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<td>B: Discussion Questions</td>
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### LEARNING OBJECTIVES / OUTCOMES

1. Discuss the relationship of caregiving to family burden.
2. Cite research findings related to caregiver quality of life.
3. Assess level of caregiver burden.
4. Define domains of caregiver stress: physical, emotional, social, and financial.
5. Delineate causes of stress for older patients.
6. Describe palliative care interventions to enhance caregivers’ quality of life.
7. Define religiosity and spirituality.
8. Delineate barriers to spiritual care at the end-of-life.
9. Identify components of a spiritual assessment.
10. Describe an interdisciplinary approach to spiritual care at the end-of-life.
**PARTICIPANT’S INTRODUCTION & OBJECTIVES / OUTCOMES**

On your own consider what YOU would like to get out of this course and why it is important to you. Write your answer in the space provided below.

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**OBJECTIVES / OUTCOMES:**

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**DEPARTMENT OF SOCIAL DEVELOPMENT: CARE & SERVICES TO OLDER PERSONS**
**CAREGIVER TRAINING MANUAL**
© 2009 VCX CIPRET
GROUP ACTIVITY: 1

**Caregiving**

Discuss the following concepts / factors:

<table>
<thead>
<tr>
<th>Item</th>
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<tr>
<td>Caregiving</td>
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<tr>
<td>The impact of a serious illness on the older person’s family and you as a caregiver.</td>
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<tr>
<td>Family involvement in the care of the older person.</td>
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<tr>
<td>Positive consequences associated with caregiving.</td>
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<tr>
<td>Adverse consequences associated with caregiving.</td>
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</table>
1. CAREGIVING

A. Definition: “Caregiving” is defined as unpaid assistance rendered to an older person by family or friends. Responsibilities can range from providing transportation, assisting with shopping, and paying bills to 24-hours-a-day hands-on care.

B. Demographics

1. Of the nearly 32.5 million older adults living in the US, approximately 7 million require some degree of assistance with personal care or instrumental tasks.

2. 71% of all long-term care is provided in the community, and 85% of all in-home care is provided by family members and friends. However, only 14% of home care is provided by paid professionals.

3. At least 3 out of 4 older persons rely solely on families and friends for support or assistance.

4. Between 2 and 3 million persons are involved in a caregiver relationship.

5. Caregivers are predominantly women (72%), including wives, daughters and daughters-in-law.

6. Many spouse caregivers are equally as frail as their spouses.

7. Approximately 25% of employed persons in the US are providing care to cognitively or physically disabled older persons.

C. Like patients with a terminal illness, family members are in transition from living with the disease to anticipating the death of their loved ones from the disease.

D. In witnessing the older person’s pain and suffering, family caregivers may experience a sense of powerlessness, and are often frightened and confused by the dramatic physical and emotional changes they perceive in their loved one as the disease progresses.

E. The SUPPORT Study (within Palliative Care): The Impact of a Serious Illness on the Older Person’s Family
### F Family Involvement in Care May Include:

- Symptom management
- Pain control
- Medical care procedures and equipment
- Evaluation and monitoring of disease and treatment
- Coordination of care
- Assistance with self care
- Assistance with cooking, cleaning and household tasks
- Patient household or family roles
- Emotional support
- Transportation
- Financial aspects of care

### G. Health care professionals are now realizing that older person caregivers are indeed “second order patients” who are in need of care and support.5

### H. Given that the “unit of care” is the older person and family, palliative care offers not only a support system to help older person live as actively as possible until death, but also help for the family to cope during the older person’s illness and in their own bereavement.6

### I. Research Related to Caregivers’ Quality of Life

1. Hinton (1994)7
   - Men and Relatives of cancer patients suffer own grief, and ill health with depression in the later stages of illness.

2. Addington-Hall et al. (1995)8
   - 81% of a national based sample of people who die are cared for by family;
   - More than half of caregivers were unable to obtain information they wanted from physicians
   - 25% wanted greater financial support and help with domestic chores.

