Patient-Centered, Family-Engaged Cancer Outcomes Research

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University of North Carolina, Chapel Hill
My views are my own.  
I have no financial disclosures.
My talk

- My background
- My work at NCI
- My program of research
- Future directions
Background: a tale of two reports...
Adolescents and Young Adults with non-Hodgkin’s lymphoma

Data from the California Cancer Registry, years of diagnosis: 1996-2005, N = 3,849 with 2,471 observations censored.

Kent et al., 2010, *Journal of Cancer Epidemiology*
My dissertation research: quality of life and survival in AYAs with leukemia/lymphoma.

Multilevel socioeconomic effects on quality of life in adolescent and young adult survivors of leukemia and lymphoma

Erin E. Kent · Leonard S. Sender · Rebecca A. Morris · Timothy J. Grigsby · Michael J. Montoya · Argyrios Ziogas · Hoda Anton-Culver

Research Article

Socioeconomic Impacts on Survival Differ by Race/Ethnicity among Adolescents and Young Adults with Non-Hodgkin’s Lymphoma

Erin E. Kent, Rebecca A. Morris, Joan A. Largent, Argyrios Ziogas, and Hoda Anton-Culver

Cancer Causes Control (2009) 20:1409–1420
DOI 10.1007/s10552-009-9367-2

Leukemia survival in children, adolescents, and young adults: influence of socioeconomic status and other demographic factors

Erin E. Kent · Leonard S. Sender · Joan A. Largent · Hoda Anton-Culver
HEALTHCARE DELIVERY RESEARCH PROGRAM
Advancing innovative research to improve the delivery of cancer-related care

- **Populations**
- **Clinicians & Delivery Systems**
- **Patient**
- **Healthcare Assessment**
  - Assess utilization, access, diffusion, and population-based outcomes
- **Health Systems & Interventions**
  - Observe and intervene on behavior and context
- **Outcomes**
  - Evaluate and improve patient experiences and health outcomes

NATIONAL CANCER INSTITUTE
THE CANCER CONTROL CONTINUUM

FOCUS

<table>
<thead>
<tr>
<th>Etiology</th>
<th>Prevention</th>
<th>Detection</th>
<th>Diagnosis</th>
<th>Treatment</th>
<th>Survivorship</th>
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<tbody>
<tr>
<td>• Environmental factors</td>
<td>• Tobacco control</td>
<td>• Pap/HPV testing</td>
<td>• Shared and informed decision making</td>
<td>• Curative treatment</td>
<td>• Coping</td>
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<td>• Genetic factors</td>
<td>• Diet</td>
<td>• Mammography</td>
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<td>• Non-curative treatment</td>
<td>• Health promotion</td>
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<td>• Gene-environment interactions</td>
<td>• Physical activity</td>
<td>• Fecal occult blood test</td>
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<td>• Adherence</td>
<td>for survivors</td>
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<td>• Medication (or pharmaceutical exposure)</td>
<td>• Sun protection</td>
<td>• Colonoscopy</td>
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<td>• Symptom management</td>
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<td>• Infectious agents</td>
<td>• HPV vaccine</td>
<td>• Lung cancer screening</td>
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<td>• Health behaviors</td>
<td>• Limited alcohol use</td>
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<td>• Chemoprevention</td>
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CROSSCUTTING AREAS

Communications
Surveillance
Health Disparities
Decision Making
Dissemination of Evidence-based Interventions
Health Care Delivery
Epidemiology
Measurement

Adapted from David B. Abrams, Brown University School of Medicine
About the Outcomes Research Branch

The mission of the Outcomes Research Branch (ORB), one of three branches in the Healthcare Delivery Research Program (HDRP), is to coordinate and sponsor research to measure, monitor, evaluate, and improve patient experiences, health outcomes, and quality of care across the cancer continuum. The purpose of this research is to understand the perspectives of cancer patients/survivors and their family members across the lifecourse, and to integrate those perspectives into healthcare delivery that facilitates patient engagement, and optimizes health and well-being.

