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Persistence of Self in Advanced Alzheimer's Disease

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Abstract

Purpose—To determine if evidence of the persistence of a sense of self or personal identity could be found in people in the middle and late stages of Alzheimer's disease. The theme of diminishing self pervades both the popular and professional literature on Alzheimer's disease.

Design—Qualitative using conversational analysis. The purposive sample was 23 residents of two urban nursing homes in the southeastern United States who were in the middle and late stages of Alzheimer's disease. Their mean Mini-Mental State examination score was 10.65. Nineteen subjects were women, four were men in this 1993-1997 study.

Methods—Analysis of 45 conversations lasting 30 minutes with nursing home residents with a diagnosis of probable Alzheimer's disease. Use of the first person indexical and other evidence, such as awareness and reactions to the changes that had taken place, in support of and counter to the notion of persistence of self, were sought in conversational analysis.

Findings—Respondents used the first person indexical frequently, freely, and coherently. Evidence was also present that participants were aware of their cognitive changes. Many struggled to provide an explanation, but none mentioned Alzheimer's disease.

Conclusions—Evidence suggests the persistence of awareness of self into the middle and late stages of Alzheimer's disease. Failure to recognize the continuing awareness of self and the human experience of the person in the middle and late stages can lead to task-oriented care and low expectations for therapeutic interventions. The bafflement noted in respondents suggests that people should be told their diagnosis and offered an explanation of what this diagnosis means.

Keywords

Alzheimer's; self concept; cognition

The theme of diminishing self is common in the popular and health care literature about the late stages of Alzheimer's disease. In her narrative on the experience of having Alzheimer's disease, Diana Friel McGowin wrote, there is "less and less of me every day" (1993, p. 33).

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Spouses say this is not the man or woman I married, or they describe the person as just a shell of what he or she once was (Jenkins & Price, 1996). Nursing home staff appear to believe the same thing, frequently avoiding all but task-oriented communication with people in the latest stages of the disease (Ekman, Norberg, Viitanen, & Winblad, 1991) on the assumption that the severely demented experience life as meaningless (Norberg & Asplund, 1990).

Similar assumptions are found in the health care literature (Downs, 1997). A person's attempts at speech in the later stages have been described as nonsensical and devoid of meaning or insight, contributing to the impression of a diminishing self (Bohling, 1991). Also noted is the lack of "reference to the speaker as ego" (Kertesz, 1994) leaving the same impression. The consciousness of the individual is described as gradually fading away (Lyman, 1989) or becoming "a continuously fading dream," (Bayles, 1995, p. 362).

The progressive decline associated with this disease is well known. Lyman (1989) used the term "self-deterioration" to characterize it and Cohen (1991) wrote of the death of the mind before physical death. Ronch (1996) adds, "The loss of self happens before the very eyes of the person whose self is vanishing." (p. 25). In the last of the six phases of the subjective experience of Alzheimer's disease proposed by Cohen, separation from self is said to occur. Humanness and a personal, subjective experience of the disease are maintained until this last stage in which the person is described as reacting only to sensory stimuli.

Maintenance of Self

An alternative perspective is beginning to appear in the literature, however. Sabat and Harre were inspired by the title of Cohen and Eisdorfer's popular book, *The Loss of Self*, to ask, "How could a self be lost?" (1986, p. 443). If something like a "social death" is experienced before physical death, it may be because the very demented are treated as if they are already dead (Lyman, 1989). Kitwood and colleagues have said this occurs because providers withdraw from these individuals, not the other way round, thus objectifying people with advanced Alzheimer's disease and banishing them from society (Kitwood & Bredin, 1992). Bell and McGregor (1995) believe that, while personality is changed, core characteristics remain, as evidenced by the fact that every demented person in their care has proven to be unique. Unfortunately, they do not elaborate on what they mean by the difference between personality and core characteristics. Feil (1993) also emphasized the continuing humanness of a person with Alzheimer's disease, exhorting readers to look at the whole person, not just the problems. "Behind their disorientation," she writes, "Lies a human knowing ... a basic humanity shines through" (p. 15).

These two perspectives, a diminishing and eventually lost sense of self and maintenance of personhood and persistence of self, raise the question of what self is and how the persistence of a sense of self can be observed in people in the late stages of Alzheimer's disease.

