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End of Life Occupations

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Objectives

• Discuss philosophy of hospice and palliative care

• Describe goal of intervention at end of life

• Describe various intervention approaches for end of life using case example
Chronic Illness

- 100 million persons in the US have at least 1 chronic illness
- 50 Million have more than 1
- 88% over age 65 have at least 1 chronic illness
- 22% over age 65 have 4 chronic illnesses
Chronic illness

- Aging population
  - 2030 - persons older than 65 years are rising
  - We are living longer…
    - living longer with chronic illness and advanced technologies that prolong life[13]

Palliative & Hospice

- Targets people with chronic conditions
  - Multiple chronic conditions
  - Functional impairments
  - Dual eligibility for Medicare and Medicaid
  - Patients using hospital services
  - Patients in last year of life
Palliative Care

- Focuses on improving life and providing comfort to people of all ages with serious, chronic, and life-threatening illnesses.

- Prevents or treats symptoms and side effects of disease and treatments

- These diseases may include cancer, congestive heart failure, kidney failure, chronic obstructive pulmonary disease, AIDS, and Alzheimer's, among others.

- Interprofessional approach – doctor, nurses, therapists, social workers, chaplains


“an approach that improves quality of life for patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of problems, including physical, psychosocial, and spiritual”

(WHO, 2011).
Hospice

“Reaffirmation of living with dignity and hope”
(Doyle, 1998)

What is Hospice

- Hospice is a special concept of care designed to provide comfort and support to patients and their families when a life-limiting illness no longer responds to cure-oriented treatments.
- Hospice care neither prolongs life nor hastens death. Hospice staff and volunteers offer a specialized knowledge of medical care, including pain management.
- The goal of hospice care is to improve the quality of a patient’s last days by offering comfort and dignity.
- Hospice care is provided by a team-oriented group of specially trained professionals, volunteers and family members.
- Hospice addresses all symptoms of a disease, with a special emphasis on controlling a patient’s pain and discomfort.
- Hospice deals with the emotional, social and spiritual impact of the disease on the patient and the patient’s family and friends.
- Hospice offers a variety of bereavement and counseling services to families before and after a patient’s death.

“Despite having the highest per capita spending on healthcare in the world, multiple studies have demonstrated that seriously ill patients and their families receive poor-quality medical care characterized by unrelieved symptoms, unmet psychosocial needs, and increased family caregiver and financial burden.”

(2,8,9,13,15)
Health care Reform

Health care reform: Implications for Palliative & Hospice Care

- Palliative and hospice care
  - Established trends of reducing overall healthcare costs
  - Improves quality of life of patient and family

“DO NOT COUNT THE DAYS; MAKE THE DAYS COUNT.”

— MUHAMMAD ALI, BOXER
ACA offers opportunities for palliative care and hospice programs to participate in the planning, development, and implementation of new delivery and payment models such as accountable care organizations (ACOs), patient-centered medical homes, and the bundling of payments for a single episode of healthcare.[2]

These models aim to improve the quality of care and control the costs for high-need, high-risk patient populations by focusing efforts on the very approaches to care and quality outcomes that palliative and hospice care has long demonstrated.

Payments may shift to a focus based more on quality of care.[2,5,17,18]
“Occupations provide a means of self-expression and engagement granting meaning and purpose to the person and family as they prepare for death and the transition on.”
- Heather Javaherian-Dysinger, 2012
“Doing the things that matter: Continuing life”

“Getting everything in order: Preparation for death”

“It takes so long to die: Waiting”

“A gentle goodbye: Death and after-death”

Occupation & Identity

It is through doing that we are, that we become.
(Wilcock)

Occupation (Christiansen, 1999; Hasselkus, 1996; Hunter, 2008; Yerxa, 1994)

– Provides purpose
– Organizes time and space
– Organizes world we live in
– Expresses identity

Participation
Perspective of Death

• What is the person’s perception or beliefs of death?

• What is the family’s perception or beliefs of death?
  - Natural event in lifespan
  - Celebration – Spiritually at peace
  - Fear
  - Other

“Happiness is the meaning and the purpose of life, the whole aim and end of human existence.”

-Aristotle

THE TRUTH IS, ONCE YOU LEARN HOW TO DIE, YOU LEARN HOW TO LIVE.

MITCH ALBOM
TUESDAYS WITH MORRIE
End of Life (Bye, Llewellyn, & Christl, 2008)

- Dying old is expected norm
- Losses along life’s path
- Spiritual questioning natural part of aging process as one gets closer to end of life
- Fear of death decreases from mid-life to old age (Neimeyer, 2004)
- Elders still fear loss of control leading up to death—process of dying
End of Life (Bye, Llewellyn, & Christl, 2008)

- Terminal illness, even in elderly can be traumatic
- Working with people at end of life is an honor and a challenge
- Need for coping
- Conflict with rehabilitative paradigm
- Quality of life

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End of Life (Bye et al, 2008)

- Good death: Process or style of dying
  - Awareness of dying
  - Social adjustments and personal preparations
  - Public preparation
  - Making farewells
Integrity or Despair?