ORB supports both methodological and applied research directed toward a variety of aims:

- enhancing the state of the science of outcomes measurement (the development, refinement and implementation of measures, measurement systems, and methods that monitor patient/survivor health);
- understanding patient symptoms and health-related quality of life (HRQOL) in cancer clinical trials, observational research and surveillance studies of cancer prevention, early detection, treatment, survivorship, and end-of-life care; and
- assessing, monitoring, and enhancing the quality of cancer care, patient experiences, and outcomes at all levels -- patient, provider, organization, and health system.
Outcomes Research: Major Goals

1. Support the development, refinement, and uptake of measures, measurement systems, and methods that monitor cancer patient care and health outcomes

2. Facilitate research to understand, monitor, and improve health outcomes and experiences of care in patients and family/caregivers across the lifespan

3. Strengthen the adoption and integration of patient-generated health data (PGHD) in clinical research and cancer care delivery to inform interventions and improve how care is organized and delivered
My program: patient-centered, family-engaged research
Social Ecological Model

- Communities
- Healthcare Settings
- Families
- Patients

Predictors

Outcomes
Patient-Centered Outcomes Research: the role of big data and surveillance
SEER Cancer Registries

- Seattle-Puget Sound
- Greater California
  - San Francisco-Oakland
  - San Jose-Monterey
- Los Angeles
- Utah
- New Mexico
- Iowa
- Detroit
- Connecticut
- New Jersey
- Atlanta
- Greater & Rural Georgia
- Louisiana
- Hawaiian Islands

**SEER Registry Initiation Date**

- **1973-1975 SEER**
- **1988-1999 SEER**
- **2000 SEER Expansion**
SEER-MHOS
Surveillance, Epidemiology and End Results – Medicare Health Outcomes Survey

Survey includes:
• Health-related quality of life (SF-36, VR-12)
• Activities of daily living
• HEDIS effectiveness of care
• Comorbidities
• Sociodemographics
• Age-related impairments in hearing, vision, and mobility

• Launched 2010
• Over 140,000 SEER-linked beneficiaries
• Over 2 million beneficiaries without cancer

80+ Data Use Agreements
44+ publications

https://healthcaredelivery.cancer.gov/seer-mhos/
Health-Related Quality of Life in Older Adult Survivors of Selected Cancers: Data From the SEER-MHOS Linkage

Erin E. Kent, PhD; Anita Ambs, MPH; Sandra A. Mitchell, PhD, CRNP; Steven B. Clauser, PhD; Ashley Wilder Smith, PhD, MPH; and Ron D. Hays, PhD

- N=16,095 cancer survivors/ N=1,224,549 individuals without cancer
- Physical health deficits
- Multiple myeloma and pancreatic malignancies reported lowest scores

Figure 1. Average adjusted physical (PCS) and mental (MCS) and component scores by cancer site. Asterisk indicates at least a 2.0 point difference from no history of cancer.
• N=445 PrCa/ N=2225 controls propensity-matched
• Post-dx decrements
• 1 year post-dx HRQOL rebounded
Among MM, 10% increase in frailty index (3-4 deficits) associated with 16% increased risk of death

Mean frailty index 0.28

Median OS

- frail MM: 26.8 months
- non-frail MM: 43.7 months

Fig 3. Kaplan-Meier estimates for overall survival for patients with multiple myeloma according to frailty status as determined by the deficit accumulation approach (P = .015).

Published in: Hira S. Mian; Tanya M. Wildes; Mark A. Fiala; JCO Clinical Cancer Informatics 2018, 2, 1-13.
DOI: 10.1200/CCI.18.00043
Copyright © 2018 American Society of Clinical Oncology
Trends in health disparities over time:
Mental Component Summary

Cancer

Non-cancer

Adjusted by: comorbidities, gender, SEER registry region, educational attainment (cancer models also adjusted by months from DX to survey and stage at DX)

Adjusted margins for opioid use by pain limitation and cancer status

SEER-CAHPS
Surveillance, Epidemiology and End Results – Consumer Assessment of Healthcare Providers and Systems

- Launched 2015
- Over 205,000 cancer respondents
- More than 724,000 non-cancer respondents

Survey includes:
- Patient/Physician Communication
- Care coordination
- Access to care
- Patient perceptions of care quality

https://healthcaredelivery.cancer.gov/seer-cahps/
Cancer patient experiences within last year of life

Halpern MT, Urato MP, Kent EE. The health care experience of patients with cancer during the last year of life: Analysis of the SEER-CAHPS data set. Cancer
Future questions: patient-centered outcomes research & surveillance in cancer

1. Beyond cancer: what are key differences in patterns of care for patients with multiple chronic conditions and how do we improve care delivery for these individuals?

2. Resource refinement: how can we strengthen the current data sources we have?

3. Novel data linkages: how can we leverage additional data sources to create surveillance data for patients < 65 years old, in particular underserved and underrepresented patient populations (e.g., less prevalent cancer sites, minority populations, rural and those at intersections)?

