Using Research to Inform Practice: A Skill-Building Workshop

A Learning Institute presented by the AOSW Research Committee
Friday, June 2, 10:15 am
Presenters:

• Julianne S. Oktay, MSW PhD
  – Professor Emeritus, University of Maryland School of Social Work

• Bradley Zebrack,
  – Professor, University of Michigan School of Social Work

• Karen Kayser, MSW, PhD
  – Professor, University of Louisville School of Social Work

• Elizabeth Rohan, PhD, MSW
  – Health Scientist, CDC

• Sophia Smith, MSW, PhD
  – Associate Professor, Duke University School of Nursing

• Daniela Wittmann, LMSW, PhD
  – Clinical Assistant Professor, University of Michigan Comprehensive Cancer Center
Workshop Overview

• Overview: 10:15 – 10:30
  – Julie Oktay

• How you can use research to enhance practice and elicit system change – 10:30 – 11:15
  – Brad Zebrack (With Sophia Smith and Daniela Wittmann)

• Introduction to Focus Group methodology 11:15-11:45
  – Karen Kayser and Elizabeth Rohan
Research in Oncology Social Work

• Early oncology social workers combined research and practice.

• Focus of oncology social work research
  – Focus on the clients’ experience
  – Life course development
  – Person-in-Environment (Family, community, culture)
  – Social Justice
Research and AOSW Strategic Goals

• Mission
• To advance excellence in the psychosocial care of persons with cancer, their families, and caregivers through: 

  Research

  Professional Development

  1. Identify, set, evaluate and disseminate best practices in oncology social work

  2. Elevate the position and visibility of oncology social work among the general public, the oncology community and policy makers

  3. Create avenues and provide tools for oncology social work professional development through advocacy, education and research

  4. Advance the knowledge base of the field by building the research capacity in oncology social work and supporting the bi-directional relationship of research and practice
Primary Types of OSW Research

- Local Relevance
  - Program Development
    - Needs Assessment
    - Program Evaluation
    - Data Mining
  - Professional Development
    - Quality Improvement
    - Single-System Designs
    - Participatory Action Research
    - Reflective Practice
    - Systematic Case Studies
    - N-of-1 Studies

- Research-based Practice
  - Implementation Research
  - Observational Studies
  - Randomized Controlled Trials (RCTs)
  - Meta-Analysis of RCTs
  - Nomothetic Research
  - General Relevance

- Practice-based Research
  - Comparative Effectiveness Research
  - Phenomenology of Lived Experience
  - Ethnographic Study of Culture & Its Effects
  - Language & Discourse Analysis
  - Idiographic Research
  - Theory Generation
HOW YOU CAN USE RESEARCH TO ENHANCE PRACTICE AND ELICIT SYSTEM CHANGE

Brad Zebrack, PhD, MSW
University of Michigan School of Social Work
Overview

• OSW Staffing Standards

• Using data to inform practice and program development

• Using data to influence systems

• Developing a Practice-Based Research Networks for OSW
What is the standard for OSW Staffing?
“Based on the time and tasks associated with managing highly distressed patients, social work department heads have estimated that oncology social workers can manage 10-12 highly distressed patients per month, or approximately 120 per year, in addition to also maintaining activities related to monitoring a current caseload, conducting psychosocial and psycho-educational programs and groups, facilitating patient access to community resources, discharge planning and transitioning patients from the hospital to community care.”

CITATION: Zebrack, B; Burg, M; Vaitones, V. (2012). Distress screening: An opportunity for enhancing quality cancer care and promoting the oncology social work profession. Journal of Psychosocial Oncology, 30; 615-624.
Determine your cancer program’s CoC designation:
http://datalinks.facs.org/cpm/CPMApprovedHospitals/Search.htm

CALCULATE AND COMPARE
Cancer Registry/Program database

1. # of social workers dedicated specifically to oncology
   – E.g. 3.80 FTE (Full-Time Equivalent)

2. # of “analytic cases” in a given year (Caseload)
   – Cases diagnosed and/or receiving all or part of first course of therapy at your facility
   – Different from new cases

3. # of out-patient visits in a given year (Coverage)
   – Includes but not limited to scheduled clinic appointments, out-patient procedures, infusion/radiation appts
Caseload:

# of analytic cases ÷ # SW FTEs

Example: 4,000 cases ÷ 3.0 FTEs = 1 SW: **1,333** cases

<table>
<thead>
<tr>
<th>Cancer Program Type</th>
<th>Best Case</th>
<th>Worst Case</th>
</tr>
</thead>
<tbody>
<tr>
<td>NCI-designated Cancer Program (n=11)</td>
<td>1: <strong>389</strong></td>
<td>1: <strong>2,061</strong></td>
</tr>
<tr>
<td>Compr Comm Cancer Program (n=28)</td>
<td>1: <strong>131</strong></td>
<td>1: <strong>3,014</strong></td>
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<tr>
<td>Comm Cancer Program (n=21)</td>
<td>1: <strong>224</strong></td>
<td>1: <strong>1,437</strong></td>
</tr>
<tr>
<td>Academic Cancer Program (n=12)</td>
<td>1: <strong>270</strong></td>
<td>1: <strong>1,380</strong></td>
</tr>
<tr>
<td>Other (n=7)</td>
<td>1: <strong>158</strong></td>
<td>1: <strong>612</strong></td>
</tr>
</tbody>
</table>

