Using context as a memory aid for people with Alzheimer's disease

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Introduction

There are over 18 million people with Alzheimer's disease (AD) worldwide, and over the next 20 years, the number will double.

People in the early stages of AD have trouble remembering recent memory episodes and thus lack "context" in their day-to-day lives, leading to a loss of independence and a higher risk for depression.

Capture and access techniques in context-aware computing have the potential to supply the missing context of memories necessary in their lives for maintaining independence and possibly even delaying the progression of the Alzheimer's disease.

Questions

Activities
What are the everyday routines of people with AD and their caregivers?
What activities are people with AD engaging in when their memory failures occur?

Memory
What kinds of memory episodes are forgotten?
What cues are most effective for memory recollection?

Strategies
What personal strategies does the person with AD use to compensate for memory impairment?
What forms of memory support does the caregiver provide the person with AD?

Coping Mechanisms

	Benefits	Limitations
Instrumentation People with AD often use assistive instruments and tools to help them record memories and future tasks for subsequent review. Examples include notebooks, diaries, calendars, and planners.	Effortful recording/processing results in better memory encoding User decides what is important to record Simple interaction	Requires extra effort, especially for people who are not fully aware of their memory deficits User-recorded accounts may be incomplete Limited typically to written material
Caregiver Caregivers are individuals who look after the person with AD such as a spouse, relative, or professional nurse.	Always available Provides a (usually) accurate account of experienced episodes Proactive reminders before events Using cues to reinforce recollection behavior Prevent hazards and assist in activities of daily life	Constant availability can lead to caregiver strain Patient relies on a memory account not from their own perspective but from the caregiver's Need to balance how much advanced notice is given to the patient to avoid repetitive questioning Facilitating cued recollection takes time and effort Patient may become too dependent on caregiver if caregiver is too "good" of a memory aid; never "exercising" their intact abilities
Routines Routines are the regular everyday activities the individual engages in such as sorting mail, getting dressed, and cooking meals.	Requires little or no explicit memory to follow routines Allows for staying productive	Difficult for patient to learn and maintain new routines after disease onset Episodic memory can be (falsely) shaped by routines

Possible Solution

Passive capture and review of memory context of recently experienced episodes as **cues for memory retrieval and reconstruction**

Elements of the context of a memory: *objects, people, sounds, location, temperature, weather, physiological state, imagery, time*

Passive capture minimizes effortful user interaction

Facilitates and requires mental reconstruction of memory episodes from context information when reviewed (Tulving 1973, Bird 1991, Murnane 1993)

Mental "exercise" that may delay the progression of Alzheimer's disease (Hultsch 1999, Valenzuela 2003, Small 2004)

Ethnography

Who: Individuals in the early stages of Alzheimer's disease and their caregivers
Where: Home environment
Methods:

Semi-structured interviews
To identify *perceived awareness* of deficits and practical memory problems

Contextual inquiry
To observe *routines and memory problems* as they arise in practice

Diary Study
To get an account of memory failures from the *perspective of the caregiver*.

Results: Used to inform the design of a context-aware memory aid for people with AD and other types of episodic memory impairment