Understanding the Experience and Selfhood of People with Alzheimer's Disease: Context is Key

Steven R. Sabat

Department of Psychology

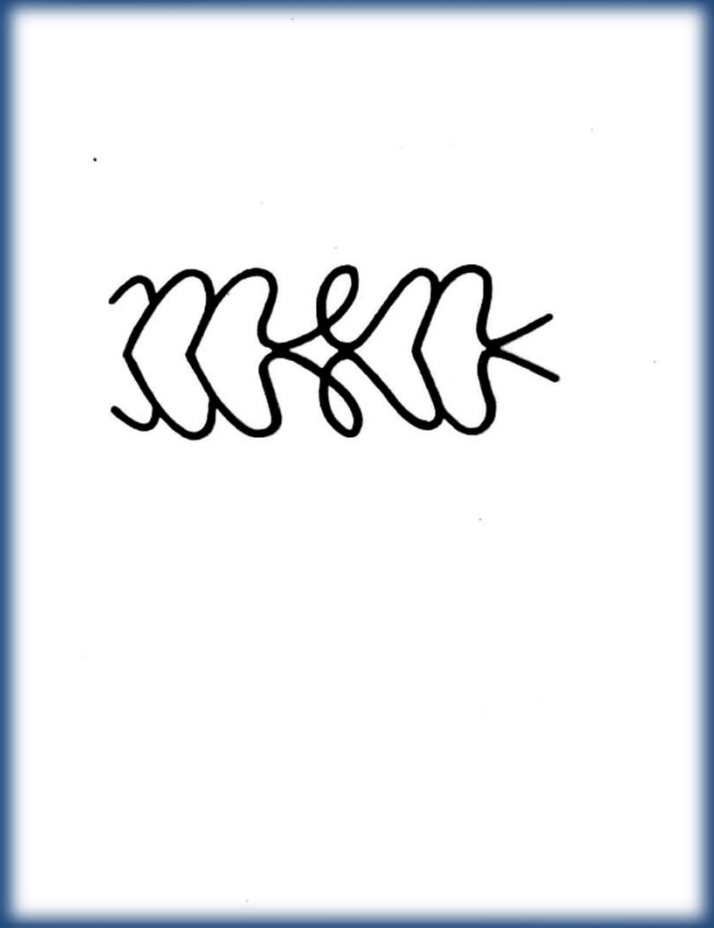
Georgetown University

Washington, D.C. U.S.A

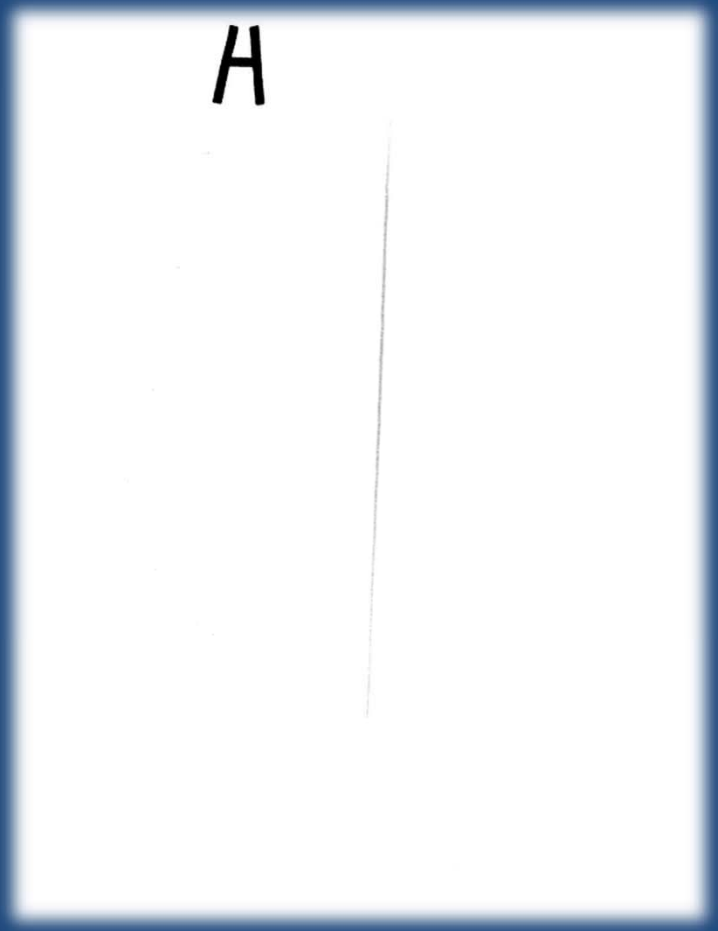
Ways to Understand Dementia

- Biomedical Approach
- Existential Phenomenological Approach
- Bio-psycho-social Approach