Coverage:

# of out-pt visits ÷ # SW FTEs

*Example: 25,000 visits ÷ 3.0 FTEs = 1 SW: 8,333 visits*

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<th>Best Case</th>
<th>Worse Case</th>
</tr>
</thead>
<tbody>
<tr>
<td>NCI-designated Cancer Program (n=11)</td>
<td>1: 3,600</td>
<td>1: 26,343</td>
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<tr>
<td>Compr Comm Cancer Program (n=28)</td>
<td>1: 1,455</td>
<td>1: 126,431</td>
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<tr>
<td>Comm Cancer Program (n=21)</td>
<td>1: 1,535</td>
<td>1: 29,714</td>
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<tr>
<td>Academic Cancer Program (n=12)</td>
<td>1: 1,572</td>
<td>1: 37,961</td>
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<tr>
<td>Other (n=7)</td>
<td>1: 1,162</td>
<td>1: 39,673</td>
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</tbody>
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Caveat

- SW Roles and Responsibilities vary within and across cancer programs
  - Case managers
  - Discharge planners
  - Clinical
  - Managerial/administrative

- Current state of knowledge

- We need more specific data
TO INFORM PRACTICE & PROGRAM DEVELOPMENT
What do you do with the data?

What can you do with the data?
Breakdown by sub-groups

Distress Scores, n=100

- n=30
- n=50
- n=20

Distress by Clinic

- Breast Clinic
- Head/Neck
- Urology
- Sarcoma

Mild (0-3)
Moderate (4-7)
Severe (8-10)
Identify prevalence rates of patient concerns

DT and Symptom Checklist

- What do we know about psychosocial aspects of fatigue, sleep, pain, and their relationship with outcomes (e.g., tx adherence, costs)?
Breakdown by Sub-groups (Age)

DT and Symptom Checklist

- Fatigue
- Pain
- Depression
- Transport
- Deal w/partner

- 65+ yrs
- 40-64 yrs
- 15-39 yrs
Breakdown by Sub-groups (Age)

DT and Symptom Checklist

65+ yrs

Fatigue: 50%
Pain: 40%
Depression: 40%
Transport: 60%
Deal w/partner: 10%

65+ yrs
Breakdown by Sub-groups (Age)

DT and Symptom Checklist

- Fatigue: 70%
- Pain: 20%
- Depression: 20%
- Transport: 20%
- Deal w/partner: 40%

40-64 yrs
Breakdown by Sub-groups (Age)

DT and Symptom Checklist

15-39 yrs
• You now have EVIDENCE!

• “Empirical data” – systematic observation
TO INFORM SYSTEMS CHANGE
Compare your patient data to national data

Percent of cases by DT Scores

APAQCC: 46% of all cases had a DT score of 4 or higher
Zabora et al., 2003, reports distress by cancer type
Comparison to other Cancer Programs

Zebrack, et al., (2016). Institutional capacity to provide psychosocial oncology support services: A report from the Association of Oncology Social Work, Cancer, 122(12): 1937-1945
Questions – Small groups

• Where are clinical care issues, guidelines discussed in your cancer program?

• Are you present at those discussions? And what happens when you are?

• How have you been successful in influencing clinical care?

• What data/information have you used or needed to influence clinical care?
How might we demonstrate impact of psychosocial care?

100 Patients

- 30 Depressed / Distressed
- Not Depressed / Distressed

70 Not Depressed / Distressed

30% 70%

What are your colleagues concerned about?
Patient Reported Outcomes (PROs)

- Depression, anxiety
- Pain, Fatigue, Vitality/Energy
- Treatment or medication adherence
- Missed clinic appointments
- 30-day hospitalizations

All have $$$ attached
Patient-Reported Outcome: Pain

100 Patients

30 Depressed / Distressed

70 Not Depressed / Distressed

30% 70%

12 Moderate-Severe Pain (40%)

10 Moderate-Severe Pain (14%)

In the past month...
Track Clinical Care

100 Patients

T1

30% 30 Depressed / Distressed

Adequate Psychosocial Response

Not Adequate Psychosocial Response

70% 70 Not Depressed / Distressed

Standard Care (Adequate)

T2: Re-measure Pain
Hypothesis Time!

When X happens, Y happens
When X does NOT happen, Z happens
What was the reduction in pain?

Change in Pain Scores, on average

<table>
<thead>
<tr>
<th>Pain Score</th>
<th>T1</th>
<th>T2</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>7.2</td>
<td>5.4</td>
</tr>
</tbody>
</table>

Distressed, Adequate response
What was the reduction in pain?

Change in Pain Scores, on average

- Distressed, Adequate response
- Distressed, not adequate response
What was the reduction in pain?

