3 patterns described the meaning of memory loss within everyday life for people with early Alzheimer disease

QUESTION
What does the experience of memory loss mean to people with cognitive impairment and early Alzheimer disease?

DESIGN
Qualitative study using a Heideggerian hermeneutical phenomenological method.

SETTING
St John’s, Newfoundland, Canada.

PARTICIPANTS
12 people (age range 59–83 y, 75% women, Mini-Mental State Examination score range 20–28) who had acknowledged memory problems, probable early-stage Alzheimer disease or mild cognitive impairment, and could still tell a story.

METHODS
In individual interviews, participants were asked to tell a story about living with Alzheimer disease or mild cognitive impairment and prompted for details about memory loss. Interviews were audiotaped, transcribed verbatim, and analysed thematically.

MAIN FINDINGS
3 patterns with relational themes described the experience of memory loss. (1) Experiencing breakdown was described by 2 relational themes. Participants faced “awakening to breakdown” when they first noticed memory changes that were out of the ordinary; for some, this realisation led to feelings of terror and frustration. They often described forgetting to do routine activities (eg, flushing the toilet), forgetting to do or how to do meaningful activities (eg, how to bake, find words during conversations), or experiencing difficulty with learning new information. 1 participant revealed that when her son suggested a visit to the doctor, she “burst into tears then, ‘cause I know too something is up, and to tell the truth I even suspected what it was.” Participants described “living with forgetting” and the daily uncertainty and fear associated with not remembering. This was sometimes experienced through the body. 1 woman told of putting her dress on backwards, knowing it wasn’t right but being unable to identify why, and subsequently realising that her life had changed permanently. For some, forgetting meant loss of their connection to familiar objects or places, which was sometimes associated with feelings of loneliness or isolation, or language difficulties, which affected relationships with others. (2) Temporality was described by 5 relational themes, representing how connections across time make events in our lives meaningful. Some participants experienced “being-in-the-world” as a loss of connection between past and present, where periods of time in their memory were lost. This led some to think about what death might be like. Some lost a sense of the passage of time. For some participants, “forgetting the past” meant that memories were fragmented or completely lost, and their normal way of being-in-the-world was threatened or lost. “Looking ahead” was the third theme identified. (3) Managing forgetting consisted of 4 themes and sometimes included help from family members. Most participants found that forgotten things could be “remembered with cues.” Some coped by “writing things down,” with remembering becoming a more conscious act. Most participants “recognised what made remembering better or worse” and often used their bodies as a guide. Being tired, upset, or trying to force recall made remembering more difficult, whereas relaxing and allowing memories to surface made it easier. Some participants “used laughter” to help them cope with the problems of forgetting.

CONCLUSION
5 patterns described what the experience of memory loss meant to people with early Alzheimer disease or mild cognitive impairment and how it affected their everyday lives.

ABSTRACTED FROM

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This study, grounded in the philosophical tenets of Heideggerian hermeneutic phenomenology, uncovers the experience of people living with early dementia within the context of their meaningful activities and relationships. It builds on previous research that first contributed to our understanding of the phenomenon of living with memory losses associated with cognitive impairment. The study framework and methods were well suited to its intent and allowed the researchers to capture powerful stories that were evidence of the changes inherent in the dementia experience. Excerpts from interviews suggest that relationships with people and time are disrupted in ways that cause the person to feel disconnected from the world around them, evoking fear and anxiety. Thus, the study supports a movement toward relationship-centred care and embodiment approaches, where interventions are directed at accommodating breakdown of bodily flow and change of one’s way of “being-in-the-world,” and the voices of patients guide clinicians and family caregivers to look for the meanings behind behavioural manifestations of dementia. The findings also provide evidence that the experiences of people with early-stage dementia are accurately captured in sensitivity exercises used by educators, content previously inferred through clinical wisdom.

Further qualitative research could involve consecutive interviews and include more men to determine how awareness of memory loss changes through disease progression and the effect of gender on the meaning of activities and relationships. In addition, studies involving people with dementia and their family caregivers may provide a sense of the effects of early-stage dementia on “being-in-relationship.”

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