Biomedical view of dementia

Lyman (1989) suggested that the biomedical view of dementia includes three features:

• First, dementia is pathological and individual, an abnormal condition of cognitive impairment, dysfunction, and mental disorder.

• Second, dementia is somatic or organic in etiology, caused by progressive deterioration of brain regions that control memory, language, and other intellectual functions, resulting in stages of increasingly severe impairment.

• And third, although there is currently no cure, dementia is to be diagnosed, treated, and managed according to medical authority.

Biomedical view cont.

• Important to note that the biomedical view can help bring order to the dementia care.

• It is clear that the deterioration of the person is not a simple consequence of neuropathology; social and interpersonal factors enter into the process too.

• The impact of AD and other dementia cannot be accounted for solely in terms of neuropathology.
The person with dementia experiences two kinds of change, going on in tandem. First, there is the gradual advancing failure of mental powers such as memory, reasoning, and comprehension, much of which can be attributed directly to the brain being less efficient. Second, there are changes in the social-psychological environment, in patterns of relationship and interaction.

This perspective emphasizes modifiable conditions that affect the illness experience, in contrast with the biomedical model’s deterministic view, which attributes the individual’s functioning and behavior problems to the neuropathology of dementia.

It is possible to understand the individual with AD in terms of:

1. the organic disease process.
2. the ways in which others in the social world interact with and react to the AD sufferer.
3. the AD sufferer’s reaction to others and to the effects of the disease.

Yet this requires making a decision about the way in which we understand the afflicted—we must decide to see him or her as one whose behavior can be affected by others, who has a valid experiential world, whose behavior can be driven by meaning, and who may be tormented by his or her disabilities and what they mean, and as one whose sense of pride, dignity, and the need to avoid humiliation can remain alive long after many cognitive abilities have declined.

A more comprehensive approach to AD involves the understanding that a balance between resources and deficits, outer and inner demands can be accounted for at each step or stage of the dementing process (Hagberg, 1997).
Four principles

1. The human value of people with dementia, regardless of age or cognitive impairment, and those who care for them.

2. The individuality of people with dementia, with their unique personality and life experiences influencing their response to dementia.

3. The importance of the perspective of the person with dementia.

4. The importance of relationships and interactions with others to the person with dementia, and their potential for promoting well-being.

Post (1995) warns against the tendencies of our "hypercognitive culture" to reduce the moral status of the person with AD and neglect the emotional, relational, aesthetic, and spiritual aspects of well-being that are open to the individual, even in the advanced stages of the disease.

Dementia is the psychobiological result of interacting social, psychological, and physical or chemical forces in persons with certain emotional, anatomic, metabolic, and/or genetic variables.

How a person experiences the pathological process, what it means to him/her, and how this meaning influences behavior and interaction with others are all integral components of disease as viewed as a total human response.
Dementia Staging

- Global Deterioration Scale (GDS) developed by Reisberg (1982) is the most common.
- Broken down into 7 different stages.
  - 1-3 are the pre-dementia stages
  - 4-7 are the dementia stages
- Important to remember that these are rough stages
  - While progression is expected, it is not necessarily linear

GDS cont.

- Stage 1: No cognitive decline
  - No subjective complaints of memory. No memory deficits observed.
- Want to also acknowledge those people with positive family histories...many of these people, even without any symptoms, often experience increased anxiety, fear, negative expectations, and catastrophizing.
Stage 2: Very mild cognitive decline
- Subjective complaints of memory deficit.
- No objective evidence from interview or tests.

Why take SCD seriously?
- SCD may create emotional distress because individuals are aware of decline in their "mental sharpness."
- SCD individuals might consume unnecessary and potentially harmful OTC supplements touted to promote memory.
- Individuals may unnecessarily limit their independence by not driving or limiting financial management.
Why take SCD seriously cont.
- SCD might impair medication adherence
- SCD may be an early sign of dementia
- SCD may predict nursing home placement
- Addressing SCD gives health care providers an opportunity to address anxiety or depression that often accompanies SCD
- Evaluation of potential causes of SCD may uncover reversible conditions that can be treated

(From Desai and Schwartz Current Psychiatry 2011)