Concept of Self

Self-awareness can be defined as the ability to monitor oneself through changing circumstances and to respond to the perceived changes. *Self-concept* can be thought of as the capacity to think of oneself as an entity inclusive of, but more than, the physical body (Jenkins & Price, 1996). Humanness is distinguished by the capacity for self-reflection, linguistic expression, and choice (Fischer, 1996).

As with Goffman's (1959) distinction between personal and social identity, Sabat and Harre (1992) differentiate the self of personal identity from the multiple "selves" or personae one presents publicly. The latter may evolve or change as the person interprets the responses of others (Charmaz, 1987). Like Kitwood and colleagues, Sabat and Harre believe that the public

personae or “selves”—as opposed to the personal identity or self—can be damaged or even lost through others’ failure to understand the person with Alzheimer’s disease. To support their argument that the self of personal identity persists, they present evidence of reference to self from three case studies of people with Alzheimer’s.

Our own informal observations and conversations with those in the late stages of the disease also seemed to indicate that they retained a sense of themselves as people. Despite their limitations, they responded to their names and reacted emotionally to both frustrations and pleasurable experiences. It seemed to us that they had not lost their sense of self even though much of the literature and common wisdom on the subject indicated they had.

To further explore this observation, a qualitative study was done to determine whether more objective evidence of the persistence of self could be found in people in the late stages of Alzheimer’s disease. The question was whether evidence exists of awareness of self as an entity inclusive of, but more than, a physical body in people with moderate to severe Alzheimer’s disease.

Methods

A total of 45 tape-recorded conversations of nursing home residents with Alzheimer’s disease and advanced practice nurses were analyzed. The 30-minute conversations were part of a larger study of the effect of exercise and conversation treatment on the ability to communicate in the later stages of Alzheimer’s disease.

The study was conducted in two large urban U.S. nursing homes in the Southeast. All the people interviewed were long-term residents of these facilities. Consents were obtained from proxy healthcare surrogates under the guidelines of the university’s Committee for Protection of Human Subjects and according to the laws of Florida. Participants themselves consented to the sessions and were told they were being tape-recorded.

The purposive sample consisted of 23 residents in 45 sessions who had a clinical diagnosis of middle or late stages Alzheimer’s disease based on psychiatric review using criteria from the National Institute of Neurological and Communicative Disorders (NINCDS) and the Alzheimer’s Disease and Related Disorders Association (ADRDA) (McKhann et al., 1984) and cognitive test scores. Also, to be eligible for the larger study, which involved exercise, subjects had to be able to walk at least 10 feet with assistance.

Four (17%) of the 23 subjects were men. Only those subjects who participated in the conversation treatment were included in this analysis. Mini-mental examination scores (MMSE) (Folstein, Folstein, & McHugh, 1975) ranged from 2 to 18 (mean 10.65, median 11) out of a possible range of 0 to 30. An MMSE score between 10 and 19 is considered middle stage Alzheimer’s disease; a score of 9 or less is considered late stage (Folstein, 1997). None of these individuals was mute. (The MMSE score is reported in brackets following each quote from participants in the Results Section.) Of the original 25 participants who met the criteria for inclusion, two were eliminated from analysis because their responses could not be interpreted. One, whose MMSE score was 0, rarely vocalized any words. Although she appeared to be listening to us when we spoke to her, the only recorded verbal response from her was “yes.” The second, whose MMSE was 2, spoke in a combination of Yiddish and English that neither project staff nor a native Yiddish speaker could accurately transcribe.

One of the purposes of qualitative research is to “construct a possible interpretation of the nature of a certain human experience” (van Manen, 1990). For this study, our purpose was the search for evidence for or against the continuation of a sense of self in those in the middle and later stages of Alzheimer’s disease. Conversation analysis has its roots in phenomenology,

ethnomethodology, and language philosophy and has been used in such disciplines as social psychology, communication, and cognitive science (Psathas, 1995). Conversation analysis is based on three premises (a) interaction exhibits identifiable patterns (b) interaction is contextually oriented, and (c) no details in these interactions can be dismissed as accidental or irrelevant (Heritage, 1987).

Fundamental to the method of analysis in this study is the notion that personal identity may be evidenced through the use of the first person pronoun, "I." Sabat and Harre (1992) suggest that if a person with Alzheimer's disease uses this first person indexical coherently, he or she has displayed an intact self. Thus persistence of self may be identified through the coherent use of the first person in conversation if one accepts their proposition.

