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Learning Objectives

- After this course, participants will be able to...

- Explain underlying issues that can arise in caregiving and be able to apply the information shared to solve problems in their day to day practice.

- Give better informed answers to family and medical staff that can improve the care and quality of life for those receiving their care.

- Describe potential solutions to common problems that arise and that can generate care management for the person receiving care.
Introduction

- This webinar will review of the professional literature on caregiving (theory, types, roles, responsibilities, adjusting to change over time, outcomes).

- The presenter will offer insights into current practices in professional and personal caregiving; plus offer reflections on value and access to resources.

Review of the literature

Many articles are qualitative or mixed method in nature.

Themes:
- Auto-ethnography: sharing one’s own lived experience
- Social participation/providing care/personal meaning
- Role reversal/objectivity/loss of insight because of emotional connection
- Coping with decline
- Caregiver being able to address end of life issues
Review of the literature

- Continuum of caregiving
  - from low to high intensity.
- Drawing Boundaries
  - Intimacy and caregiver comfort with boundaries
- Altruism and Love
  - Are there times when professional should intervene for either the patient or the caregiver?
- Anger and Bad Faith
  - Disillusionment with the way care is provided

Review of the literature
How does this fit with Occupational Therapy?

The Occupational Therapy Practice Framework: Domain and Process (AOTA, 2014) categorizes

SOCIAL PARTICIPATION—“The interweaving of occupations to support desired engagement in community and family activities as well as those involving peers and friends” (Gillen & Boyt Schell, 2014, p. 607); involvement in a subset of activities that involve social situations with others (Bedell, 2012) and that support social interdependence (Magasi & Hammel, 2004). Social participation can occur in person or through remote technologies such as telephone calls, computer interaction, and video conferencing.
Definitions of ‘caregiver’

- A *caregiver* or carer is an unpaid or paid person who helps another individual with an impairment with his or her activities of daily living. Any person with a health impairment might use caregiving services to address their difficulties.  

Caregivers: Family members

- Adult children for elderly parents
- Spouse
- Parent for child or young adult
- Siblings
- Non-related/ pseudo-family members
Caregivers: paid

- Companions
- Home health workers
- CNAs
- Private duty nurses
- Personnel in adult day care programs
- Assisted living personnel
- Employees of a skilled facility
- Hospital employees
- Hospice workers (paid and unpaid)

Paid professionals

- Physicians
- Nurses
- Therapists (OT, PT, Speech, Recreational, Dance/movement, Art or Music)
- Psychologists
- Physician’s Assistant
Spiritual support

- Minister/Priest/Rabbi/Iman
- Chaplains
- Lay ministry
- A peer who shares beliefs

Non-direct interested parties

May be advocates/but don't participate in direct care
Non-caregivers
- Politicians
  - Need The Health Insurance Portability and Accountability Act of 1996 (HIPPA) releases to participate in solving problems
Ethics: Life altering versus life ending decision making

- Assisted oral feeding and tube feeding
- Challenging behaviors
- Driving and dementia
- Electronic medical records
- Electronic tracking
- End of life care
- Genetic testing
- Placebo control
- Protection of participants in research
- Right to treatment
- Telling the truth in diagnosis
- Therapeutic medication goals (Alzheimer’s disease, cancer, etc.)


Advance directives: Life and death decision-making

- The term “advance directives” refers to treatment preferences and the designation of another person to make decisions in the event that a person should become unable to make medical decisions on her or his own behalf.
- Living will
  - Written document
  - General or specific
  - Specifies life sustaining measure use upon incapacitation
- Durable Power of Attorney (DPOA)
  - Allows an individual to make bank transactions, sign social security checks, apply for disability, or simply write checks to pay the utility bill
  - Allows the DPOA to assign others to act on a person’s behalf for specific affairs.
- Health-care proxy
  - Designates another person to make health-care decisions
  - Assumes that discussions have occurred between the person and the proxy to outline specific wishes under given circumstances.

http://www.medicinenet.com/advance_medical_directives/article.htm
Right to self determination

- Mental capacity to decide for oneself
- four specific abilities should be assessed:
  - the ability to understand information about treatment
  - the ability to appreciate how that information applies to their situation
  - the ability to reason with that information
  - the ability to make a choice and express it.