3. Beeney et al. (1997)9
Caregivers’ experience conflict among feelings of loss, sadness, guilt, difficulty knowing how to talk with patients; pressures are placed on caregivers by health professionals to be supportive and assume the burden of care.

25% of caregivers lose their job, and 1/3 lose their major source of income or savings.

5. Mc Skimming et al. (1999), through focus groups, identified several major themes of family caregivers:
   - “It is my illness too.”
   - “I know my loved one best.”
   - “I am exhausted.”
   - “I am afraid of missing the doctor.”
   - “I appreciate his reassurance of comfort and dignity rather than focusing on prognosis.”
   - “I appreciate the doctor saying I’m sorry and hearing from him after the death.”

6. Andershed et al. (1999), through qualitative inquiry, identified the themes of caregivers:
   - To Know: Have an understanding of patient’s situation, diagnosis, prognosis, and assistance required.
   - To Be: Being physically present with patient, and an openness to a deeper level of the patient’s world.
   - To Do: Offering physical care and providing support by being the patient’s spokesperson.

J. Positive Consequences Associated with Caregiving:

1. Satisfaction in caregiver role
2. Moral development
3. Increased self-esteem
4. Sense of fulfillment of family obligations / roles

K. Adverse Consequences Associated with Caregiving:

1. Depression / Anger / Anxiety / Isolation
2. Fatigue / Hypertension / Back pain
3. Increased psychoactive medication use
4. Caregivers may be at higher risk for substance abuse, domestic violence, noncompliance with medical advice, and abuse or neglect of their impaired relative.
5. Women must often leave the workforce as a result of caregiving activities.

L. Family Caregiver Assessment

1. The organization and functioning of the family
   • Membership
   • Structure and roles; older person’s role in the family
   • Family cohesion
   • Decision making processes
2. Dynamics of the caregiving system
3. Assess family’s strengths, weaknesses, opportunities and threats
4. Families’ life-cycle stage and developmental tasks of each member
5. Ethnic, cultural, spiritual values associated with illness and caregiving
6. Family’s previous experience with illness and death
7. Family’s past and present coping skills
8. Level of distress of the family related to:
   • Age, gender, socioeconomic status
   • Availability of resources
   • Social support
   • Marital adjustment
9. Family communication patterns
   • Open, closed, direct, indirect, verbal and non-verbal messages
   • Acceptance or inhibition of expression of emotions
   • Boundaries of communication with regard to cultural expectations (who interacts with who, in what setting and in what way)
10. Understanding of the Older Person / Family Caregiver’s:
    • Knowledge of the older person’s illness
    • Own health issues and needs
    • Expectations regarding care
    • Past experiences with health professionals
    • Willingness to participate in care
    • Level of caregiver knowledge and skill
M. Assess Level of Caregiver Burden

1. Assess type of burden: What bothers or distresses them?
2. What assistance do they need?
3. What care tasks are difficult?
4. What can we do to overcome areas of burden?
5. What available resources are being used?
6. What additional resources are available?
7. Who is at risk for burden from caregiving?
8. How does this change over time?

N. Resources Available to Caregivers

1. Adult day care
2. Respite programs
3. Caregiver support groups
4. Community mental health services
5. Organizational resources
GROUP ACTIVITY: 2

Caregiving

Describe evidence that has led to the realization that family caregivers are now considered “second order patients” and are in need of care and support themselves.
GROUP ACTIVITY: 3

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<td>Physical Stress</td>
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<td>Emotional Stress</td>
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<tr>
<td>Social Stress</td>
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<tr>
<td>Financial Stress</td>
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</table>
2. STRESS

A. Caregiver’s Stress

1. Physical Stress
   - Physical activity
   - Concern for eating properly
   - Substance use
   - Use anti-depressants/hypnotics
   - Little health promotion (screening, flu shots)
   - Co-morbidity
   - Actual mortality

