Addressing The Spiritual Needs of Persons with Dementia

NACC Webinar
Week 1, Nov. 19, 2019
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Objectives / Learning outcomes:

At the conclusion of Session I, participants will:

- Identify, discuss and analyze complexities of the spiritual needs of persons with Dementia.
- Identify the particular context in which the person with dementia is living in order to address specific spiritual needs.
- Identify additional challenges for the individual and the families in relationship to spiritual care.
Some Facts:

Dementia vs Alzheimer's
Dementia

- Frontotemporal Dementias
  - Alzheimer's Disease:
    - Young onset
    - Chromosome 21-associated dementias
    - Late life onset
  - Lewy Body Disease:
    - Parkinson's related
    - Diffuse Lewy Body

- Vascular Dementias:
  - Multi-infarct
  - Single-infarct
  - Subcortical
  - CADASIL

- Other Dementias:
  - Posterior Cortical Atrophy (PCA)
  - Normal pressure hydrocephalus (NPH) – associated dementia
  - Chronic traumatic encephalopathy (CTE) – associated dementia
  - Genetic syndromes
    - Huntington's Disease (HD)
  - Infectious diseases
    - e.g., Creutzfeldt-Jakob disease (CJD)
  - Metabolic diseases
    - Neuronal Ceroid Lipofuscinosis (NCL; Battens disease)
  - Toxicity: induced by long-term exposure
    - Wernicke-Korsakoff Syndrome (WKS; Alcohol-induced dementia)
    - Methamphetamine induced
NUMBERS GIVE CONTEXT

- World Wide there are 50 Million People living with Dementia.
- 5.8 million Americans are living with Alzheimers. By 2050 this number is projected to rise to nearly 14 Million.
- Between 2000 and 2017 deaths from heart disease have decreased by 9% while deaths from Alzheimers have increased by 145%.
- Every 65 seconds someone in the United States Develops the Disease.
- 1 in 3 seniors dies with Alzheimers or another dementia. It kills more than breast cancer and prostate cancer combined.

https://www.alz.org/alzheimers-dementia/facts-figures
Four Truths About All Dementias:

- At least two parts of the brain are dying
- It keeps changing and getting worse – progressive
- It is not curable or fixable – chronic
- It results in death – terminal

<table>
<thead>
<tr>
<th>Alzheimers</th>
<th>Lewy Body</th>
<th>Vascular</th>
<th>Frontotemporal</th>
</tr>
</thead>
<tbody>
<tr>
<td>New details lost first</td>
<td>Movement problems – Falls</td>
<td>Sudden changes in ability – some recovery</td>
<td>Many types</td>
</tr>
<tr>
<td>Recent memory worse</td>
<td>Visual disturbances</td>
<td>Symptom combinations are highly variable</td>
<td>FrONTAL: impulse and behavior control changes</td>
</tr>
<tr>
<td>Some language problems, mis-speaks</td>
<td>Delusional thinking</td>
<td>Can have bounce back and bad days</td>
<td>- Says unexpected, rude, mean, odd things</td>
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<tr>
<td>More impulsive or indecisive</td>
<td>Fine motor problems – hands and swallowing</td>
<td>Judgment and behavior <strong>not the same</strong></td>
<td>- Apathy – not caring</td>
</tr>
<tr>
<td>Gets lost – time/place</td>
<td>Episodes of rigidity and syncope</td>
<td>Spotty losses</td>
<td>- Problems with initiation or sequencing</td>
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<tr>
<td>Several forms and patterns</td>
<td>Insomnia – sleep disturbances</td>
<td>Emotional and energy shifts</td>
<td>- Dis-inhibited: sex, food, drink, emotions, actions</td>
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<tr>
<td>Young onset can vary from late life onset</td>
<td>Nightmares that seem real</td>
<td>Least predictable</td>
<td><strong>Temporal</strong>: language change</td>
</tr>
<tr>
<td>Down Syndrome is high risk</td>
<td>Emotional changes</td>
<td>Caused by problems with blood flow, oxygen, nourishment of brain cells</td>
<td>- Difficulty with speaking – missing/changing words</td>
</tr>
<tr>
<td>Notice changes over time</td>
<td>Fluctuations in abilities</td>
<td>Related to tau pathologies</td>
<td>- Rhythm OK, content missing</td>
</tr>
<tr>
<td>Related to beta-amyloid plaques and tau pathologies</td>
<td>Drug responses can be extreme and strange</td>
<td></td>
<td>- Not getting messages</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Related to tau pathologies</td>
</tr>
</tbody>
</table>
Stages of Dementia

- **Early Stage or Mild Dementia / Alzheimers**
  - Problems with communicating right word or name
  - Trouble remember when first introduced
  - Increasing trouble planning or organizing

- **Mid Stage or Moderate Dementia / Alzheimers**
  - Forgetfulness of events of ones own personal narrative
  - Feeling moody or withdrawn – especially socially challenging situations
  - Confusion about where they are / increased risk of being lost
  - Personality changes / bladder changes / delusions, suspicious

- **Late Stage or Severe Dementia / Alzheimers**
  - Round the clock assistance needed.
  - Loss of awareness of recent experiences and surroundings.
  - Increased difficulty in community
  - Experience changes in physical abilities including the ability to walk, sit, swallow

(https://www.alz.org/alzheimers-dementia/stages)
GLOBAL DETERIORATION SCALE

- STAGE 1
  No significant decline

- STAGE 2
  Very mild cognitive decline
  Forgets names
  Difficulty finding words

- STAGE 3
  Mild cognitive decline
  Difficulty traveling
  Difficulty experienced at work

- STAGE 4
  Moderate Cognitive Decline
  Has difficulty with finances, shopping, daily tasks

- STAGE 5
  Moderate to severe cognitive decline
  Needs help bathing
  Needs help choosing clothing

- STAGE 6
  Severe cognitive decline & Loss of awareness of recent events and experiences
  Fear of bathing & Loss of toileting abilities

- STAGE 7
  Very severe cognitive decline
  Loses ability to walk and sit
  Needs assistance eating

https://www.dementiacarecentral.com/about/dementia/facts/stages/
• Approximately 60 – 80 percent of dementia is identified as Alzheimer's Disease.

