Bereavement Risk Assessment: Towards a Valid and Reliable Tool

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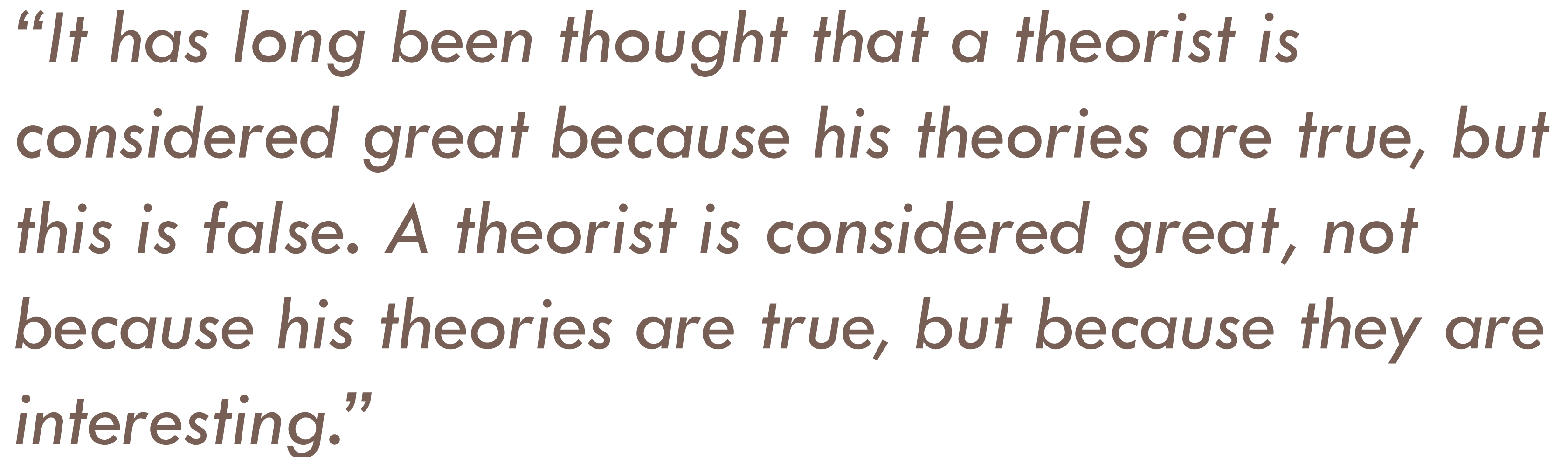
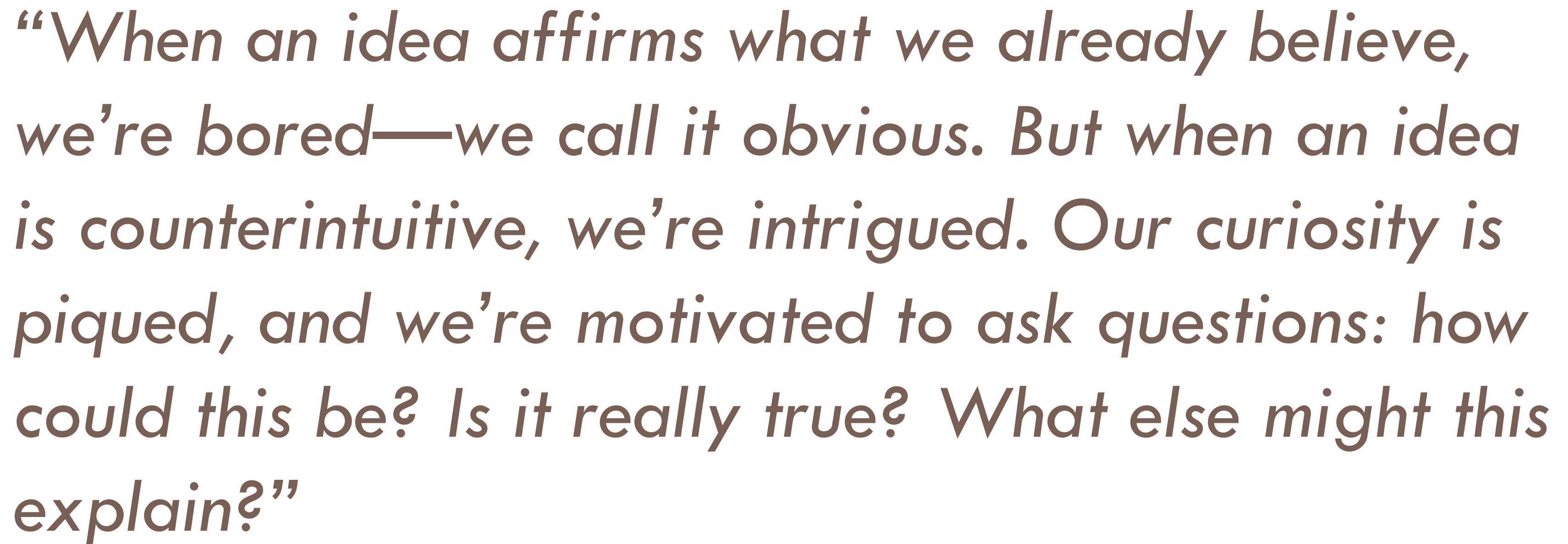
Mercy Hospice Bereavement Program Overview

- Mandatory calls at 2-3 weeks after death, and again 2-3 months later (high risk calls made within 3 days)
- Optional calls at six and nine months
- Mandatory call at one year anniversary
- Bereavement mailings at 6 weeks, 3 months, 6 months, 9 months, and 1 year
- Grief counseling/grief therapy
- Bereavement support groups
- Volunteer support (calls/visits)
- Hospice survey goes out with first mailing; Bereavement survey goes out with last mailing



Murray Davis, "That's Interesting!" - 1971



Adam Grant, 2013

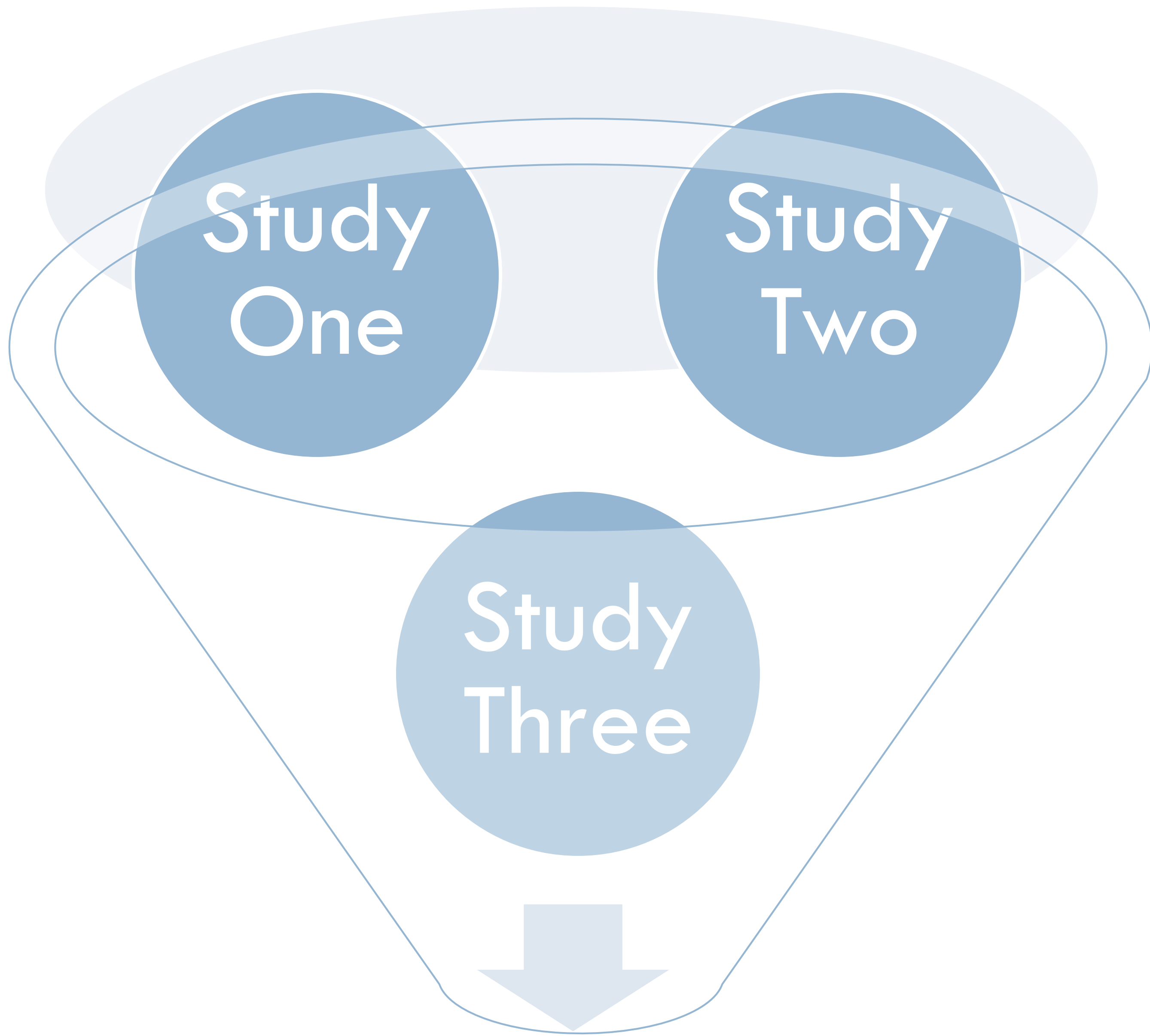
Mythbusting: Crying is not high
risk behavior at time of death

Why assess bereavement risk?

