

Thanatology Certificate Program: Care for the Caregiver

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Portions Funded by the National Institute on Aging and the
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Portions contributed by Dr. Beverly Thorn

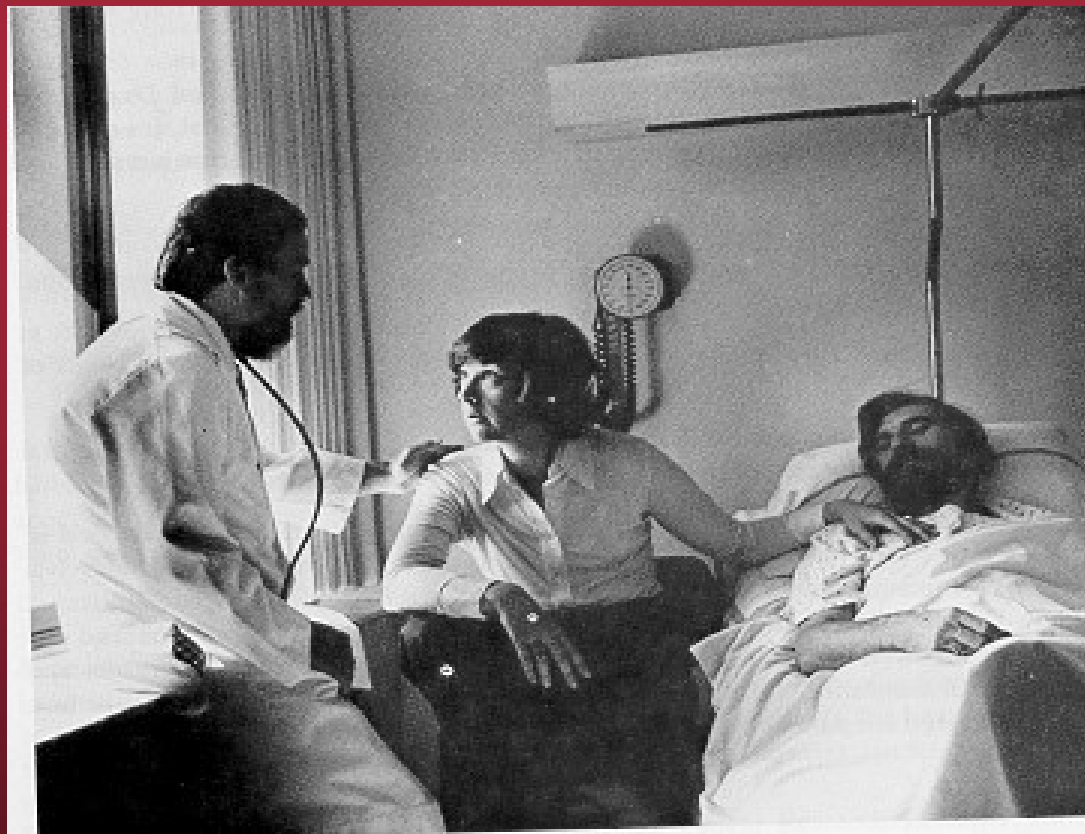


Who May Experience Anticipatory Grief?

- The person who is dying
 - Loss of physical functioning (fatigue, pain)
 - Loss of psychosocial contact (partly by choice)
 - Loss of role
- The family caregiver
- The health care professional



Professionals and Family Caregivers Must Attend to Self Care



Caregiving and Communication

- 44% of bereaved family members report a desire for better communication with health-care professionals to improve care of patients at the end-of-life
- Better communication improves quality of life and quality of care



Communicating with Health Care Professionals

- Jargon and barriers in communication
- Lack of family caregiver training in the use of standardized assessments
 - e.g., pain as the 5th vital sign and use of VAS, Faces, or NRS
- Intimidation
- “Powerful Others”



Care for the Family Caregiver / Our Clients Dealing with End-of- Life Issues



A Pause for Video Viewing

“Burdens and Blessings”