• Feelings of peace with life vs feelings or turmoil, regret

• Contributing factors for patients and caregivers:
  – Loss of ROM
  – Fatigue
  – Inability to maintain life roles (87%)

(Kealey & McIntyre, 2004)

Occupations

• Participation in meaningful occupations provides a sense of control and balance as one reconciles with end of life

• Kealy & McIntyre (2004)
  – Going outdoors
  – Taking a bath
  – Visiting friends
  – Engaging in leisure activities
“Rehabilitation in Reverse” 
(Briggs, 1999)

TABLE 25-1 Reframing the Process of Occupational Therapy

<table>
<thead>
<tr>
<th>Stage</th>
<th>Key Issues in Palliative Care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Referral</td>
<td>Respond quickly because clients' condition can change rapidly. Actively market therapy role to educate clients, caregivers, and the staff of available options.</td>
</tr>
<tr>
<td>Assessment</td>
<td>Use low-key approach—gentle, informal assessments that are not confronting or invasive to clients. Collect information from clients, caregivers, and other staff. Understand that assessment can be an emotional experience because it reveals the extent of their problems and their loss of independence.</td>
</tr>
<tr>
<td>Goal Setting</td>
<td>Use empathy and listening skills to put clients at ease and build rapport and trust. Goals should be client- and family-centered. Help clients identify goals by providing them with options and possibilities. This will facilitate choice of desired goals. Keep goals short term to ensure that clients feel a sense of success, because they may have limited time in which to achieve them.</td>
</tr>
<tr>
<td>Intervention</td>
<td>Select and implement appropriate techniques related to client needs and goals. Modify techniques as necessary for a palliative approach; e.g., consider pain and fatigue levels during therapy, use temporary means of modification rather than permanent methods, emphasize client control and quality of life rather than full functional independence.</td>
</tr>
<tr>
<td>Outcomes</td>
<td>Measure success of therapy by the achievement of client goals. Don't focus on permanency of outcomes because advancing illness and fluctuating client health are the reality. Evaluate whether therapy made a difference to the quality of clients' and caregivers' lives leading up to death.</td>
</tr>
</tbody>
</table>

Bonder & Dal Bello-Haas, 2009
Quality of Life at the End of Life

Improved quality of life is a primary outcome of all occupational therapy interventions (AOTA, 2005). Occupational therapy practitioners believe that engaging in occupations underlies health and quality of life. At the end of life when clients often face loss of previously-established occupational roles, occupations, and performance abilities, their need to identify and sustain meaningful engagement is heightened. Family members and professionals alike may find it difficult to comprehend the diminution of life quality when illness interferes with abilities to carry out familiar occupations. The pleasure and sense of self-worth inherent in participating in familiar occupations, even those as basic as making a cup of coffee at the time one wants to have a cup of coffee, is immeasurable. The value lies not so much in the cup of coffee, which can be provided by someone else, but in having control over choosing when to have the coffee and perhaps making the coffee oneself.

Numerous researchers have examined how persons at the end of life view their quality of life and quality of care. Many of these research studies have identified factors that affect quality of life and quality of care that are similar to the factors that occupational therapy practitioners address during their interventions (see Table 1).

Table 1. Factors Influencing Quality of Life and Quality of Care at the End of Life

<table>
<thead>
<tr>
<th>Factor</th>
<th>Relationship to Occupational Therapy</th>
<th>References</th>
</tr>
</thead>
<tbody>
<tr>
<td>Maintaining functioning and involvement in desired life activities contributes to quality of life.</td>
<td>Occupational therapy practitioners believe that continuing to engage in occupations allows a person to continue to be healthy and quality of life. Modifying previous occupations so that they can still be performed and adding new occupations to replace lost ones prevents isolation, a common experience at the end of life, and</td>
<td>Arnold, Arum, Griffith, Person, &amp; Graham, 2006; Egan &amp; DeLaat, 1997; Gower, McVey, &amp; Paudie, 2009; Jacques &amp; Hasselkus, 2004; Lynes, Orsorio, Davis, &amp; Newman, 2002; Ryan, 2003</td>
</tr>
</tbody>
</table>

Continued: The Role of Occupational Therapy in End-of-Life Care

<table>
<thead>
<tr>
<th>The Role of Occupational Therapy in End-of-Life Care</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Continuing to participate in activities that are meaningful and purposeful contributes to quality of life:</strong></td>
</tr>
<tr>
<td><strong>Continuing to contribute to others and strengthen important relationships contributes to quality of life:</strong></td>
</tr>
<tr>
<td><strong>Continuing to search for meaning and purpose in life and one’s relationship to a higher being also is referred to as spirituality:</strong></td>
</tr>
</tbody>
</table>
Role of the Occupational Therapist

