

## Improving End-of-Life Care: What can we learn from the bereaved?

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Lineberger Comprehensive Cancer Center  
North Carolina Cancer Hospital  
University of North Carolina at Chapel Hill



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## DISCLOSURES

- Rosenstein and Yopp  
– Oxford University Press (royalties)

**[www.widowedparent.org](http://www.widowedparent.org)**



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## Outline

- I. Don: origin of widowed fathers project (a collaborative partnership)
- II. Justin: key findings from online survey of widowed fathers and next steps in research agenda
- III. Discussion: how can we foster participatory and collaborative research that informs EOL care?



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## Objectives

1. Differentiate the Dual Process Model of Bereavement from traditional stage models of grief and bereavement.
2. Identify major psychological challenges experienced by widowed fathers.
3. List several areas of end of life care that can be improved by the reports of the bereaved.



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## Three Recent Preoccupations

1. We continue to fail dying patients
2. Terminally ill parents (of younger children) make a particularly compelling case
3. Relevant feedback mechanisms are critical for quality improvement: **the bereaved are an important and rarely tapped source of insight about EOL care**



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“This experiment of making mortality a medical experience is just decades old. It is young. And the evidence is it is failing.”

Atul Gawande  
*Being Mortal* (2014)



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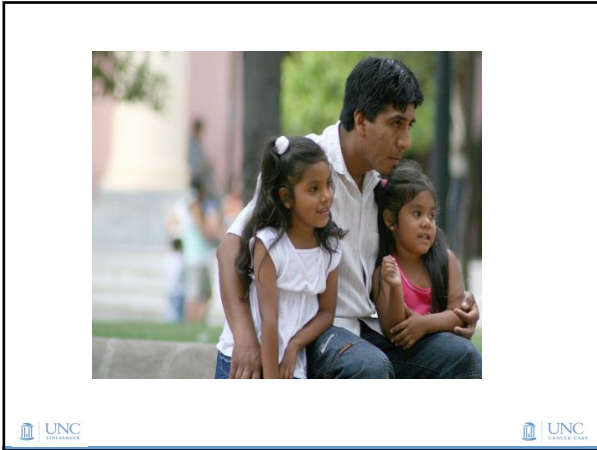
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### Index Case

- 42 y/o married mother of two with advanced lung cancer
- Following the patient's death, her husband and children were "lost at sea...struggling profoundly."



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### Index Case

- 42 y/o married mother of two with advanced lung cancer
- Following the patient's death, her husband and children were "lost at sea...struggling profoundly."
- Original motivation for a men's group:
  - **Help the kids by helping their dads** (perhaps the ticket in the door for fathers)



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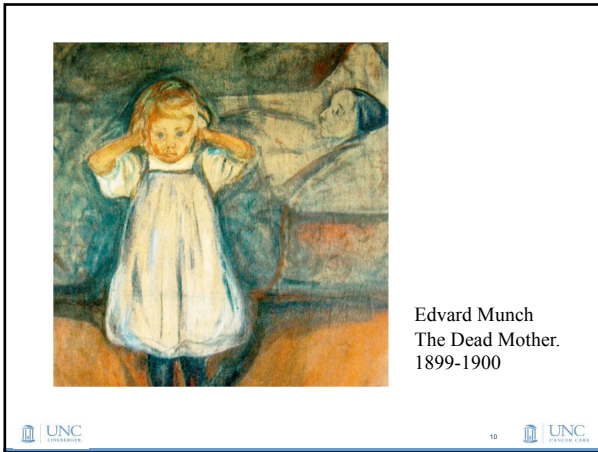
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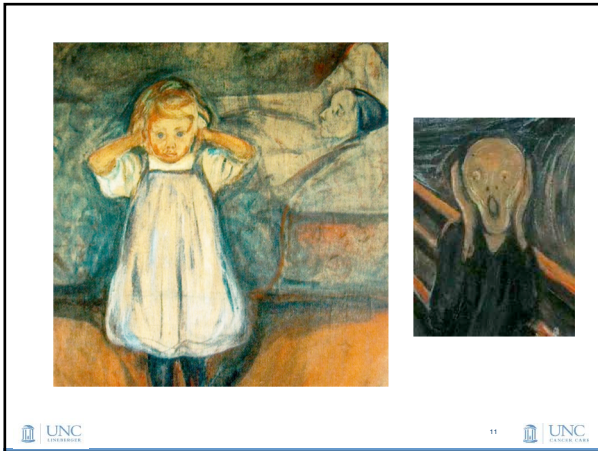
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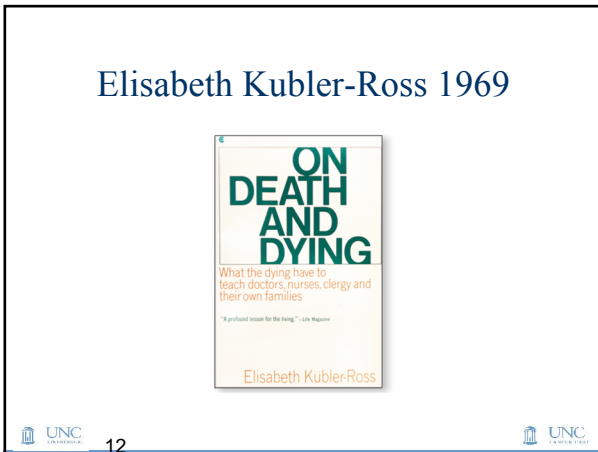
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### A Mother's Death