Family Caregivers and Professional Caregivers: Common Issues

- Family Caregivers

- Emotional strain
- Spiritual strain
- Physical strain
- Financial strain

- Professionals

- Professional strain
- Emotional strain
- Physical strain
- Spiritual strain



Care for the Caregiver(s): Common & Unique Issues

Family Caregivers

- maintaining control
- exhaustion
- denial
- anger
- guilt
- letting go



Professionals

- maintaining control
- overwork
- realism with hope
- apathy (burnout)
- guilt
- letting go

Familial Advance Planning for the End-of-Life (FAPE)

- Receipt of palliative care does not alleviate the need to make end-of-life decisions, so enhanced communication of medical treatment preferences is a critical need
- Many patients want to communicate treatment preferences
- Many patients lack decisional capacity:
 - Ability to state a treatment preference
 - Ability to understand disease process & treatment plan
 - Ability to appreciate the consequences of a tx choice
 - Ability to rationally consider the risks and benefits of a particular treatment, weigh alternatives, and give reasons for one's choice



The Legacy Project

- Seeks to assess the efficacy of the intervention on decreasing family caregivers' experience of distress during palliative care.
- Seeks to improve family caregivers daily lives by focusing on positive aspects of caregiving such as increased meaning, daily spiritual experiences and feelings of self-efficacy / mastery.
- Seeks to improve the patient's quality of life.
- Seeks to provide a tangible memento of the patient with life-limiting illness (cookbook, pix, letters)



Care Integration Team Intervention During Hospice Care

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Funded by the National Institute on Aging
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Introduction

- Palliative caregiving is extremely stressful, and advance planning has been shown to reduce stress within the family.
- Problem solving skills training reduces stress among dementia caregivers, but has not been systematically applied to treatment in the context of palliative care.
- In this pilot investigation, we looked at baseline data from the Care Integration Team Intervention study, reflecting the state of the family caregiver/care recipient dyad entering hospice care.



Problem Solving Skills Training

- Step 1: Identify the problem
- Step 2: Name all the possible solutions
- Step 3: Name and evaluate the pros and cons to the solutions
- Step 4: Choose and try one solution
- Step 5: Evaluate whether or not the solution works
- Step 6: Use what you learn



The Care Integration Team Project: Specific Aims

- To train family caregivers in the use of problem-solving skills for problems identified in symptom management, communication (with care recipients or professionals), self-care, & anticipatory grief
- To assess the impact of the intervention on family caregivers' psychological and care-related distress
 - **Mental health target**: reduced depression, anxiety, stress; increased hope, self-efficacy