2. Emotional Stress
   - Psychosomatic symptoms
   - Anxiety
   - Depression or mood disturbance
   - Uncertainty – fear
   - Loss of control
   - Lack of skill/competence
   - Stress from having strangers in the home
   - Guilt regarding their own health/desire to live
   - Conflict in delegating role responsibilities
   - Family conflict regarding differences in opinions
   - Anticipatory grief

3. Social Stress
   - Social role changes
   - Isolation – time away from family, friends, and job
   - Role demands
   - Loss of privacy and personal time
   - Loss of leisure
   - Loss of social mobility
   - Work schedules and productivity compromised, often for 2-3 years
   - Strain in relationships and problems with communication within family

4. Financial Stress
   - Changes in financial status
   - Depletion of resources
   - Lack of financial planning
   - Need to use maximum benefits of insurance
GROUP ACTIVITY: 4

Causes of Stress for Older Persons

Discuss the causes of stress for older persons according to your observations and experience in working with older persons.

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14
B. Causes of Stress for Older Persons

1. A significant source of stress for an older person is the confrontation of repeated losses: loss of primary control over decision making concerning health, mobility, living situation, and finances and loss of death.

2. Retirement is a life-changing event that oftentimes causes a great deal of stress. Although many older adults look forward to it, many others fear its approach and are unprepared. Furthermore, sometimes the reality of retirement does not live up to one’s expectations.

3. Stress from acute and chronic illness

4. Effects of Stress
   a) Stress can result in impaired decision-making, altered problem-solving abilities, hypervigilance and paranoia, as well as decreased perceptual and motor skills.
   b) The adverse effects of stress are lower for those who have strong social support systems.
3. PALLIATIVE CARE INTERVENTIONS TO ENHANCE CAREGIVER’S QUALITY OF LIFE

A. As a professional, understand your own feelings so that you are able to discuss the inevitability of death and its implications.
B. Be aware that each person in the family will process the experience of a dying family member differently. Therefore, provide opportunities for discussion.
C. As family members search for meaning, validate their feelings by serving as a sounding board.
D. Help families explore their options.
E. Identify their limits of tolerance.
F. Affirm that life will go on and the ability of the family to manage and grow from the experience.
G. Provide honest, open communication with straightforward information about the patient’s condition.
H. Avoid false reassurances, false sympathy, and overzealous attempts to show empathy.
I. Discuss the implications of advanced directives and DNR orders.
J. Do not pass judgments on family decisions and behaviors.
K. Assure families that their loved one is comfortable and care for
L. Assure that patients and families will not be abandoned.
M. Provide active presence.
N. Provide private time for patients and families.
O. Encourage life review and the completion of unfinished business.
P. Teach families about the end-of-life processes, including the physical, emotional, and spiritual signs of impending death.
Q. Understand the family members’ response to loss may be denial, anger, helplessness or guilt.
R. Provide for the physical needs of the family.
S. Address the financial implications of the patient’s death.
T. Offer spiritual care to the family.
U. Support family’s presence at the time of death with proximity or access to their loved one (flexible visiting hours).
V. Acknowledge the death; i.e. send sympathy cards.
W. Five relationship completion tasks at the end-of-life. Saying
   - forgive me
   - I forgive you
   - I love you
   - thank you
   - goodbye
4. RELIGION AND SPIRITUALITY

A. Definitions

1. Religion: refers to beliefs, practices and traditions associated with religious groups (e.g. Catholic, Protestant, Jewish, Buddhist)

2. Spirituality: refers to the personal search for meaning and purpose in life (relationship to self, others, nature, world, God)

B. Spirituality as Part of the Health Assessment

• Provides meaning in illness
• Means of coping
• Rituals, social support
• Dynamic Interaction of All Dimensions of Quality of Life

a) Physical
  • Functional ability
  • Strength/fatigue
  • Sleep and rest
  • Nausea
  • Appetite
  • Constipation
  • Pain

b) Psychological
  • Anxiety
  • Depression
  • Enjoyment/leisure
  • Pain Distress
  • Happiness
  • Fear
  • Cognition/attention

c) Social
  • Financial burden
  • Caregiver burden
  • Roles and relationships
C. Barriers to Spiritual Care