Change in Pain Scores, on average

- Distressed, Adequate response
- Distressed, not adequate response
- Not distressed, Standard (adequate) Care
WHAT WOULD YOU NEED TO CARRY OUT THIS OBSERVATION?
Practice-Based Research Networks

• Integration of research and practice

• Power of our pooled data = demonstrates impact of ONCOLOGY SOCIAL WORK!

• Increased power =
  – Greater professional autonomy
  – Greater professional value
FOCUS GROUP METHODOLOGY
What is a Focus Group?

• Method in which moderator facilitates a discussion with a small group of people (often 6-8) who have personal or professional experience with the topic being studied

• Facilitator uses discussion guide with questions and probes

• Group’s communication and interaction stimulate ideas to identify problems and generate solutions.
When Do You Use Focus Groups?

• Need for qualitative information (e.g. deeper insights of lived experience and culture of individuals or community)
• An efficient way to obtain data
• Voice of patients (Patient-centered research)
• Ideas for interventions (Intervention research)
• Community-based studies (requiring community-level rather than personal information)
Who are Your Informants?

- Individuals with knowledge or information, personal or professional experience about a particular topic of interest
- Patients and/or Family Members
- Caregivers (Formal, Informal)
- Medical Or Supportive Care Providers (Nurses, Physicians, Social Workers, Psychologists, Chaplains, Etc)
- Administrators
- Community Members
- Stakeholders
Focus Group Moderator Skills

- Creating a relaxed atmosphere
- Stimulating discussion
- Encouraging quiet people to express opinion
- Curbing monopolizers
- Maintaining neutrality re: responses
Implementing the Focus Group

- Informed Consent
- Introduction
- A few questions with probes
- Audiotaping/Field notes
- Refreshments/incentives
Data Analysis

• Transcribe Interviews
• Open code sub-sample of transcripts to develop and modify codebook (at least two research team members)
• Code all transcripts using final codebook (at least two research team members – 85% inter-rater reliability is goal)
• Identify unifying themes
• Research team discusses, confirms, refines themes
• Don’t ignore negative cases – very informative
Case Example: Delivering Palliative Care to Inner-city Communities

Aim of study – to assess the need for a palliative psychosocial intervention for patients and families in inner city communities in Boston
Problem Analysis: Focus Groups

- Sample Size: 33 (approx. 8 per group)
- Group Composition:
  - Healthcare professionals from Community Partner (social workers and nurses)
  - Group of patients and caregivers who were clients at a neighborhood health center
  - Members of a peer support group for women with HIV/AIDS at a neighborhood health center
  - Group of caregivers, healthcare professional, and patients who were members of an African-American church
Selected Case Study Interview
Questions and Findings

Questions are guaranteed in life; Answers aren't.
Q #1: What are the stresses of daily living that patients with chronic health conditions and their caregivers in your community face?
## Themes

<table>
<thead>
<tr>
<th>Palliative Care Issues</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family Relationships</td>
<td>Communicating with family toward a mutual understanding of illness and palliative needs; needing support from family; developing positive relationships with children</td>
</tr>
<tr>
<td>Social Support</td>
<td></td>
</tr>
<tr>
<td>Minority Stress</td>
<td>Feeling disempowered by healthcare providers and vulnerable due to belonging to an ethnic, racial, sexual minority or low-socioeconomic class</td>
</tr>
</tbody>
</table>
| Communication                 | a) content of communication (receiving information about their care options)  
                                | b) process (feeling heard and understood by health care providers)                                                                         |
| Caregiver Burden              | Expectations that caregiver works with complex technology in caring for patient; no respite care; time constraints; balancing caregiving with other family/work roles; social isolation |
| Spiritual Support             | Desire to address spiritual issues regarding the meaning of the illness and death but feeling rejected or judged by the faith-based community    |
What Helps Alleviate Stress?

What factors or things in the patient’s environment can help them with these stresses? What activities, people, programs can support the care of patients and caregivers?
## Themes

<table>
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<tr>
<th>What Helps?</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community Resources</td>
<td>Palliative Care Center, Adult Day Care, Food, Caregiver Respite</td>
</tr>
<tr>
<td>Social Support (for both patients and caregivers)</td>
<td>Support Groups (separate ones for patients and families), Internet Support Groups</td>
</tr>
<tr>
<td>Access to Services</td>
<td>Technology (laptops, computers for patients who are not mobile); transportation, make team portable (home visits)</td>
</tr>
<tr>
<td>Knowledge</td>
<td>Education, workshops</td>
</tr>
<tr>
<td>Strengthening Family Relationships</td>
<td>Developing positive relationships with children</td>
</tr>
<tr>
<td>Facilitating Relationship with HCP</td>
<td>Educating HCP and society</td>
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</table>
Description of Interdisciplinary Psychosocial Intervention in Palliative Care (IPIPC)

- 5 home-based sessions between Patient and Caregiver and 2 team members
- Teams include nurse, social worker, and consumer
- Follow treatment manual
- Three Goals:
  - Facilitate supportive patient/caregiver relationships
  - Connect patient and caregiver to community resources
  - Foster empowering relationships between patient/caregiver dyads and healthcare providers
Resources