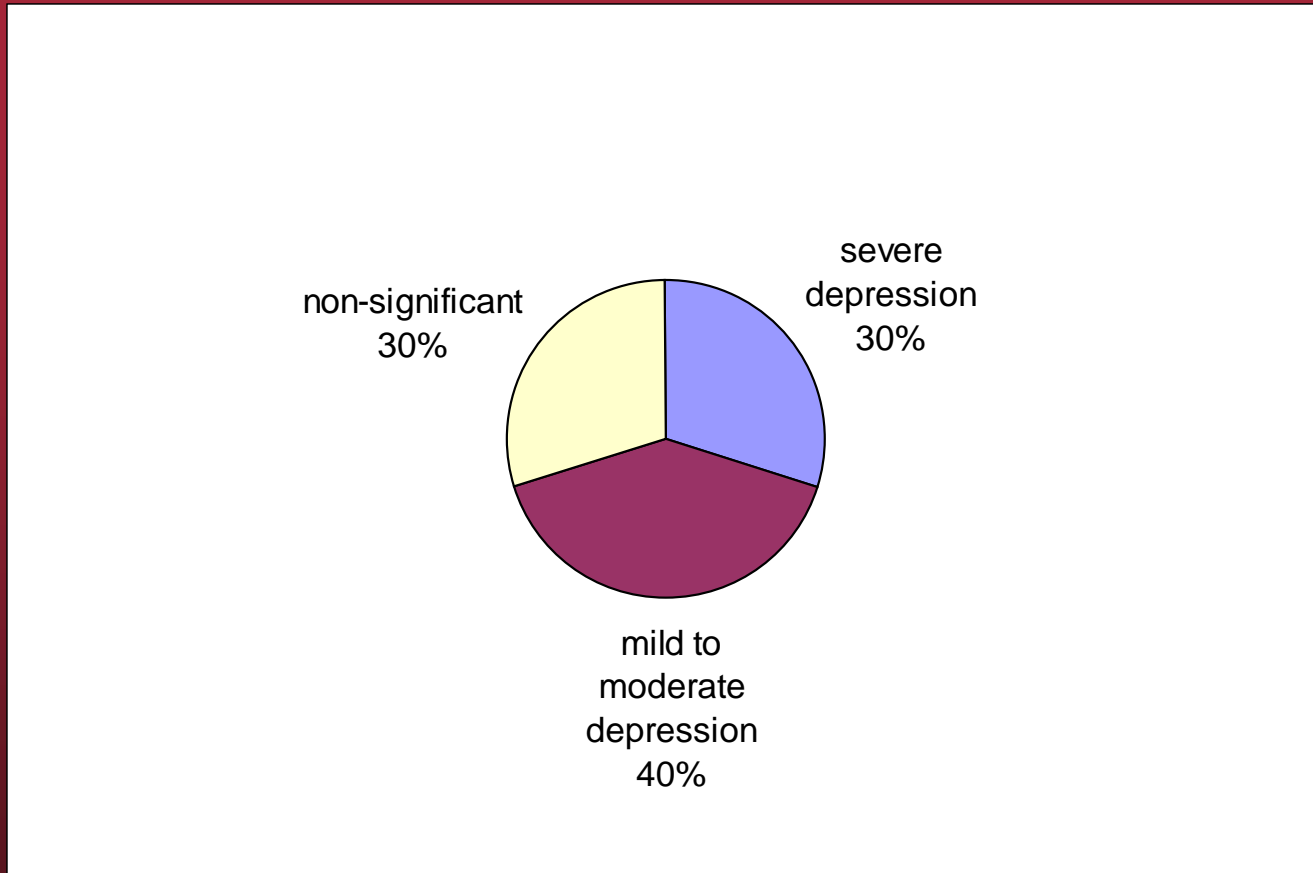
Procedure:

- Within one week of beginning hospice care, the care recipient/caregiver dyad is referred to the Care Integration Team (CIT).
- A baseline visit is scheduled and occurs during the first two weeks of hospice care.
- Two research assistants (RAs) conduct the assessment at the dyad's home.
- Assessments take approximately one hour with the CG and one half hour with the CR.