To search for use of the first person and other evidence of a sense of self, the transcripts of the 45 conversations with these nursing home residents were read through the first time without interpretation. On subsequent readings, the use of the first person indexical, other self-reference, and indications of personal identity such as response to their name or mention of cognitive changes that had occurred, were noted by the two investigators. Evidence counter to the notion of persistence of self was also sought. Initial findings were then subjected to validation by a clinical specialist in gerontological nursing and in geropsychiatric nursing because it was difficult to conduct this type of validation of findings with the subjects themselves.

Results

Conversational topics noted on the transcripts centered primarily on the person's recent activities, immediate environment, family, health, and past experiences. Frequent references to self were found in the transcribed conversations. In addition, respondents expressed some awareness of the changes in cognition that were occurring and offered some possible interpretations of these changes, indications that they continued to monitor themselves and to respond to perceived changes.

Self-Reference

In the course of conversation, the people with Alzheimer's disease frequently talked about themselves, their needs, and concerns. Although this was often in response to questions, respondents also initiated talk about themselves. All used the first person indexical in these conversations and most did so frequently. The following are examples of the ways in which they referred to themselves.

I was never a happy person [MMSE 15].

I am old fashioned in this respect [MMSE 14].

I am very unhappy [MMSE 15].

In each of these instances, the person is conveying specific information about himself or herself, both past and present. They indicated awareness of self as an autonomous person: "It's my life and that's how it is," [MMSE 8] and showed the ability to compare themselves to others: "I don't know, but others do," [MMSE 17].

Awareness of Changes

Many respondents shared life experiences. One woman, for example, talked about having been a nurse, mother, and daughter-in-law. She then added, "I'm not so smart anymore," indicative of her awareness of the changes in her cognitive abilities. "I don't know what's going on," she said. In response to a question, another subject said that she couldn't answer, but that her

daughter would know the answer. “How anybody can remember all that stuff is a miracle,” she added. “What kind of stuff?” the interviewer asked her. “Everything that you’re supposed to remember,” [MMSE 14]. Not only was she aware of her difficulty remembering, she was able to differentiate herself from others who could remember “all that stuff.” Another respondent frequently referred to herself as “Dumb Deirdre” (not her real name)[MMSE 15].

Respondent Interpretations

Some also offered explanations for these changes in cognition. One attributed the memory problem to medication and said, “Sometimes pills make you forget,” [MMSE 16]. A few attributed cognitive changes to mental illness. One said, “How would I know? I’m crazy. I don’t know what to do,” [MMSE 5]. The majority, however, identified the problem as follows but did not offer an explanation for their difficulty:

I used to like to read; I read a lot. I somehow changed [MMSE 14].

I don’t know. It’s a secret, I guess [MMSE 14].

Do you think I remember? [MMSE 5].

Many of these statements indicated bafflement regarding why they no longer remember well. None ever mentioned having Alzheimer’s disease or dementia, leading one to wonder how many had been told their diagnosis and if their bewilderment would have been lessened if they had been told what was happening to them.

Hutchinson’s (1997) research with individuals in the early stages of Alzheimer’s disease corroborates this observation. Subjects in her study seemed to be struggling to understand what was happening. Using Glaser and Strauss’s awareness context theory as a framework, Hutchinson (1997) hypothesized this struggle was because of the ambiguities of a “suspected awareness context:” the person knows that something is wrong, but has been given little or no explanation.

There was evidence that at least some subjects were struggling to make sense of their experience. Their attempts to interpret their situation ranged from spiritual questions, asking, “God, why do you hurt me?” [MMSE 16] to resignation, “You have to take everything as it is” [MMSE 17]. One man offered several explanations “I’m sick, I’m crazy, my legs can’t go now,” [MMSE 10]. Self acceptance was apparent in the statement made by another subject, “I’m doing the best that I can” [MMSE 8]. But others seemed to feel shame and self disgust, stating, “I wish I were dead. If I were dead, nobody could see me,” [MMSE 15].

Occasionally, respondents did not acknowledge having a memory problem, attributing their not-knowing to another cause: One said, “I was in Minneapolis, I just got back” [MMSE 17]. Another stated, “I was too busy” [MMSE 17].