Denial  
Anger  
Bargaining  
Depression  
Acceptance



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### A Husband's Response? A Father's Response? A Child's Response?

Denial  
Anger  
Bargaining  
Depression  
Acceptance



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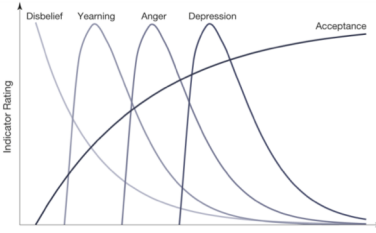
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The JAMA Network

From: An Empirical Examination of the Stage Theory of Grief

JAMA. 2007;297(7):716-723. doi:10.1001/jama.297.7.716





Indicator Rating

Time From Loss

Maciejewski PK, Zhang B, Block SD, Prigerson HG. 2007

18/2014

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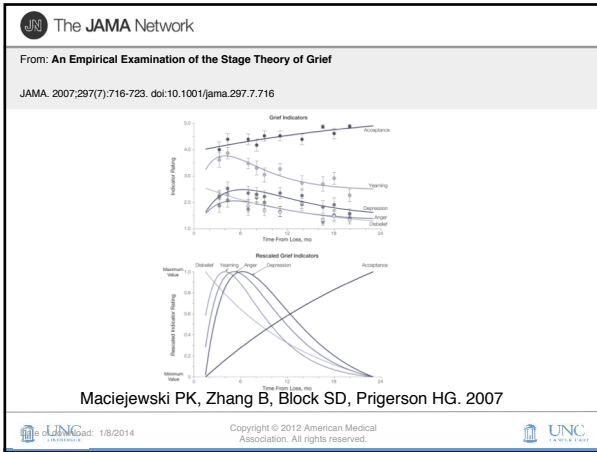
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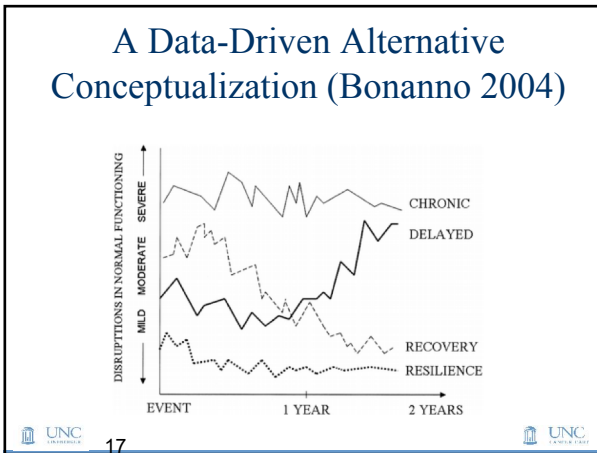
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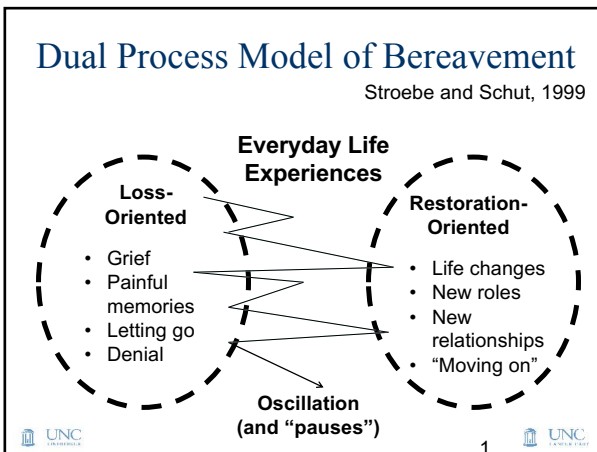
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### Preliminary Themes from Group

- Unique experience: men without peers
- Longing for lost “partner in parenting”
- Worry about children (“screwing them up further”): comfort, discipline, and fun
- “Ring thing” and dating

The UNC logo is visible in the bottom left and right corners of the image frame.