Effects of Context on Experience: Example 1

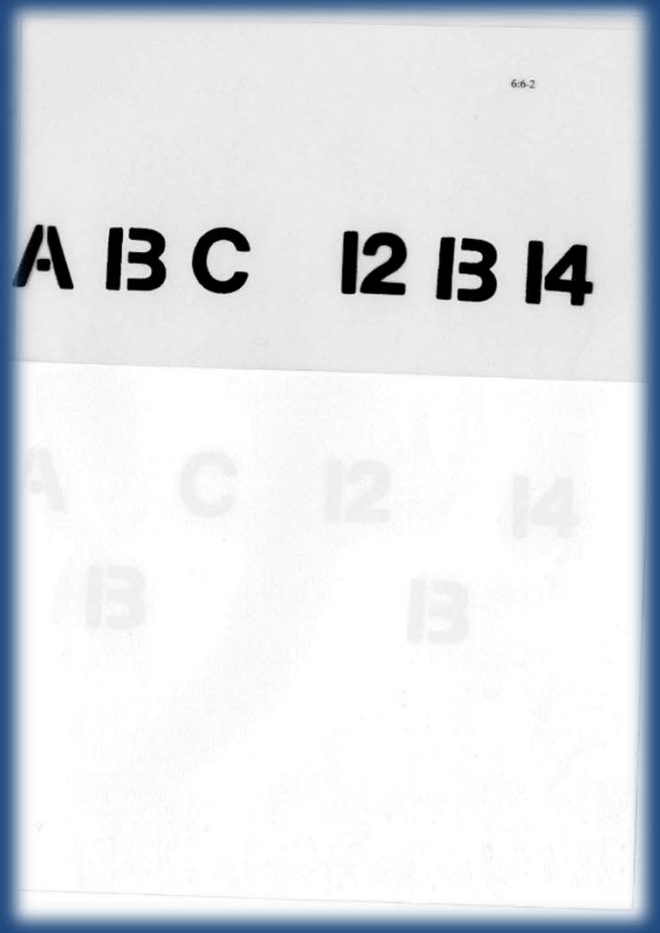


Out of Context



In Context

Importance of Context II



Identical diagnosis and degree of severity do not mean that:

- We can understand different people as people on this basis;
- Identical treatment will enhance QoL equally;
- Identical treatment will enhance carers' confidence and competence equally

So we have:

- A diagnosis
- A list of dysfunctions that mark the severity of that diagnosis
- A number of actions that may or may not be dysfunctional, depending upon the
- The context in which we view said actions,
- Including aspects of a person's selfhood.

Aspects of Selfhood

Self 1: expressed via personal pronouns

Self 2: Physical and mental attributes past and present, including beliefs about said attributes.

Self 3: Social personae constructed with cooperation of at least one other person: devoted spouse, loyal friend, demanding professional, dysfunctional patient.

Dr. M

- Refused to attend day center
- Refused to participate in drug studies
- Had a PhD in Sociology and a Master's degree in Social Work
- Was deeply embarrassed by her word-finding problems and said, "I can't talk."
- Said, "I know what my problems are, don't need tests to show me."
- Self worth strongly connected to intellect.

Mrs. D

- Attended Day Center three days per week at minimum; loved attending
- Called “life of the party” there, engaged other participants, made new attendees feel welcome; sang songs, told jokes—this was her “work”
- Had high school diploma, no college
- Made fun of her own verbal errors
- Didn’t hold intellect as core aspect of self

Dr. B

- Attended Day Center 2-3 days per week
- Kept to himself apart from greeting participants politely
- Refused to be involved in activities; called most, “filler”
- Gravitated to staff members and me, differentiated himself from the group
- Happy to leave each day he attended

Visit with Mr. U

- “After you left Al was his old self. Took a nap downstairs (however, not long enough). I don't know how you did it, but I can't thank you enough.”
- **“you are a miracle worker”**

(from email letter dated 11 June 2006)

Delineating life stories

- Helps formal/professional caregivers understand their clients as people in their totality and relate to them as such, rather than as “dementia patients” solely or primarily
- Places clients’ actions in meaningful context
- Provides client or relative with recognition and validation of highly valued personal attributes, thereby enhancing feelings of self-worth
- Renews emotional bonds between relatives and reduces anxiety and despair

Therefore:

- A person with dementia is still a person with a history
- That history is the context in which we must understand that person and his or her experience of and reaction to the effects of dementia and how he or she is treated by others.
- Understanding persons is a key non-pharmacological, low cost intervention that begs to be used.

Thank you kindly.