• Dementia / Alzheimer's is NOT a normal part of aging. It is a disease.

• Dementia / Alzheimer's is NOT mild cognitive impairment that comes with aging. Though some MCI can progress in to Alzheimer's.
• Persons with dementia can not help what is happening.
• You may believe they “know”...but they don’t.
• Persons with dementia can not control what is happening to them.
• And thus it is **absolutely wrong** to criticize or get angry.
• When dementia gets frustrating we must remember it is the disease that is frustrating not the person.
• Does the intellectual capacity define a person’s worth and dignity?
• “Human beings are much more than sharp minds, powerful remember-ers and economic successes.” S. Post,
Spiritual Care for persons with dementia...

Why should I bother... They don’t recognize or remember anyway?
Develop a personal “Theology of Dementia” for your life, ministry and for those under your care.

My theology of Dementia is a compilation of my personal assumptions and faith background that undergird my approach to my life and my vocations.
My Theology of Dementia

All persons are inherently created in the image and likeness of our Divine Creator and imbued with the Spirit of our Creator God.

All persons have innate dignity and are worthy of and deserve love and care.

In particular, those most marginalized and suffering from physical and mental decline deserve greater attention so as to be brought into relationship so they may know their dignity and worth through love and care received.
“How can a tragedy such as Dementia be dignified?
...How can Dementia Honor God?”

“Over and over again, I have seen God honored when others respects the inherent dignity of those afflicted with dementia. It happens because the dignity of everyone, including those with dementia, is rooted in nothing less than the fact that we are all made in the image and likeness of God...” (Dunlop, 2017)
The relational needs of all persons and more so for those journeying with dementia...

Relational Isolation leads to Social Isolation leads to Spiritual Isolation and desolation. Particularly for persons with Dementia Spiritual Care is all about relationship.

https://www.amazon.com/Trinity-CANVAS-Picture-Catholic-Religious/dp/B01M0AVCAJ
What are some of the challenges of providing spiritual care for persons with dementia?

Dunlop identifies various emotional challenges for a person with dementia in the early stages and their spiritual needs:

- Alienated
- Apathetic
- Bored
- Depressed
- Dominated
- Embarrassed
- Fearful
- Frustrated
- Hopeless
- Ignored
- Inattentive
- Irritable
- Lonely
- Meaningless
- Suspicious / paranoid
Other changes...

- Grief and Loss of becoming increasingly disconnected from their faith community.
- Inability to read their bible or prayer books.
- Inability to function well in a crowded space.
- Some *may* increasingly become aware of their dependence on God.
- Many times rote prayer or ritual actions remain.
Can you see and love the image of God in the least of your brothers and sisters? Christ uses only that as his description of the final judgment (Matt. 25). Nothing about commandments, nothing about church attendance ...simply a matter or our ability to see.

Can we see Christ in the “nobodies” who can’t play our game of success? In those who cannot reward us in return? When we can see the image of God where we are not accustomed to seeing the image of God then we see with eyes not our own.

R. Rohr: Seeing the Divine Image, Jan. 1, 2016Center for Contemplation and Action

www.CAC.org
Dancing with Dementia
By Christine Bryden

“I treasure your visit as a ‘now’ experience in which I have connected Spirit to Spirit.

I need you to affirm my identity and walk along side of me. I may not be able to affirm you. But you have brought connection to me. You have allowed the Divine to work through you.”
Ministerial Context:
Where am I called to serve?

1. **At home**

~I am a caregiver for my loved one.
~At home with caregivers that provide for physical needs
~At home with Hospice Care
~As a spiritual provider, I visit individuals that are cared for at home
In an Independent Living Community or CCRC
In an Assisted Living Facility
In a Memory Support Community
In a Long Term Skilled Nursing Care Facility

~What does spiritual care look like for the residents under my care in this community?
~Is it a community connected to a particular faith community, church, parish?
~Is it strictly a secular institution that allows (or does not allow) religious services?
~Are religious offerings communal or individual?
Where to begin?

Understanding communication...
The KEY to providing authentic spiritual care to persons journeying with dementia is this....

It is critical that you believe that what you do can and does make a difference.

Even if our loved ones with dementia don’t remember... **you must believe in what you do** and in what you bring to the person that God has placed in front of you...and then in humility be open to learning from them and receiving.
REMEMBER!

ALL PASTORAL CARE HAPPENS IN THE PRESENT MOMENT. IN THE IMMEDIATE.

THIS IS MOST CRUCIAL TO REMEMBER FOR OUR LOVED ONES WITH DEMENTIA AND WHEN WE ARE PROVIDING SPIRITUAL CARE.
Early Stages

• May still attend services
• Prayer, ritual, song
• Encounter and engagement with others

Mid Stage

• Describes as feeling abandoned
• Increasing isolation and disconnect
• May become less tense and more relaxed and content.
• Ritual, Prayer, Touch, eye contact

Late Stage

• May exhibit feelings of abandonment
• Increasing isolation and disconnect
• May become less tense and more content
• Ritual, Prayer, Touch, eye contact
Questions...