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## Preliminary Themes from Group

- Unique experience: men without peers
- Longing for lost “partner in parenting”
- Worry about children (“screwing them up further”): comfort, discipline, and fun
- “Ring thing” and dating
- Revisiting end of life decisions: personal regrets and a conviction that there is much room for improvement in EOL care



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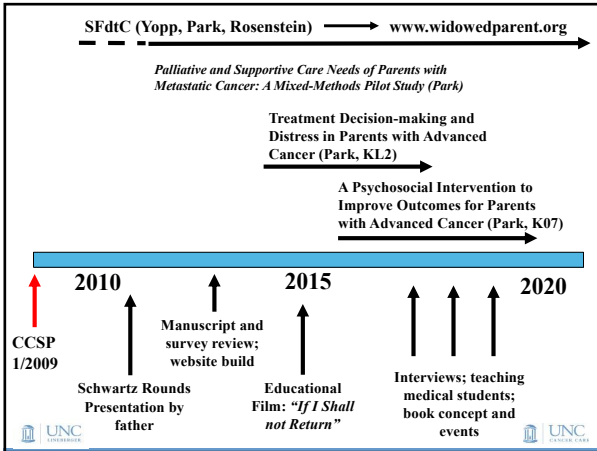
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## Dual Rationale for Website

1. Single fathers due to cancer have no advocacy group and need resources
2. Vehicle to address research gap



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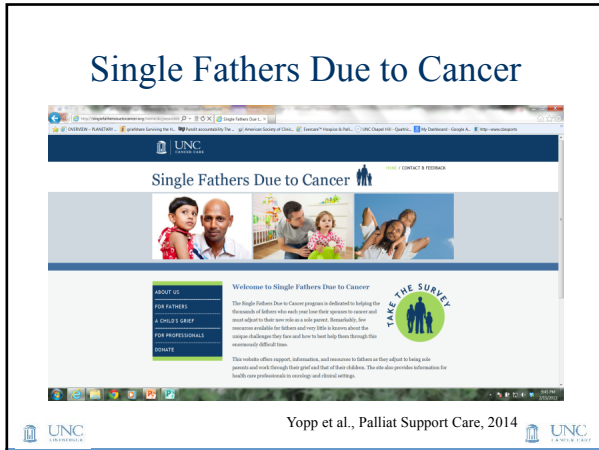
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### Study

- Inclusion criteria:
  - Father with at least one child (< 18) at home
  - Child's mother died from cancer
- Domains assessed:
  - End-of-life variables
  - Parenting self-efficacy / satisfaction
  - Psychological functioning

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### Survey Details

- Baseline and follow-up surveys
- Quantitative and qualitative data
- Designed for flexibility
  - Several components
    - Demographics
    - Validated instruments (CES-D; TRIG)
    - Topic-driven modules (EOL, parenting, dating)

Yopp et al., Palliative and Supportive Care, 2014

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### Methodological Limitations

- Problems of access and sampling
- Self-selection (biased sample)
- Can not insure fidelity of data



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### Participant Characteristics

- Mean age 46 ± 7 years
- 89% Caucasian
- 74% college graduates
- 84% employed
- 83% not in a relationship
- 77% annual income > \$50,000



Park et al. BMJ Support Palliative Care, 2016



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### Baseline Findings

- Reported meeting parenting expectations

Park et al., 2015; Yopp et al., 2015



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### Baseline Findings

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### Baseline Findings

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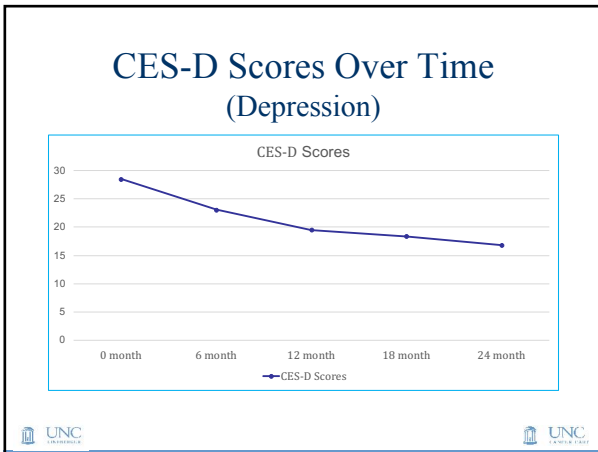
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### Baseline Findings

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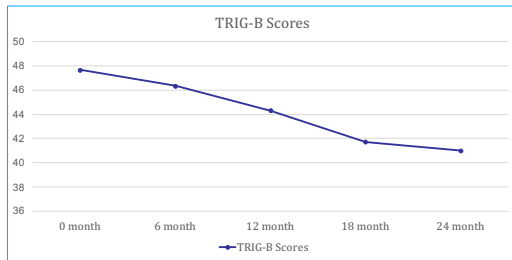
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### TRIG-B Scores Over Time (Grief)



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### Back to the Initial Question...