How does your hospice assess bereavement risk?

Why is a bereavement risk assessment tool needed?

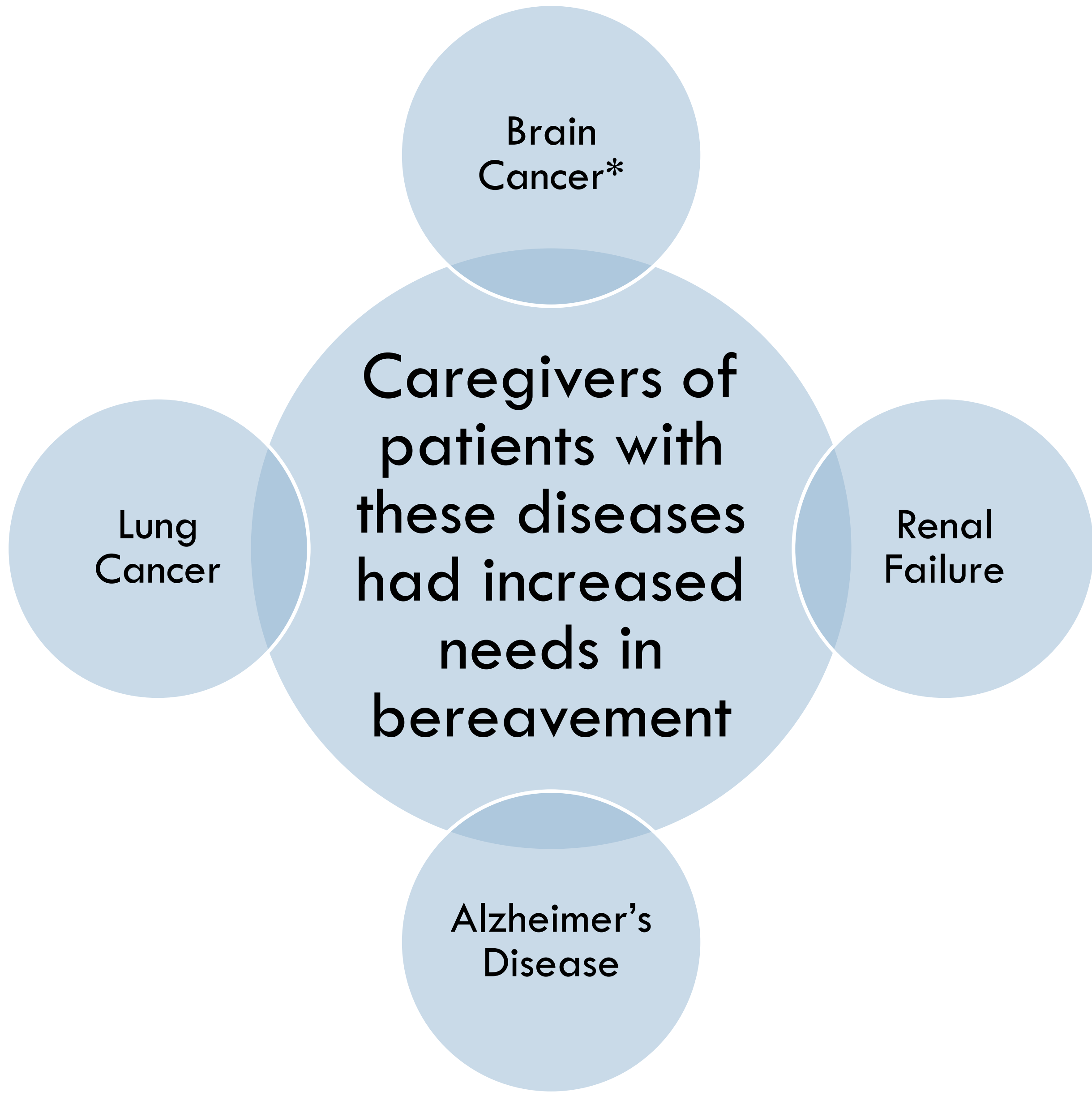
Inspiration for Research Study:
Three Previous Studies



Inspiration

"Hospice Disease Types Which Indicate a Greater Need for Bereavement Counseling"

(Jones, B., 2010)


Brain Cancer*
Lung Cancer
Caregivers of patients with these diseases had increased needs in bereavement
Renal Failure
Alzheimer's Disease

61 percent of those needing additional bereavement services had LOS of 30 days or less (2007)

62 percent of those needing additional bereavement services had LOS of 30 days or less (2008)

"Bereavement Needs Assessment in Specialist Palliative Care: A Review of the Literature"

(Agnew, A., Manktelow, R., Taylor, B.J., & Jones, L., 2010).

Study Two

- A search of the literature related to bereavement, risk assessment and grief utilizing CINAHL, MEDLINE, PsycINFO, and Cochrane Database.
- 10 measurement tools were included, separated into two groupings:
  1) Continuous bereavement screening and assessment tools
  2) Normal or complicated bereavement assessments

Study Two

- **Continuous bereavement screening and assessment tools** (suitable for use from the *point of a patient's admission* and continuing into early bereavement):
  - Bereavement Risk Index (BRI)
  - Colorado Bereavement Services Project
  - Family Relationships Index (FRI)
  - Matrix of Range of Responses to Loss
  - Risk Assessment of Bereavement

- **The Inventory of Bereavement Risk falls into this category**

Study Two

- **Normal or complicated bereavement assessments** (Assessments undertaken around six months into bereavement to determine whether a person has normal or complicated grief):
  - Adult Attitude to Grief Scale (AAG)
  - Core Bereavement Items (CBI)
  - Grief Evaluation Measure (GEM)
  - Inventory of Traumatic Grief (ITG)
  - Texas Revised Inventory of Grief (TRIG)

Study Two: Continuous bereavement screening and assessment tools

- **BRI**: Completed by nursing staff based on observations or information collected during discussions with IDT. Brief and simple to use, its mode of completion excludes direct service user involvement raising issues of consent and accuracy regarding the assessment and decision making process. Short hospice LOS and limited knowledge of relatives could also lead to incomplete assessments. This tool has been reported to have limited reliability in predicting bereavement outcome.

Study Two: Continuous bereavement screening and assessment tools

- **Colorado Bereavement Services Project**: Completed by trained staff, it uses an asterisk scoring system to identify risk assessment and stressors and resources and strengths. Starred items are considered of major significance and five or more starred items generally indicate high risk. Suicidal ideation automatically considered high risk. The ranking of low, moderate or high risk is subjective, based on the items ticked and the professional undertaking the assessment.

Study Two: Continuous bereavement screening and assessment tools

- **FRI**: A simple and effective 12-item, true-false response scale. Used in palliative care settings as a screening tool that identifies dysfunctional families. The FRI is a well-validated measure of an individual's perception of their family's functioning, and includes such constructs as interpersonal relationships and organizational structure. Kissane et al. found the level of family functioning to be a powerful predictor of bereavement outcome and suggests that clinicians assess family issues in practice.

Study Two: Continuous bereavement screening and assessment tools

- **Matrix of Range of Responses to Loss**: Adapted from the theoretical concepts underpinning Machin's Adult Attitude to Grief Scale. Assessment using the matrix requires observations of family reactions and engagement in conversations about how individuals are dealing with their situation. The concepts of overwhelmed, controlled and resilient can be considered alongside the traditional risk factors. Has not been tested for validity or reliability.