4. How do we use data at multiple scales to reinforce cancer centers as rapid learning healthcare systems?
Social Ecological Model

- Communities
- Healthcare Settings
- Families
- Patients

Predictors

Outcomes
Social Ecological Model

Communities

Healthcare Settings

Families

Patients

Predictors

Outcomes
Family-engaged Outcomes Research
Informal/Family Caregivers

- Individuals that assist family members/friends by providing care which is:
  - typically uncompensated
  - usually in the home setting
  - involving significant efforts for extended time

- Caregiving can require demanding tasks

- Approximately 43.5 million people serve as informal caregivers in the US, and the care is valued at $470 billion
Cancer-specific caregiving

- Unique aspects of caregiving in the context of cancer
  - Rapid deterioration of health
  - High levels of emotional stress
  - Multi-modal therapies
  - More and more outpatient/home care
  - Recurrence, and fear of recurrence
Caring for Caregivers and Patients: Revisiting the Research and Clinical Priorities for Informal Cancer Caregiving

Sponsored by the National Cancer Institute and the National Institute for Nursing Research
May 4-5, 2015
NCI Shady Grove TE406

NCI Planning Committee: Co-chairs Erin Kent (NCI), Julia Rowland (NCI)
Wen-Ying Sylvia Chou (NCI/DCCPS/BRP), Kristin Litzelman (NCI/DCCPS/BRP),
Ann O'Mara (NCI/DCP), Nonniekaye Shelburne (NCI/DCCPS/EGRP)

Caring for Caregivers and Patients: Research and Clinical Priorities for Informal Cancer Caregiving

Erin E. Kent, PhD, MS¹; Julia H. Rowland, PhD¹; Laurel Northouse, PhD, RN²; Kristin Litzelman, PhD¹;
Wen-Ying Sylvia Chou, PhD, MPH¹; Nonniekaye Shelburne, MS, CRNP, AOCN¹; Catherine Timura, PhD, MPhil³;
Ann O'Mara, PhD, RN, MPH⁴; and Karen Huss, PhD, RN⁵

Kent et al., 2016, Cancer, PMID: 26991807
Key recommendations: cancer caregiving research

- Expanding Assessment of Prevalence and Burden
- Improving Interventions
- Maximizing the Positive Impact of Technology
- Integrating caregivers into the healthcare system

Kent et al., 2016, Cancer, PMID: 26991807
E1. Are you currently caring for or making health care decisions for someone with a medical, behavioral, disability, or other condition?

Mark all that apply.

1. Yes, a child/children Caregiving_Child
1. Yes, a spouse/partner Caregiving_Spouse
1. Yes, a parent/parents Caregiving_Parent
1. Yes, another family member Caregiving_AnotherFam
1. Yes, a friend or other non-relative Caregiving_Friend
1. No ➔ GO TO E11 on page 10 Caregiving_No
Adjusted PROMIS® Instrumental Support
n=311 caregivers, $r^2 = 0.23$

![Bar chart showing PROMIS® Instrumental Support categorized by PHQ-4 Distress Category.](chart)

PHQ-4 Distress Category
- Low/None (0-2)
- Mild (3-5)
- Moderate (6-8)
- Severe (9-12)

PROMIS® Instrumental Support
- Low/None (0-2) 52.3
- Mild (3-5) 49.4
- Moderate (6-8) 48.9
- Severe (9-12) 39.7

Data source: HINTS V Cycle 2, Kent et al., In Prep
CAHPS for Cancer Care Surveys
Consumer Assessment of Healthcare Providers and Systems

- Radiation Therapy Survey
- Drug Therapy Survey (Chemotherapy)
- Cancer Surgery Survey

- **Surveys** developed and tested with funding from the AHRQ, NCI, and California Health Care Foundation
- Released in June, 2017
- May be assessed at independent community oncology practices and cancer centers, or used in research studies

Selected Quality Measure From the Cancer Care Survey
- Involvement of family members and friends in cancer care

Main findings:
- ~2.8 million adults serving as a caregiver
- Caring: 32.9 hrs/wk
- 43% performing complex tasks without preparation
- 50% high emotional stress
- 25% high financial strain

http://www.caregiving.org/cancer/
Average number of mentally unhealthy days by caregiving intensity and support service endorsement

Kent & Dionne-Odom, Accepted, Journal of Oncology Practice
Additional observational findings

Original Article

Social Factors in Informal Cancer Caregivers: The Interrelationships Among Social Stressors, Relationship Quality, and Family Functioning in the CanCORS Data Set

Kristin Litzelman, PhD; Erin E. Kent, MS, PhD; and Julia H. Rowland, PhD

Interrelationships Between Health Behaviors and Coping Strategies Among Informal Caregivers of Cancer Survivors

Kristin Litzelman, PhD, Erin E. Kent, PhD, MS, and Julia H. Rowland, PhD

Original Article

The Role of Medical/Nursing Skills Training in Caregiver Confidence and Burden: A CanCORS Study

Michelle A. Mollica, PhD, MPH, RN; Kristin Litzelman, PhD; Julia H. Rowland, PhD; and Erin E. Kent, PhD