Assessed by directed clinical interview
- history from therapists or other caregivers
- physical assessment
- laboratory evaluation and possibly even neuroimaging studies

Formal assessment tools
- the Aid to Capacity Evaluation (ACE)
- the MacArthur Competence Assessment Tool (MacCAT)


High stake circumstances

- Feeding and swallowing
  - Motor functions of swallowing
    - Problems initiating
      - Motor planning
      - Weakness
    - Delayed swallowing
      - Problems with timing of the motor sequence
      - Post surgical problems
      - Surgery/radiation
      - Structural alteration
    - NPO recommendations
    - Feeding tube/ no feeding tube
  - Lack of teeth
    - Edentuous
    - Limiting consistencies of food

- Ability to self feed
  - Appetite related
    - Depression
    - Decreased sensory appreciation for food
  - Motor control of utensils

- Thriving issues
  - Failure to thrive in elderly persons is defined by The Institute of Medicine as weight loss of more than 5%, decreased appetite, poor nutrition, and physical inactivity, often associated with dehydration, depression, immune dysfunction, and low cholesterol.
  - Failure to thrive is not a single disease or medical condition; rather, it's a nonspecific manifestation of an underlying physical, mental, or psychosocial condition.

Case studies

• Case 1
  • Elva is an 88 year old woman who has dementia and lives alone at home with her single, adult daughter. She has other medical diagnoses including: insulin dependent diabetes type II, degenerative joint disease (spine, knees, hands and wrists), fibromyalgia, and hypertension. She has lost many of her teeth, but eats a mechanically soft diet well. She is a frequent faller.
  • She has a paid caregiver in the community who is being paid by the family to stay with Elva in the hospital, to assure her safety and meet her basic needs and to advocate for the patient and family.

Case 1 dilemma

• Elva can walk to the toilet and toilet herself with stand by assist and use of a rolling walker. The nurses want to put her in a pull up and restrict her walking. What should be done (in the best interest of the patient, given institutional policies and procedures)?
  • The MD has recently changed Elva’s medication and she is a little sedated. Someone randomly decides to send Elva for a swallowing test. You know the family might object. What should be done?
Case studies

Case 2

- Bill is an 85 year old man who has Lewy Body disease. He has documented dementia and is at risk for wandering or making a judgment error concerning a personal safety issue. He is a resident on a locked unit in a nursing facility. Can Bill be left alone while the aide takes a bathroom break?
- Bill has documented swallowing problems and you have been told he is on nectar thick liquid restriction. He desperately wants a glass of cold water. What should you do? He also wants some M&Ms. What should you do?

Case 3

Case 3

- Jack is a 17 year old with classic Pelizeaus-Merzbacher Disease (PMD); a leukodystrophy/degenerative CNS disorder characterized by lack of growth of the myelin sheath. He has spastic quadriplegia, nystagmus, motor delays, and cannot speak except using computer assisted speech.
- Jack is cognitively normal. He wants to engage with others in the class and wants to use his computer assisted technology.
Case studies

Case 3

- A substitute teacher is filling in who doesn't know Jack. She tells you that they would prefer that you speak for Jack and should not hook him up to use the computer for the day she is in charge.

Other concerning issues: advocacy

- People who have some degree of ability should be assisted to participate:
  - Sliding Boards
  - Communication devices
  - Assistive technology
  - Assist to toilet/frequency of toileting and response to need/urge to go
  - Desire to communicate with family/people of significance to them
Other concerning issues: avoiding harm

- People with immune concerns should not be placed in high risk circumstances without due consideration:
  - Medical units and exposure to resistant infections
  - Consider use of a hospitalist, if they must be an inpatient

- Transportation and transfers
  - Does the community have accessible transportation?
  - Does the family have the means to safely & physically transfer the patient?

Helpful links

- National Alliance for Caregiving

- Rosalynn Carter Institute for Caregiving
  [http://www.rosalynncarter.org/EBP_links/](http://www.rosalynncarter.org/EBP_links/)

- AARP
  [http://www.aarp.org/home-family/caregiving/](http://www.aarp.org/home-family/caregiving/)

- Family Caregiver Alliance
  [https://www.caregiver.org/resources-health-issue-or-condition](https://www.caregiver.org/resources-health-issue-or-condition)
Helpful links

- A Place for Mom (Caregiver tool kit)
  http://www.aplaceformom.com/senior-care-resources/caregiver-toolkit
- American Library Association: Caregiver's Toolkit
  http://www.ala.org/groups/caregivers-toolkit
- Medicare.gov: Caregiver resource kit
- Aging in place

Bibliography

Bibliography


Discussion

- Group comments
- Q & A