Study Two: Continuous bereavement screening and assessment tools

- **Risk Assessment of Bereavement:** Completed by hospice nursing staff based on their observations and information gathered during the patient's admission and is used to inform the nature of bereavement follow up services. Underpinned by the theories of Parkes and Worden but not tested for validity or reliability.

“Complicated Bereavement: A National Survey of Potential Risk Factors”

(Ellifritt, J., Nelson, K.A., & Walsh, D., 2003).

National Bereavement Risk Survey

- Bereavement Risk Assessment Questionnaire developed to rate 19 possible factors for assessing complicated bereavement
- Four point scale used (0 = no risk, 3 = significant risk)
- Questionnaire mailed to 508 bereavement coordinators nationwide - 262 responded

National Bereavement Risk Survey

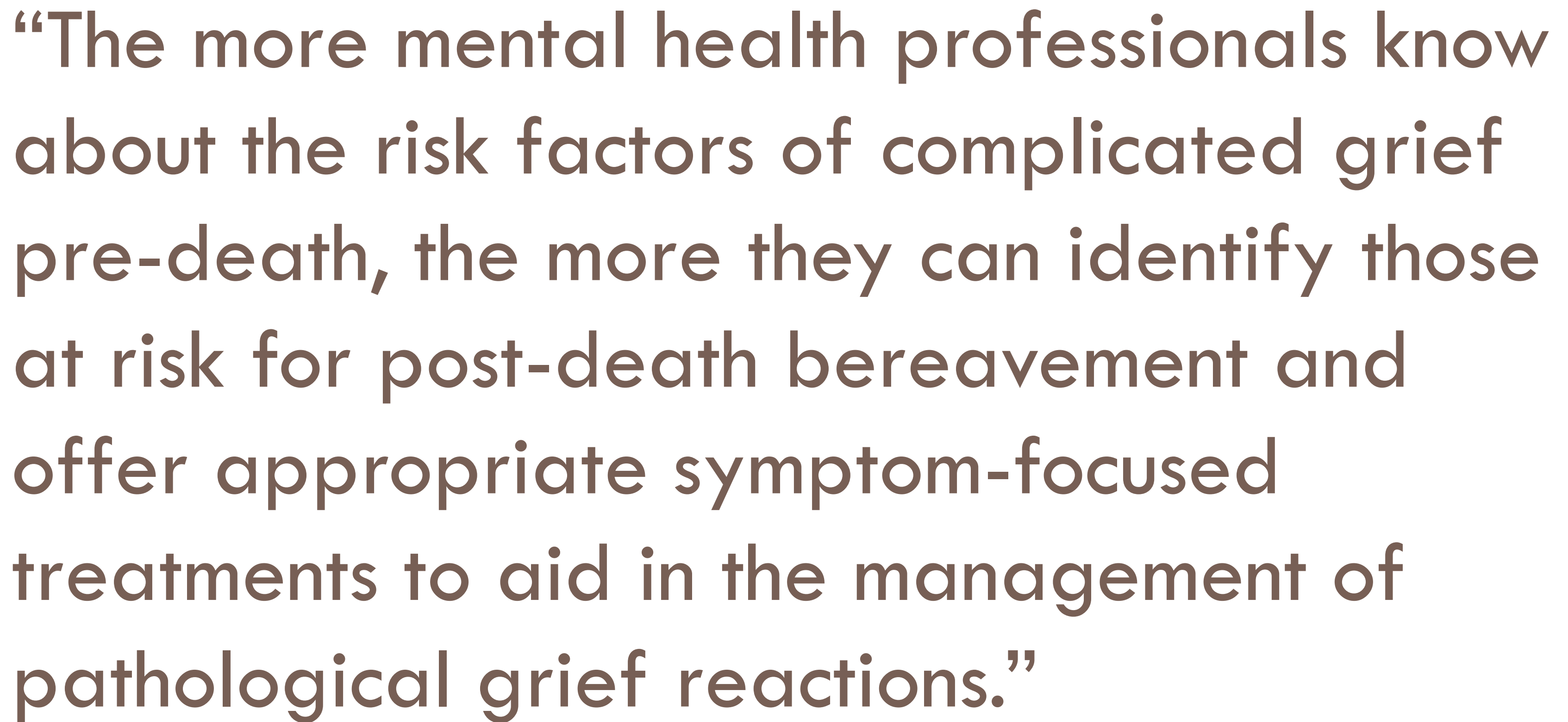
- Most rated the following as significant bereavement risks:
  - Perceived lack of cg social support (70%)
  - Caregiver history of drug/alcohol abuse (68%)
  - Caregiver poor coping skills (68%)
  - Caregiver history of mental illness (67%)
  - Patient is a child (63%)

National Bereavement Risk Survey

- Other bereavement risk factors of significance:
  - Survivor experiencing a concurrent life crisis (52%)
  - Death of another close family member or friend within the last three months (46%)
  - Survivor will be (is) emotionally dependent (42%)
  - Angry outbursts (more than five per week) (41%)
  - Survivor unwilling to face the facts of the patient's illness (40%)
  - Loss within the last three months (job, divorce, etc) (37%)

National Bereavement Risk Survey Conclusions

- No relationship between professional discipline and responses
- Consensus among bereavement professionals regarding important risk indicators
- It's possible to assess bereavement risk in caregivers of seriously ill patients prior to the death of the patient, allowing palliative care teams to allocate resources and services to those at greatest risk for complicated bereavement
- **"The need for predictive tools remains an important deficit in bereavement care. There is a need for a standard tool that will predict caregivers of seriously ill patients at high risk for complicated bereavement."**



"The more mental health professionals know about the risk factors of complicated grief pre-death, the more they can identify those at risk for post-death bereavement and offer appropriate symptom-focused treatments to aid in the management of pathological grief reactions."
~Tomarken, et al., 2008

What does CMS have to say about Bereavement Risk Assessment?

"The hospice must assess any grief/loss issues of the patient's family through an initial bereavement risk assessment that is incorporated in the plan of care."

~Interpretive Guidelines 418.54(c)(7)

What does CMS have to say about Bereavement Risk Assessment?

- "Social, spiritual and cultural factors that may impact a family member or other individual's ability to cope with the patient's death would include, but not be limited to:

What does CMS have to say about Bereavement Risk Assessment?

- History of previous losses
- Family problems
- Financial/legal concerns
- Communication issues
- Drug and alcohol abuse
- Health concerns
- Mental health issues
- Presence of absence of a support system
- Feelings of despair, anger, guilt or abandonment

