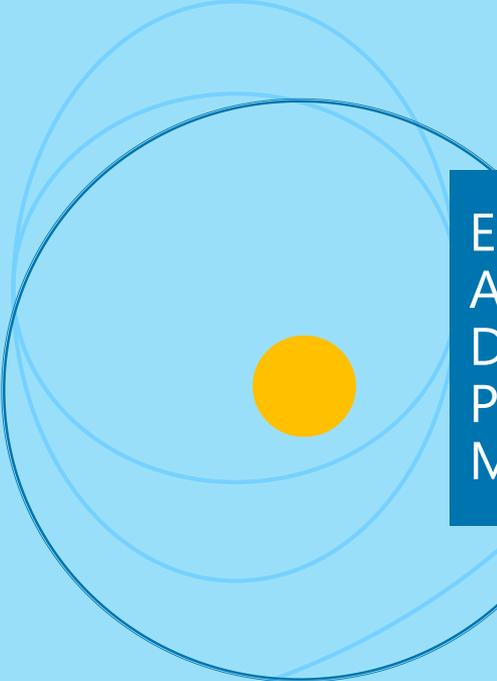


When Mom or Dad has cancer

The intersection of parental status with patient and family outcomes



Eliza "Leeza" Park
Assistant Professor
Department of
Psychiatry &
Medicine

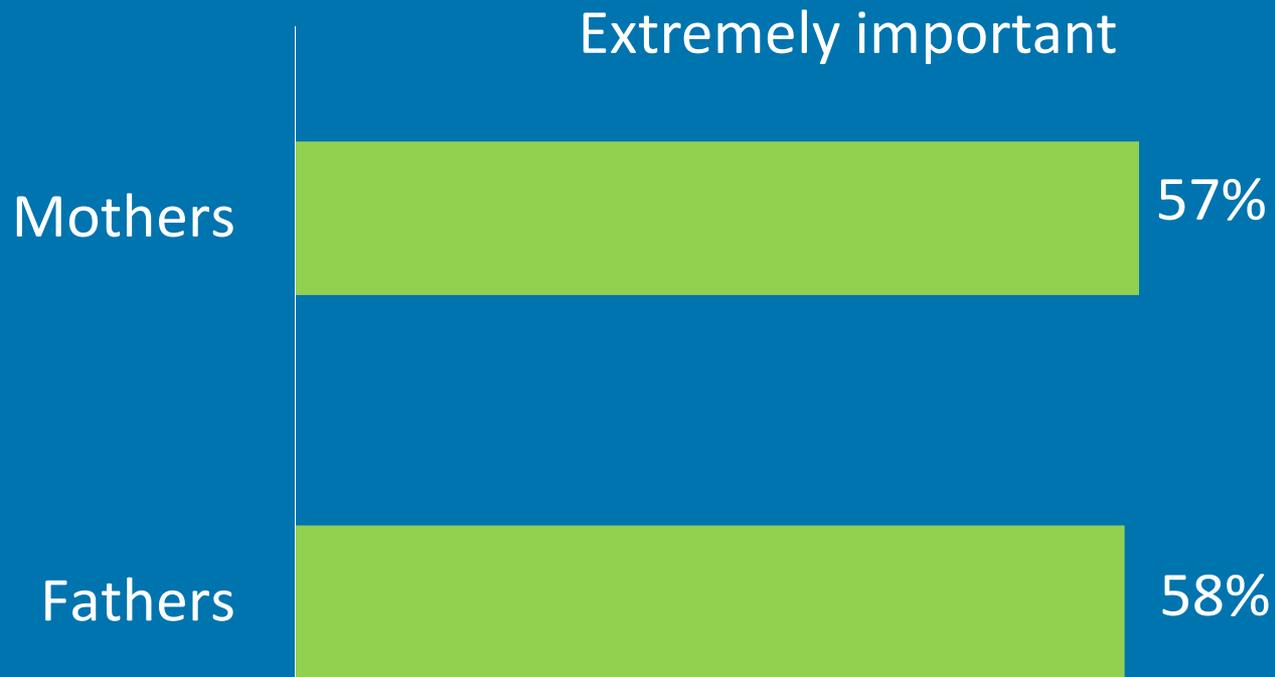


Why study parents with advanced cancer?

Research informed by clinical practice

- Learning from my mistakes
- When current interventions are ineffective

Being a parent is central to our identity



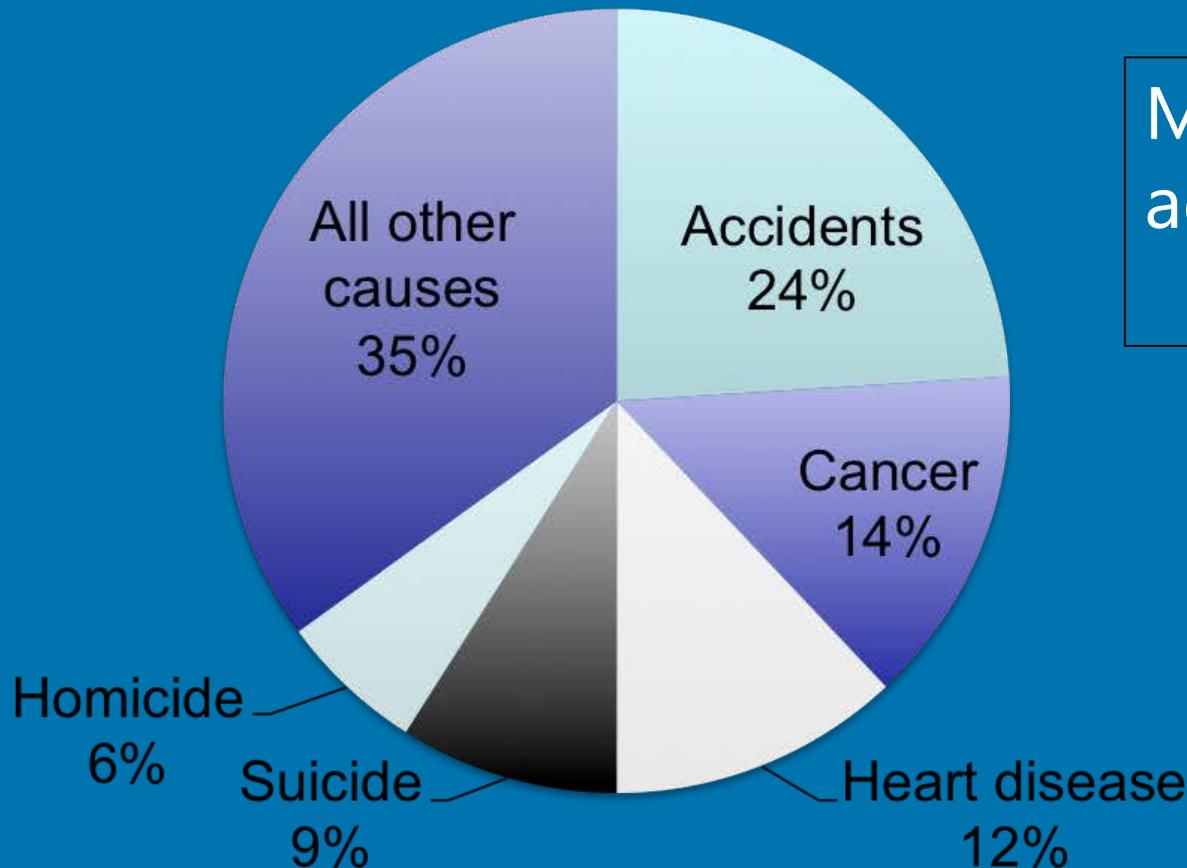
Being a parent is central to our identity



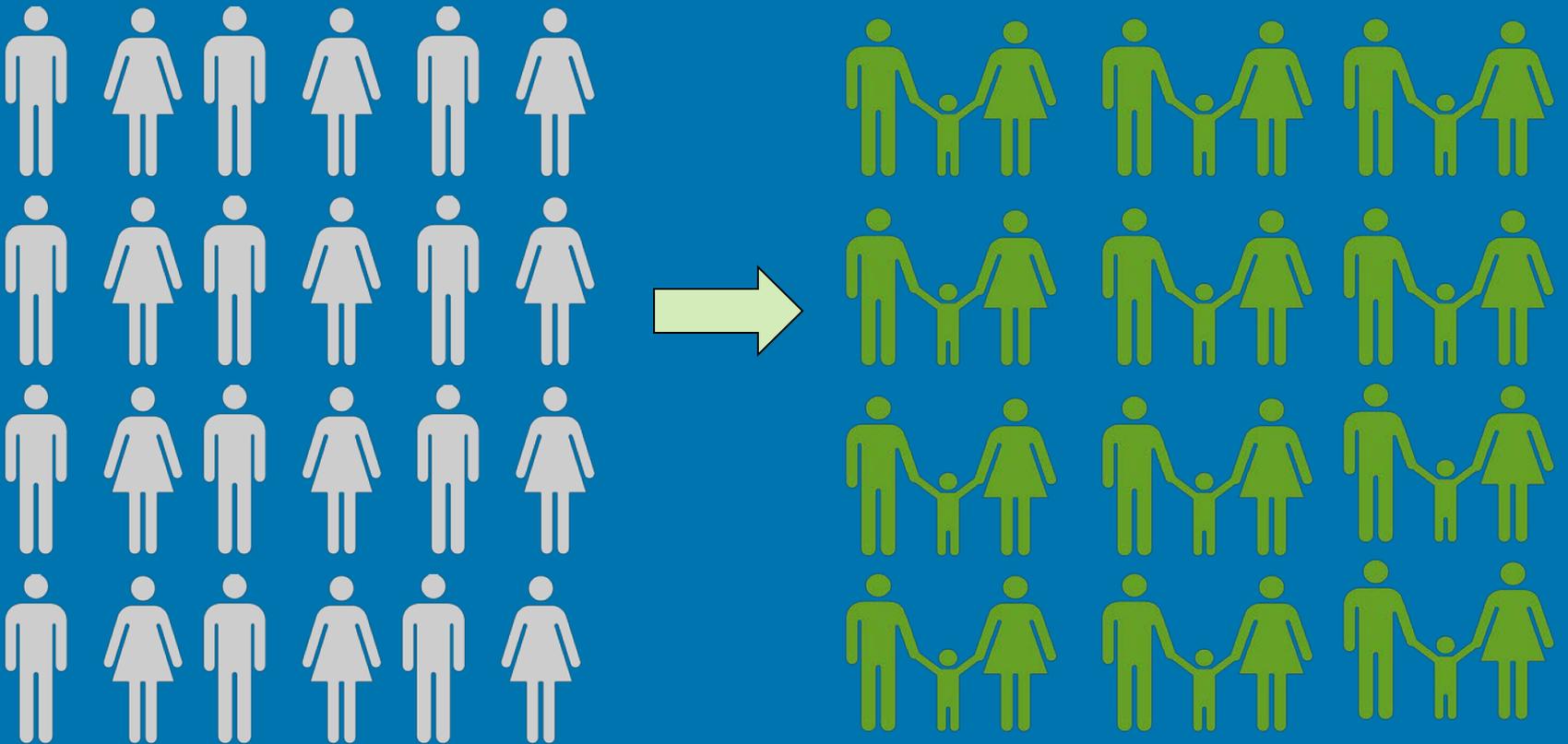


Cancer is the leading disease-specific cause of early parental death in the US

Men and women,
ages 25-44 years



Individual patient ... magnified by family-impact





Psychosocial outcomes

What is it like to be a parent with serious illness

Treatment preferences

Healthcare decisions through the lens of parental identity

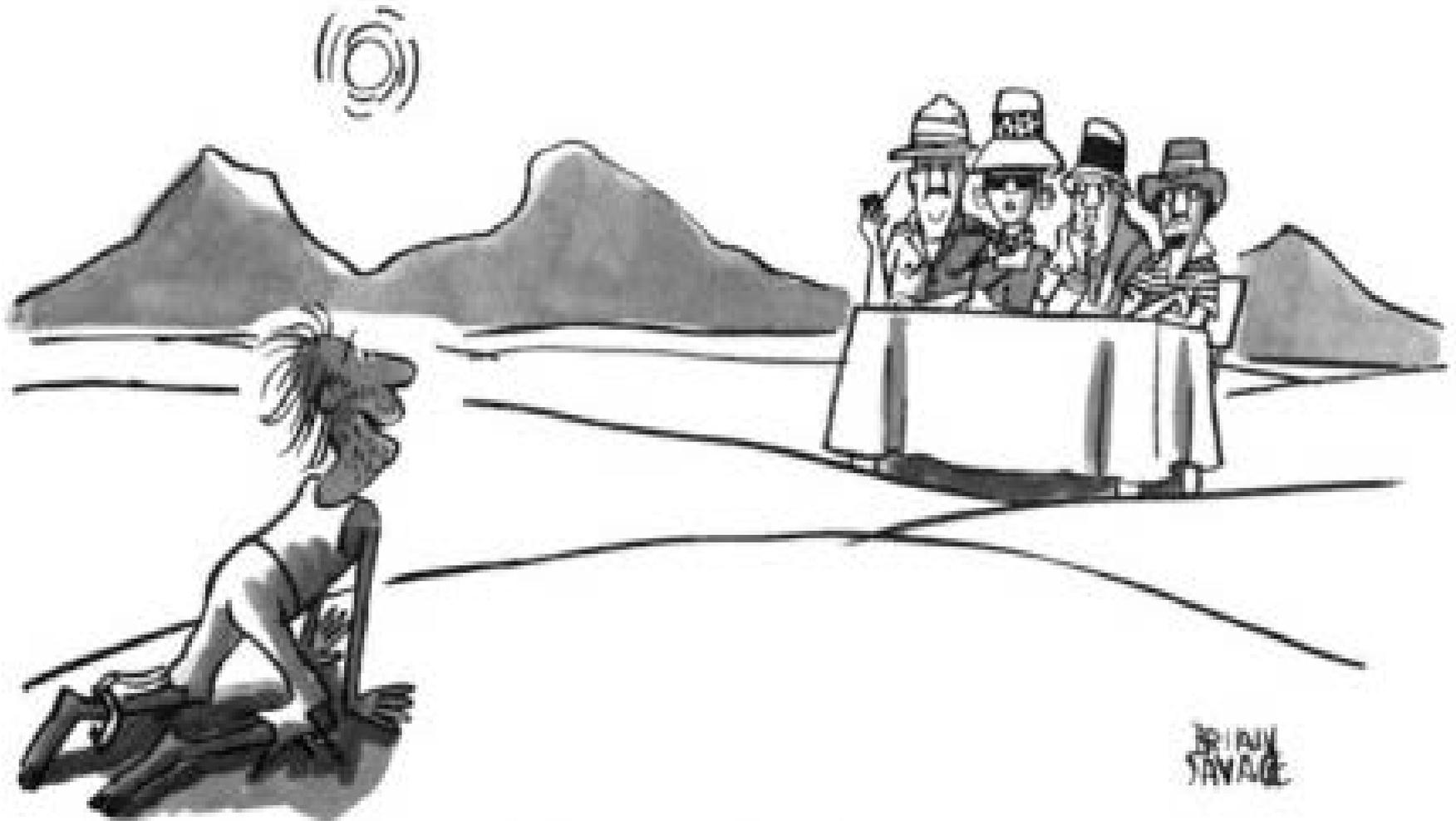
Lessons from the bereaved

What happens to the family

Toward intervention

What can we do to improve outcomes?