How Does Caregiver Well-Being Relate to Perceived Quality of Care in Patients With Cancer? Exploring Associations and Pathways

Kristin Litzelman, Erin E. Kent, Michelle Mollica, and Julia H. Rowland

MEPS
A Review of Family Caregiving Intervention Trials in Oncology

Betty Ferrell, RN, PhD, MA, FAAN, FPCN, CHPN ©1; Elaine Wittenberg, PhD2

• 1983-2009: 29 RCTs (Northouse, 2010)
• 2010-2016: 50 RCTs (Ferrell & Wittenberg, 2017)

• Similarities: Majority of trials are still…
  • Psychoeducational interventions
  • Couples-based interventions
  • Limited in non-White populations
  • Strongly dose-dependent

• Differences
  • Less reporting of intervention fidelity in later review
  • Shift toward more telehealth or home-based delivery
Intervening with cancer caregivers to improve patient & caregiver health outcomes and optimize healthcare utilization:
PAR-18-246 (R01), PAR-18-247 (R21)

- Fund interventions that support the success of informal cancer caregivers for adult cancer patients, as measured by the following outcomes:
Intervening with cancer caregivers to improve patient & caregiver health outcomes and optimize healthcare utilization:
PAR-18-246 (R01), PAR-18-247 (R21)

<table>
<thead>
<tr>
<th>PI</th>
<th>Title</th>
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<tbody>
<tr>
<td>Milbury</td>
<td>Yoga Intervention for Family Caregivers of Patients with Brain Tumors</td>
<td>1R21CA218309</td>
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<tr>
<td>Prigerson &amp; Lichtenthal</td>
<td>Enhancing &amp; Mobilizing the POTential for Wellness &amp; Emotional Resilience (EMPOWER) in Caregivers of ICU Cancer Patients</td>
<td>1R21CA218313</td>
</tr>
<tr>
<td>Shen &amp; Trevino</td>
<td>A communication-based intervention for advanced cancer patient-caregiver dyads to increase engagement in advance care planning and reduce caregiver burden</td>
<td>1R21CA224874</td>
</tr>
<tr>
<td>Badger</td>
<td>Improving Informal Caregivers' and Cancer Survivors' Psychological Distress, Symptom Management and Health Care Use</td>
<td>1R01CA224282</td>
</tr>
<tr>
<td>Sun &amp; Kim</td>
<td>A Multimedia Self-Management Intervention to Prepare Family Caregivers and Patients for Lung Cancer Surgery</td>
<td>1R01CA217841</td>
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</table>
SBIR NIH/NCI FY17 363: Connecting Cancer Caregivers to Care Teams: Digital Platforms to Support Informal Cancer Caregiving

- Develop evidence-based technologies to
  1. Alleviate cancer caregiving burden
  2. Assist family/informal caregivers to manage care
  3. Juggle caregivers’ own healthcare needs
  4. Enhance caregivers’ connections with healthcare team

https://sbir.cancer.gov/funding/contracts/nihnci363

Maximizing the Positive Impact of Technology

Integrating caregivers into the healthcare system
SBIR NIH/NCI FY17 363: Connecting Cancer Caregivers to Care Teams: Digital Platforms to Support Informal Cancer Caregiving

<table>
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<tr>
<th>Company</th>
<th>Title</th>
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<tr>
<td>Bright Outcome, Inc.</td>
<td>Develop an electronic caregiver support system aimed at addressing caregiving needs and caregiver personal needs</td>
</tr>
<tr>
<td>Care Progress LLC</td>
<td>Create a smart phone application that will allow caregivers to access patient electronic health record information and communicate with clinicians</td>
</tr>
<tr>
<td>Medable Inc</td>
<td>Develop and implement a digital application to assist informal caregivers with developing an interactive care plan for home-based care for cancer survivors</td>
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https://sbir.cancer.gov/funding/contracts/nihnci363
Future questions: family-engaged research in cancer

1. Characterize impact of cancer & cancer treatment on family & family caregivers

2. Develop methods to link patients with their family members in existing data sources

3. Caregiver registry?

4. Improve and scale interventions for cancer survivors and their family members

5. Design with implementation intentions
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- HDRP Staff

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- Hoda Anton-Culver
- Rachel Cannady
- Wen-Ying Sylvia Chou
- J. Nicholas Dionne-Odom
- Rebecca Ferrer
- Kristin Litzelman
- Maggie Longacre
- Matt Loscalzo
- Michael Montoya
- Laurel Northouse
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- Carly Parry
- Bryce Reeve
- Julia Rowland
- Leonard Sender
- Grace Whiting
- Robin Yabroff

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Thank you

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