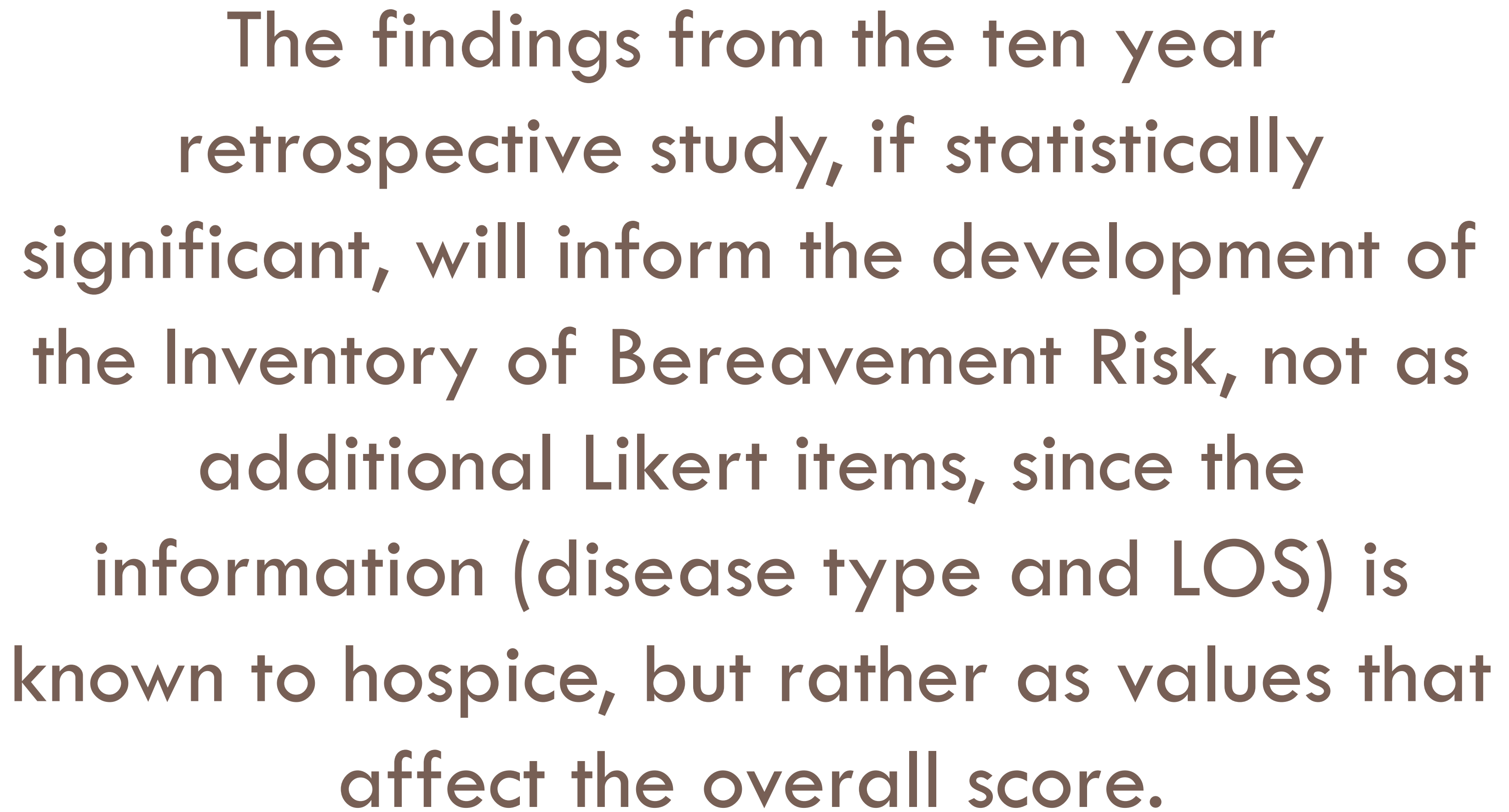
IRB Approved Research Study

Two Elements:

- Ten Year Retrospective Study
- Inventory of Bereavement Risk

Ten Year Retrospective Study Hypothesis

Increased Utilization of
Bereavement Services


The findings from the ten year retrospective study, if statistically significant, will inform the development of the Inventory of Bereavement Risk, not as additional Likert items, since the information (disease type and LOS) is known to hospice, but rather as values that affect the overall score.

Preliminary Findings of Ten Year
Retrospective Study

42 Days

- Mean LOS of all patients

16 Days

- Median LOS of all patients

46 Days

- Mean LOS ≥ 1 BE visit

21 Days

- Median LOS ≥ 1 BE visit

46 Days

- Mean LOS ≥ 1 BE visit ≤ 0.99 DT

19 Days

- Median LOS ≥ 1 BE visit ≤ 0.99 DT

56 Days

- Mean LOS ≥ 3 BE visits

24 Days

- Median LOS ≥ 3 BE visits

32 Days

- Mean LOS ≥ 5 BE visits

12 Days

- Median LOS ≥ 5 BE visits

EFFECT OF LOS ON BEREAVEMENT

60
50
40
30
20
10
0

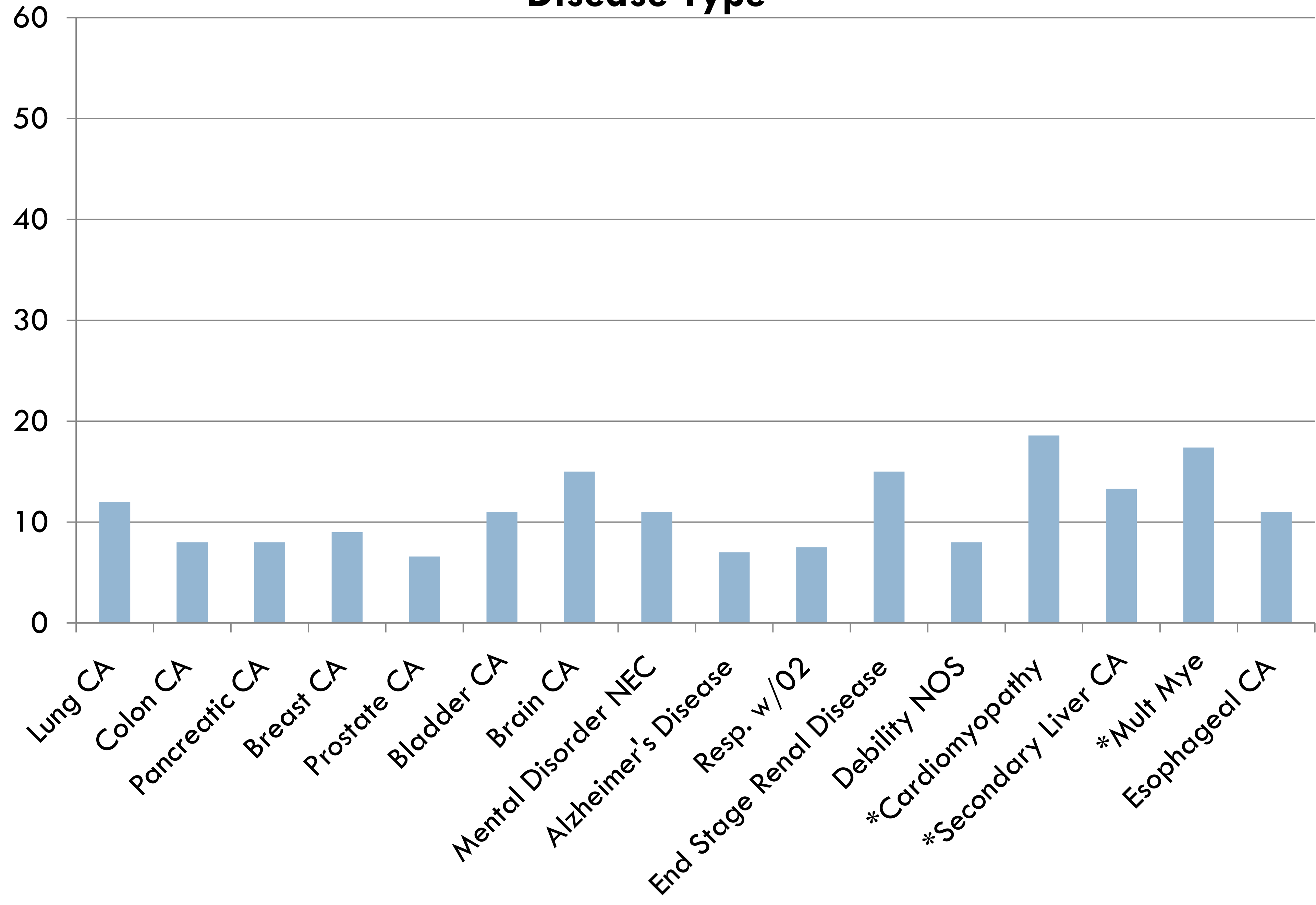
Avg. LOS
Median

- All Patients
- ≤0.99 DT ≥1 BE visit
- ≥1.00 DT ≥1 BE Visit
- ≥1.00 DT ≥3 BE Visits
- ≥1.00 DT ≥5 BE Visits