Observational studies to confirm clinical wisdom



"Thank God! A panel of experts!"

Psychological outcomes of parents with advanced cancer

What distinguishes parents with advanced cancer from other patients?

More likely to be
depressed

More likely to be anxious

Have higher intensity of
worry

Distinct concerns from other populations

Adult cancer patients without
children

Parents with early stage
cancer

Older adults with advanced
cancer

What might be contributing to these outcomes?



Effects of declining health and parental availability

Changes to routines, activities, availability

Finding ways to be a good parent despite illness

Bearing witness to the losses of what you can no longer do and what you will not live to see

Impact of early mortality on their children

Fear of “screwing up” their children

“Running out of time” to teach life lessons and values

Abilities and availability of co-parent

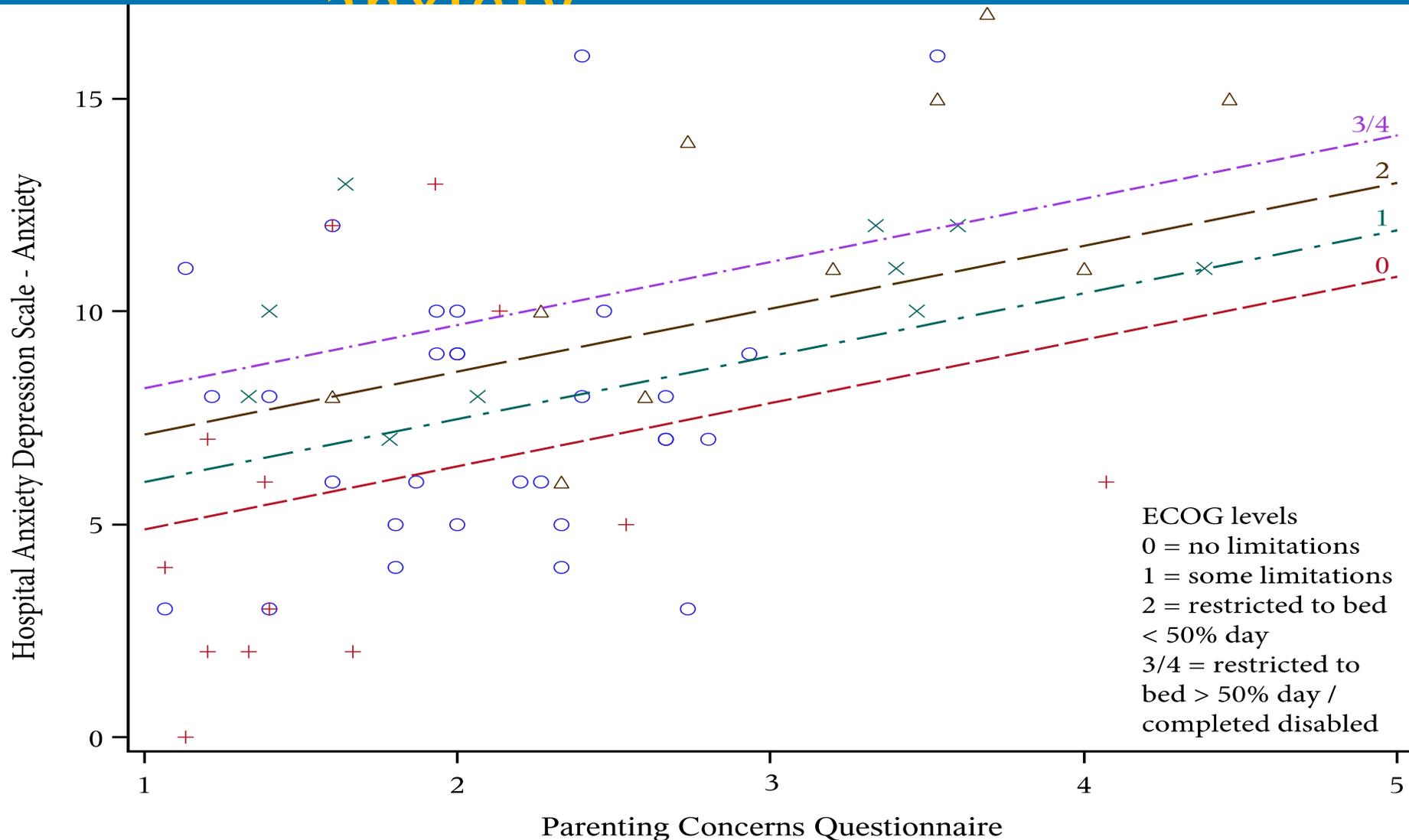
Who will take care of the children?

How will my children be raised without me?

Communication with children

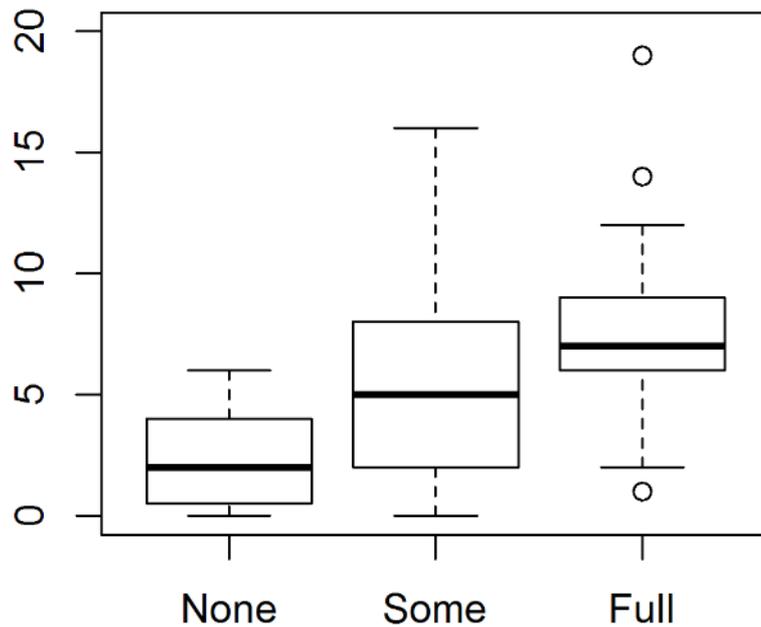
About disease trajectory, mortality, when there is no “cure”

Parenting concerns linked with higher symptoms of anxiety

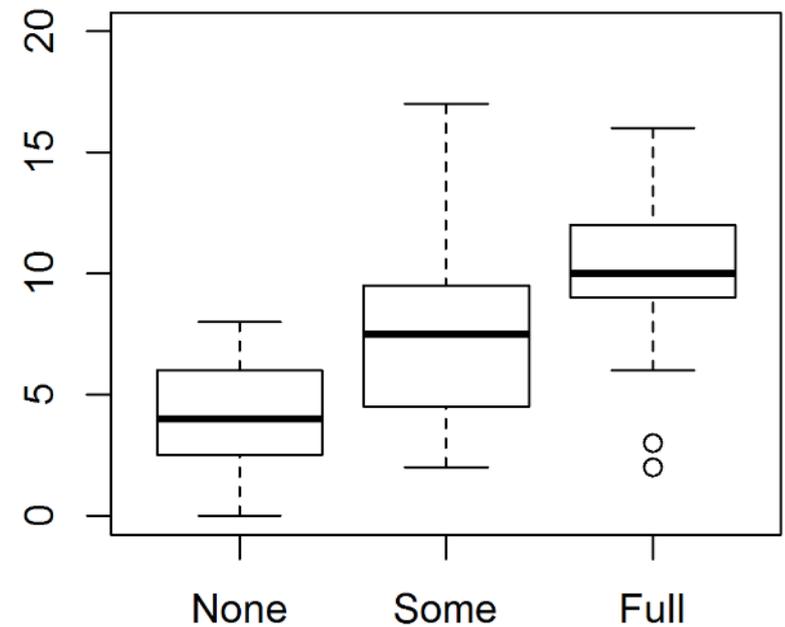


Parental communication with children may be linked to overall mood symptoms

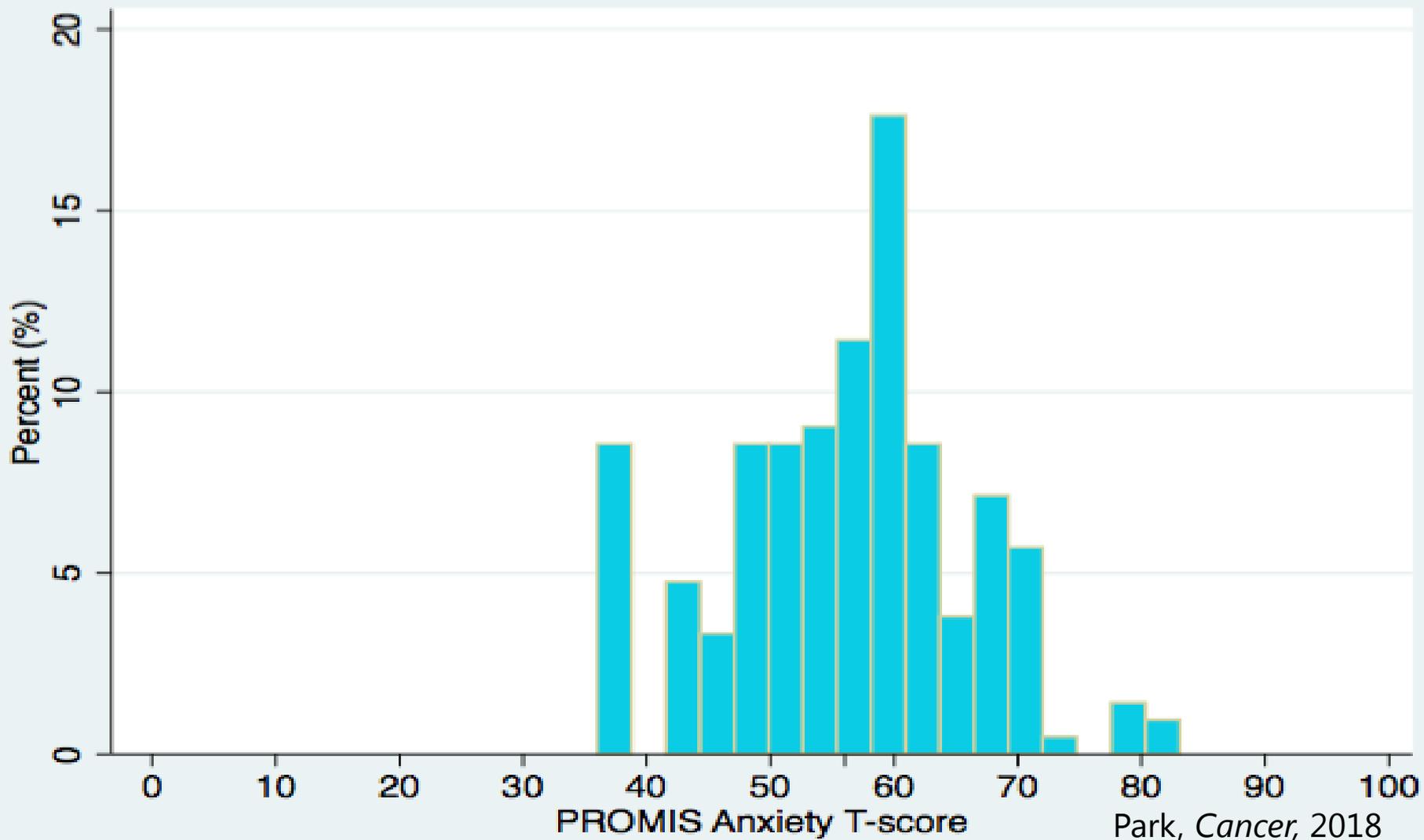
HADS Depression



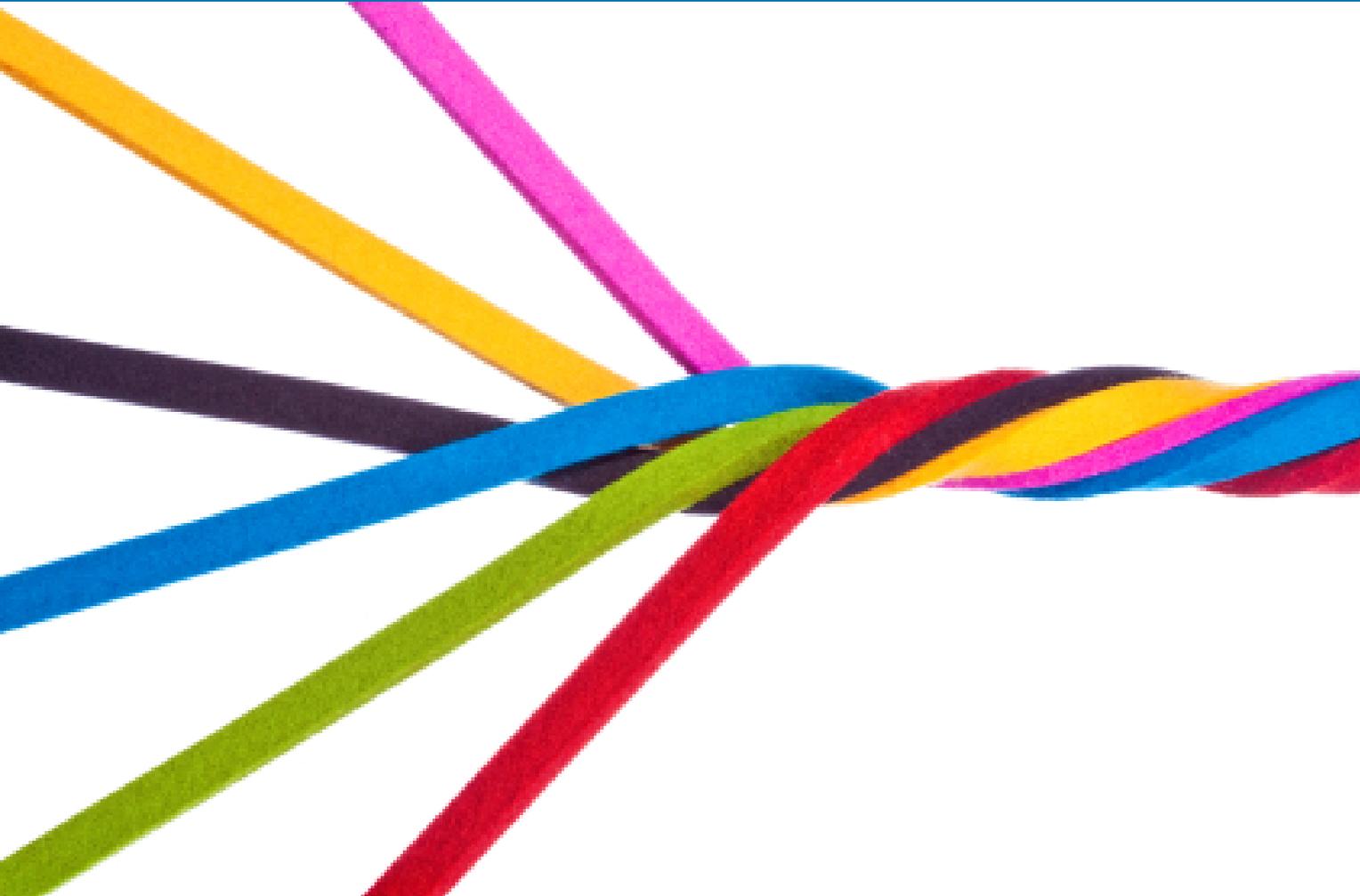
HADS Anxiety



Anxiety symptom severity scores among a web-based sample of 224 mothers with metastatic cancer

