timing

- Time frame= up to 4 years
- Critical time points from end of tx
 - 6 months
 - 1 year

Survivors' Suggestions for Improvement

- Improved communication
- Survivor and L/L--specific services
- Improved care coordination, continuity
 - Exit interview
 - Point person
 - Follow-up across survivorship trajectory
 - Appropriate
 - Repeated
 - Duration of up to 3 years > tx cessation

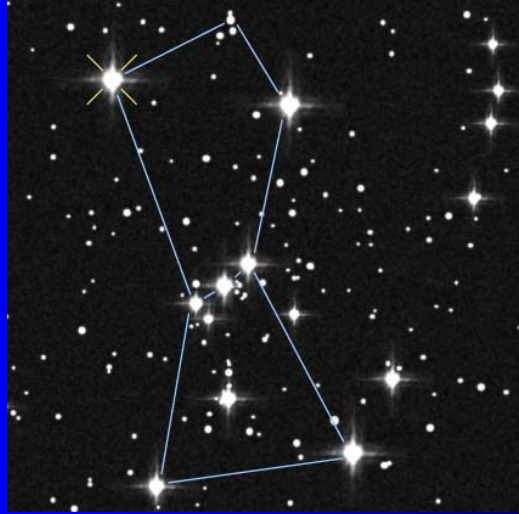
Discussion

- Re-entry
 - Overlooked phase of survivorship
 - Relatively undefined phase
- Extended timeframe for L/LS
- Problems with services are primarily a function of problems with care coordination and communication.
- Need to attend to timing, duration, and process aspects of service delivery in addition to content

Implications

- Paradigm level
- Health services delivery/systems level
 - Care coordination
 - Communication*
 - Models of Care
- Clinical level
 - Process
 - Timing
 - Duration
 - Content

The galaxy of services



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