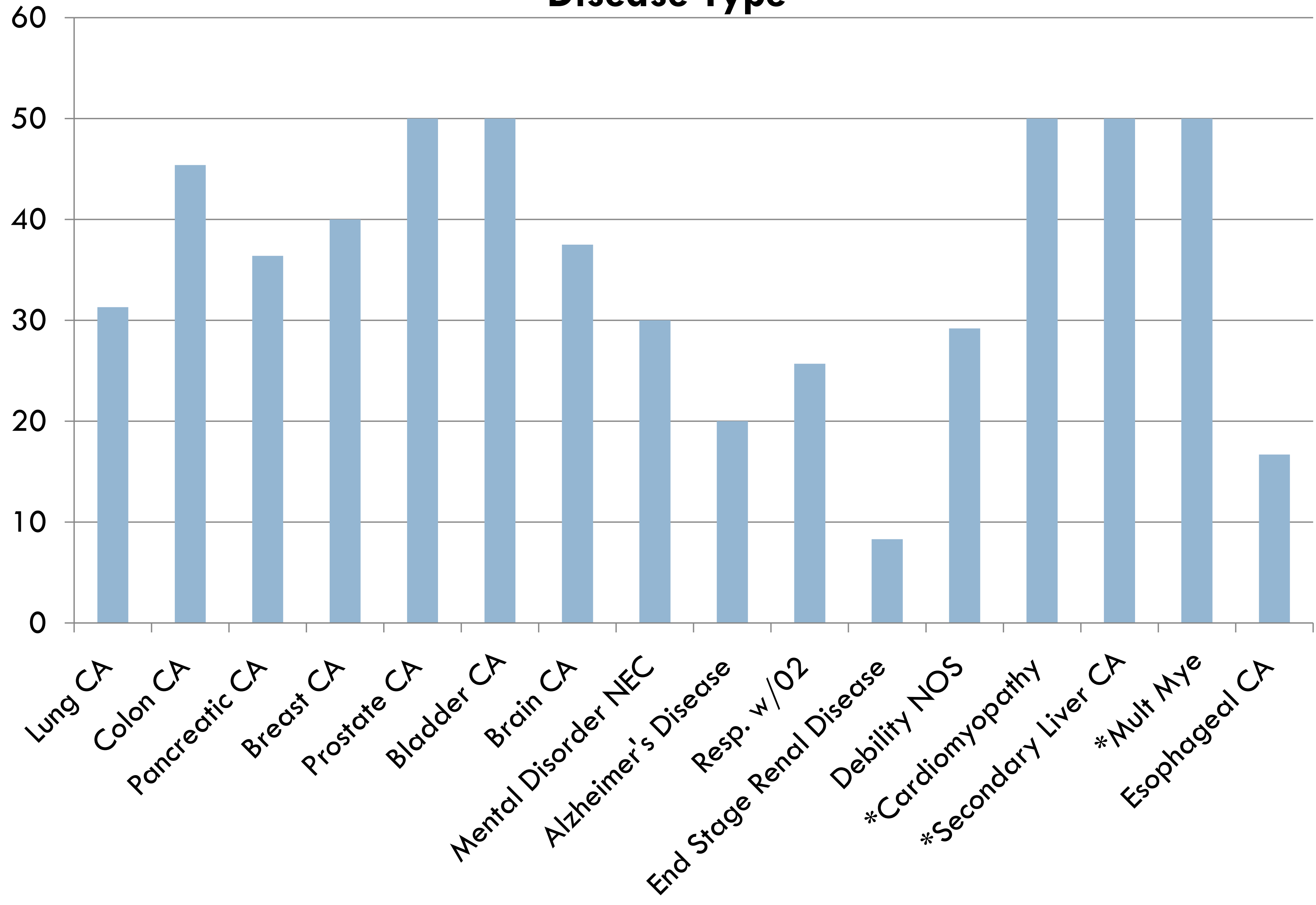
Is Length of Stay Protective?

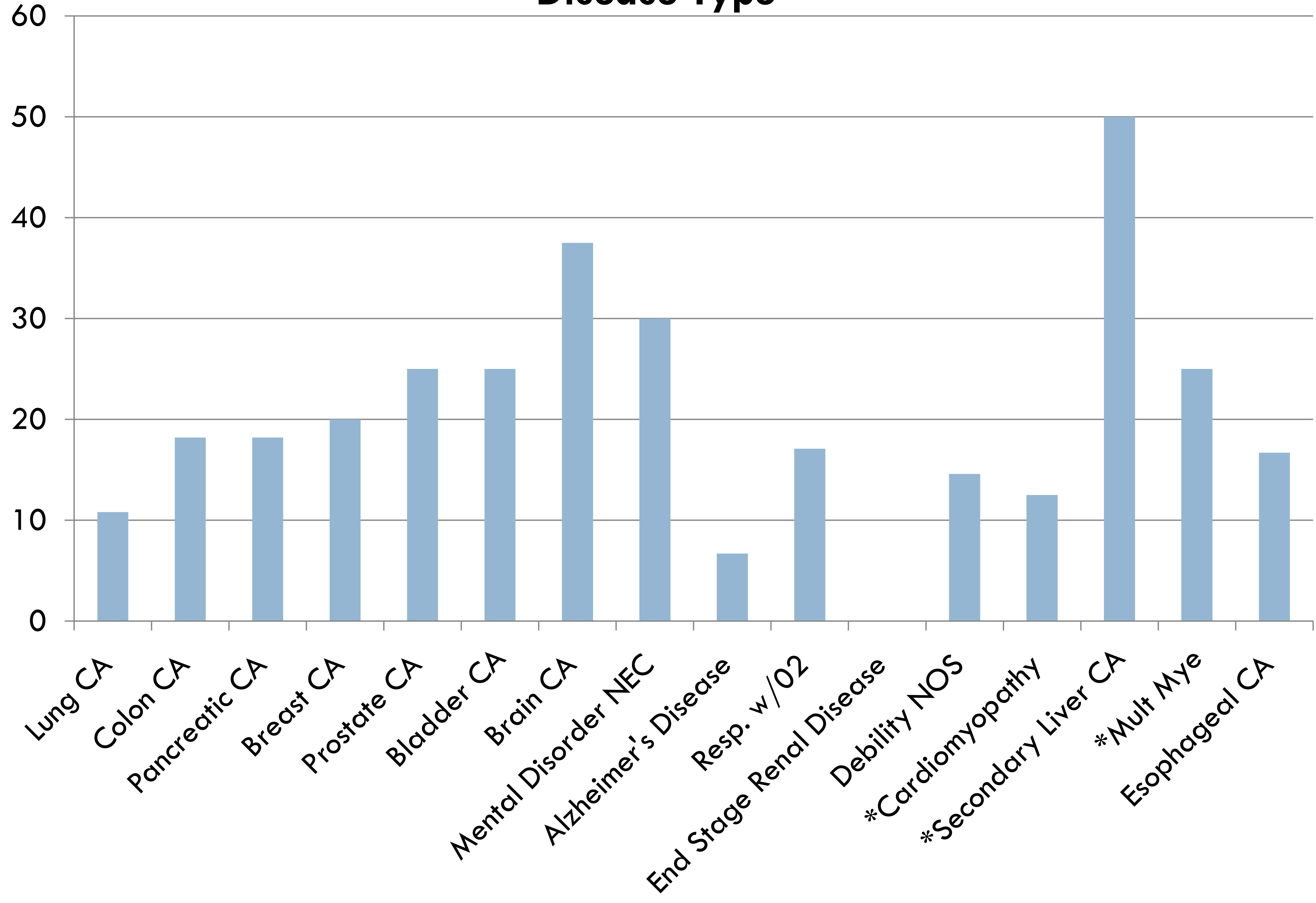
7.7 percent of caregivers receiving at least one BE visit were attached to patients with LOS of ≥ 3 months (38 of 499)

3.7 percent of caregivers receiving at least one BE visit were attached to patients with LOS of ≥ 6 months (18 of 499)