What can we learn from the bereaved to about EOL care?

*\* specifically for parents with advanced illnesses*



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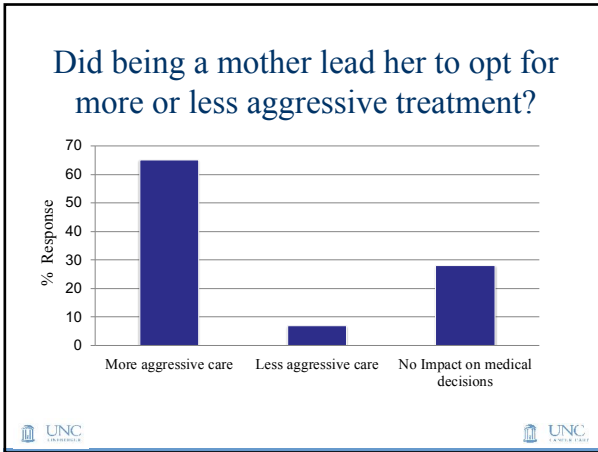
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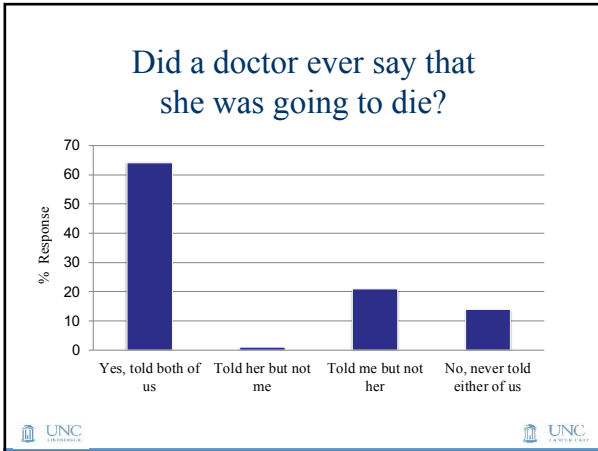
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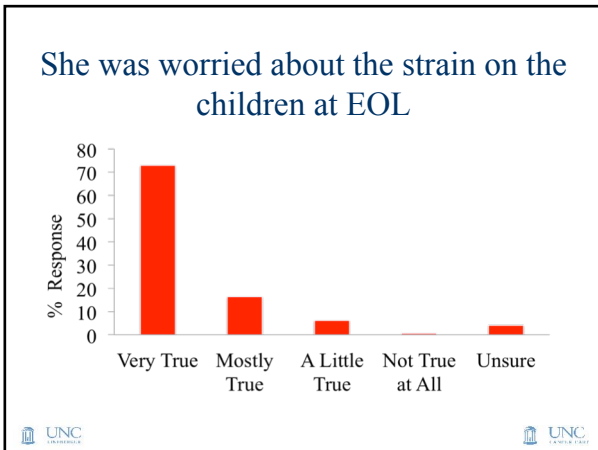
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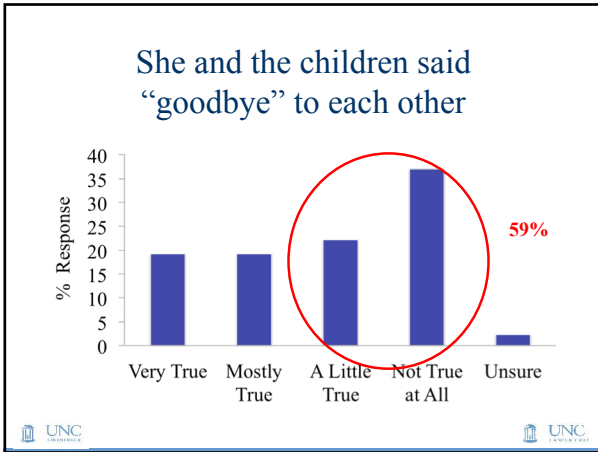
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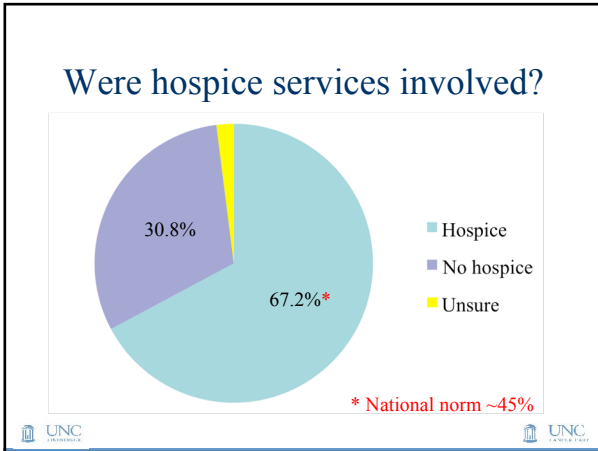
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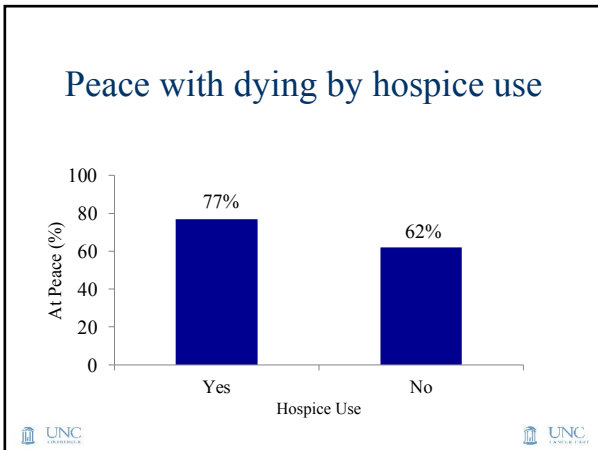
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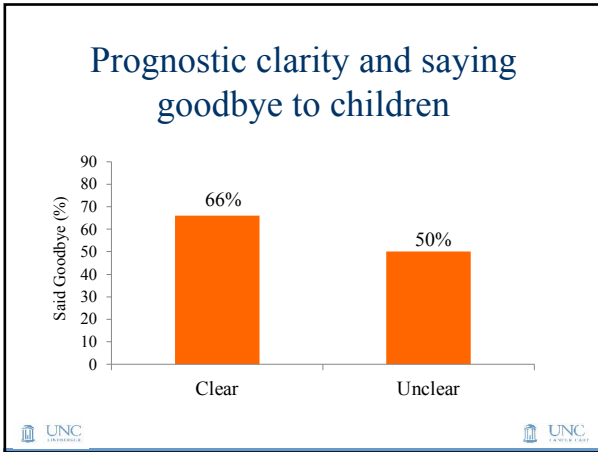
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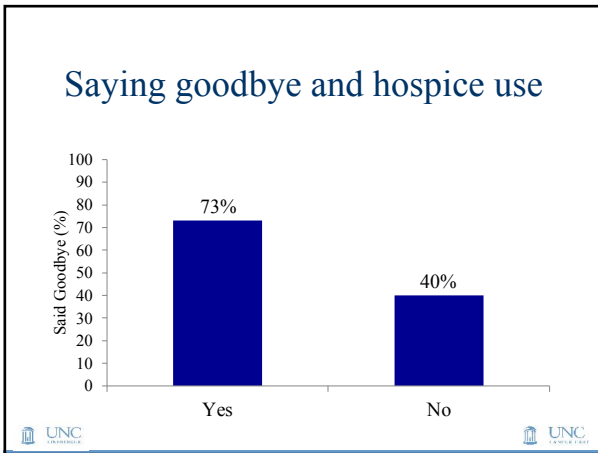
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- ### The most important topics a father should discuss with mother at EOL
- 61% Raising the children in ways that reflect her wishes, values, hopes
  - 42% How she wants to be remembered
  - 39% Whether/how to talk to children about impending death
  - 35% Whether/how to talk with children about death after she dies

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### Findings from interviews with bereaved fathers

1. Hospice services associated with better outcomes
2. Need for proactive symptom management
3. Communication is critical
  - Team needs to be “on same page”
  - Patients want prognostic clarity
  - Patients want individualized care
4. Bereaved outcomes are linked with pt’s EOL care

Cartwright 1973; Hatano 2017; Kaal 2016; Kumar 2016; Wright 2013



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### Methodological aspects of “after death” interviews

- Limited and complex literature
- Concerns about recall bias; lack of congruence with patient perspective; influence of depression and anxiety on the reports of bereaved, etc
- Validity of this approach



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### What next?



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