1. Spirituality confused with religiosity
2. Lack of training
3. Poor understanding about what the spiritual dimension comprises
4. No prior self-assessment
5. Discomfort with the dimension

D. Correlation Between Faith and Health

1. Recent studies have linked religious beliefs and practices to better mental and physical health, including less depression, better coping with illnesses, less functional disability, and lower risk of death after cardiac surgery.
2. 82% of adults believe in the healing power of prayer.
3. 56-79% believe spiritual faith did or can help one recover from illness, injury or disease.
4. 63% believe doctors should talk with their patients about spirituality.
5. 75% of elderly inpatients rate religious beliefs as a very important means of effectively coping with their illness.
6. Spirituality and/or religious commitment are associated with medical benefits including relief from physical, mental and addictive disorders, enhanced quality of life, and survival.

E. Health Professionals’ Spiritual Self-Assessment

1. Personal beliefs
2. Sources of meaning/hope
3. Values
4. Religious affiliation
5. Belief in the divine; transcendence
6. Relationships: to others, God, nature
7. Cultural assessment
F. Spiritual Assessment of Others

1. General Points
   - Religious affiliation alone as not sufficient
   - No right way, no right time
   - Reassessment with changing conditions/circumstances
   - Trusting relationship
   - Basic knowledge of major religions, and cultural practices of populations
   - Served
   - Always perform an individualized assessment
   - Never stereotype or generalize

2. Learn How to Ask:
   - Open-ended questions
   - Assess positive and negative aspects
   - Be non-judgmental to not impose your own beliefs

3. When to Ask:
   - History (any discipline)
   - After assessing religious affiliation
   - Talking cues from patient’s personal items
   - Verbal cues
     - Questions: “why…”, “I wish…”
     - Clues about spiritual nature
   - Non-verbal cues
     - Affect
     - Moaning/crying

4. What to Ask
   - Spiritual/religious affiliation
   - Definition of personal spirituality
   - Subjective/objective indicators
   - How a person finds meaning/joy in life
   - If spirituality been a source of comfort; helped/not helped to cope with difficulties in the past
   - Fears, spiritual distress
   - What are preferred spiritual interventions
   - Who should address/participate in spiritual interventions
   - Definitions of hope
G. Assessment of Spiritual Distress

1. Reasons for Spiritual Distress
   - Disruption in usual religious activity
   - Personal and family disasters
   - Loss of significant other
   - Behaviors contrary to society/cultural norms

2. Characteristics of Spiritual Distress
   - Feeling separated or alienated from the deity
   - Dissatisfaction with personal past or present
   - Depression
   - Crying
   - Self-destructive behavior or threats
   - Fear
   - Feelings of abandonment
   - Feelings of hopelessness

H. Tools: Spiritual Scale. (See attached.)

I. Spirituality and Religion within Palliative Care

1. Given the opportunity, many patients may choose to talk to a pastor, priest, rabbi, or other spiritual advisor with whom they have an existing relationship.
2. Older Persons who lack a formal religious affiliation, have lost faith, are alienated from their religion, or are atheist or agnostic may prefer to discuss spiritual and existential issues with their health care providers.
3. Screening for unaddressed spiritual and existential concerns is often useful for older persons and providers comfortable with more in depth discussions. Some helpful questions may include:
   - “What do you still want to accomplish during your life?”
   - “What thoughts have you had about why you got this illness at this time?”
   - “What might be left undone if you were to die today?”
   - “What’s your understanding about what happens to you after you die?”
   - “Given that your time is limited, what legacy do you want to leave your family?”
   - “What do you want your children and grandchildren to remember about you?”
J. Interdisciplinary Approach/Resources
1. All team members are responsible for holistic care.
2. Referral to chaplain, massage therapist, art therapist, music therapist.
3. Use of individual’s personal clergy, faith community, identified supports.

