Family caregiving at the end-of-life: Special issues in dementia and cancer

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Goals for today

• Review fundamental issues in family caregiving and end of life
• Describe stresses that families face in end-of-life care—similarities and differences by illness
• Describe impact of caregiving stress, both while providing care and during bereavement
• Effectiveness of psychosocial interventions for caregivers at the end-of-life
• Cultural diversity, caregiving, and end of life
Fundamentals—caregiving is increasingly common

- **52 million** informal and family caregivers provide care to someone aged 20+ who is ill or disabled
- Nearly **one out of every four households** (23% or 22.4 million households) is involved in caregiving to persons aged 50 or over
- **5 million** informal caregivers provide care for someone aged 50+ with dementia

Family Caregiver Alliance, http://www.caregiver.org
Fundamentals of caregiving

- Most family caregivers are women; spouses and daughters; “informal” (unpaid)
- AD caregiving, 60 hours per week at home; 9 hours even after NHP; 5-10 year “career”
- Hospice lung cancer caregivers, over 100 hours per week
- Differences with other conditions and disabilities (DD, stroke, SCI)
What do caregivers do?

• “Whatever it takes”
• May range from occasional assistance to full-time care
• Includes physical care, symptom management, emotional support, help with activities of daily living
• Includes support while care recipient is in a facility
• Concept of “caregiving career”
Aging, end-of-life, and family caregiving

- Four phases: before illness strikes, diagnosis and treatment, advanced illness and dying, bereavement
- End of life decision making—advance directives, hospice, withholding treatment
- End of life care has unique stressors

Can caregiving stress affect mental and physical health of the family caregiver?

- The answer is an unqualified “yes”
- Domains include depression, self-rated health, immune system functioning, blood pressure, infectious illness, and mortality
- Effects are not uniform and risk and protective factors are also important


Cancer and dementia caregiving at the end of life—What do families say?

• Cancer
• Dementia
• Common concerns

Some common themes

- Witnessing suffering
- Strain on work, family roles
- Ethical dilemmas
- Mental and physical strain
- Grief and loss

- Need for social support, help caregiving
- Family conflict
- Shared decision making
- Rewards of caregiving
Special concerns, dementia

• Loss of the person before death
• Long term caregiving “career”
• Nursing home placement
• Managing incontinence, immobility, bedsores
• Hospice eligibility
• Role engulfment
• Loss of communication
• Assessing symptoms without verbal communication
• Feelings of relief
Special concerns, cancer

- Hope for a cure
- Denial
- Communication with physicians, dying person
- Side effects of treatment
- Intensity of strain with rapid decline
- Is hospice care “giving up”?
- Pain management, sedation
- Managing constipation, loss of appetite, shortness of breath
Frailty (47%), terminal illness (22%), organ failure (16%), sudden death (7%), and with only 8% of deaths not fitting.

From National Hospice and Palliative Care Organization (NHPC), 2006. In 2004 figures, cancer is the primary diagnosis in 46% of hospice admissions.
LifePath Hospice Family Caregiver Project

- Focused on stressors and well-being of spousal caregivers of hospice patients with lung cancer, dementia; noncaregivers.
- Patients over age 50.
- Interviews and questionnaires in caregiver’s home.
- Follow-up after patient death.
- N=40 per group at baseline (total N=120).
Descriptive information and caregiving stressors

- Dementia caregivers provided 75 hours of care per week, for 49 months; cancer caregivers provided 115 hours of care per week, for 14 months.
- Dementia patients are more severely impaired in cognition, ADL and IADL, cancer patients more pain, appetite loss, constipation.
Key findings—impact on caregiver

- Both cancer and dementia caregivers have higher depression, and lower life satisfaction and self-reported health than noncaregivers.
- Individual differences in caregiver depression predicted by caregiver health, social support, family conflict, and appraisal—not severity of patient impairments or extent of caregiving.