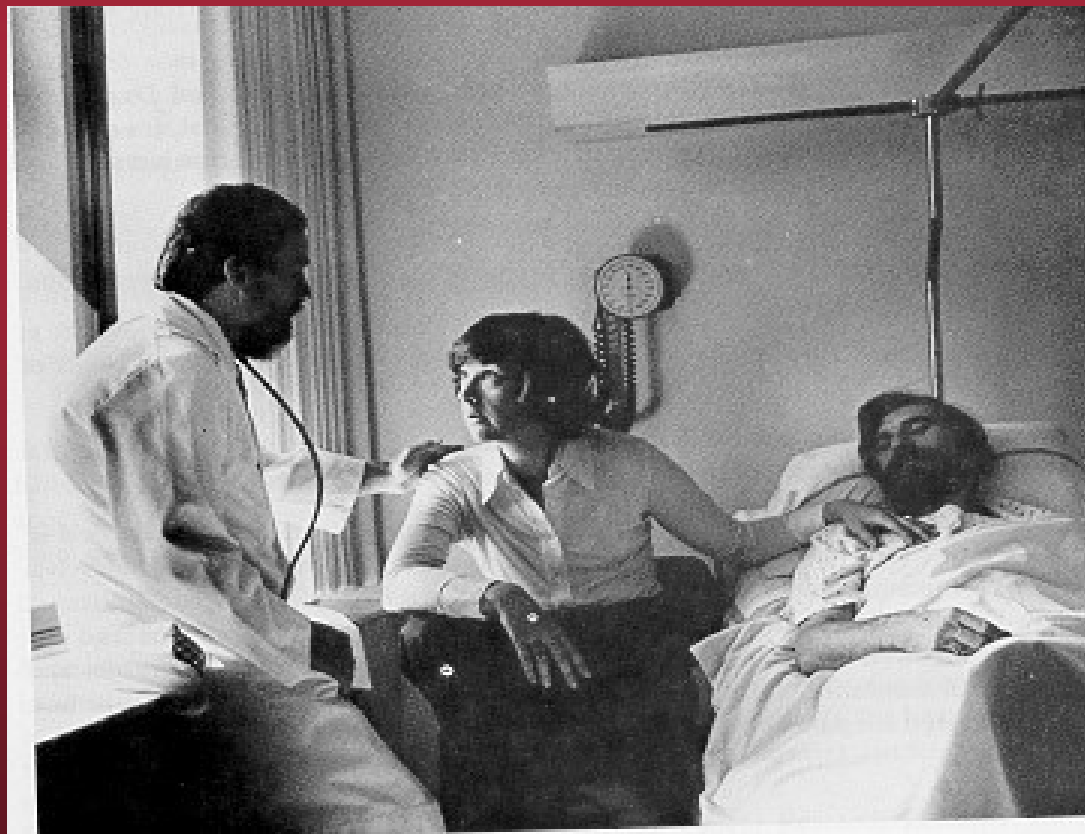


Results: Family Caregiver Depression

70% of family CGs had at least mild to moderate symptoms of depression as measured by the CES-D



Professionals and Family Caregivers Must Attend to Self Care



Issues for Health Care Professionals

- Overwork
- Multiple Loss and Grief
- Boundaries
- Burnout



Overwork

- Occupational realities of working with the dying
- Institutional realities
- Unrealistic self-expectations & errors in thinking :
 - “If I don’t do it, no one will”
 - “I can do it better than anyone, so I should”
 - working harder to make up for mistakes
 - “Helpaholism”
 - “I’m in this alone”
 - “There’s no way out of this”



Multiple Loss and Grief

- Stigma of working with the dying
- Professional caregivers not expected to grieve
- “Bereavement overload” (Kastenbaum, 1969) - falling over the edge of hope
- Our early experiences with loss shape our approach/response to present-day losses
- Re-living past deaths with each new death
- Letting go, and letting go, and letting go



Boundary Issues

- Occupational realities of working with the dying: multiple roles
 - caregiver as health care provider
 - caregiver as advocate
 - caregiver as primary support person
 - caregiver as individual/couples/family therapist
 - caregiver as bereavement counselor
- Personal issues involved in becoming a caregiver (Berry, C. R., When Helping You is Hurting Me, 1988, Harper)



Symptoms of Caregiver Burnout

- Reduced productivity/impaired performance
- Lowered energy/enthusiasm/humor
- Chronic fatigue/insomnia/bodily aches & pains
- Less interest in co-workers, clients, families
- Opposition to change
- Failure to manage basic life maintenance activities
- Dislike of work environment
- Expressed dislike for recipients of services
- Increases in “going by the book”



Self-Care at Work

- Case conference/staff retreats
- Expect (and seek) positive feedback from supervisors
- Consult with a back-up expert
- Assignment of specific duties and knowing expectations
- Drawing/maintaining clear boundaries on professional obligations
- Enlisting help of volunteers
- “Time out” activities
- Varying tasks
- Building in mental health days



Self-Care at Home

- Meditation, relaxation exercises
- Therapeutic massage
- Regular exercise!!!
- Nutrition as a self-nurturing activity
- Recreation and pleasant events
- Sharing experiences/feelings with friends & family
- Professional support group
- Individual therapy



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