This handout is for reference only. It may not include content identical to the powerpoint. Any links included in the handout are current at the time of the live webinar, but are subject to change and may not be current at a later date.
Objectives

• Discuss philosophy of hospice and palliative care

• Describe goal of intervention at end of life

• Identify 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

Palliative Care

“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: Implications for Palliative & Hospice Care

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

• 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]
END OF LIFE AND OCCUPATION
“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”

Just of Life Occupations

As occupational therapists, we can help people engage in their end-of-life occupations.

Personal Audit awareness: Pretend that you have been told by your doctor that you have only six months to live. You have 30 WEDDING TO DO. Complete the following tasks in order:

Step 1: Make a list of ten things you would want to do in the time you have remaining.

<table>
<thead>
<tr>
<th>30 Things to Do</th>
<th>30 Things to Do</th>
<th>30 Things to Do</th>
<th>30 Things to Do</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Step 2: Rank these as if you had 6 months to live.

<table>
<thead>
<tr>
<th>30 Things to Do</th>
<th>30 Things to Do</th>
<th>30 Things to Do</th>
<th>30 Things to Do</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Step 3: Rank these as if you had 4 weeks or less to live.

<table>
<thead>
<tr>
<th>30 Things to Do</th>
<th>30 Things to Do</th>
<th>30 Things to Do</th>
<th>30 Things to Do</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Step 3: Rank the items in order of importance. Assign the number 1 to the most important, 2 to the next most important, and so on, until all items are ranked. Do this first with the perspective of 6 months to live, then reflect on the perspective below.

Step 4: Compare lists and refines with Darmones. What types of occupations did you identify? What interests were involved in these things with you? How priorities and differences in topics as well as priorities.

Step 4: How prepared is the time to reduce to six weeks. Look at your list and rank it again given your closer time frame. What changes if any did you make? Why? Do you see a trend as to what is most important to you at the end of your life?

Step 5: Reflection...

- What were your feelings and emotions?
- What barriers might prevent me from changing?
- What are some of the benefits of participating in this kind of activity?
- What are some of the barriers to participating in this kind of activity?
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?
  o Natural event in lifespan
  o Celebration – Spiritually at peace
  o Fear
  o Other
“Happiness is the meaning and the purpose of life, the whole aim and end of human existence.”

-Aristotle
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
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.</td>
</tr>
<tr>
<td></td>
<td>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.</td>
</tr>
<tr>
<td></td>
<td>Collect information from clients, caregivers, and other staff.</td>
</tr>
<tr>
<td></td>
<td>Understand that assessment can be an emotional experience because it reveals to clients the extent of their problems and their loss of independence.</td>
</tr>
<tr>
<td></td>
<td>Use empathy and listening skills to put clients at ease and build rapport and trust.</td>
</tr>
<tr>
<td>Goal Setting</td>
<td>Goals should be client- and family-centered.</td>
</tr>
<tr>
<td></td>
<td>Help clients identify goals by providing them with options and possibilities. This will facilitate choice of desired goals.</td>
</tr>
<tr>
<td></td>
<td>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.</td>
</tr>
<tr>
<td></td>
<td>Modify techniques as necessary for a palliative approach, e.g., consider pain and fatigue levels during therapy, use temporary home modifications 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.</td>
</tr>
<tr>
<td></td>
<td>Don’t focus on permanency of outcomes because advancing illness and fluctuating client health are the reality.</td>
</tr>
<tr>
<td></td>
<td>Examine 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 so 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 when desired.

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).

<p>| Table 1. Factors Influencing Quality of Life and Quality of Care at the End of Life |
|-----------------------------------------------|-----------------------------------------------|</p>
<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 his or her life—and in central to health 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, A., Arata, G., Person, &amp; Graham, 2006; Egans &amp; DeLanty, 1997; Goode, J., McVey, S., &amp; Pauley, 2009; Jacques &amp; Haselkorn, 2004; Lyons, Oroncora, Davis, &amp; Newman, 2002; Ryan, 2005</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**

