Understanding People with Alzheimer's disease: A Bio-Psycho-Social Approach

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#### Ways to Understand Dementia/Alzheimer's Disease

Biomedical Approach Existential Phenomenological Approach Bio-psycho-social Approach Social Identities or personae: A social constructionist view

- Are jointly constructed
- Require the cooperation of at least one other person
- Have unique behavior patterns that distinguish one from another
- Each person commonly has multiple social personae

# Self of Attributes

- Mental and physical attributes, both
- Past and present
- Includes beliefs (e.g., religious, political, spiritual)
- Includes beliefs about attributes: some of which we are proud, some of which we are ashamed, embarrassed.

# Person with Alzheimer's

- Others see his or her negative attributes quickly and often focus on them.
- Feels embarrassed, angry, depressed regarding negative attributes and often helpless in their face.
- Emotional reactions often not appreciated as logical and appropriate, but rather as "symptoms" to be "managed".
- Needs to be understood in light of the above.

# **Malignant Positioning**

- Person with Alzheimer's is seen increasingly as a patient, not as a person.
- Actions are interpreted in pathological terms ("irrational hostility" rather than "righteous indignation"; "aimless wandering" rather than "walking").
- The above is consistent with the story line of being an Alzheimer's patient or being called, "demented".

#### Patients are

- Recipients of care
- Managed, treated, told what to do
- Subservient, in a junior position re others
- Lacking in independence and agency
- Alzheimer's patients are not often viewed as being semiotic subjects.
- Christopher Reeve example

#### Persons are

- Givers and recipients of care
- Not subservient, but on an equal social plane with others, can be junior or senior to others as well
- Are interacted with rather than managed
- Exercise independence and agency and are viewed as semiotic subjects, e.g. Gen. U

# The Case of Mrs. E

- 81 years old, considered in the mild to moderate stage according to standard measures
- Aware of problems recalling information
- Performed ADLs without assistance
- Fluent speech
- Engaging personality
- Taking Aricept and Imipramine (depression and anxiety related)

Malignant Positioning of Mrs. E by her primary carer

- "She has no attention span"
- "She has a problem with the concept of time"
- "She has a lot of trouble learning"

# Problems constructing a valued social identity

- Malignant positioning leads to lack of cooperation in joint construction of positive social identity
- The dominant social identity is "Alzheimer's patient", "dysfunctional patient", "burdensome patient", all based on attributes the person diagnosed finds abhorrent.

# Mrs. E was, in healthy days

- "take-charge organizer"
- "energetic, devoted helper"
- Homemaker and mother/spouse
- Independent career woman/law enforcement officer/WW II pilot

# Social Identity at home

- Limited to being a "patient who is managed" by aides who engaged in malignant positioning
- Infantilized by primary carer who positioned her mother in a malignant way.

# Social Identity at Day Centre

- Emphasized her positive attributes
- Worked to reposition herself in positive ways
- Differentiated herself from other day centre participants
- Gained cooperation from student interns to construct social identity of valued, wise counsellor
- Extended help to other participants, supported their feelings of self worth

#### Recommendations

- Eliminate malignant positioning by recognizing and validating person's positive attributes, past and present.
- Engage the person as having those attributes.
- Refrain from referring to people with Alzheimer's as "patients". All of us are patients in relation to medical professionals, but we are more than that and so is a person with Alzheimer's.

#### Recommendations

- Cooperate with person with the person with Alzheimer's to construct valued social identities based on positive attributes valued by person diagnosed.
- Recall that long standing dispositions and inclinations can survive even when so-called cognitive function as "measured" by standard tests is thought to be impaired.
- Understand the larger context in which person's actions occur.

#### Recommendations

- Recall distinction between irrational hostility and righteous indignation.
- Social cognition is not measured by the MMSE.
- Diagnosis of probable Alzheimer's alone must not drive interpretation of actions.
- Refusal to be positioned malignantly is an indicator of relative well-being, not a symptom of disease.

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#### References

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