Thanatology Certificate Program:
Care for the Caregiver

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Portions Funded by the National Institute on Aging and the Substance Abuse and Mental Health Services Administration
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 healthcare 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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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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