It is evident in all these statements made by the respondents that the first person pronoun is used frequently, freely, and coherently. Many indicated that they did not know the answer to a question or a particular fact, but few attributed their not-knowing to a specific cause. It is important to note that these individuals had been regularly engaged in conversation and may have responded more volubly and more clearly than those who have not received such treatment.

It is also notable that, while respondents talked about physical need (hunger, thirst, fatigue, pain), their self-references were not limited to the physical body. Statements referring to physical concerns were not included in this analysis in accord with the definition of self concept as being more than a physical body (Jenkins & Price, 1996).

Contradictory Cases

Reference to self in the third person, either as “he” or “she” or by the person’s name was uncommon. One man whose nickname was “Buster” (changed to protect anonymity) responded to the question, “Who’s Buster?” with “He’s right here [MMSE 5],” but this may have been affected by the way in which the question was asked.

Ronch (1996) describes an individual named “Molly” who was found searching through other people’s belongings. When asked what she was looking for, she replied, “I look for Molly and I can’t find her.’ After describing some of her own limitations, she added, “That’s not me, not the real Molly. So I go around looking for Molly but she’s nowhere to be found” (p. 26). Ronch (1996) interprets this as evidence of ego alienation and a search for the vanishing categorical self, defined as self-understanding that affirms one’s existence as a unique and separate individual. An alternative interpretation could be bewilderment over the changes in herself and a wish to return to a past, more competent, being. It is notable that Molly uses both the first person and the third person pronouns to refer to herself. It is possible she is using the first-person for her present self and the third-person pronoun for her past self.

Discussion

Respondents used the first person indexical frequently and coherently. They also showed awareness of cognitive changes that had occurred and seemed to be struggling to provide an explanation for these changes. Evidence of the persistence of self is of particular significance because it helps to shape attitudes toward and expectations of individuals in the later stages of Alzheimer’s disease. Much of the literature about the later stages of Alzheimer’s disease has represented the individual as losing an awareness of self and hence the essence of humanness. There is widespread acceptance of the notion that the disease affects a person not only physically and cognitively, but affectively as well.

With a presumed loss of ability to respond affectively, caregivers see the person as unable to interact, communicate, or possess feelings. Jenkins and Price (1996) refer to this as a “tendency to envisage the person in terms of cognitive functions” (p. 87). Suggestions for communication strategies, for example, focus primarily on ways to prevent behavior disturbances or to accomplish the basic activities of daily living, with little attention paid to expression of feelings or ways to call forth the self that may be hidden behind the disease. This lack of awareness or appreciation of personhood leads to task-oriented care and low expectations for therapeutic or remedial work with victims of this disease. If there is a “death of self” before physical death, and communications are “devoid of meaning or insight” then custodial care is all that can be offered and there is little purpose in initiating conversation in order to understand the individual.

Caregivers’ attitudes may be based on observations and assumptions about the diminishing humanness of individuals in their care. Several investigators have written about negative attitudes toward people with Alzheimer’s disease in nursing homes and the resultant poor quality of care. Norberg and Asplund (1990), for example, write that most staff in their study believed that severely demented residents experienced life as meaningless. Other writers have lamented the widespread indifference found among professionals and nonprofessionals in nursing homes where few attempts are made to establish relationships with patients (Burnside, 1994; Williams, 1986). Ekman, Norberg, Viitanen, and Winblad (1991) found that caregivers spent less time with severely demented patients and had more negative reactions to demented patients as compared to nondemented patients. “Nervous,” “afraid,” “frustrated,” “sad,” and “physically and mentally exhausted,” were terms nursing students used to describe how they felt about their first experiences caring for cognitively impaired people (Beck, 1996).

Conclusions

Caregivers' attitudes are based on beliefs and assumptions about the diminishing humanness of people in their care (Cotrell, 1997). In view of pervasive negative attitudes, there is need for further study of the subjective experiences of people with Alzheimer's disease. It is only with this perspective that a fuller understanding and appreciation of people who have the disease can be achieved.

With an understanding of personhood as more than cognitive functions measured by mental status scores, we can also search for strategies that will assist caregivers in developing ways of caring that avoid dehumanization, foster the expression of feelings, and encourage therapeutic relationships. Buckwalter and colleagues (1995) warn against casting people with Alzheimer's disease into preconceived roles based on the level or stage of the disease, thereby missing the opportunity to call forth the individuality of each person. Taft and colleagues (1993) call for "caring communities that diminish the sense of anonymity and isolation of persons with AD" (p. 36). Haggstrom and Norberg (1996) suggest that what seem to be lost abilities "can be released by integrity promoting care" (p. 435).

