



Reaction of the Family in the Face of the Wish to Hasten Death

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Who are caregivers?

- Formal caregivers
- Informal caregivers (ICs)
- WHO estimates that ~8% of the global population is dependent on others for care
 - 1/3 US households in 2009 had a caregiver
 - 65.7 million Americans, 4.6 million of whom provide care to patients with cancer
 - Informal caregivers are predominantly female and providing care to a parent, and over 1/3 provide care to two or more people



What do caregivers do?

- Instrumental support
 - Activities of daily living (ADL)
- Emotional support
- On average, informal caregivers provide care for 8.3 hours/day, for 13.7 months
- ~1/3 informal caregivers provide care for 5+ years
- Annual economic value of caregiving in the U.S. was recently estimated at \$375 billion



Caregiver Burden

- Multi-dimensional
 - Psychological
 - Anxiety
 - Depression
 - Physical/Medical
 - Cardiovascular disease
 - Poor immune functioning
 - Fatigue/sleep difficulties
 - Higher rates mortality
 - Financial
 - Temporal



Caregiver Burden

— Existential

- Guilt
- Responsibility for oneself v. the patient
- Changes in and questions about identity
- Loss of the relationship with the patient
- Anticipatory grief





Family Reactions to the WTHD

- To date, no systematic, empirical studies of family/caregiver reactions to the WTHD
- What do we know thus far that will inform how we address family/caregiver reactions to the WTHD?



Family Reactions to the WTHD

- Patient expression of the WTHD results, in some cases, from the perception of being a burden to families/caregivers (Ganzini et al. 2002; Morita et al., 2004)
 - Patients feel that they can “save” the family/caregiver from pain/suffering
 - WTHD can be expressed in response to seeing a decline in caregiver functioning/well being
 - WTHD can be experienced as an act of love



Family Reactions to the WTHD

- Families/Caregivers are sometimes asked to assist with hastened death
 - The ultimate existential dilemma
 - Similar to signing DNR/DNI orders, this places extreme pressure and responsibility on the family/caregiver and after death, can contribute to experience of post-traumatic stress symptoms



Family Reactions to the WTHD

- Patient expression of a WTHD has the potential to lead families/caregivers to:
 - Question the nature and quality of the relationship
 - A crisis in meaning



Family Reactions to the WTHD

- Patient expression of a WTHD has the potential to lead families/caregivers to experience their own WTHD:
 - More likely when burden is high, the caregiving trajectory has been long, and the patient's neurocognitive capacity has been compromised
 - More likely when there is decreased meaning derived from the caregiving role





What Do We Know about Communication?



Communication

- Open communication between families/caregivers and patients about goals of care and DNR/DNI orders leads to improved psychological well being after the patient's death (Hartog et al., 2015)
 - Among 610 caregivers of pts receiving care in an ICU for sepsis, after death, 51% experienced sx of PTSD, 48% anxiety, and 33% depression
 - Satisfaction with medical care and communication about care predicted less anxiety ($p = 0.025$)

Communication

- Accurate prognostic awareness (PA) is associated with improved psychosocial outcomes (Applebaum et al., 2014, 2015; Diamond et al., 2015)
 - For patients with incurable cancer, prognostic awareness (PA) is associated with favorable psychological states and end-of-life outcomes.
 - For caregivers, accurate PA is associated with improved bereavement outcomes for caregivers.

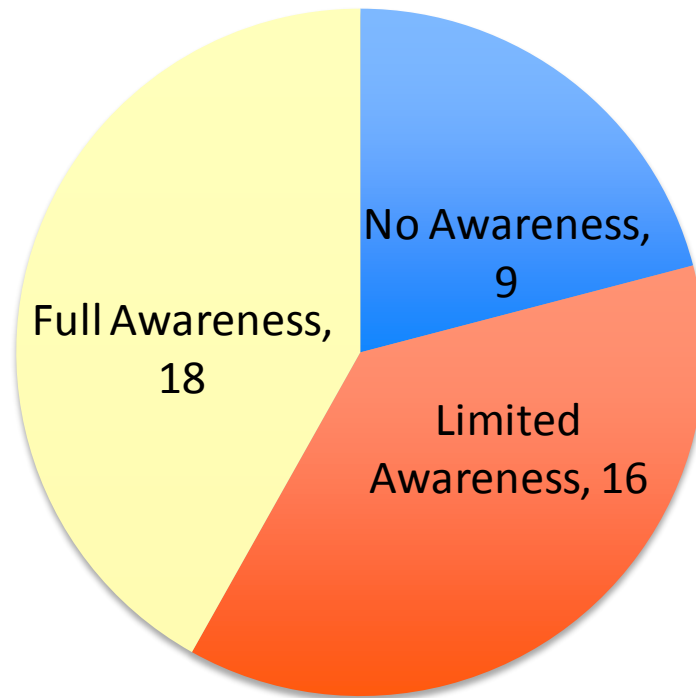


PA, Communication (Diamond & Applebaum, 2015)