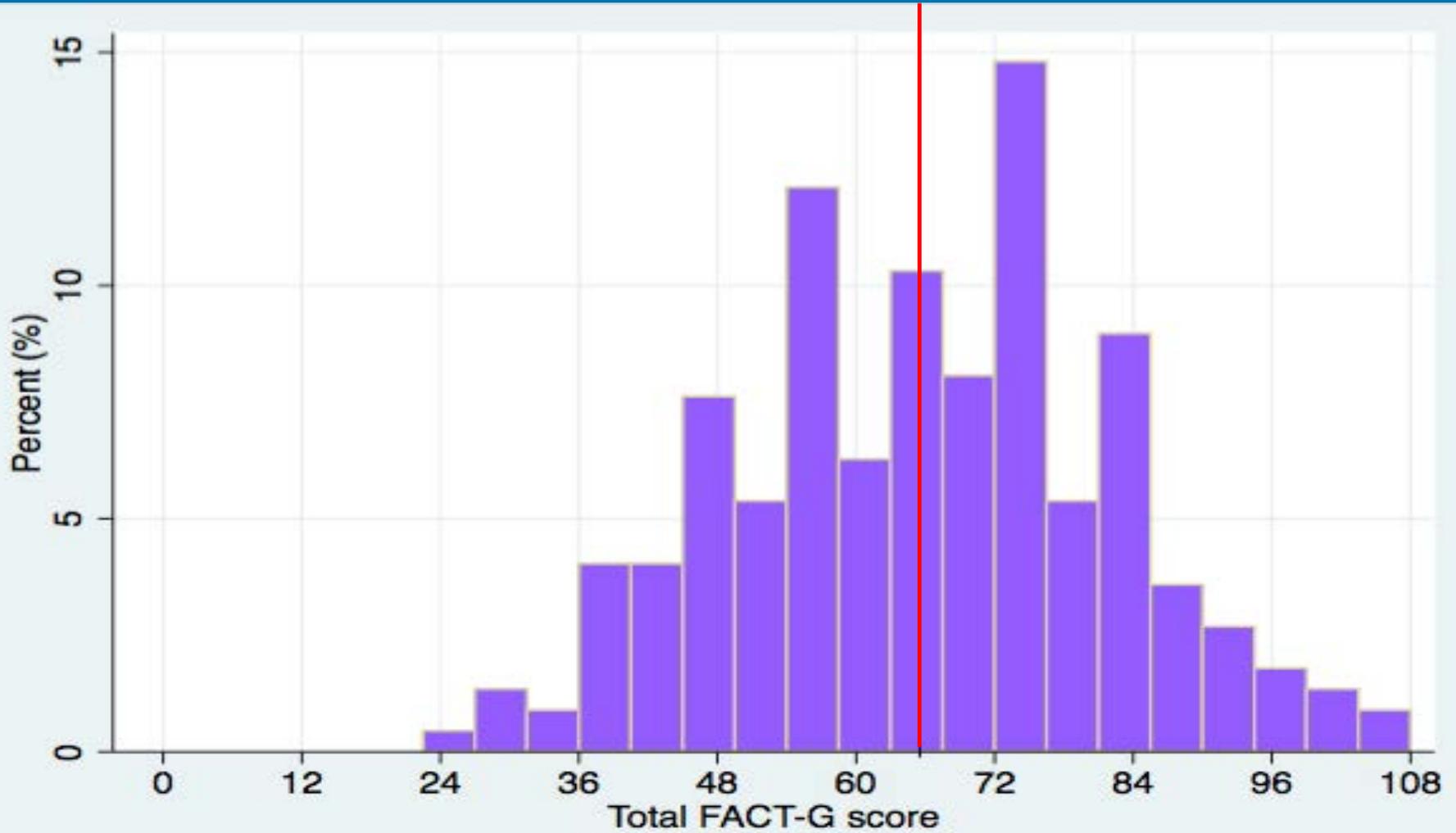


Understanding Health-Related Quality of Life (HRQOL)

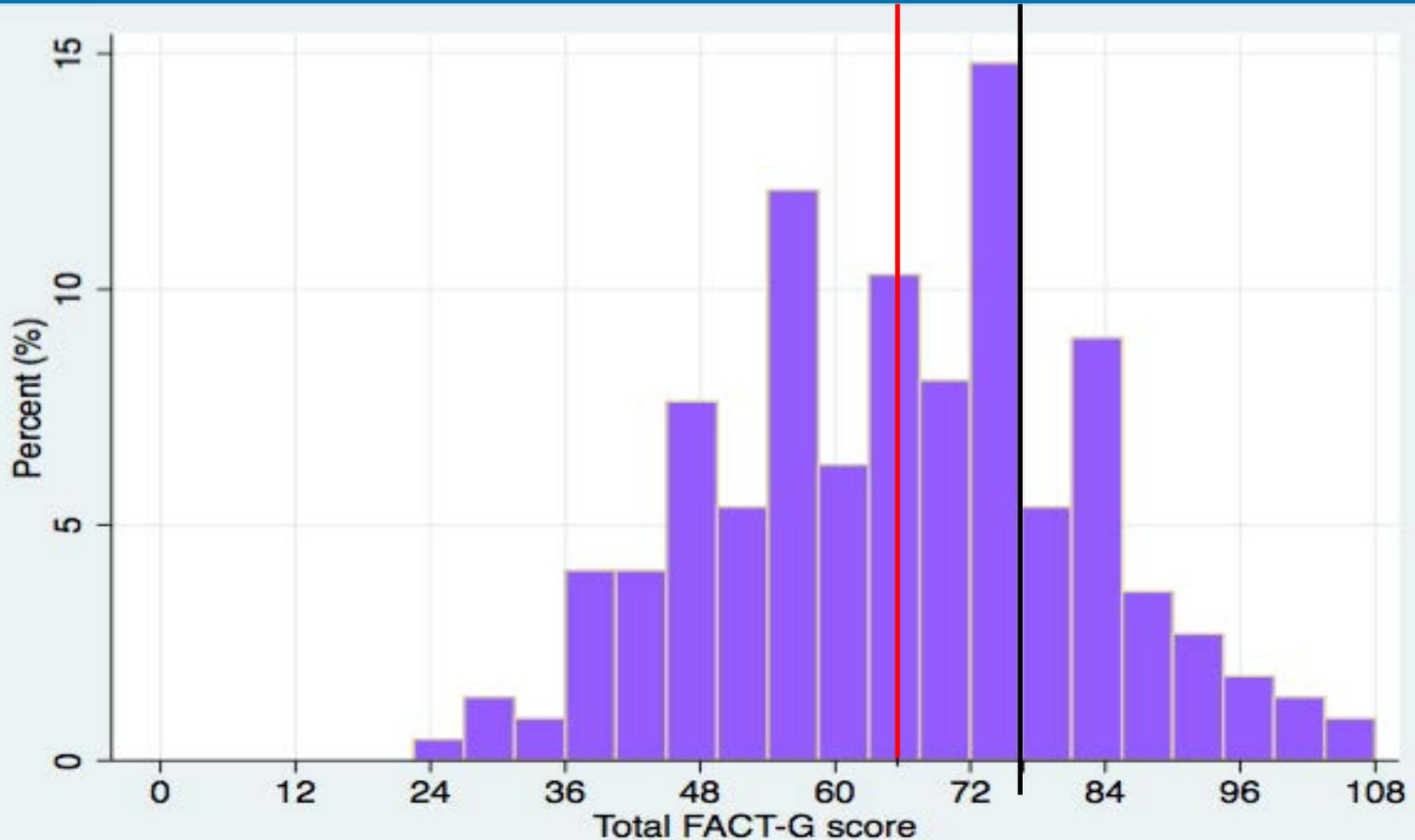


WHERE
CANCER
AND
PSYCHIATRY
OUTCOMES
MEET

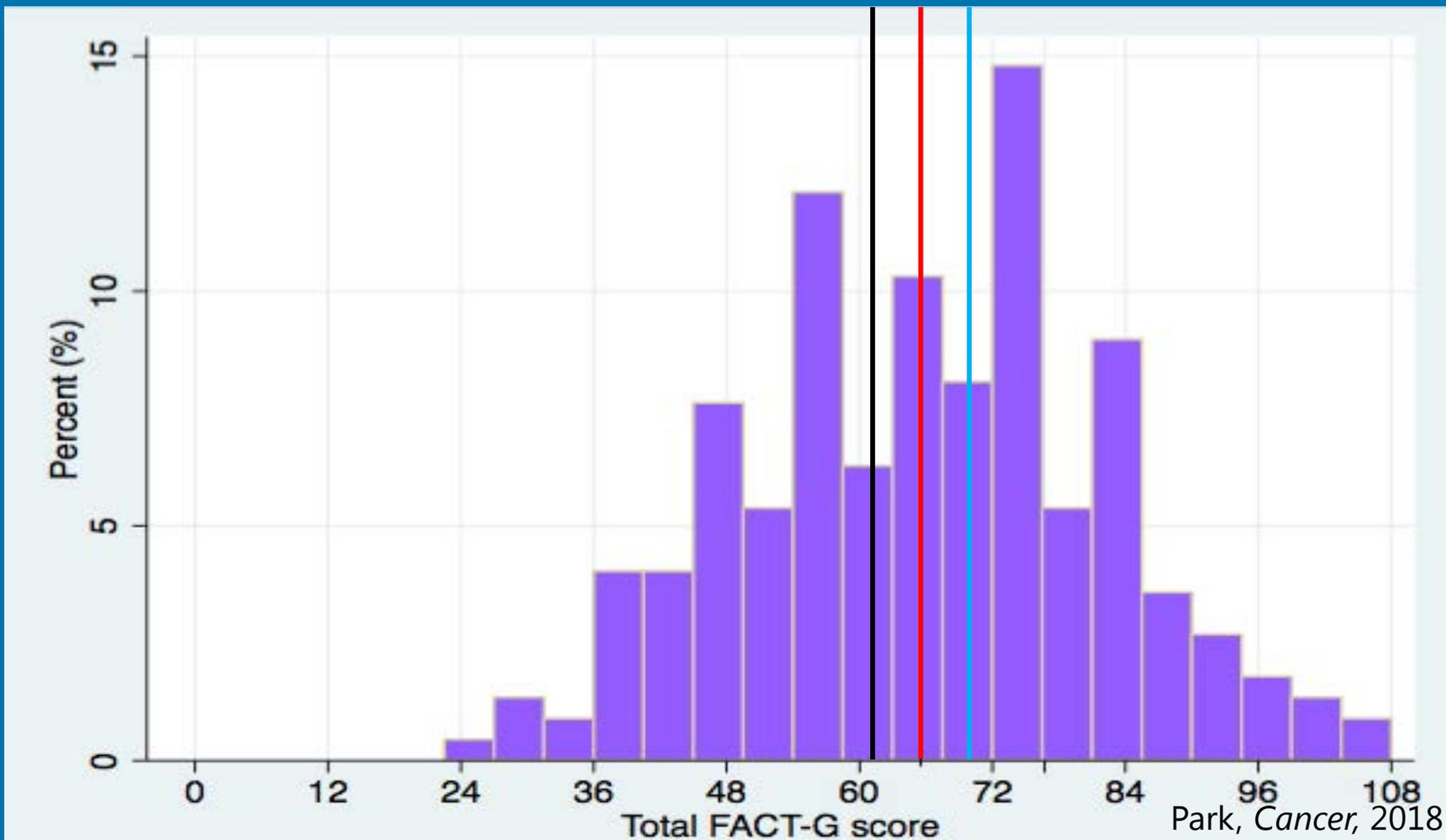
HRQOL scores among women with metastatic breast cancer



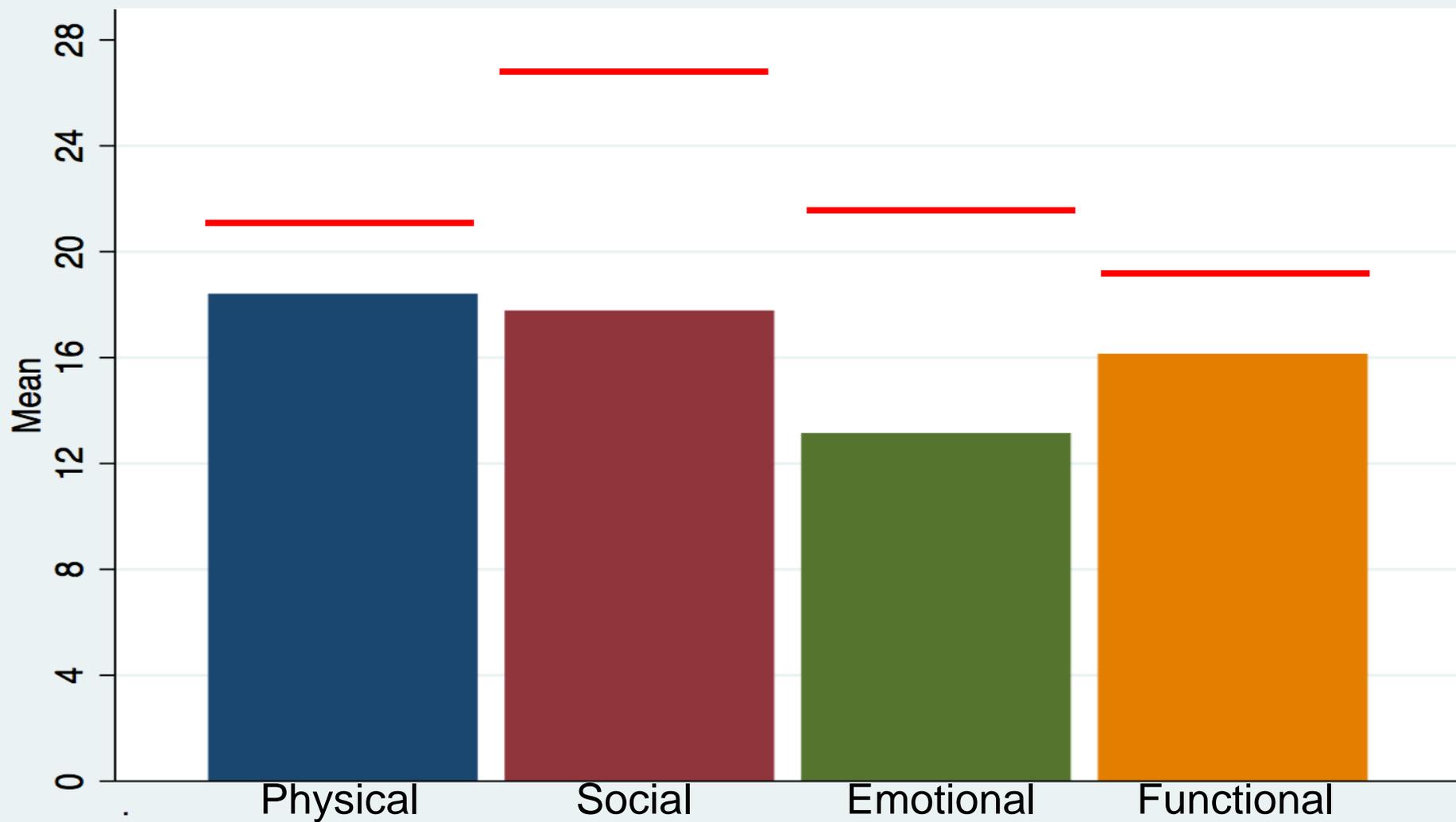
Compared to all adults with metastatic cancer



Compared to adults with cancer and reduced functioning (any stage)



HRQOL Components





Parents with cancer are less satisfied with their healthcare

Compared to advanced cancer patients without minor children, parents report lower healthcare satisfaction

General satisfaction

Interpersonal manner

Physician communication

Time spent with their physician

No differences for technical quality, financial aspects, or physician accessibility

In a 20-minute follow-up oncology encounter . . .