• Participation in occupations
  – Assessing and modifying leisure interests
  – Self-care
  – Meals
  – Family rituals and routines
    • Holidays and celebrations

• Family education
  – Transfers, mobility, routines, emotional support
  – Options for services

• Positioning & Skin Protection

The Role of Occupational Therapy

• Adaptive Equipment & Mobility

• Emotional & Spiritual support

• Relationships & Sexuality

• Home modifications and design for end of life experience

• Legacy building
Role of the Occupational Therapist

- Emotional & spiritual support
  - A deep experience of meaning
    (Urbanowski & Vargo, 1994)
  - Experiencing meaning is a source of motivation for living life
    (Frankl, 1959)
  - Yet, experiencing meaning can also give one strength to accept death, and grow in one’s spiritual journey.

<table>
<thead>
<tr>
<th>Patient Unmet Activity of Daily Living Needs</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>TABLE 1: Unmet activities of daily living needs identified by patients and caregivers using Screening Tool — Activities of</strong></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Activity</th>
<th>Patient (n = 30)</th>
<th>Caregiver (n = 30)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Resolved or no</td>
<td>Unmet need</td>
</tr>
<tr>
<td>Washing self</td>
<td>27</td>
<td>3 (10%)</td>
</tr>
<tr>
<td>Dressing self</td>
<td>27</td>
<td>3 (10%)</td>
</tr>
<tr>
<td>Showering self</td>
<td>21</td>
<td>9 (30%)</td>
</tr>
<tr>
<td>Cooking</td>
<td>20</td>
<td>6 (20%)</td>
</tr>
<tr>
<td>Eating</td>
<td>29</td>
<td>1 (3%)</td>
</tr>
<tr>
<td>Walking</td>
<td>23</td>
<td>7 (22%)</td>
</tr>
<tr>
<td>Stairs</td>
<td>16</td>
<td>12 (40%)</td>
</tr>
<tr>
<td>Transfers</td>
<td>20</td>
<td>10 (33%)</td>
</tr>
<tr>
<td>Work</td>
<td>10</td>
<td>2 (7%)</td>
</tr>
<tr>
<td>Writing</td>
<td>29</td>
<td>1 (3%)</td>
</tr>
<tr>
<td>Transport</td>
<td>16</td>
<td>5 (17%)</td>
</tr>
<tr>
<td>Leisure</td>
<td>21</td>
<td>7 (22%)</td>
</tr>
<tr>
<td>Other areas</td>
<td>21</td>
<td>9 (30%)</td>
</tr>
</tbody>
</table>

Bold figures indicate the most frequently encountered responses.

Can we bill for OT at end of life?
If you don’t take the chance to live life, what can you say at the end of it?
-Naveen Andrews
Building a Legacy

Adapting Occupations for End of Life
Appendix:

Items for Measuring the Quality of Dying and Death (QODD)

Each item was asked with the following leader: “How would you rate this aspect of (patient’s name) dying experience?” The response scale was from 0 to 10 where 0 was a “terrible experience” and 10 an “almost perfect experience”.

1. Feeling pain under control
2. Having control of pain
3. Being able to feed oneself
4. Having control of bladder, bowels
5. Being able to breathe comfortably
6. Having energy to do things one wants to do
7. Spend time with your children as much as you want, (or I have no children)
8. Spend time with your friends and other family as much as you want
9. Spend time alone
10. Be touched and hugged by loved ones
11. See goodby to your loved ones
12. Have the means to end your life if you need to
13. Discuss your wishes for end-of-life care with your doctor and others
14. Feel at peace with dying
15. Avoid stress about pain in your loved ones
16. Be unafraid of dying
17. Find meaning and purpose in your life
18. Die with dignity and respect
19. Laugh and smile
20. Avoid being in distress or mechanical ventilation
21. Location of death (home, hospital, hospice)
22. Die with loved ones present
23. Stay at moment of death (alone, asleep)
24. Have a visit from a religious or spiritual advisor
25. Have a spiritual service or ceremony
26. Have health care costs paid
27. Have funeral arrangements in order
28. Spend time with spouse, partner (or I have no spouse/partner)
29. Spend time with pets (or I have no pets)
30. Clear up past feelings (or there were no bad feelings to clear up)
31. Arrive at important events (or there were no important events to attend)

CASE STUDY EXAMPLES

(AOTA, 2011)
AOTA, 2011

Kumi, a 50-year-old woman from Japan, had difficulty expressing her desires even with the support of an interpreter. She appeared depressed and usually stayed in her room sleeping with the lights off rather than visiting with her daughters when they arrived at the facility.

Fatima wanted to maintain her role as a mother despite being diagnosed with terminal cancer. Because Fatima had two small children, a referral was made to occupational therapy to identify strategies for her to participate in caring for her children and engaging in other occupations related to being a mother.

continued
A different kind of Hope
A gift to her family
References