

# Symposium 25: Cancer caregiving experiences across the care continuum: from diagnosis to bereavement

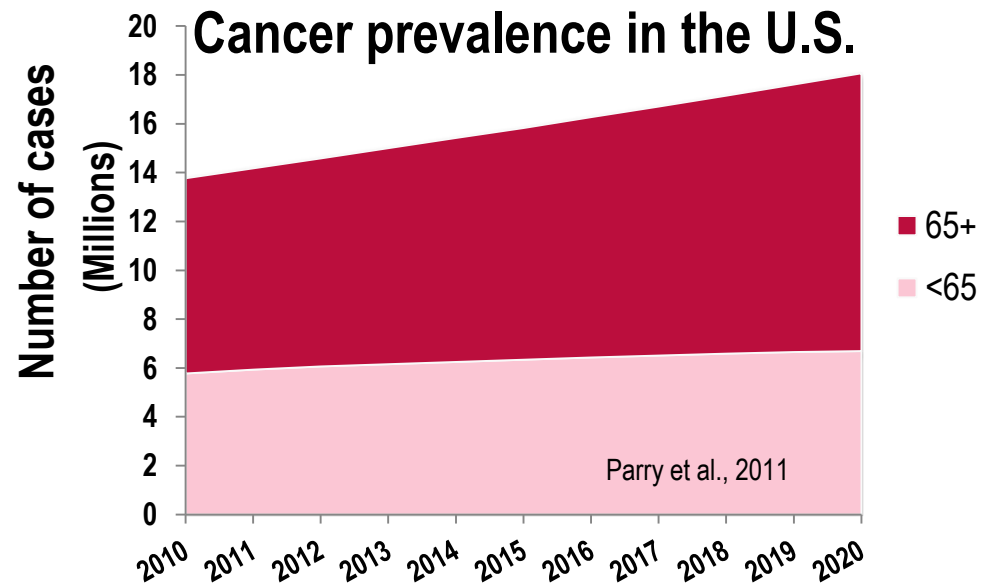
Erin E. Kent, PhD

Outcomes Research Branch, Healthcare Delivery Research Program  
Division of Cancer Control and Population Sciences

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# Prevalence of informal cancer caregiving

- Approximately 43.5 million U.S. adults providing significant care to a loved one with a chronic health condition, valued at \$470 billion
- Cancer is the 4<sup>th</sup> most common reason for the need of a caregiver
- As the number of cancer survivors continues to grow, the number of cancer caregivers is also expected to increase



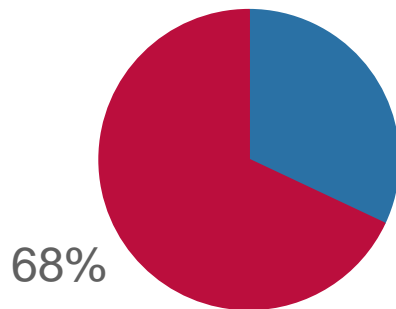
# Challenges that caregivers face

- 22% of caregivers indicate that caregiving makes caregiver health worse
- 20% report high level of physical strain
- 18% report high financial strain
- 23% report difficulty in managing patients activities of daily living



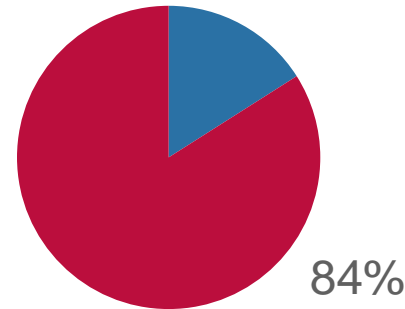
*Q45: In your experience as a caregiver, have you ever had: a doctor, nurse, or social worker ask you what you need/needed?*

To take care of your care recipient



■ Yes ■ No

To take care of yourself



■ Yes ■ No

# **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, PhD, MPH; Ann O'Mara (NCI)

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

Erin E. Kent, PhD, MS<sup>1</sup>; Julia H. Rowland, PhD<sup>1</sup>; Laurel Northouse, PhD, RN<sup>2</sup>; Kristin Litzelman, PhD<sup>1</sup>;  
Wen-Ying Sylvia Chou, PhD, MPH<sup>1</sup>; Nonniekaye Shelburne, MS, CRNP, AOCNP<sup>1</sup>; Catherine Timura, PhD, MPH<sup>3</sup>;

- Increase research on the most vulnerable caregiving populations
- Incorporate risk stratification to target distressed patients and caregivers
- Refine models of caregiving burden with careful attention to measurement

Kent et al., 2016, *Cancer*, PMID: 26991807

# Trevino: Risk factors and correlates of grief challenges in cancer caregivers

- Background: Bereaved caregivers too often report high and persistent distress
- Objective: Describe specific grief challenges
- Design: Longitudinal, prospective multi-site study to test the Grief Challenges Inventory to determine its properties
- Findings:
  - Psychometric properties promising
  - Number of grief challenges numerous, variability high
  - Spouse/partners and those who are less educated more likely to report higher level of challenge
  - Poor QOL in certain domains is predictive and predicted by higher grief challenges
  - Points toward new intervention targets

K. Trevino: ket2017@med.cornell.edu

# Trevino: Risk factors and correlates of grief challenges in cancer caregivers

## Questions:

- Do circumstances related to the patient's death have an impact on grief challenges?
- What might interventions that act on grief challenges look like for bereaved caregivers, and when should they be initiated?