Ideally we want people to use their premorbid coping mechanisms to manage the anxiety and fear generated by these concerns.
- Some will start to use defense mechanisms to protect themselves from acknowledging losses and to keep themselves from further fragmenting.
- As symptoms and dementia progresses, increased energy is required in an attempt to maintain some sense of a core (this happens throughout the disease progression)

GDS cont.
- Stage 3: Mild cognitive decline (Mild Cognitive Impairment)
  - Earliest clear-cut deficits. Although subtle these concerns are often noted by those close to individual.
  - May see any number of concerns including repeating questions, executive dysfunction, decline in job performance, unable to learn new skills, concentration deficits, mild language difficulties.
Mild Cognitive Impairment (MCI)

- The MCI stage is marked by symptoms of memory problems and/or other cognitive domains, enough to be noticed and measured, but not compromising a person’s independence. Person must also not be demented.

- Does the person have increased difficulty with any of the following activities?
  - Learning and retaining new information
  - Handling complex tasks
  - Reasoning ability
  - Spatial ability and orientation
  - Language
  - Behavior

MCI cont.

- Cognitive testing is strongly recommended at this stage. > 1.5 SD below mean (on average)

- People with MCI may or may not progress to Alzheimer’s dementia. This is where the biomarkers and other history (genetic factors, medical, etc.) are important. The research seeks to separate MCI with MCI due to AD.

- Researchers will particularly focus on standardizing biomarkers for amyloid and the other possible signs of injury to the brain. Currently, biomarkers include abnormal levels of beta-amyloid in the CSF, reduced glucose uptake in the brain as determined by PET, and atrophy of certain areas of the brain as seen with structural magnetic resonance imaging (MRI).

GDS cont.

- Stage 4: Moderate cognitive decline (mild dementia)

- Clear-cut deficits including:
  - Decreased knowledge of current events
  - Some deficit in memory of personal history
  - Decreased concentration
  - Decreased ability to manage ADLs (finances, meals, shopping, etc.)
  - Frequent use of deficits in orientation, recognition of familiar places/people, ability to travel to familiar locations.
Stage 5: Moderately severe cognitive decline (moderate dementia)
- Person needs some assistance.
- Unable to recall major relevant aspects of current life (address, telephone, names of close family members such as grandchildren), etc.
- Some disorientation to time and date.
- Generally retain knowledge of many major facts about themselves.
- Require no assistance with toileting and eating. May need help choosing proper clothing.

Stage 6: Severe Cognitive Decline (moderately severe dementia)
- May occasionally forget name of spouse.
- Largely unaware of recent events and recent experiences.
- May be unaware of surroundings.
- Diurnal rhythm frequently disrupted.
- Frequently unable to distinguish familiar from unfamiliar persons in their environment.
- BPSD common

Stage 7: Very Severe Cognitive Decline (severe dementia)
- Verbal abilities become lost over the course of this stage.
- Requires assistance with toileting. Incontinent.
- Requires assistance with feeding.
- Basic psychomotor skills are lost with the progression of this stage (e.g. – walking, etc.)
It's time to stop confusing care with treatment.

There is a need to give purpose.

Personhood often looks at the psychological, emotional, and social aspects while sometimes looking negatively at the biomedical aspect. Fact of the matter is that in dementia care, there is a need to include ALL of these things.

Want to see the person through their continuum.

Dementia is a part of that continuum, not all of it.

Important to clarify the difference between primary and secondary symptoms of AD (Solomon & Szwabo, 1992).

Primary symptoms: those that can be directly related to the neurologic deficit such as memory loss, disorientation, aphasia, diminished problem-solving skills, agitation, and apraxia.

Secondary symptoms: those that can be attributed to the individual's attempt to cope with the disorder, limitations in coping skills, an exaggeration of pre-morbid personality, or psychological or behavioral responses by the individual to stimuli in the environment.

The individual with AD experiences multiple stresses, many of which are related to the experience of loss.

When resources are lost (whether the prime cause is neurological or social-psychological), grief reactions commonly occur.

Consequently, living with AD involves the active creation and recreation of meaning and identity, and the negotiation of empowerment, as part of the daily work of living with disability and disablement.
“It must be said from the outset that a disease is never a mere loss or excess – that there is always a reaction, on the part of the affected organism or individual, to restore, to replace, to compensate for and to preserve its identity, however strange the means may be.”

-Oliver Sacks, 1985.