Oncology providers are tasked with (at least) the following:

Pain and symptom management

Emotional and psychological support

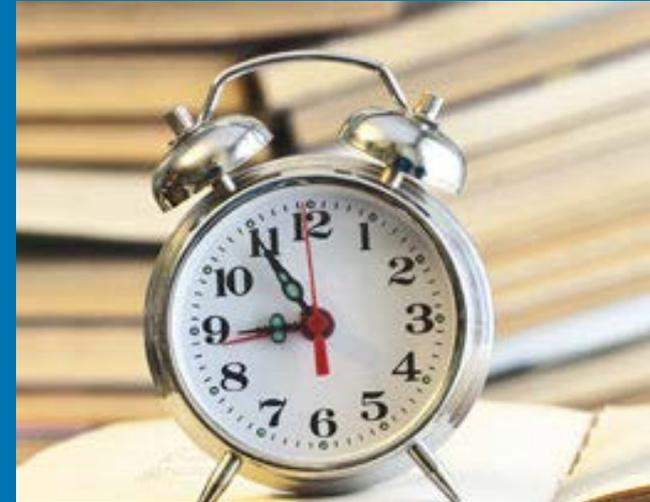
Monitoring of treatment effects and toxicity

Physical examination

Review laboratory and imaging

Adjust treatment plan and discuss with patient

Assess and review prognosis and/or disease understanding



Treatment preferences of parents with advanced cancer



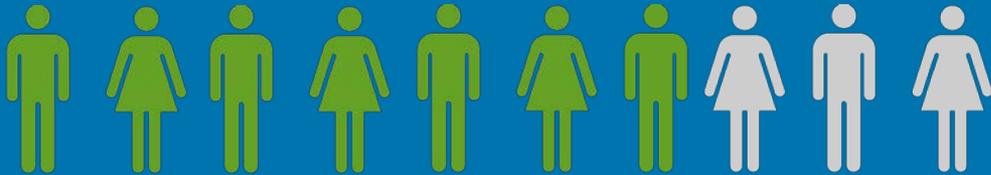
“Remain calm and list your goals in order of priority.”

What do parents want?

Time with their children
The ability to be a parent

How does this get translated into healthcare decisions?

Someone to live for

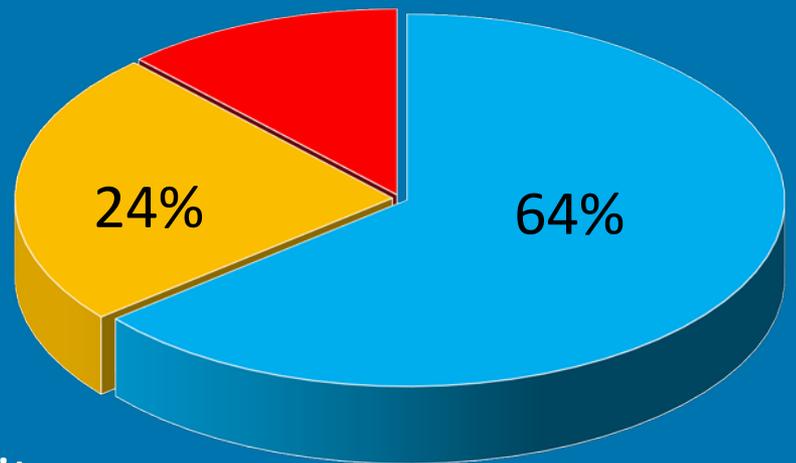


29/42 (70%) reported that children influenced anti-neoplastic treatment decisions

64% reported pursuing life-extending therapies

24% prioritized preserving physical functioning to be able to parent

Most assumed that their oncologist understood the importance of their parental role, even in absence of explicit discussion



How do we distinguish the effects of younger age from parenthood?

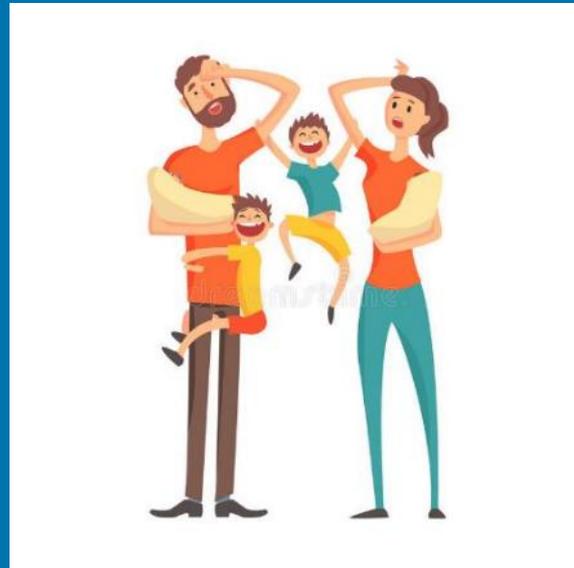
Prospective cohort study of 120 adults

60 adults with minor children

60 adults with no children

Frequency matched age in 5-year increments

Mean age = 45 years (SD 8)



Study participants and design



Patient population at high risk of disease progression and need for anti-neoplastic decision-making

Stage IV solid tumor malignancy with progression beyond first-line treatment (exception for NSCLC/SCLC)

Structured interviews and battery of standardized measures with medical chart review

- No between-group differences in performance status, current receipt of chemotherapy, duration of illness, or previous lines of treatment
- Parents more likely to be female (70% vs 60%) and married/partnered (83% vs 62%)

Is it about acceptance of prognosis?

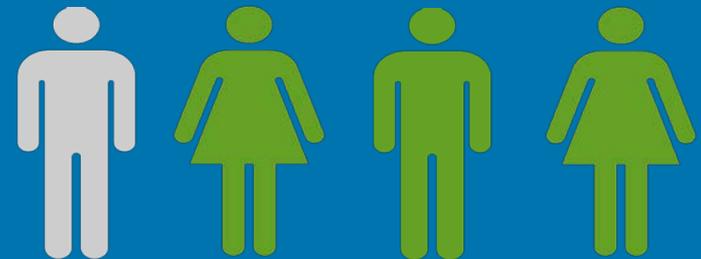
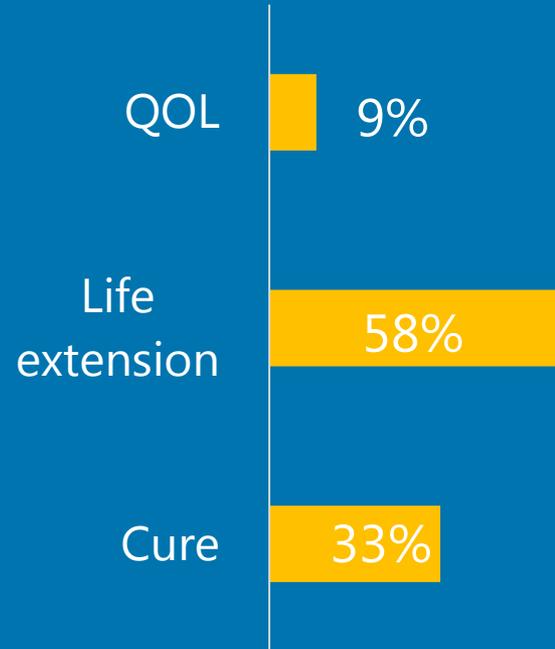
Equally likely to report life-extension as their primary goal of anti-neoplastic treatment

Non-significant differences in acknowledgment of terminal illness

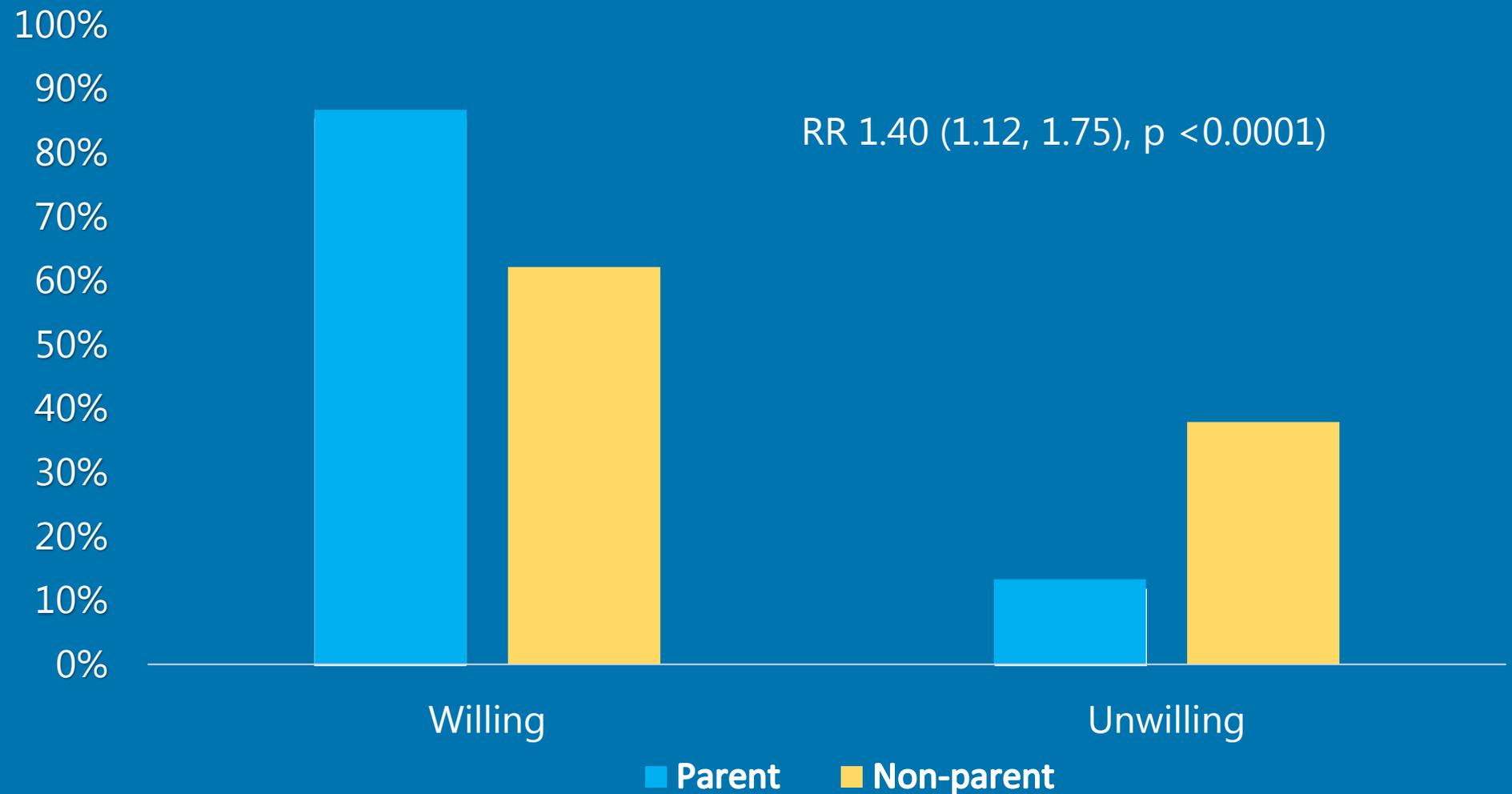
Non-significant differences in hope for "cure"

Conflicting data on completion of advance directives

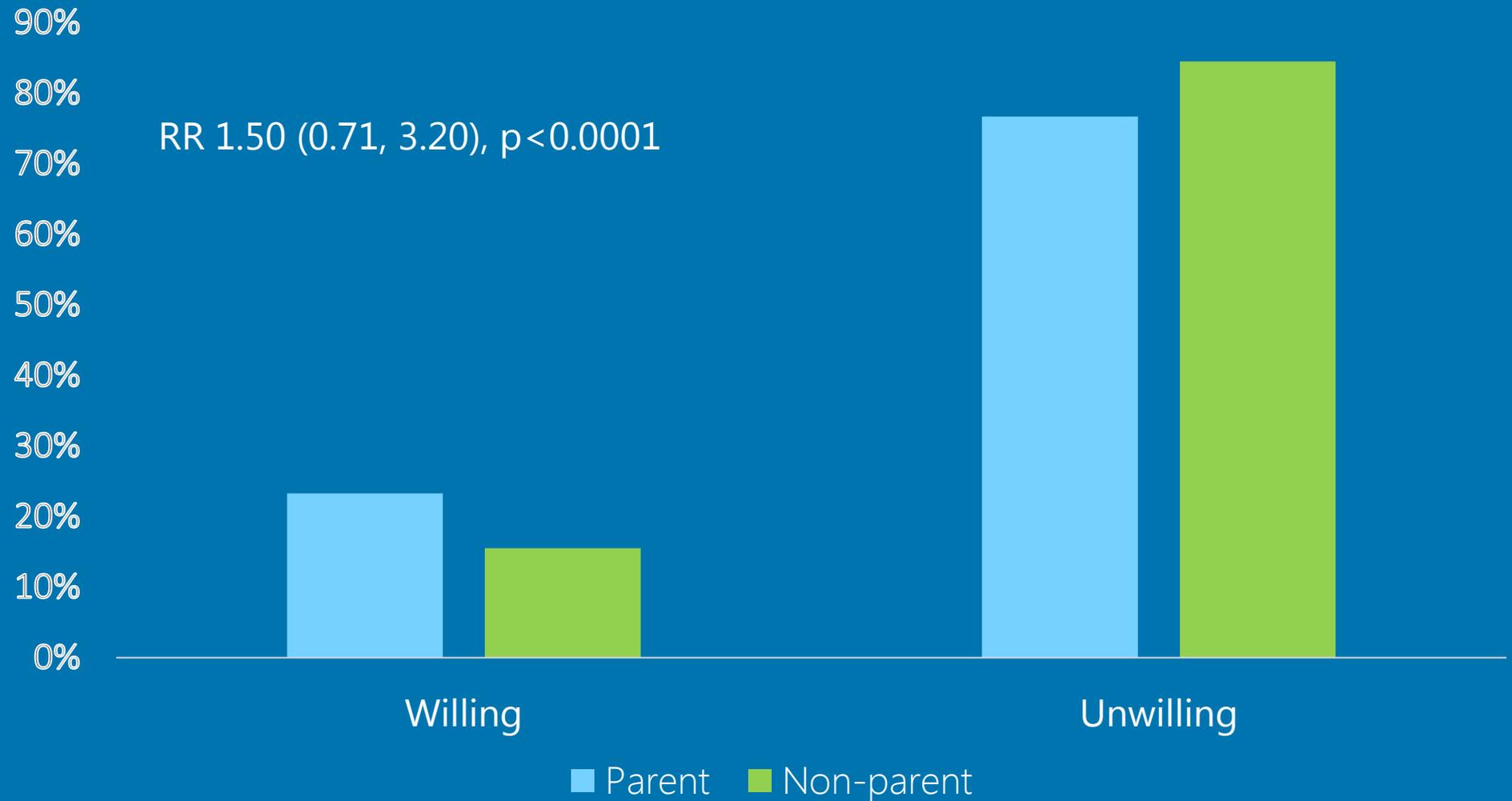
75% parents reported children had strong influence on decision-making