Examples of perceived benefits reported by caregivers

• Giving back to someone who has cared for them.
• A sense of pride, accomplishment, meaning, or purpose to life.
• Enjoyment of the little moments of pleasure with a loved one.
• Feeling pleased that they can keep providing care despite being told by doctors and family members that it is impossible to continue providing care.
• Sense of personal growth, becoming a more caring and sensitive person, more empathy for others.
Bereavement follow up

• At 4-month followup, **no differences** between cancer and dementia caregivers
  – Depression unrelated to diagnosis, severity of impairment, subjective stressfulness
  – Higher depression related to shorter length of illness and hospice stay, and to poorer social support and social engagement

Caregiver satisfaction with hospice care for patient, self

• Both dementia and cancer caregivers report very high satisfaction with hospice care on a 0 (not at all) to 3 (extremely) scale.

Effectiveness of caregiver interventions

- Psychosocial interventions for caregivers improve clinically relevant domains
- Effects greatest for structured and individualized interventions
- Support groups alone not effective in decreasing caregiver depression

According to stress process models, caregiver intervention can:

- Decrease stressors (lighten the load)
- Alter appraisals (primary, how aversive the stressors are; secondary, what perceived resources people have to cope)
- Teach skills or in other ways build internal resources
- Provide or rally external resources
Stress and coping: A balancing act

- Primary caregiving stressors
- Secondary stressors
- Other chronic strains and life events

- Internal coping resources
- External coping resources

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NYU Family Caregiving Intervention Project

• “AD Caregiver Well-Being Counseling/Institutionalization” (M. Mittelman, PI)
• National Institute of Mental Health and National Institute on Aging
• Project began in 1987, some caregivers followed 17 years
• Flexible and sustained caregiver intervention administered by highly skilled and dedicated counselors
The NYU intervention

- 406 caregivers randomly assigned to usual care or an intensive caregiver intervention program at NYU
  - 2 sessions individual counseling
  - 4 family sessions
  - support group membership
  - ad hoc counseling without limit

- Described in detail in a recent book

Weeks

Depressive Symptoms

Usual Care

Treatment
Long-term impact—after bereavement

- Recent analyses from the NYU study show the treatment group has lower depression until 4 months after bereavement
- Both groups show lower depression after bereavement—relief effect
- Caregivers who receive treatment are more likely to be resilient over the career of caregiving
A Caregiver Intervention to Improve Hospice Outcomes

Principal Investigator:
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Moffitt Nursing
Aging Studies Geriatric Med.
Nursing
Aging Studies LifePath

Funded jointly by the National Cancer Institute and the National Institute for Nursing Research 1 RO1 CA77307-01A3, 1999-2004
Study Sample

- 354 patient/caregiver dyads
- Randomized into 3 groups
- *Patient inclusion*: Adults, cancer, family caregiver, literate, score of 7 correct on Pfeiffer SPMSQ, problem with 2 of the following: pain, dyspnea, constipation.
Experimental Conditions (in addition to hospice care)

I. Standard Care = no visits
II. Standard Care + supportive visits
III. Standard Care + Cope (problem solving skills to manage symptoms)

Visit 1: Between days 3 and 5
Visit 2: Between days 5 and 7
Visit 3: Between days 7 and 9
Primary outcomes

- Caregiver Quality of Life Index-Cancer
- Appraisal of Burden of Cancer symptoms—Memorial Symptom Assessment Scale (e.g. pain, diarrhea, shortness of breath) distress
- Appraisal of Burden Specific to Caregiving Tasks—Caregiving Demands Scale (e.g. providing ADL help)

Our experience

• Very high attrition (@70% at 30 days)

• Most commonly, attrition was due to patient decline (29%) or death (21%), and the caregiver feeling overwhelmed (23 %) which was largely associated with patients’ worsening condition.
Findings

• At the 30 day follow-up, the coping skills intervention led to significantly greater improvement in
  – caregiver quality of life
  – burden of caregiving tasks, and
  – burden of patient symptoms, than did the other two conditions.
Note, changes indicate increased quality of life, decreased symptom burden, and decreased caregiving task burden, in the COPE group.
Bereavement issues and caregiving

• Traditional conceptions, e.g. “grief work” necessary, delayed grief, not supported by evidence

• Concerns about the efficacy of traditional grief therapy

• How does caregiving affect bereavement?