K. Spiritual Care
1. Assessment
2. Therapeutic use of self
   - Listening
   - Presence
   - Non-abandonment
3. Creating the proper environment
4. Referral to Clergy or Spiritual Advisor

L. Documentation of Spiritual Well-Being

   1. Where
      - Interdisciplinary progress notes
      - Spiritual assessment form if available
      - Other
   2. What
      - Respect privacy/confidentiality
      - Nursing dx
      - Pertinent findings
      - Changes
      - Referrals

M. Even if providers do not discuss the issues in depth with the patient, they can validate the importance of such topics and encourage the patient to continue to explore them. They can also help arrange contact with an appropriate religious or spiritual advisor.
V. SUGGESTED READINGS


Reading Assignments - Please read these articles prior to reviewing this module.


2. “Spirituality and Health” by Victor Sierpina, MD and Michelle Sierpina, MS
VI. REFERENCES


### Appendix: A

**Spiritual Scale**


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<tr>
<th></th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Neutral</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
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<tr>
<td>1.</td>
<td>In the future, science will be able to explain everything</td>
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<td>2</td>
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<td>4</td>
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<td>2.</td>
<td>I can find meaning in times of hardship</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
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<td>3.</td>
<td>A person can be fulfilled without pursuing an active spiritual life.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
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<td>4.</td>
<td>I am thankful for all that has happened to me.</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
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<td>5.</td>
<td>Spiritual activities have not helped me become closer to other people.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
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<td>6.</td>
<td>Some experiences can be understood through one’s spiritual beliefs</td>
<td>5</td>
<td>4</td>
<td>3</td>
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<td>7.</td>
<td>A spiritual force influences the events in my life.</td>
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<td>4</td>
<td>3</td>
<td>2</td>
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<td>8.</td>
<td>My life has a purpose.</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
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<td>9.</td>
<td>Prayers do not really change what happens.</td>
<td>1</td>
<td>2</td>
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<td>4</td>
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<td>10.</td>
<td>Participating in spiritual activities helps me forgive other people.</td>
<td>5</td>
<td>4</td>
<td>3</td>
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<td>11.</td>
<td>My spiritual beliefs continue to evolve.</td>
<td>5</td>
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<td>12.</td>
<td>I believe there is a power greater than myself.</td>
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<td>2</td>
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<td>Statement</td>
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<td>13. I probably will not reexamine my spiritual beliefs.</td>
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<td>14. My spiritual life fulfills me in ways that material possessions do not.</td>
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<td>15. Spiritual activities have not helped me develop my identity.</td>
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<td>16. Meditation does not help me feel more in touch with my inner spirit.</td>
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<td>17. I have a personal relationship with a power greater than myself.</td>
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<td>18. I have felt pressure to accept spiritual beliefs that I do not agree with.</td>
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<td>19. Spiritual activities help me draw closer to a power greater than myself.</td>
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<td>20. When I wrong someone, I make an effort to apologize.</td>
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<td>21. When I am ashamed of something I have done, I tell someone about it.</td>
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<td>22. I solve my problems without using spiritual resources.</td>
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<td>23. I examine my actions to see if they reflect my values.</td>
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24. During the last week I prayed (check one)

- 10 or more times
- 7 - 9 times
- 4 - 6 times
- 1 - 3 times
- 0 times
25. During the last week I meditated (check one)

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<td>7 - 9 times</td>
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<td>1 - 3 times</td>
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<td>0 times</td>
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26. Last month I participated in spiritual activities with at least one other person (check one)

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DISCUSSION QUESTIONS: PLEASE PROVIDE ANSWERS TO THE FOLLOWING QUESTIONS AND RETURN IT TO:

Activity 5

Provide methods that you have utilized in your practice to “treat” caregiver stress.
(1 page).

Activity 6

It is well accepted that “spirituality” provides a certain level of comfort and reassurance when a person is faced with a difficult situation, such as being a caregiver to an ill loved one. Thinking of the definition of spirituality, discuss briefly and in your own words, what spirituality means to you and why it is important to providing care to older adults. (1-2 pages).