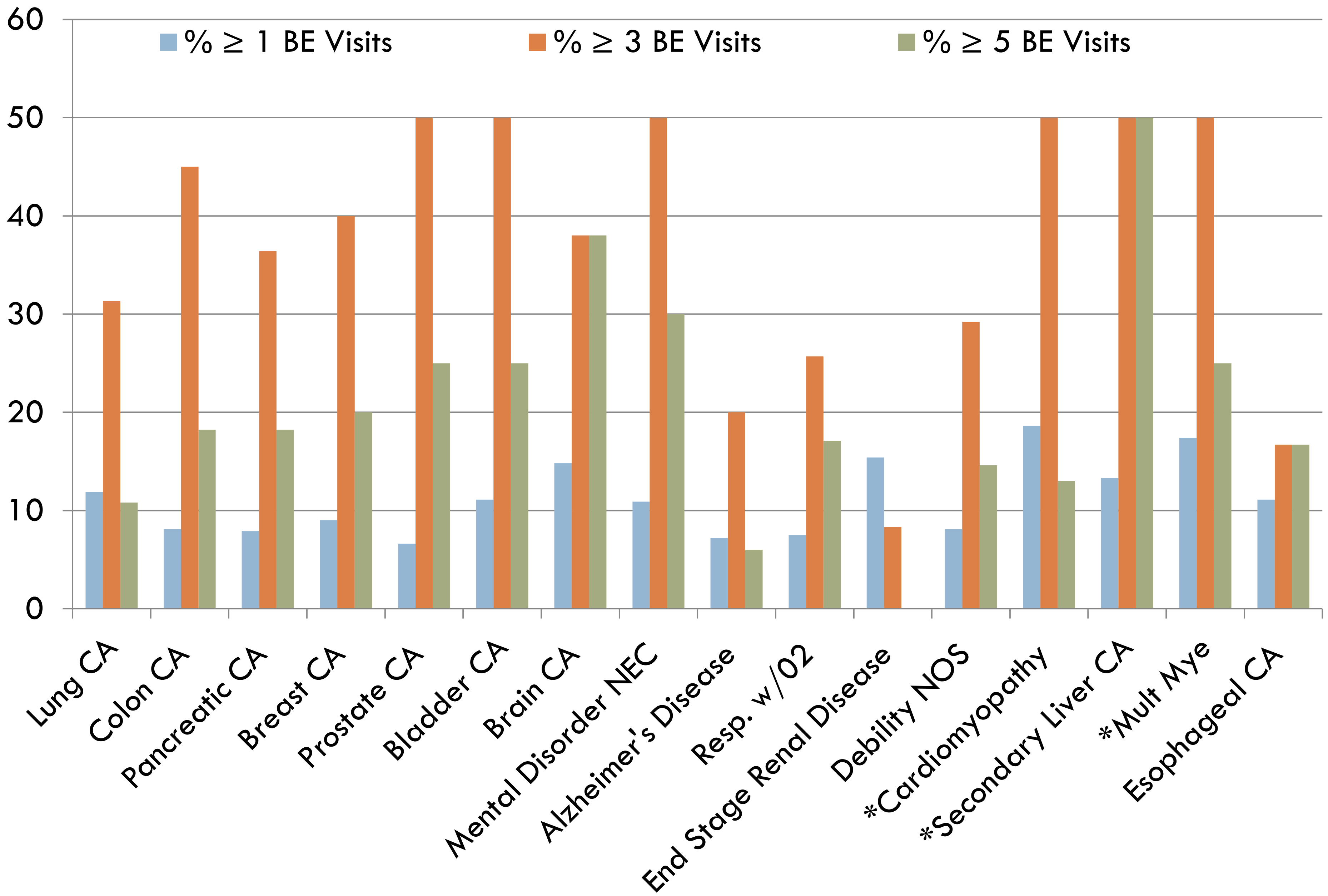


Percent of Total Survivors Receiving ≥ 1 BE Visit By Disease Type
60
50
40
30
20
10
0
Lung CA
Colon CA
Pancreatic CA
Breast CA
Prostate CA
Bladder CA
Brain CA
Mental Disorder NEC
Alzheimer's Disease
Resp. w/02
End Stage Renal Disease
Debility NOS
*Cardiomyopathy
*Secondary Liver CA
*Mult Mye
Esophageal CA

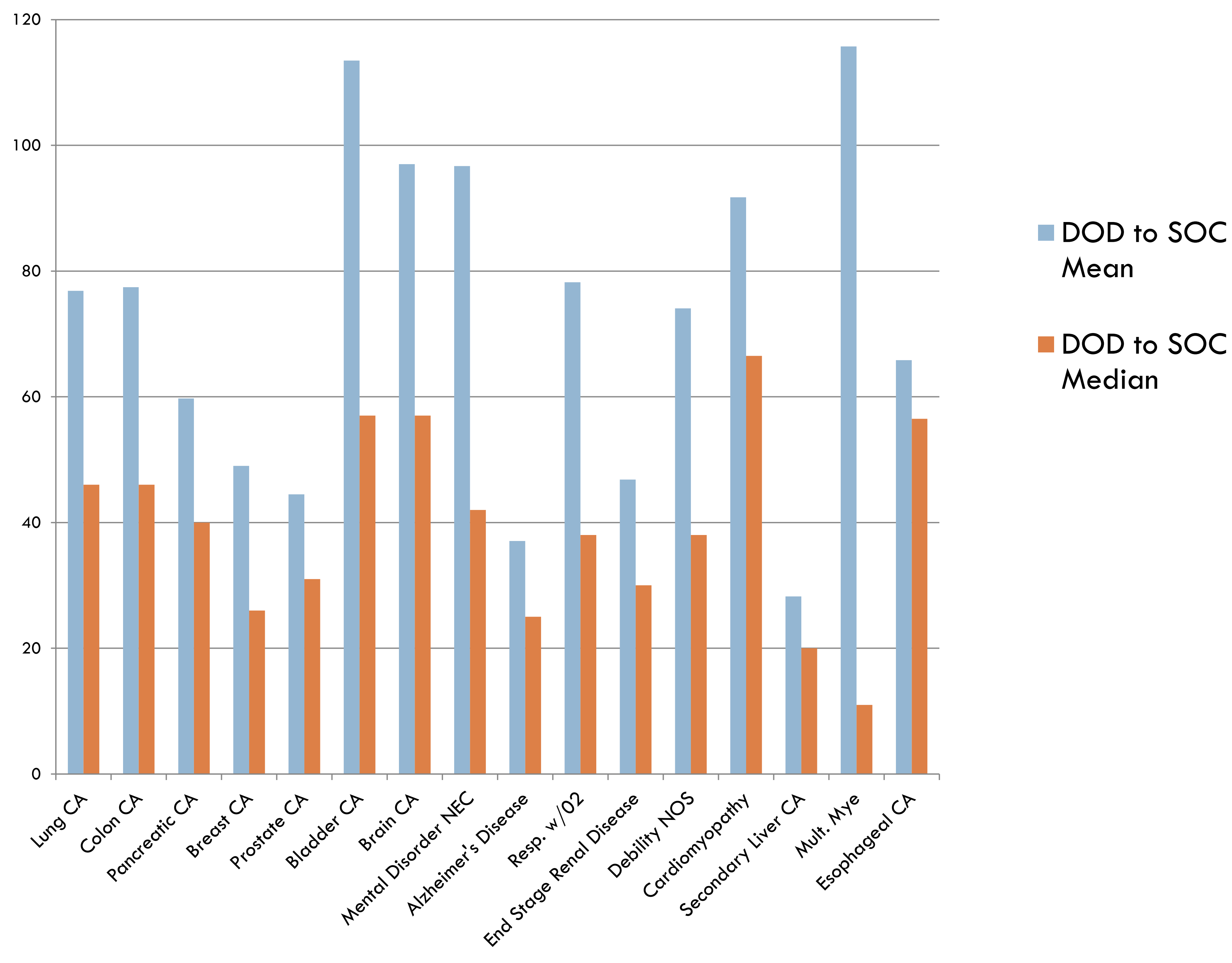

Percent of Those Survivors Receiving ≥ 3 BE Visits By Disease Type
60
50
40
30
20
10
0
Lung CA
Colon CA
Pancreatic CA
Breast CA
Prostate CA
Bladder CA
Brain CA
Mental Disorder NEC
Alzheimer's Disease
Resp. w/02
End Stage Renal Disease
Debility NOS
*Cardiomyopathy
*Secondary Liver CA
*Mult Mye
Esophageal CA



Percent of Those Survivors Receiving ≥ 5 BE Visits By Disease Type
60
50
40
30
20
10
0
Lung CA
Colon CA
Pancreatic CA
Breast CA
Prostate CA
Bladder CA
Brain CA
Mental Disorder NEC
Alzheimer's Disease
Resp. w/02
End Stage Renal Disease
Debility NOS
*Cardiomyopathy
*Secondary Liver CA
*Mult Mye
Esophageal CA



60
50
40
30
20
10
0
% ≥ 1 BE Visits
% ≥ 3 BE Visits
% ≥ 5 BE Visits
Lung CA
Colon CA
Pancreatic CA
Breast CA
Prostate CA
Bladder CA
Brain CA
Mental Disorder NEC
Alzheimer's Disease
Resp. w/02
End Stage Renal Disease
Debility NOS
*Cardiomyopathy
*Secondary Liver CA
*Mult Mye
Esophageal CA



120
100
80
60
40
20
0
Lung CA
Colon CA
Pancreatic CA
Breast CA
Prostate CA
Bladder CA
Brain CA
Mental Disorder NEC
Alzheimer's Disease
Resp. w/02
End Stage Renal Disease
Debility NOS
Cardiomyopathy
Secondary Liver CA
Mult. Mye
Esophageal CA
DOD to SOC Mean
DOD to SOC Median

Preliminary Conclusions of Ten Year Retrospective Study

- Patient LOS $\geq$ 3 months seems associated with protective factors in bereavement
- Caregivers who received $\geq$ 5 BE visits were attached to patients with significantly shorter mean and median LOS
- The relationship between hospice disease type and utilization of bereavement services remains inconclusive at present

Goal of Inventory of Bereavement Risk

- **Question** posed by research colleague Dr. Francis Yuen – is the goal to develop:

A. A simple risk measurement using a self-report that could reflect the general trends and orientation/the likelihood of risk?