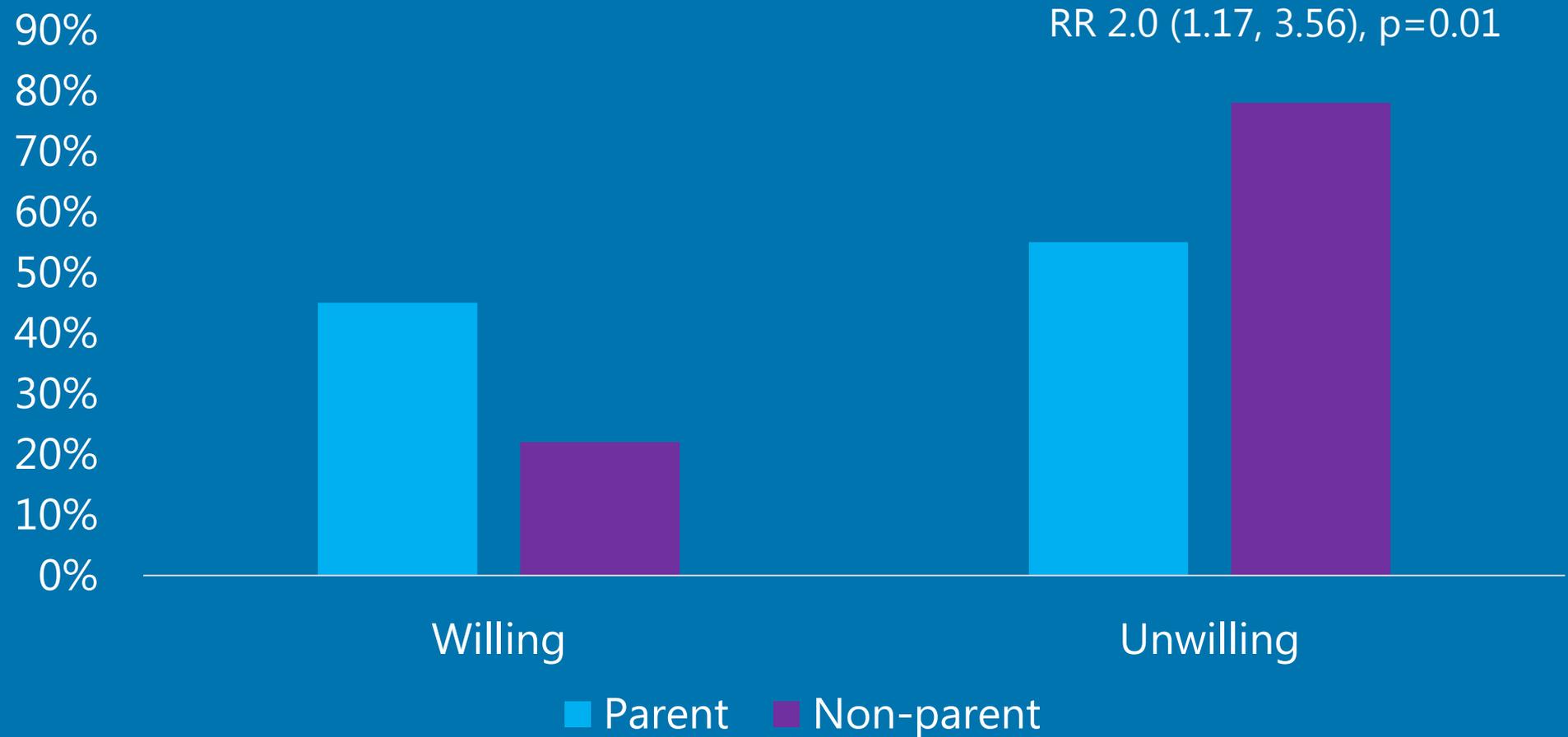
Willingness to live in pain all the time



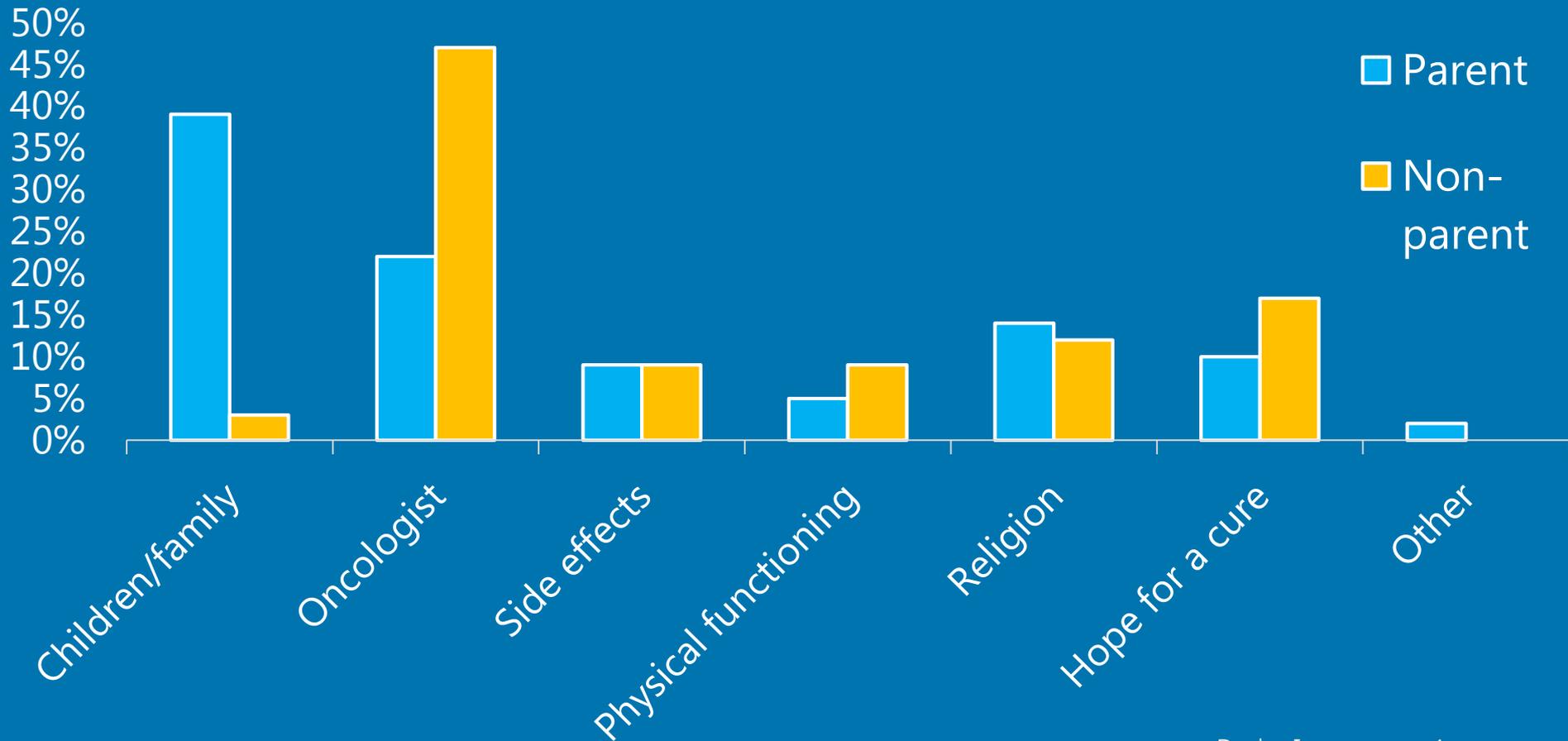
Willingness to receive mechanical ventilation