# Thompson: Examining gender differences in caregiving burden

- Background: Shifts in survival are also shifting caregiving experiences for many cancers
- Objective: Understand the characteristics associated with increased caregiver burden
- Design: Prospective study of patients/caregivers with multiple myeloma, CLL, and NHL, followed within 6 months of treatment initiation for 2 years
  - Semi-structured interviews (n=115)
  - Employment, relationship quality, HRQOL, caregiving burden
- Findings:
  - Employment associated with better role/social functioning
  - Non-working women report poorest outcomes

M. Thompson: [maria.thomson@vcuhealth.org](mailto:maria.thomson@vcuhealth.org)

# Thompson: Examining gender differences in caregiving burden

## Questions:

- How can we bridge the work of caring and employment? How can employers help their employees better navigate caregiving challenges?
- In our increasingly mobile society, how do we grapple with geographically dispersed families and the impact to caregivers?
- Why do non-working female caregivers report the worst outcomes, and how might interventions better target them?



# Reblin: Nurse-caregiver-patient communication profiles in cancer home hospice visits

- Background: Caregivers often overwhelmed/unprepared for the new roles and tasks they face
- Objective: Describe and predict home hospice nurse-caregiver communication profiles
- Design: Project IMPACT (NCI P01CA138317), Prospective multisite study of end-of-life care (home hospice).
  - Audio-recorded nurse home visits (n=537, average 5 visits/dyad), utterance coded
  - Used cluster analysis to identify communication profiles
- Findings:
  - 5 major visit communication profiles identified
  - Healthier caregivers more likely to have more medical communication
  - Lower SES predictive of distress visits

# Reblin: Nurse-caregiver-patient communication profiles in cancer home hospice visits

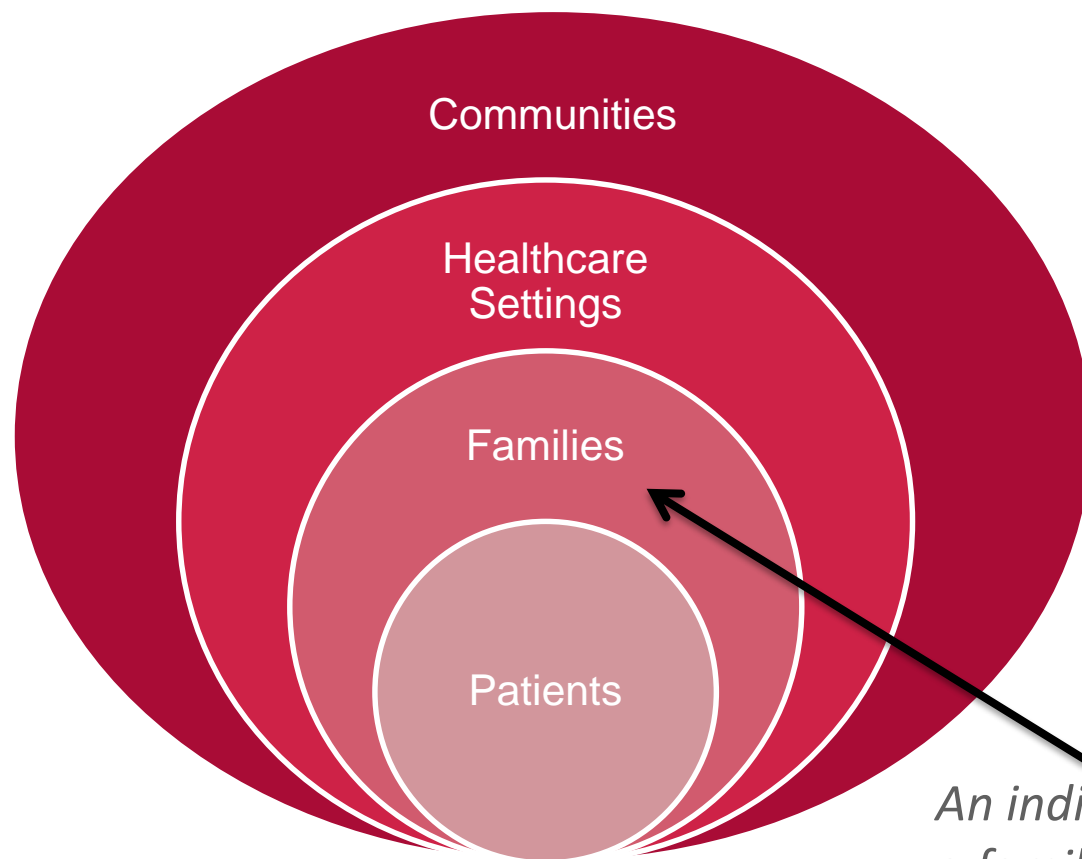
## Questions:

- How does both the content and style of communication between nurses and caregivers/patients differ in the home vs. clinic setting?
- What is really going on in terms of the relationship-building aspects of communication, and can this be built upon?
- What lessons should interventionists take from this work, particularly for low SES and other more vulnerable families?

# Research on cancer caregiving is building...

- IOM study on family caregiving of older adults (summer, 2016)
- Cancer caregiving report sponsored by the National Alliance for Caregiving, Cancer Support Community, and National Cancer Institute (late spring, 2016)
- Funding Opportunity Announcements:
  - NINR: Promoting Caregiver Health Using Self-Management (R01), RFA-NR-16-003
  - NCI: Cancer Caregiving Interventions, coming soon...
- The C. A. R. E. Act (Caregiver Advise Record Enable Act), sponsored by AARP

# Social Ecological Framework



*An individual doesn't get cancer;  
a family does.  
-T. T. Williams*



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