Or

B. A statistically and empirically tested psychometrically appropriate assessment scale that has been normed?

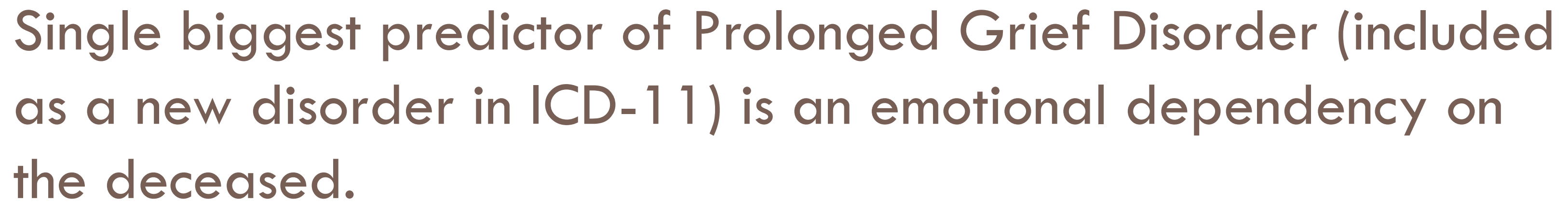
Goal of Inventory of Bereavement Risk

Answer:

B. A statistically and empirically tested psychometrically appropriate assessment scale that has been normed.

Content of Inventory of Bereavement Risk

- Influenced by:
  - National Survey of Bereavement Risk Factors
  - CMS Guidelines
  - Previous Research on Bereavement Risk
  - Bereavement Theories (Worden, Neimeyer, etc.)
  - Clinical Experience



Single biggest predictor of Prolonged Grief Disorder (included as a new disorder in ICD-11) is an emotional dependency on the deceased.

Hospice can be protective, hospitalizations a risk, and the quality of life of the patient in the final week and even the patient's therapeutic alliance with the oncologist influences changes in mental health of the bereaved caregiver.

Holly Prigerson, Ph.D., Dana-Farber Cancer Institute, Personal Communication, 2013

"A caregiver's pessimistic view of the world is one of the strongest predictors to developing complicated grief pre-death."

The measure of dispositional optimism as opposed to state optimism in the Life Orientation Test-Revised suggests that pathological pre-grief reactions are related to an individual's enduring personality characteristics as opposed to other psychosocial risk factors (e.g., social support, depression, mental health access or use) or demographic factors (e.g. relationship to patient, income level, race, education, gender).

Tomarken, et al., (2008)

Roll out of the Inventory

- All research team members had to complete and pass the training course on "Protecting Human Research Participants" from NIH before IRB submission.
- Completion of inventory encumbered with two HIPAA consents (patient and caregiver), one informed consent, and a patient information sheet.

Inventory of Bereavement Risk

Details of Inventory of Bereavement Risk (IBR)

- 27 item, 5 point Likert Scale (in present form)
- Self-administered
- 10 reverse scored items (acquiescence bias)
- 15 minutes to complete
- Numeric value assigned to low, moderate and high bereavement risk
- Clinical utility **BEFORE** and **AFTER** death
- Research team members blind to results during study
- Suicidal intent/plan excluded from inventory (automatic high risk)
- Not diagnostic
- Avoids use of term "loved one;" modeled after ITG (Prigerson), utilizing blanks
- Categorized as "continuous bereavement screening and assessment tools"
- Subjects followed over 13 month period after death to assess whether IBR score correlates with level of utilization of bereavement services/risk