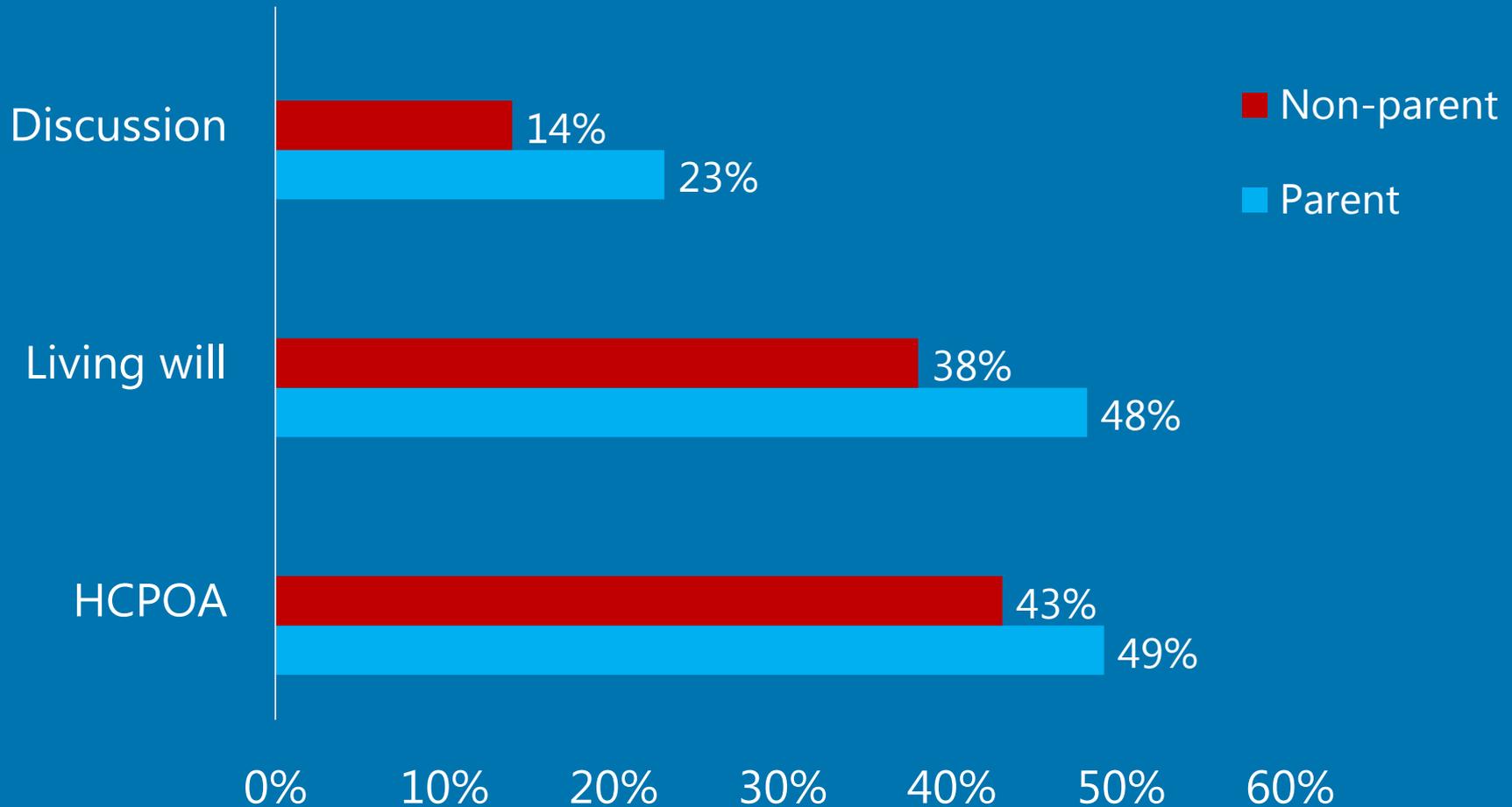
Willingness to receive a feeding tube



Most recent treatment decision



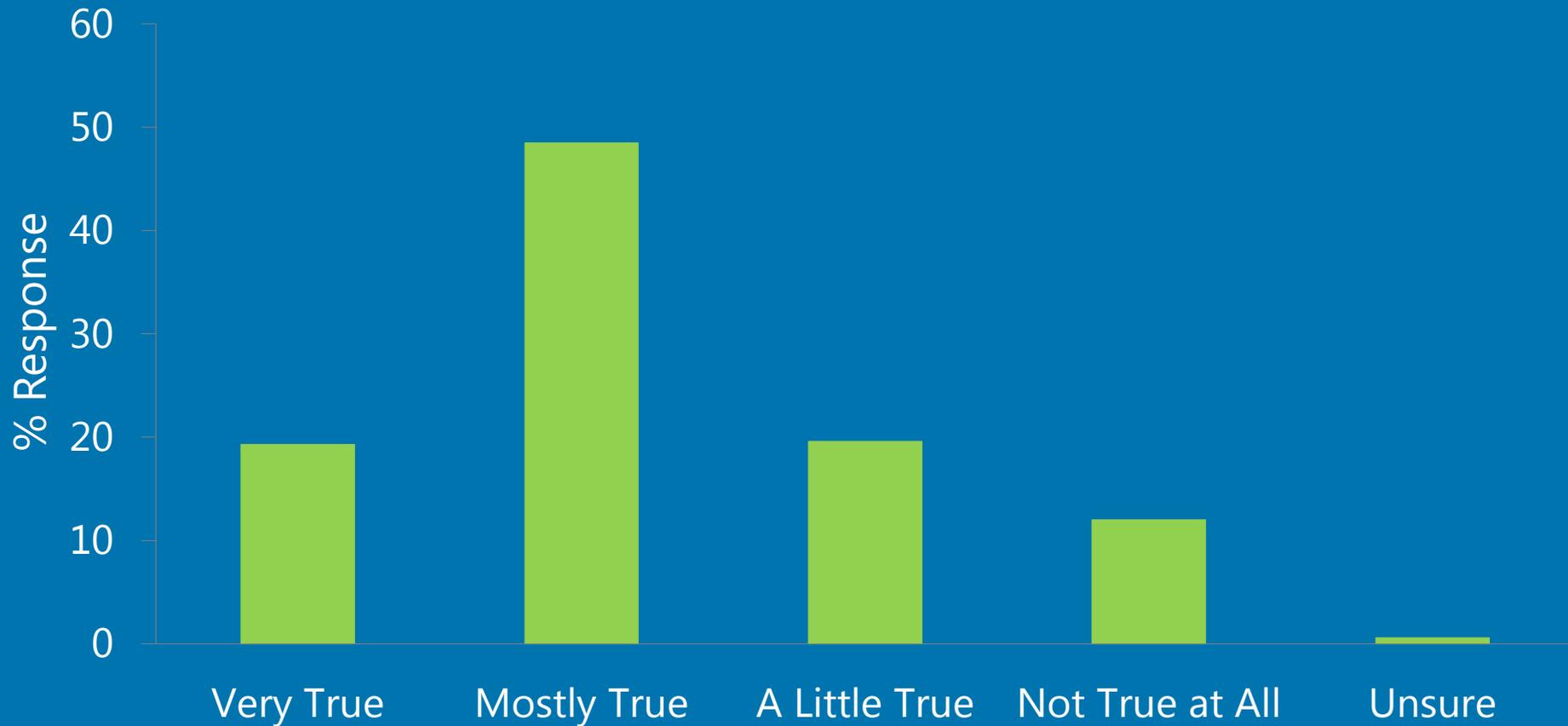
No differences in advance care planning



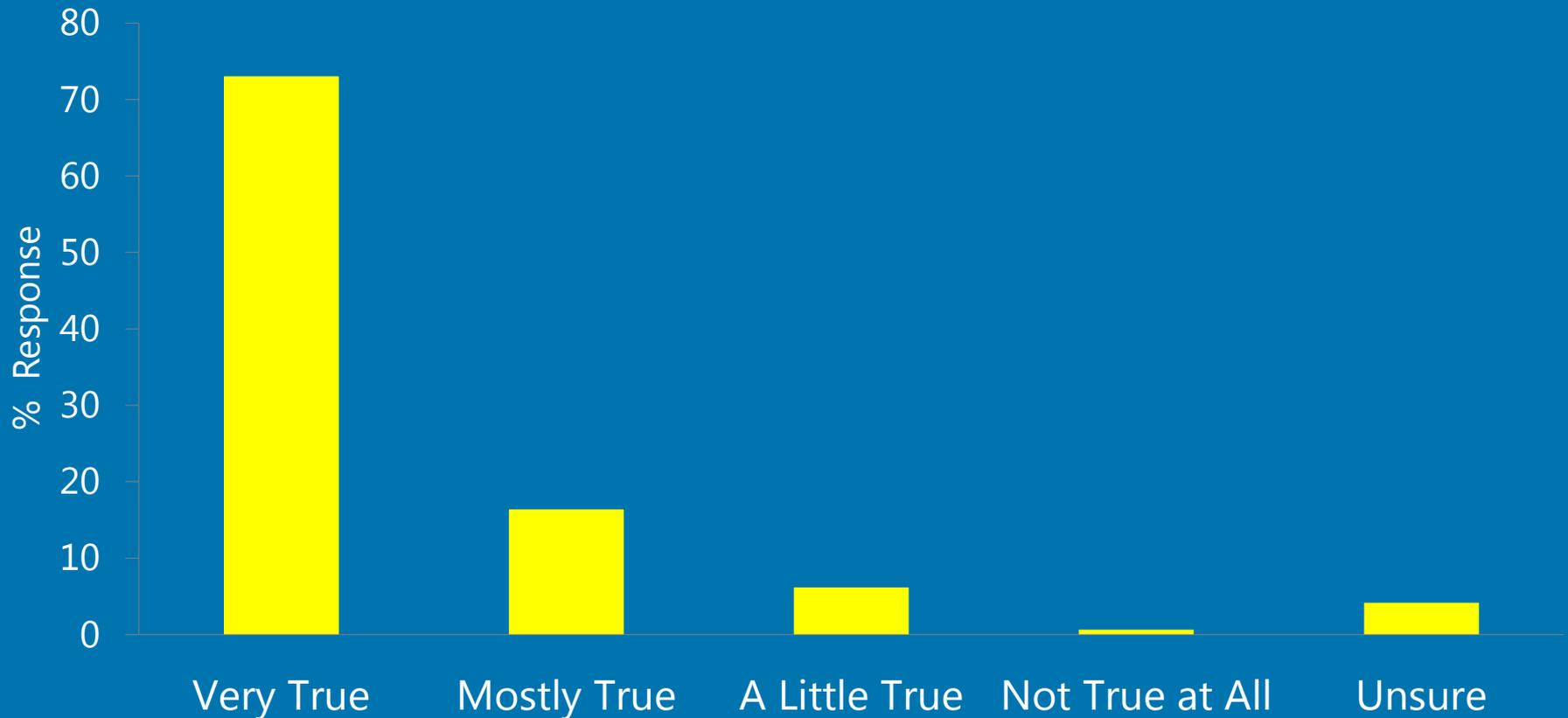
Learning from the bereaved



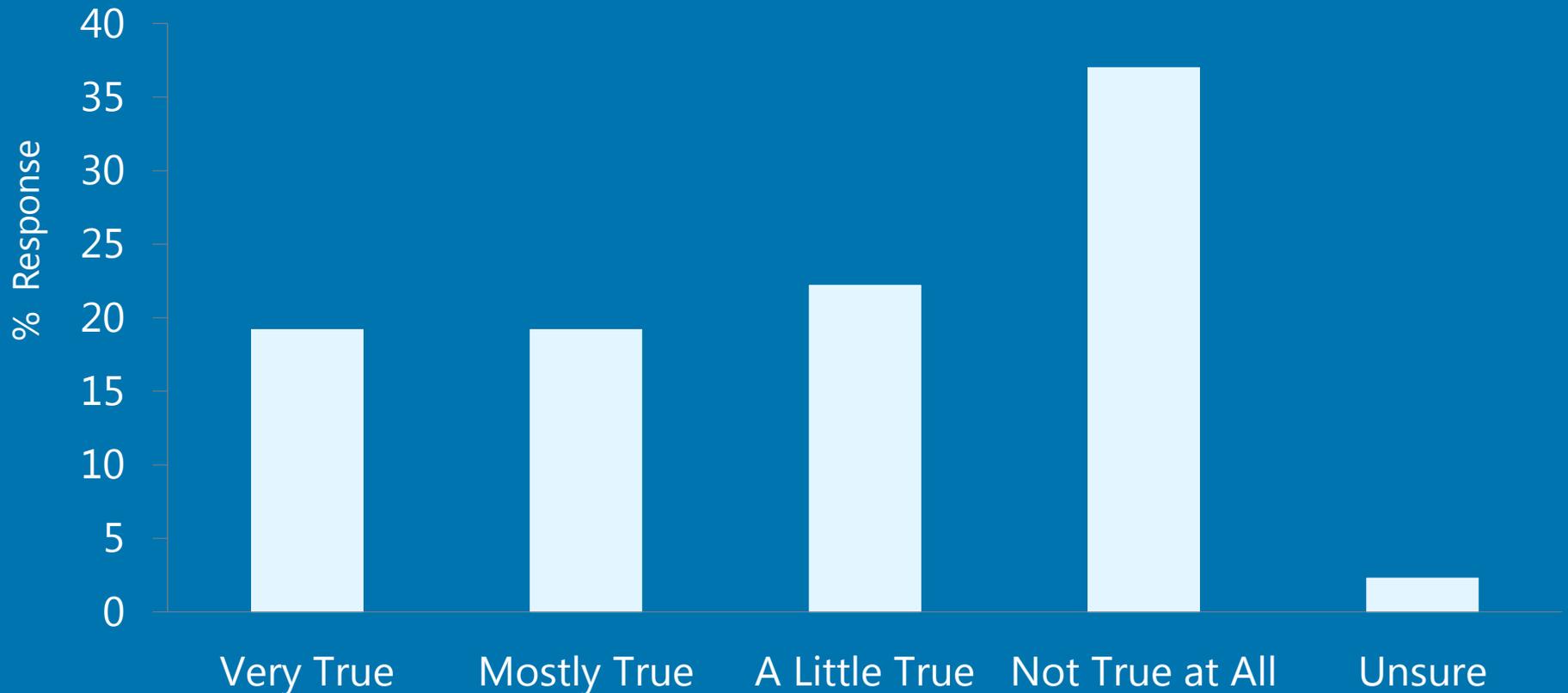
Her pain was under control



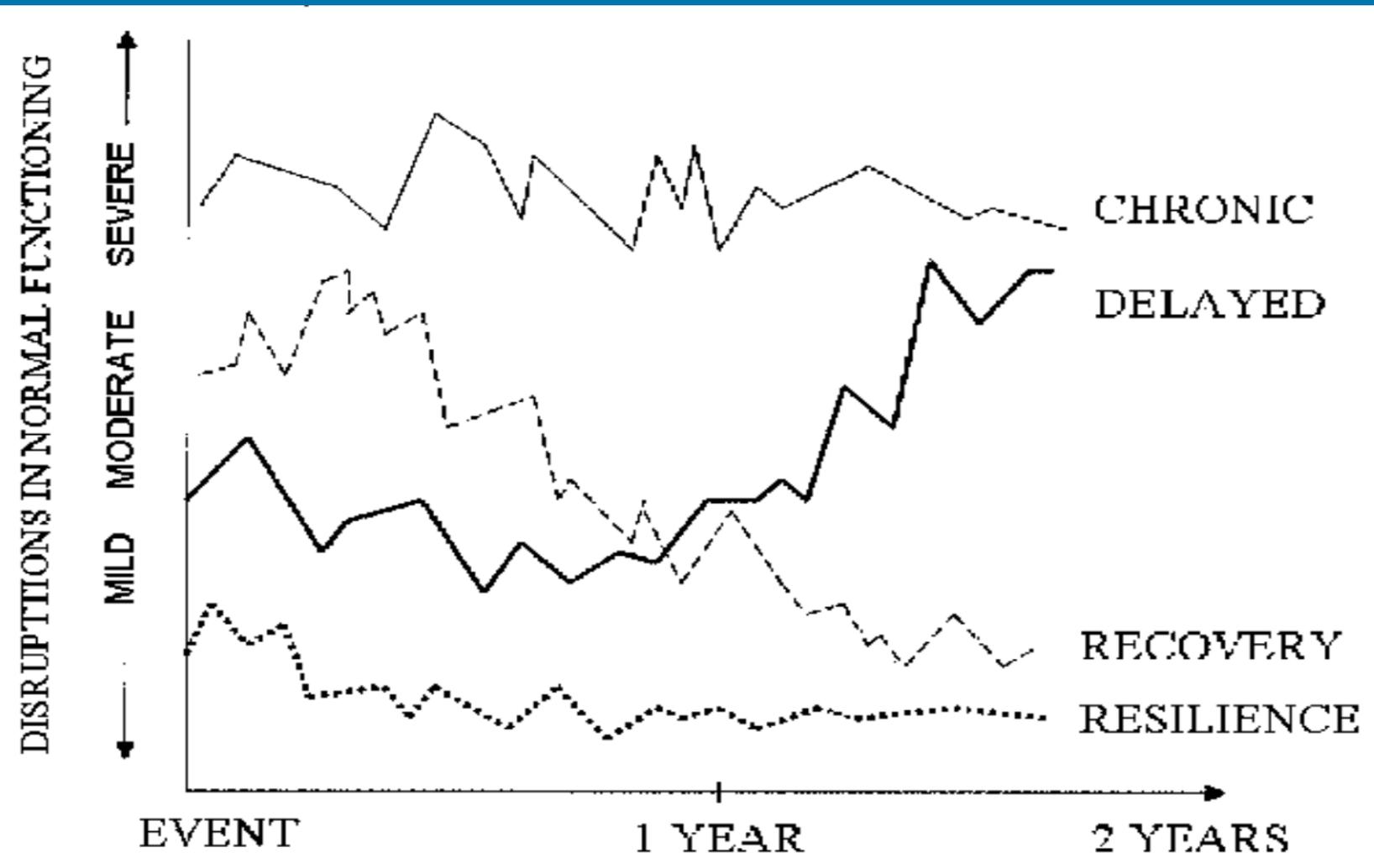
She was worried about the strain on the children at the end of life