Through further study of the subjective experience of people with Alzheimer's disease, we can offer care that nurtures and celebrates personhood. With this perspective, a fuller understanding and appreciation of people who have the disease can be achieved.

Clinical Sidebar by Maura F. Miller

Gerontologic nurses have pivotal roles as providers of care to people with advancing cognitive decline. Unfortunately their role as direct caregiver is vanishing as health care is reorganized. Professional nurses are moved away from patients and into positions in administration, education, and research. Given this current reality, gerontologic nurses must take a leadership role in disseminating nursing research findings to family caregivers, nursing assistants, professional nurses, and others. In most institutional environments, nursing assistants are the direct provider of hands-on care, but the least educationally prepared to meet the psychological, emotional, spiritual, and physical needs of patients with advancing cognitive decline.

As dementia progresses, patients with Alzheimer's often lose the ability to engage in conversation. It takes additional effort and time to involve patients in meaningful conversation and to draw out feelings, thoughts, and memories. Conversational dialog with nurses reinforces a patient's awareness of self and remaining strengths. Conversational topics identified in this article focus on the patient's daily activities, immediate environment, family, health, and past experience.

In the day-to-day work environment of a nursing home, there are not always opportunities for staff and patients to connect and initiate meaningful conversations and relationships. In my past clinical work at the Miami V A Nursing Home Care Unit, a social worker and I co-lead a dementia group for patients with advanced Alzheimer's. The purpose of the group was to provide opportunities for socialization, affirmation of the person, and validation of the remaining self. We brought patients to the meeting room, welcomed them, introduced ourselves, and asked each group member to say their name and write it on a name tag. Many patients had difficulty identifying who they were. Some wrote their childhood name, Hebrew name, or nickname signifying intact old memories of self. Discussions were often focused on holiday themes and memories. One discussion on Valentine's Day led to thoughts about family, love, and being loved. One veteran stated: "Valentine's Day ... my wife brought me here because she didn't love me anymore. She put me here and it broke

my heart ... “Talking to patients is not a difficult nursing intervention, albeit a potentially emotion alone.

Patients with Alzheimer’s disease often talk about themselves, their needs, and concerns—in response to questioning. Unfortunately, opportunities for conversations may be hindered by poor nurse-to-patient ratios, overwhelming physical care needs, and nonappreciation—by both administration and nursing—of the need for staff-to-patient discourse as an intervention. For quality of care, staff should be taught and expected to engage in conversation with their patients during caregiving. This mechanism is important for decreasing task-oriented and impersonal care and providing opportunities for patients to talk about their feelings, needs, and wants. Administrators should include staff-to-patient dialogue as a performance expectation and provide adequate staffing ratios to ensure opportunity and unstructured conversations with patients.

It is important for nurses to assess patients’ awareness of their strengths and deficits, their ability to express their feelings and develop relationships. Professional nurses can reinforce positive memories, thoughts, and feelings which exist for each individual and focus care toward encouraging the remaining self. The Health Care Finance Administration (HCFA) mandates that nurses complete a comprehensive assessment of a patient and develop an individualized plan for care, upon the patient’s admission to a nursing home. The literature is devoid of assessment tools to measure cognitively impaired person’s perceived level of self-awareness. Understanding a cognitively impaired persons’ awareness of their remaining self is important so that nursing care can be personalized and individualized, evaluated, and revised to meet patients’ changing care needs. Clearly more nursing research is needed on this topic so that valid and reliable nursing assessment tools can be developed for appropriate level of care.

An erroneous perception of some caregivers is that cognitively impaired patients have lost the ability to interact or communicate. Therefore, low expectations for care and negative attitudes toward individuals in the later stages of cognitive decline may negatively affect patient outcomes. Negative patient outcomes include hastening the loss of self and the ability to engage and be engaged in an interactive relationship.

It is important for nurses to assess each patient as a unique person and attempt to connect with the self that remains. A greater understanding of the person behind the dementia may lead to a positive change in staff values and improved quality of life for cognitively impaired people.

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