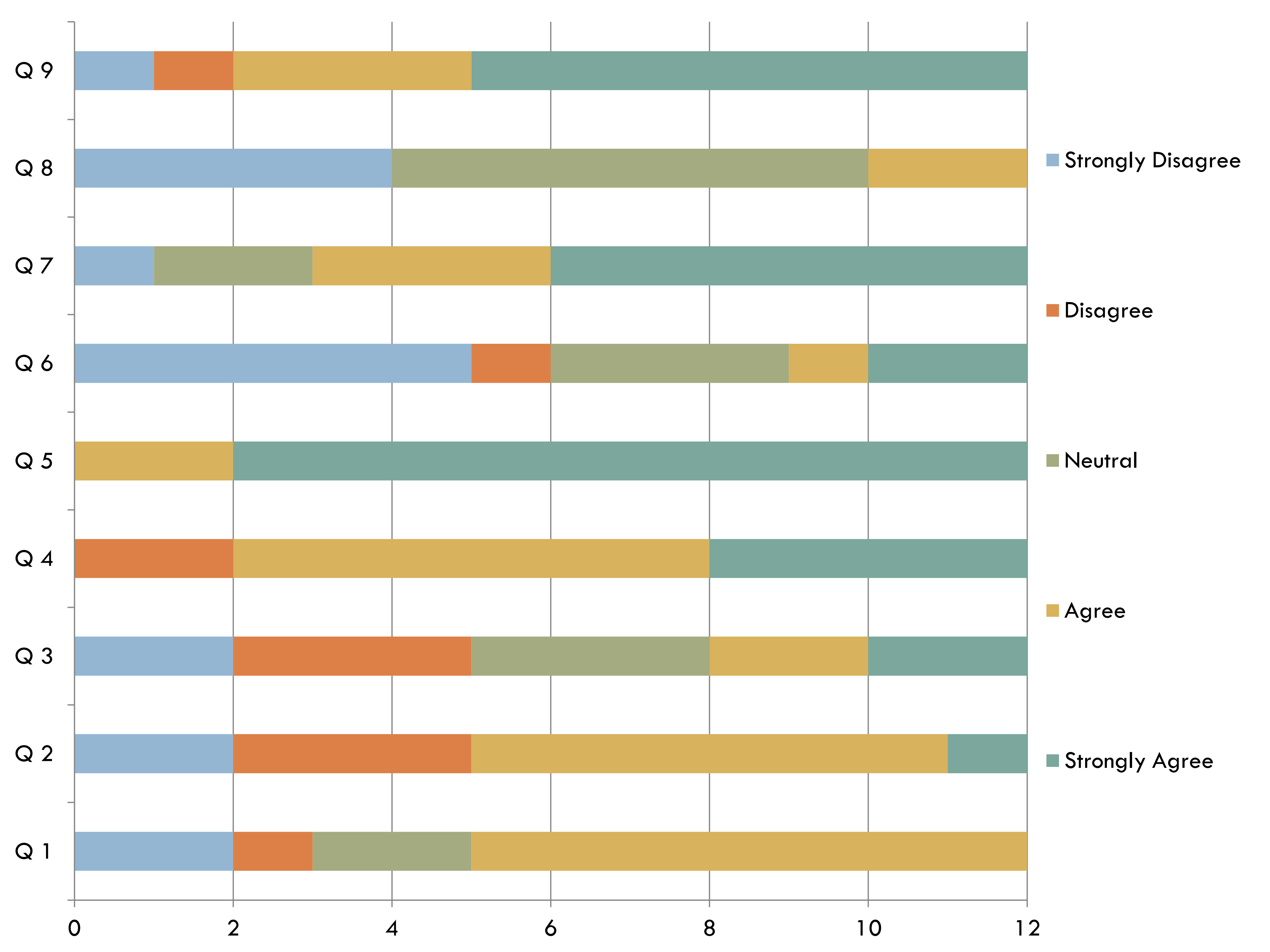
Cronbach's Alpha

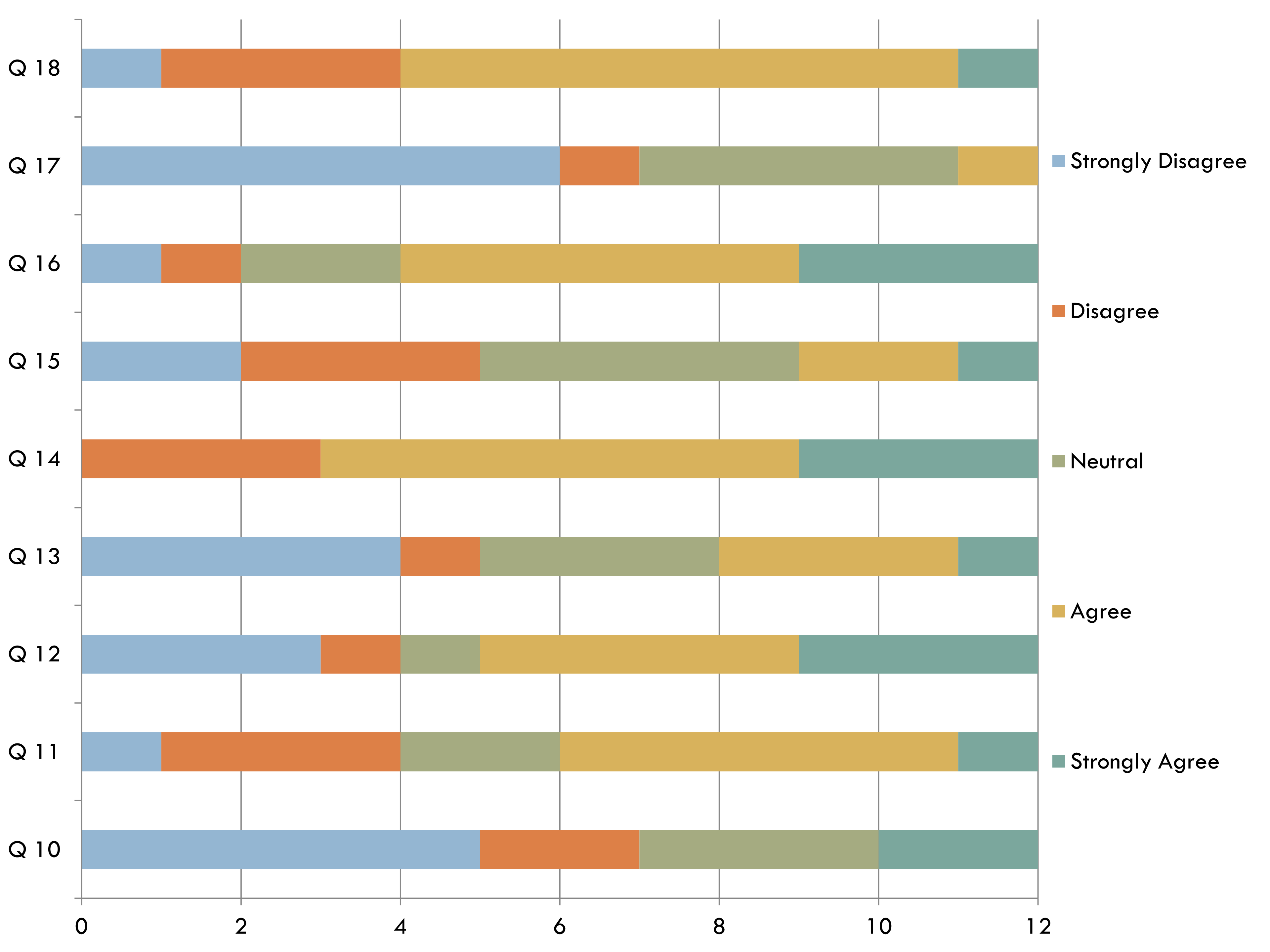
- **IBR (n = *12): Cronbach's Alpha of .793**

  (Alpha value expected to increase after elimination of statistically insignificant items)
- 0.9 Excellent
- 0.7 - 0.9 Good
- 0.6 - 0.7 Acceptable
- 0.5 - 0.6 Poor
- ≤ 0.5 Unacceptable

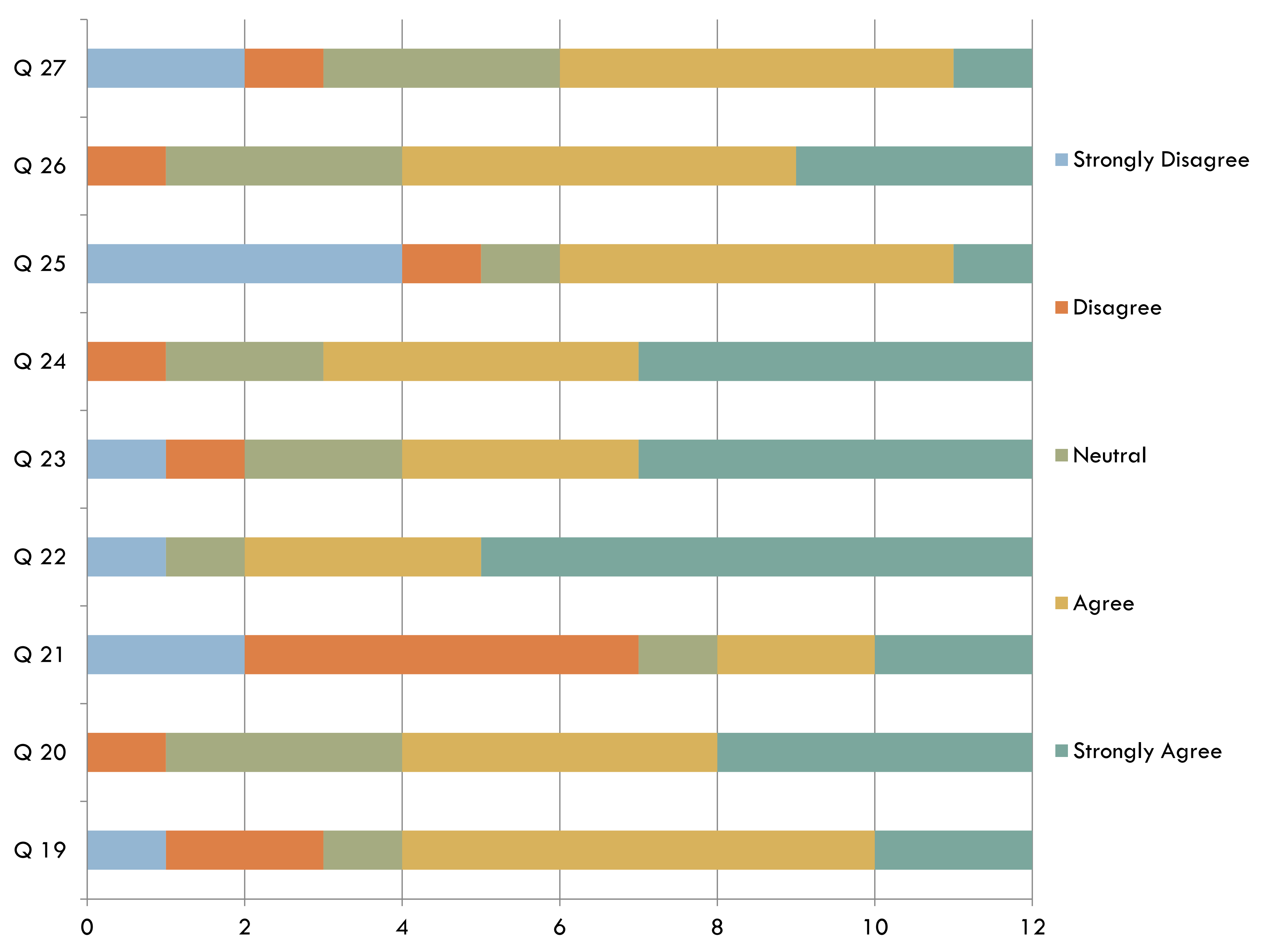
*Sample size not yet statistically significant

Stacked Bar Plotting of
Likert Responses (N = 12)


Q 9
Q 8
Q 7
Q 6
Q 5
Q 4
Q 3
Q 2
Q 1
0
2
4
6
8
10
12
Strongly Disagree
Disagree
Neutral
Agree
Strongly Agree



Q 18
Q 17
Q 16
Q 15
Q 14
Q 13
Q 12
Q 11
Q 10
0
2
4
6
8
10
12
Strongly Disagree
Disagree
Neutral
Agree
Strongly Agree


Q 27
Q 26
Q 25
Q 24
Q 23
Q 22
Q 21
Q 20
Q 19
0
2
4
6
8
10
12
Strongly Disagree
Disagree
Neutral
Agree
Strongly Agree

Summary

- Mercy Hospice well positioned to complete study, with over 650 deaths per year
- Implementation of IBR to continue over two year period, with sample size of 300+ as goal; further data analysis to be completed on ten year retrospective study as well
- Ultimately fills void in hospice practice through development of valid and reliable risk assessment tool
- Results to be published in scientific journal
- Utility before death of patient involves earlier identification of risk factors and intervention to mitigate bereavement complications/development of prolonged grief disorder
- Meets expectations of CMS Conditions of Participation
- Please Email me if you would like updates on study or more detailed information on data analysis as it becomes available

Stay tuned!