She and the children said "goodbye" to each other



Grief that does not follow the typical trajectory

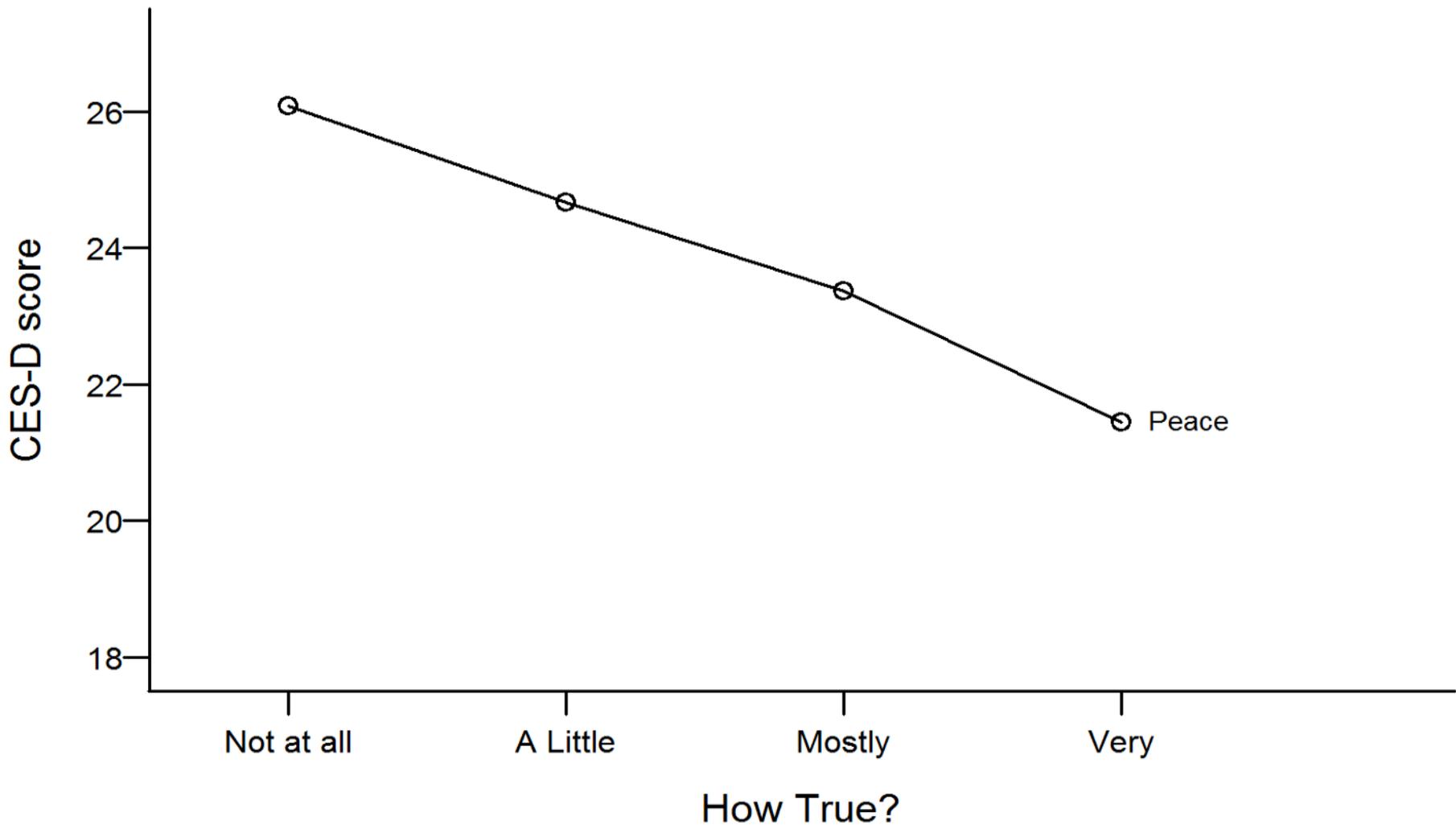


Grief starts before death

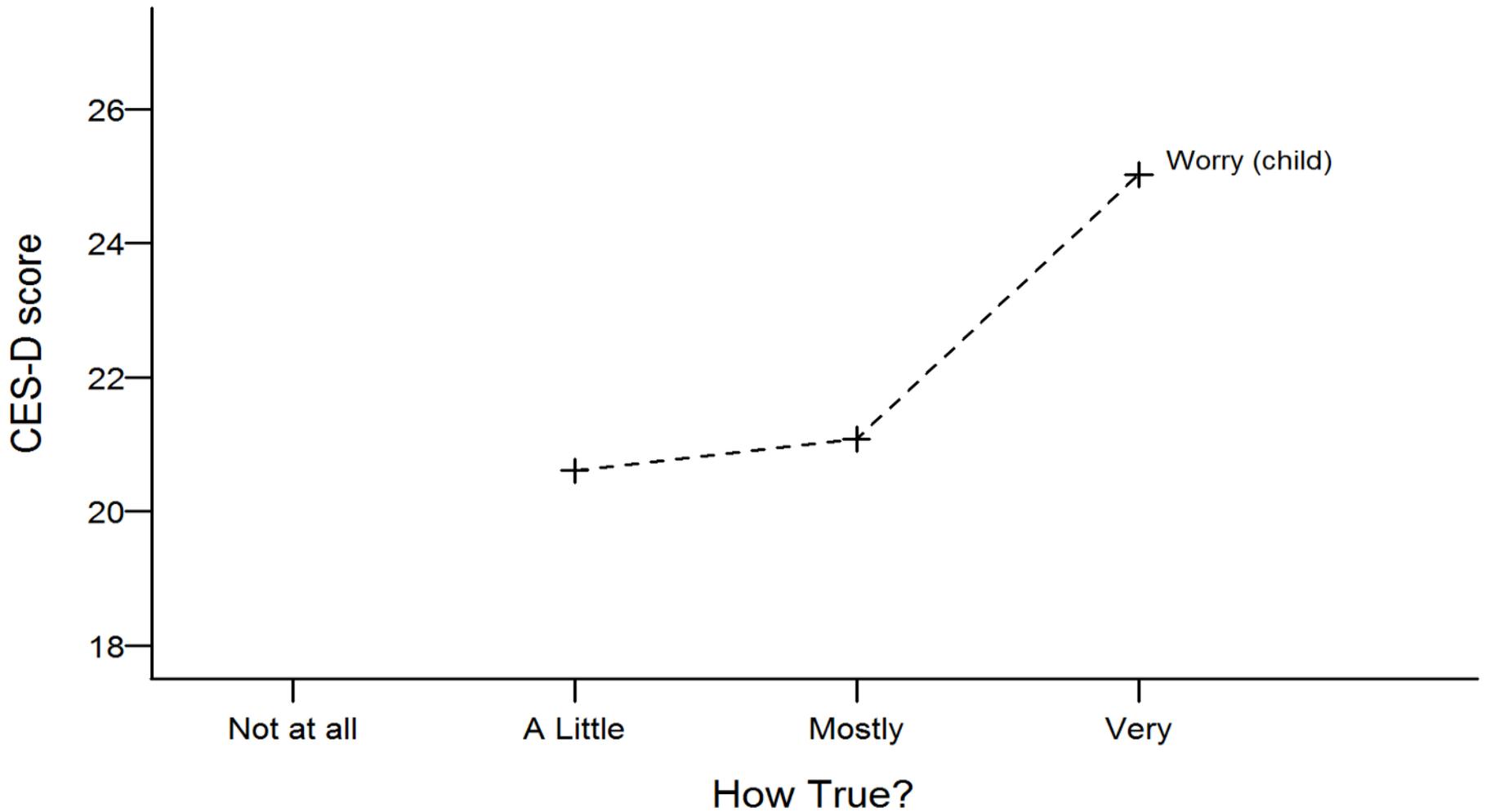
- Stressors of caregiving for ill patient and children
- Divergent needs at the end of life
- Inadequacy of resources (real or perceived) for their own care
- Higher rates of depression and anxiety symptoms than caregivers without dependent children
- Higher rates of mood disorders than patients themselves



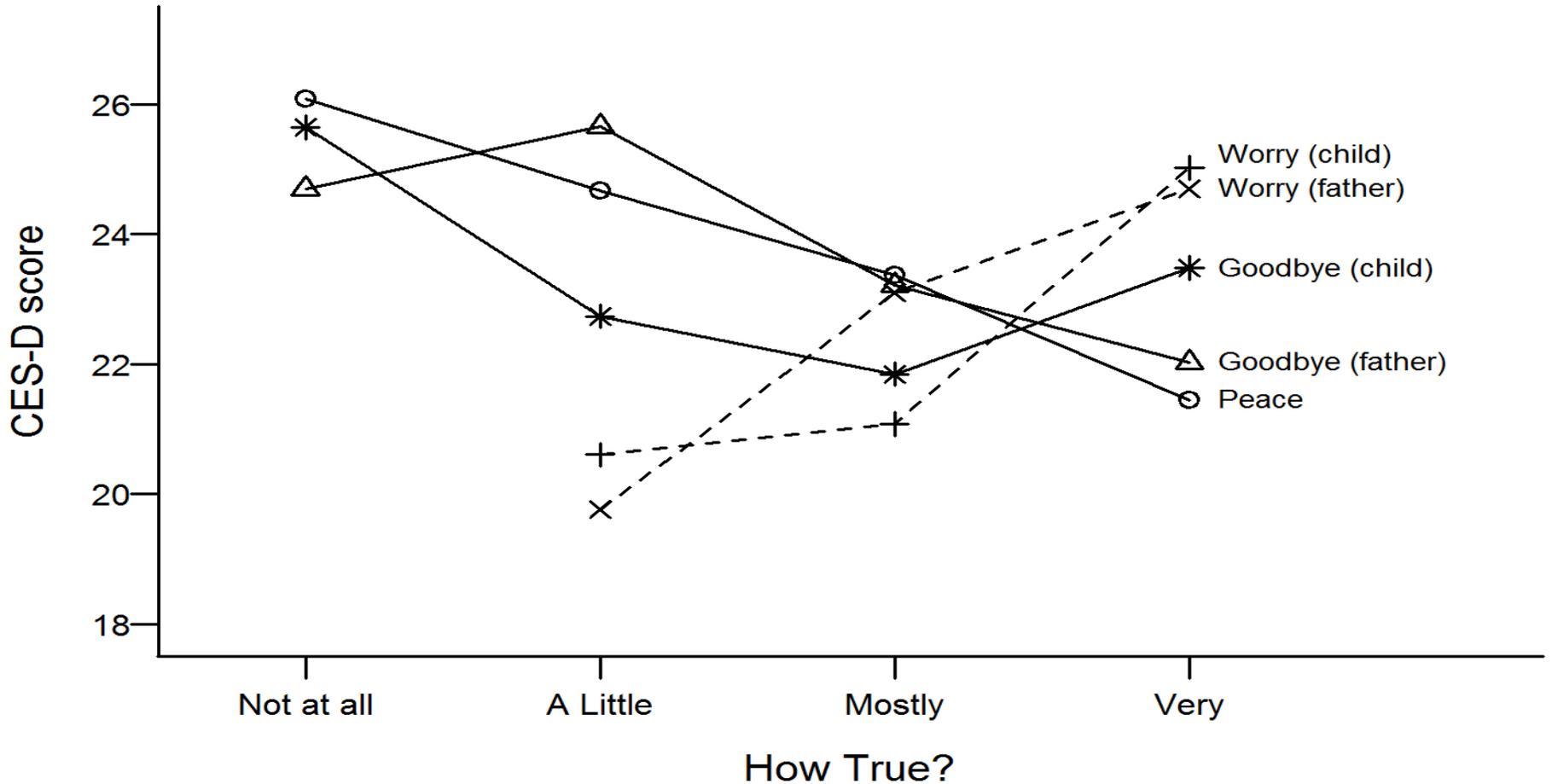
Maternal peace with dying and father's depression



Maternal worry about children and father's depression



Maternal end-of-life characteristics and father's depression



Kübler-Ross Grief Cycle

Denial

Avoidance
Confusion
Elation
Shock
Fear

Anger

Frustration
Irritation
Anxiety

Bargaining

Struggling to find meaning
Reaching out to others
Telling one's story

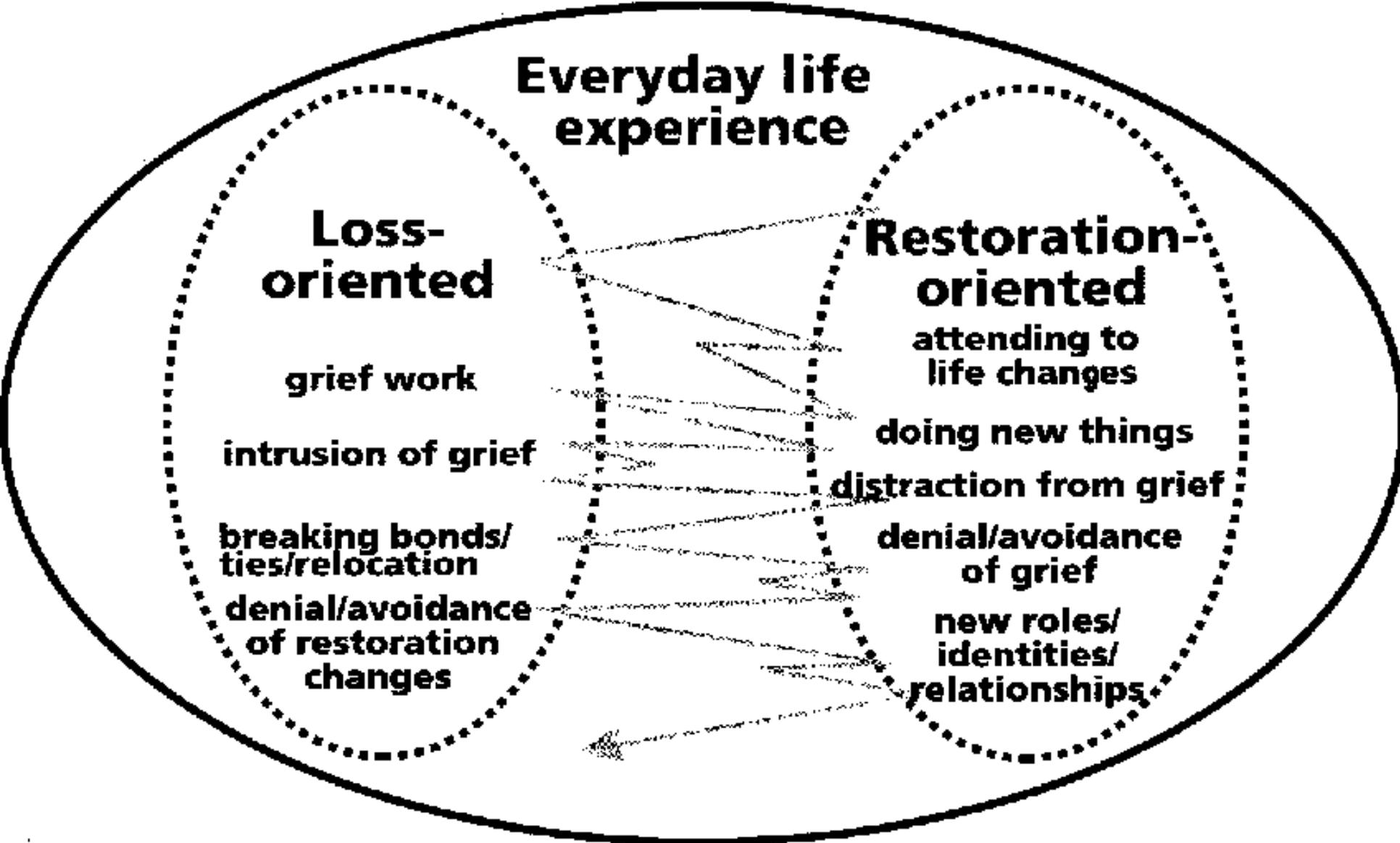
Depression

Overwhelmed
Helplessness
Hostility
Flight

Acceptance

Exploring options
New plan in place
Moving on





The dual process model of coping with bereavement

What about the children?