<table>
<thead>
<tr>
<th>Role</th>
<th>Contributes to the containment of self-worth</th>
<th>Source(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Maintaining a sense of control contributes to quality of life.</td>
<td>By participating in daily life occupations that they value as purposeful and meaningful, individuals make choices that give them a sense of control, identity, and competence.</td>
<td>Christiansen, 1999; Egan &amp; DeLauter, 2003; Singer, Martin, &amp; Kohler, 1999; Vickers &amp; Miller-Plage, 2001</td>
</tr>
<tr>
<td>Continuing to contribute to others and staying connected to important relationships contributes to quality of life.</td>
<td>Engaging individuals in tasks and activities is a central focus of the occupational therapy intervention process. Completing tasks such as writing letters to grandchildren or recording favorite recipes within an individual’s social context allows a person to feel productive and to strengthen social relationships.</td>
<td>Enos, 2003; Gomard et al., 2009; Hunter, 2008; Lyons et al., 2002; Singer et al., 1999; Stachanore et al., 2000</td>
</tr>
<tr>
<td>Continuing to search for meaning and purpose in life and one’s relationship to a higher being also is referred to as spirituality.</td>
<td>Occupational therapy practitioners recognize spirituality as an important client factor. They believe that the process of engaging in occupations helps the person connect to the meaning and purpose in life, which enhances spiritual well-being, quality of life, and ability to cope. Engaging in occupations can counteract feelings of hopelessness, helplessness, and uselessness that may develop during the end of life. Occupational therapy practitioners help individuals identify meaningful occupations in which they want to engage and teach coping strategies that allow continued participation.</td>
<td>AOTA, 2008; Chochinov &amp; Cass, 2003; Egan &amp; DeLauter, 1997; Lin &amp; Booze Wu, 2003; Panz &amp; Briggs, 2004; Prince- Paul, 2008; Unruh, Smith, &amp; Scannell, 2009</td>
</tr>
</tbody>
</table>
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.
PATIENT UNMET ACTIVITY OF DAILY LIVING NEEDS

TABLE 1: Unmet activities of daily living needs identified by patients and caregivers using Screening Tool — Activities of

<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</td>
</tr>
<tr>
<td></td>
<td>need identified</td>
<td>need</td>
</tr>
<tr>
<td>Washing self</td>
<td>27</td>
<td>3 (10%) 0</td>
</tr>
<tr>
<td>Dressing self</td>
<td>27</td>
<td>3 (10%) 0</td>
</tr>
<tr>
<td>Showering self</td>
<td>21</td>
<td>9 (30%) 0</td>
</tr>
<tr>
<td>Cooking</td>
<td>20</td>
<td>6 (20%) 4</td>
</tr>
<tr>
<td>Eating</td>
<td>29</td>
<td>1 (3%) 0</td>
</tr>
<tr>
<td>Walking</td>
<td>23</td>
<td>7 (22%) 0</td>
</tr>
<tr>
<td>Stairs</td>
<td>16</td>
<td>12 (40%) 2</td>
</tr>
<tr>
<td>Transfers</td>
<td>20</td>
<td>10 (33%) 0</td>
</tr>
<tr>
<td>Work</td>
<td>10</td>
<td>2 (7%) 18</td>
</tr>
<tr>
<td>Writing</td>
<td>29</td>
<td>1 (3%) 0</td>
</tr>
<tr>
<td>Transport</td>
<td>16</td>
<td>5 (17%) 9</td>
</tr>
<tr>
<td>Leisure</td>
<td>21</td>
<td>7 (22%) 2</td>
</tr>
<tr>
<td>Other areas</td>
<td>21</td>
<td>9 (30%) 0</td>
</tr>
</tbody>
</table>

Bold figures indicate the most frequently encountered responses.


(10/8/2015)
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. Having pain under control.
2. Having control of events.
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. Say goodbye 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 worry about being on your loved ones.
16. Be satisfied dying.
17. Find meaning and purpose in your life.
18. Die with dignity and respect.
19. Laugh and smile.
20. Avoid being on drips or mechanical ventilation.
21. Location of death (home, hospice, hospital).
22. Die with/without loved ones present.
23. Bear as moment of death (awake, asleep).
24. Have a visit from a religious or spiritual advisor.
25. Have a spiritual service or ceremony.
26. Have health care costs provided.
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 bad feelings. (or there were no bad feelings to clear up)
31. Attend important events. (or there were no important events to attend)
CASE STUDY EXAMPLES
(AOTA, 2011)

Anoka, a 60-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.

A different kind of Hope
A gift to her family
References