- Prospective study of fully-oriented patients with malignant glioma (MG) and caregivers.
- Participants underwent a semi-structured assessment of their awareness of incurability and life expectancy (for themselves or their loved ones)
- Interviews were audio-recorded and consensus-scored by two independent raters
- 43 patients with malignant glioma (MG) and 25 matched caregivers



Patients

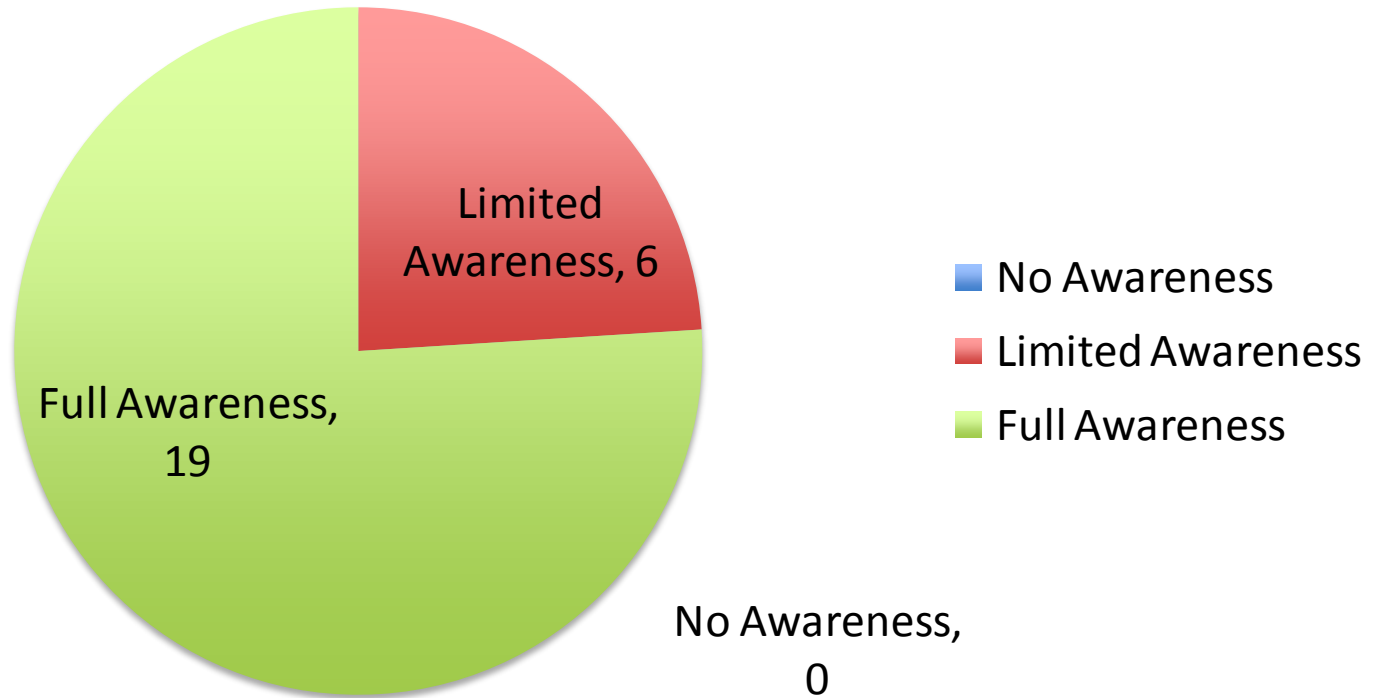


- No Awareness
- Limited Awareness
- Full Awareness

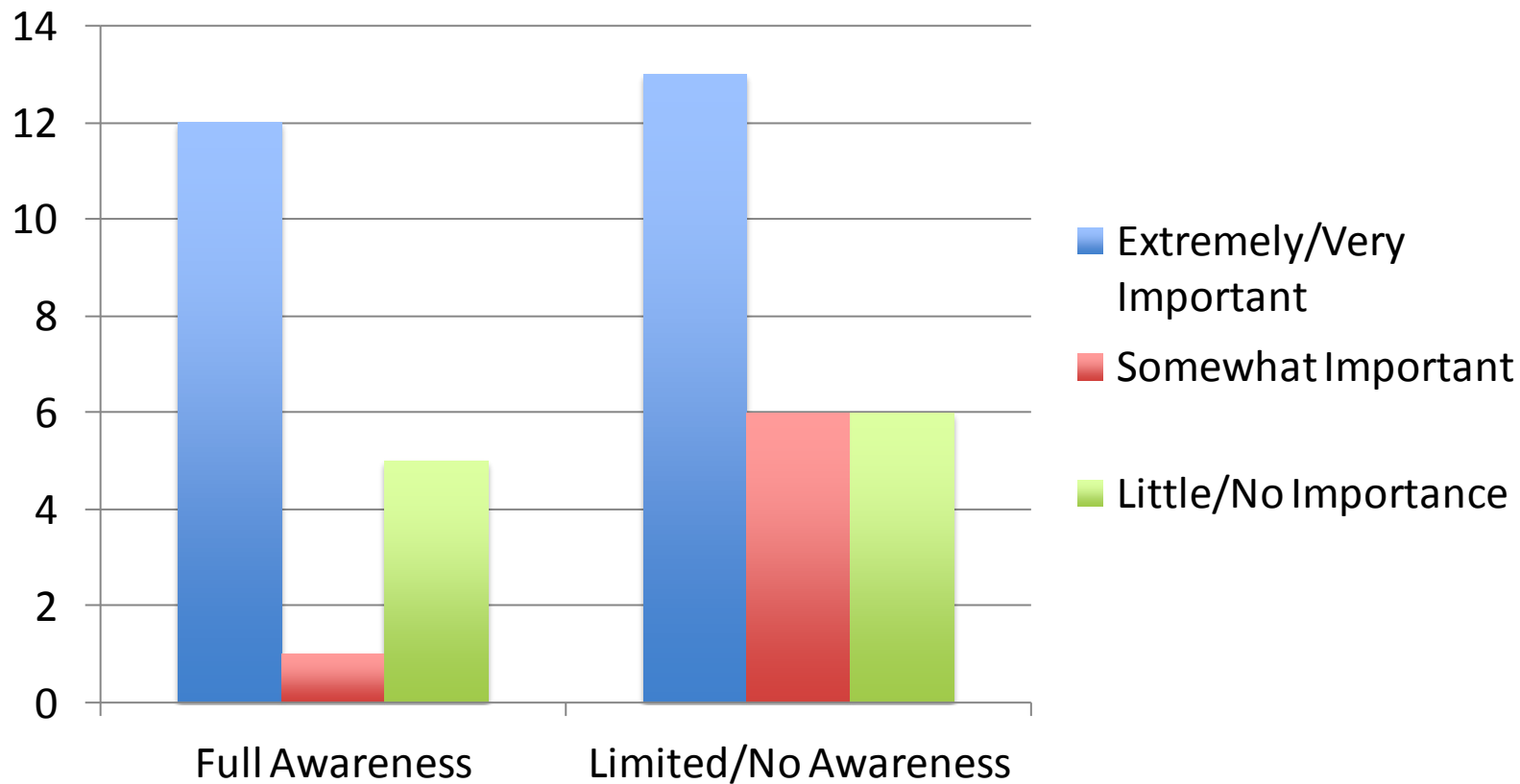




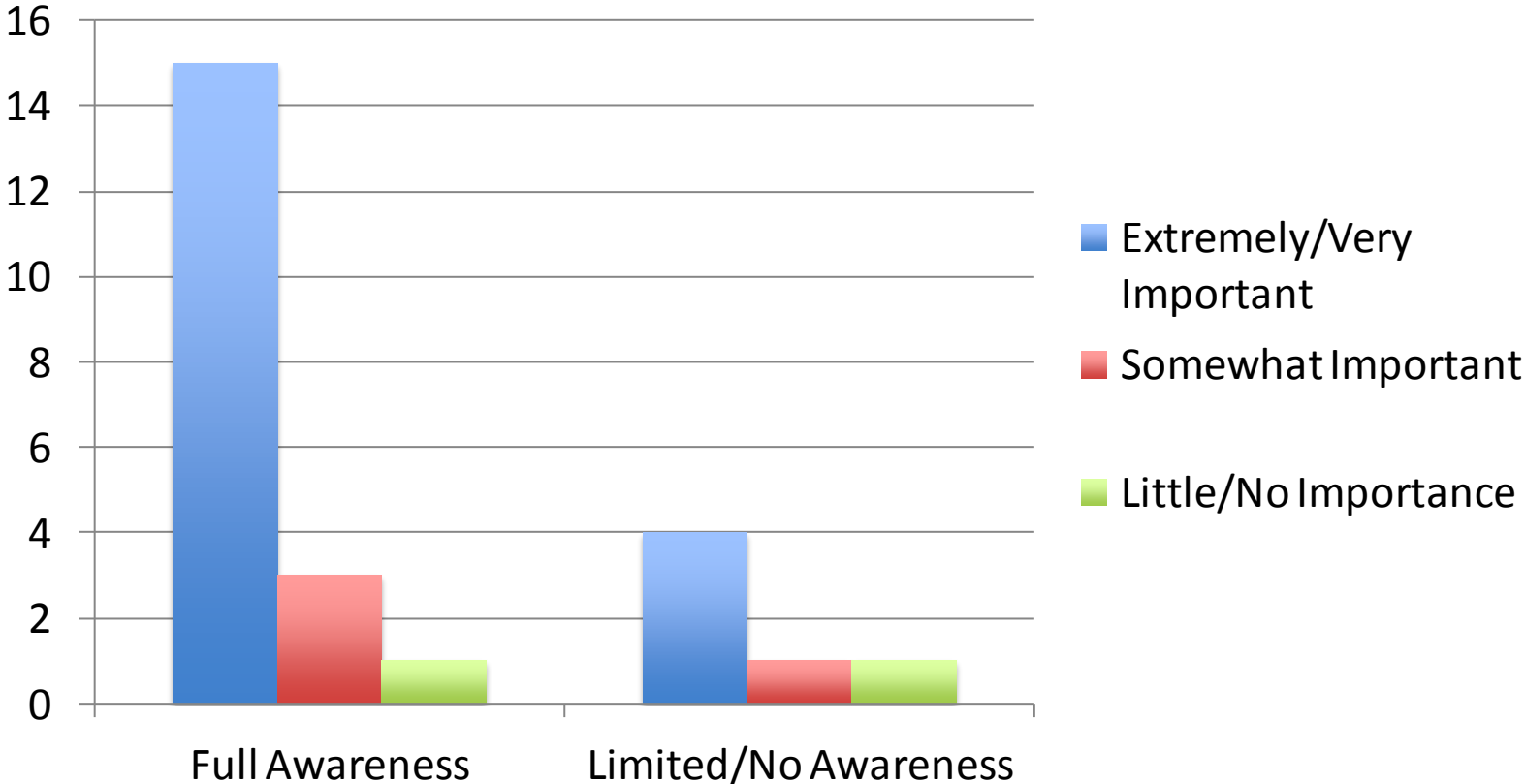
Caregivers



Patients PAxImportance



Caregivers PAxImportance






Case Study



- Kathy, age 54, wife of John, age 66, dx with GBM 9 months prior
- 2 adult daughters outside of NYC area, both Kathy and husband no longer working
- John presenting with significant neurocognitive and personality changes, and required assistance with many ADLs
 - Significant change from baseline
 - Diminished sense of self
- Before John's dx, Kathy worked full time, took art classes, enjoyed time with girlfriends, "care-free," but had a "forced retirement," no spontaneity, fearful, felt she had no choice in becoming a caregiver
 - Significant change from baseline
 - Diminished sense of self



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- After last scan, couple told there are no new treatments available and transition to hospice was inevitable; soon after, John expresses WTHD to Kathy
 - This conversation was terrifying to Kathy, who felt increasingly helpless and powerless as a result
 - In session, Kathy reported feeling “like a failure” and increased depressive sx (confirmed via self-report on the PHQ-9)
 - In session, encouraged Kathy to explore what lies behind John’s WTHD
 - WTHD is eventually used as an opportunity to facilitate communication about fears regarding end-of-life care





Future Directions

- Expression of WTHD among patients should trigger evaluation of caregiver/family psychosocial functioning
- Development and validation of measure of WTHD among caregivers
- Evaluate impact of improved physician/patient/caregiver communication on shared-WTHD





Thank you!

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