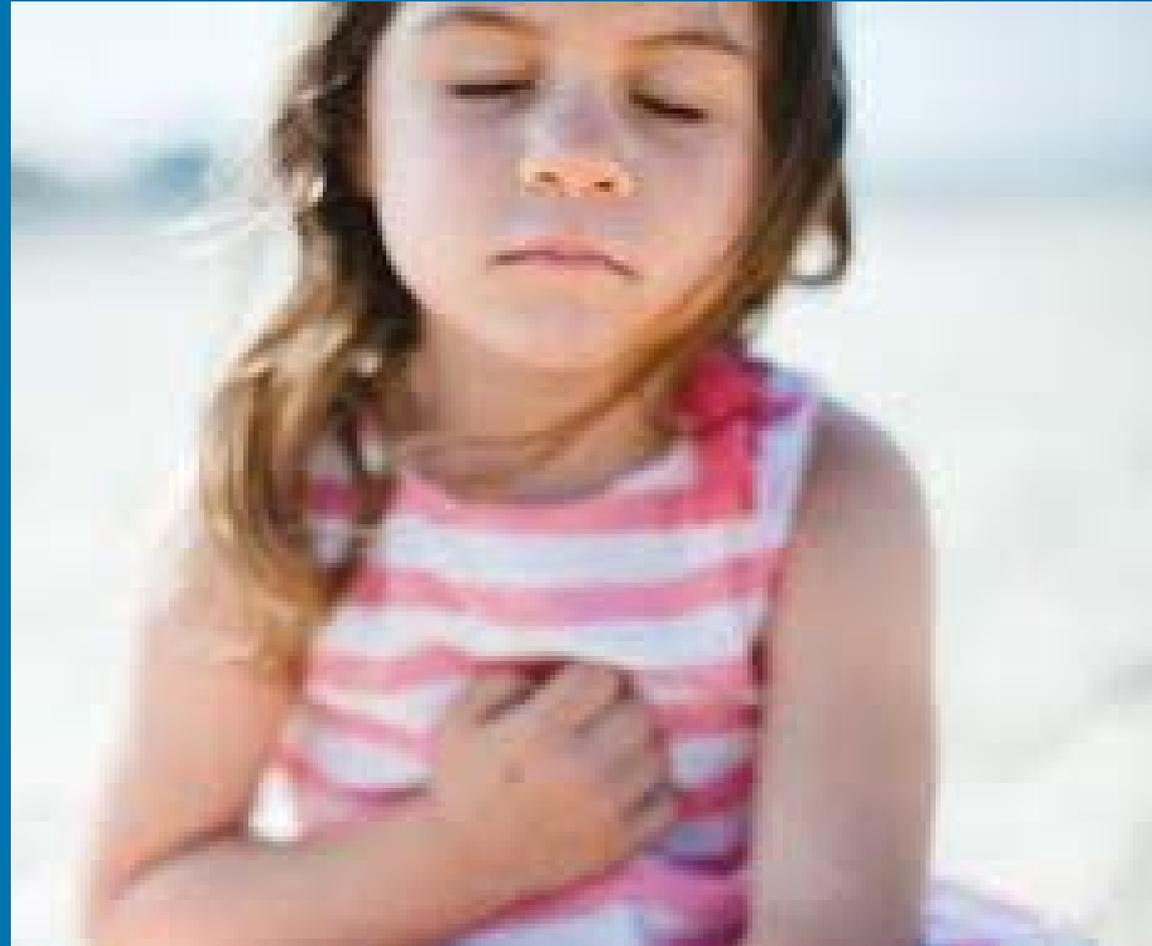
Children at risk for depression and anxiety disorders throughout lifespan

Most symptomatic during period of parental terminal illness

Surviving parent's mood and parenting skills

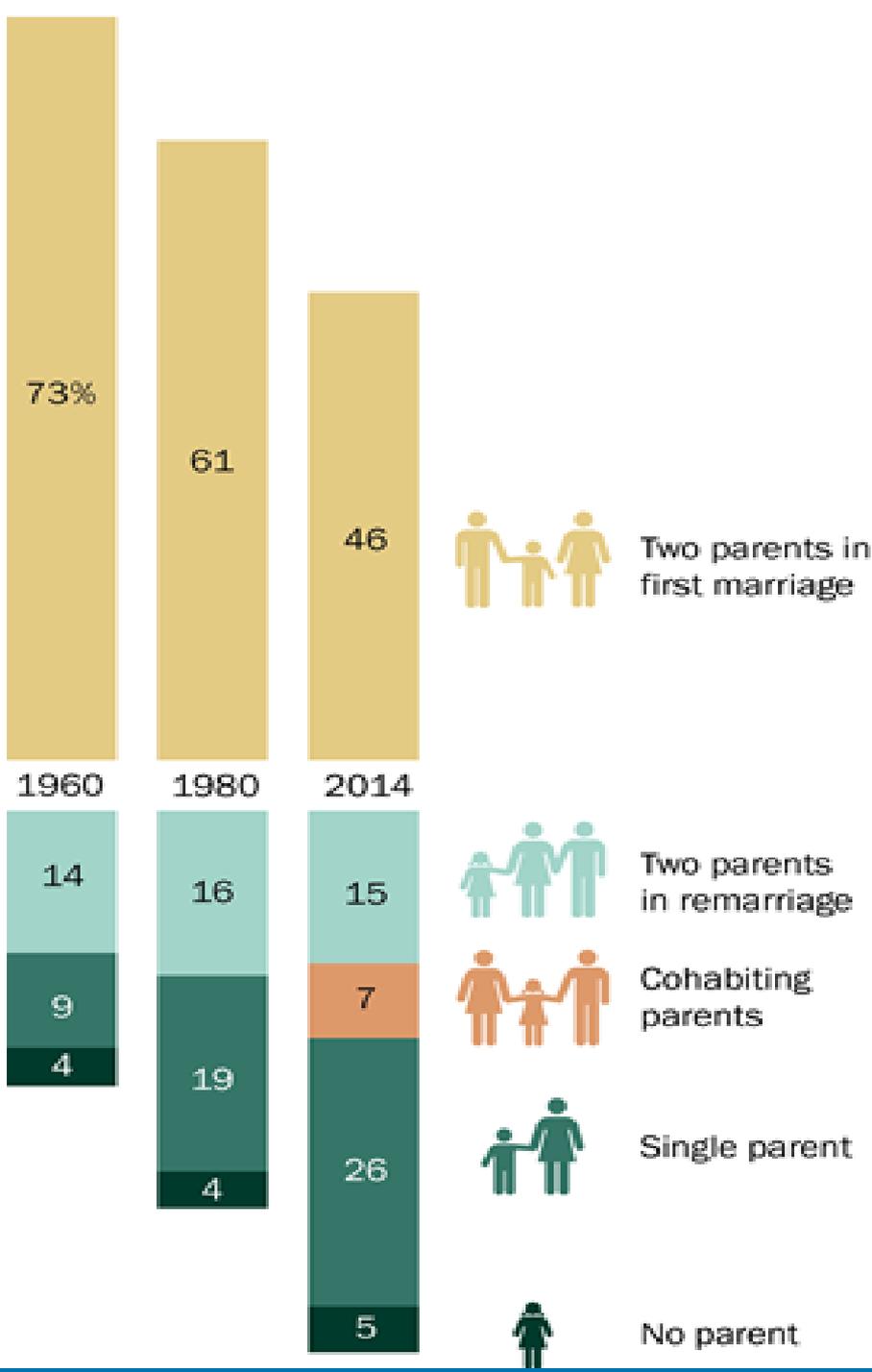
Likely more important than the loss itself

Impact cannot always be measured by a DSM diagnosis



What a US family looks like is changing

Less than half of US children live with two married parents in their first marriage



Note: Based on children under 18. Data regarding cohabitation are not available for 1960 and 1980; in those years, children with cohabiting parents are included in "one parent." For 2014, the total share of children living with two married parents is 62% after rounding. Figures do not add up to 100% due to rounding.

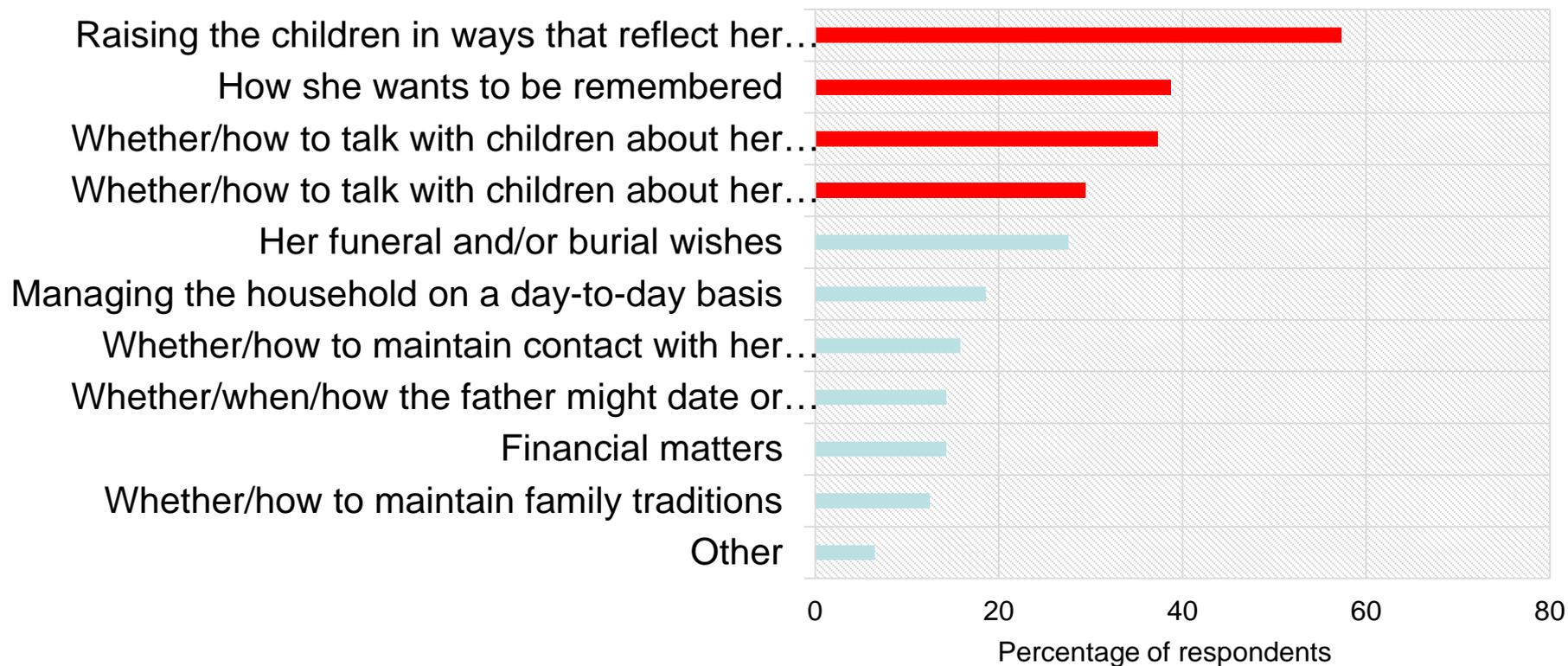
Source: Pew Research Center analysis of 1960 and 1980 decennial census and 2014 American Community Survey (IPUMS)

PEW RESEARCH CENTER

Moving toward intervention



Bereaved fathers' communication priorities with mother



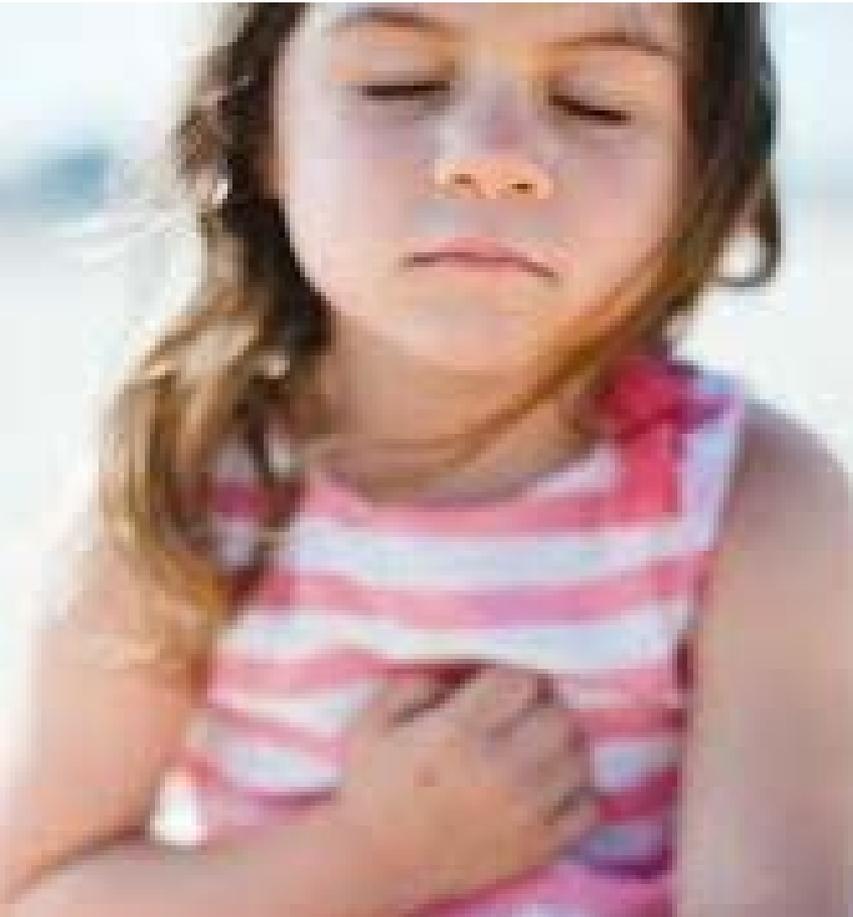
*Respondents were asked to choose top three priorities, so percentages will not add up to 100.



Despite knowledge of having an incurable illness, many parents with an advanced or incurable cancer do not have important conversations with their loved ones with respect to their wishes, values, concerns regarding their children



A Psychosocial Intervention to Improve Outcomes for Parents with Advanced Cancer



Address concerns about children's future well-being

Raising children that incorporates patient's values and memory

Communication guidance

Balancing honesty while protecting children from overwhelming information

Coping with competing demands of parenting & illness

Both now and in the future

"Can you put your hand on your heart? Mommy gave you that heart. Whenever you want to feel mommy you can put your hand on your heart."



Final thoughts

Parents with advanced cancer and their co-parents are at high risk for poor psychosocial outcomes

Higher rates and intensity of anxiety

Higher rates of depression and grief in bereaved

Worse HRQOL

Treatment preferences influenced by factors other than direct benefits and harms of anti-neoplastic therapy

There is a need for evidence-based interventions for these patients and their families

Research collaborators and mentors

Mi-Kyung Song, PhD
Laura Hanson, MD
Don Rosenstein, MD
Justin Yopp, PhD
Allison Deal, MS

Deborah Mayer, PhD
Elisabeth Dellon, MD
Paula Rauch, MD
Carey Anders, MD
Chang Xu, MS
Stephanie Chien, BA
Claire Hailey, MD

Teresa Edwards, MA
Michelle Manning, MPH
Nina Muriel, MD



Ann Partridge, MD, MPH
Savannah Bowers, BS
Kate Stanton, BA

Savannah Bowers
Katie Reeder-Hayes, MD
Zev Nakamura, MD
Laura Quillen, BA
Courtney Nelson, BA
Catherine Swift, BA

Funding acknowledgements

NIH (1K07CA218167)
Doris Duke Charitable Foundation (2015213)

Selected references

- Check DK et al. Concerns underlying treatment preferences of advanced cancer patients with children. *Psycho-Oncology* 2017; 26(10): 1491-97.
- Nilsson ME, et al. Mental health, treatment preferences, advance care planning, location, and quality of death in advanced cancer patients with dependent children. *Cancer*. 2009;115(2):399-409.
- Park EM, et al. Parenting Concerns, Quality of Life, and Psychological Distress in Parents with Advanced Cancer. *Psycho-Oncology*, 2016 Aug;25(8):942-8.
- Park EM. [End-of-life parental communication priorities among bereaved fathers due to cancer](#). *Patient Educ Couns*. 2017 May;100(5):1019-1023.
- Siegel K, et al. Depressive distress among the spouses of terminally ill cancer patients. *Cancer Pract* 1996;4:25-30
- Yellen SB, Cella DF. Someone to live for: social well-being, parenthood status, and decision-making in oncology. *Journal of clinical oncology*. 1995;13(5):1255-64.
- Yopp JM, et al. Overlooked and Underserved: Widowed fathers with dependent-age children. *Palliative & Supportive Care*. 2015 Oct;13(5):1325-34.

Thank you

www.widowedparent.org



[Home](#)

[For Parents](#)

[Your Child's Grief](#)

[The Survey](#)

[For Professionals](#)

[Our Book](#)

[About Us](#)