Feelings (the experience of dementia)
- Fear of abandonment
- Fear of being controlled
- Fear of humiliation
- Sense of persecution
- Sense of menace
- Sense of weirdness
- Sense of being excluded

Feelings cont.
- Panic
- Grief
- Frustration at deficits
- Sadness at loss of familiar life
- Anxiety about being a burden
- Frustration at loss of abilities
Feelings cont.

- Anger at dementia
- Anger at others' reactions
- Feeling useless, worthless
- Feeling bewildered

Global states & “Burnt-out” states

- These feelings lead to experiencing global states:
  - Terror
  - Misery
  - Rage
  - Chaos

- And the global states lead to “burnt-out” states:
  - Despair
  - Depression
  - Vegetation
  - Exhaustion
  - Apathy
The needs of individuals affected by dementia are extensive, and the management of the clinical syndrome is complex, extending beyond traditional bounds of medical practice.

Dementia care requires a broader focus extending to family members, caregivers, and support networks.

Dementia care is complex and rewarding care.

Rather than think of people with dementia as out of reach because of forgetfulness, or as unworthy because of cognitive disability, the moral task is to bring them into discourse in creative ways. - S. Post (1995)

Part of the problem is that eventually the person "in here" can no longer negotiate the "out there".

The cooperation and support given by others can be enhanced or limited by the ways in which others view and/or interact with the AD afflicted.

The discussion of perspectives outside of and in addition to the biomedical model may broaden, deepen, and even reframe our understanding of personhood and its meaning for the care and treatment of individuals with dementia (McCurdy 1998).
We intuitively conceive of ourselves as strongly unified beings, at least psychologically.

In dementia, the inner sense of stability and security, held in place through memory, is deteriorating. Thus, the tasks of aging (Erikson's Integrity v. Despair) and the need to seek emotionally meaningful experiences (Socioemotional Selectivity Theory) become much more difficult.

Needs: Comfort

- Persons with dementia experience a sense of loss. This could be bereavement, the failing of abilities, or the ending of a long-established way of life.
- To comfort is to provide a kind of warmth and strength which might enable them to remain in one piece when they are in danger of falling apart.

Needs: Attachment

- Loss of primary attachments undermines the sense of security and if several bonds are broken the impact can be devastating.
- People with dementia may continually find themselves in situations that they experience as "strange" and this powerfully activates the attachment need.
- Attachment creates a safety net and reassurance that helps us function.
Needs: Attachment cont.
- Empathy and secure attachment reduces catastrophic affect extremes.
  - The security of attachment is challenged in dementia.
  - When attachment decreases, the experience of vulnerability increases.
- Evidence suggests that cognitive and emotional systems develop parallel to each other...it is also plausible that these systems decline in parallel to each other.

Needs: Inclusion
- This is the desire to be part of something.
  - Often in dementia, this is observed through "attention seeking" behavior such as clinging or hovering.
  - Being part of the group is essential to our survival.
  - Social environment and social interaction, more often than not mediated by caregivers, can influence deteriorating brain structure.

Needs: Occupation
- To be involved in the process of life in a way that is personally significant.
  - People with dementia are meaning seeking in the same way we all are...and their struggles to make sense of loss are akin to our own.
Needs: Identity

- The need to have a sense of continuity with the past and hence a narrative, a story to present to others.
- To some extent, identity is conferred by others, as they convey to a person subtle messages about his or her performance.
- The goal is to maintain personhood in the face of failing mental powers.
- If one need is met then this will have an effect on the other needs as well.
- We can continue to love a person even after he/she has changed drastically, and even when we are deeply troubled by his/her present state.
- We need to do more than just focus overwhelmingly on problems and limitations.
- People with dementia are often hardly as disabled as they are socially expected to be.

- If I am no longer a woman, why do I still feel one? If no longer worth holding, why do I crave it? If no longer sensual, why do I enjoy the soft texture of silk against my skin? If no longer sensitive, why do moving lyric songs strike a responsive chord in me? My every molecule seems to scream out that I do, indeed, exist, and that existence must be valued by someone! Without someone to walk this labyrinth by my side, without the touch of a fellow traveler who understands my need of self-worth, how can I endure the rest of this unchartered journey? (Living in the Labyrinth, Diana McGowin 1993)