**FIGURE 1. A working taxonomy of grief reactions.**
Resilient ($n = 94; 45.9\%$); chronic depression ($n = 16; 7.8\%$); chronic grief ($n = 32; 15.6\%$); common grief ($n = 22; 10.7\%$); depressed/improved ($n = 21; 10.2\%$).

“Reviews of studies of bereavement interventions indicate that grief counseling may not be helpful for many people experiencing normal grief and may even have negative effects (e.g., Jordan & Neimeyer, 2003; Schut, Stroebe, van den Bout, & Terheggen, 2001). Reviews indicate that interventions may be more helpful for individuals experiencing complicated grief.”

Report on Bereavement and Grief Research
November 2003
Center for the Advancement of Health
Anticipatory grief

- Unexpected deaths are more difficult to adapt to
- Long duration of caregiving provides both chronic strain, and opportunities for anticipatory grief
- But—remember variability in bereavement trajectories
End of life care and the effects of bereavement among family caregivers of persons with dementia

About the study

• Resources for Enhancing Alzheimer’s Caregivers Health (REACH), N= 1222 caregiver and care recipient dyads at six sites (Boston, Birmingham, Memphis, Miami, Philadelphia, and Palo Alto), assessed while caregiving, longitudinally

• N=217 followed after bereavement, up to 18 months after death, using last pre-death assessment as baseline

• Treatment outcome papers appeared in 2003 Special Sections of Psychology and Aging and The Gerontologist
End stage dementia caregiving and reaction to death

- 59% of caregivers reported feeling “on duty” all the time during the pre-death assessment.
- 53% of CRs rated as in pain “often” or “all the time”.
- Death rated as “very much” a relief to CR by 77%, “somewhat” by 17% (94% combined).
- Death rated as “very much” a relief to caregiver by 28%, “somewhat” by 44% (72% combined).
Note, baseline CES-D, Mean=15.8.
Improvement, but sustained distress in a substantial minority

• High initial distress and subsequent improvement
• But, at 44-60 weeks post bereavement, CES-D=11.5, and 30% above depression cut point; 21% taking antidepressants
• Baseline depression is a strong predictor of depression during bereavement
Cultural Factors: Variability in Views of Death and Dying

- advance directives
- life support
- disclosure and communication of diagnosis, prognosis, and preferences; and
- designation of primary decision makers
  - Fatalism vs acceptance vs struggle
  - Open vs closed topic
  - Death rituals
  - Grief and bereavement

“I was determined to find meaning and purpose…I knew that it was not the events that destroy us but how we choose to internalize them.”

“From my heritage, I learned very early that there are some circumstances in our lives that for a time, at least, we cannot change.”

Lela Knox Shanks
Examples of modifying interventions for diverse caregivers from REACH

- African-Americans: Workshops in church, in-home caregiver training
- Mexican-Americans: Group sessions, education, female only, including social interaction
- Cuban-Americans: In-home family therapy, telephone technology

Cultural differences in reaction to death in caregivers

- 47 White, 16 African-American caregivers interviewed about 4 months after death of care recipient with dementia
- 72% of White caregivers reported deciding to withhold treatment at EOL; only 29% of African-American
- African American caregivers less likely to report anticipatory grieving, make prior funeral plans

Reactions to AD patient death

Higher ratings of relief in Whites, higher ratings of loss in African-Americans.
Conclusions

• Important to understand commonalities and differences across illnesses
• Diverse conditions not more or less stressful, but different
• Caregiver interventions are promising for cancer and dementia
• Complexities in understanding caregiving and bereavement
• Importance of cultural diversity