Patients' expressions of awareness of memory problems in early stage Alzheimer's disease reflected varying combinations of self maintaining and self adjusting styles of responding

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Q What is the nature of patient awareness of memory changes in early stage Alzheimer's disease (AD)?

DESIGN

Qualitative interview study using interpretive phenomenological analysis.

SETTING

A memory clinic in a large university hospital in the UK.

PARTICIPANTS

12 English speaking patients who were 57–83 years of age (mean age 71 y, 75% men), had a medical diagnosis of AD of minimal severity (Mini-Mental State Examination [MMSE] score ≥ 18 out of 30), were living with a partner or caregiver willing to participate, and were capable of providing informed consent.

METHODS

Patients and their spouses participated separately in 2 indepth interviews, 3 months apart. Topics included previous experiences, views of self, coping styles, recognition and impact of memory changes, contact with healthcare services, and views of the future. Interviews were audiotaped, transcribed, and analysed using an interpretive phenomenological approach.

MAIN FINDINGS

Participant's accounts of their awareness of memory changes resulted in a tension between a self maintaining stance (ie, maintaining continuity with a prior sense of self) and a self adjusting stance (ie, confronting difficulties and adjusting sense of self accordingly). Patients exhibited 5 processes in an ongoing, reiterative cycle of developing memory difficulties. (1) *Registering the changes*. All participants acknowledged some difficulties with memory, which "surfaced" gradually with a "growing realisation" that something was wrong. This resulted in "negotiating a shared view" with their partners. (2) *Reacting to the changes* in memory varied from minimising the impact to focusing directly on a sense of disintegration. Some expressed fears of going "gaga," "mad," or "barmy." (3) Most patients and families *explained the changes* by normalising and attributing them to ageing, "wear and tear" of a busy job, or switching off after retirement. Some participants were not informed of their diagnosis, with a "conspiracy of silence" maintained by spouses and clinicians. (4) *Experiencing the emotional impact* reflected a struggle between "putting on a protective coating" and "spending time in the depths." Some participants expressed a need to protect themselves from emotional pain and said that their memory problems were not worrisome to their families. In others, this recognition led to feelings of "slow dismay" and "being in a void." Losses in the domains of control (eg, restrictions on driving) and competence (eg, loss of status and authority with children) caused participants to feel less willing to make decisions or attempt things

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that were previously manageable. They felt embarrassed and "nervous" in social situations and feared becoming a nuisance or burden. (5) All patients attempted to *adjust to the changes* in some way. All used some self maintaining strategies, including "holding on" (trying harder to overcome problems), "compensating" (appearing to be carrying on, developing "devices" to deal with people, and strategising to cover up memory failures), and maintaining the status quo. Some participants also used a self adjusting coping style reflected in a developing sense of "fighting back." Although fighting back was helpful, an ongoing process of balancing hope and despair was needed.

CONCLUSION

Awareness of memory problems in patients with early stage Alzheimer's disease was mediated through the adoption of self maintaining or self adjusting response styles.

Commentary

The study by Clare *et al* contributes to an emerging body of knowledge and insights about living with the progressive changes in early stage AD, primarily from the perspectives of patients, as well as their family caregivers. This investigation was based on a biological manifestation of the diagnostic symptom anosognosia, or disturbances of awareness, that was expanded to emphasise a psychosocial context. The researchers found that 12 patients with MMSE scores of 19–29 reported not only substantial levels of awareness, but also subjective meanings and multiple affective responses to changes in memory.

Interpretive phenomenological analysis of 2 consecutive interviews with each patient-caregiver dyad was an effective method to identify the awareness of gradual changes in early stage AD as a threat to patients' self concepts. Patients' responses to this threat ranged from self maintaining to self adjusting.

These findings have several important implications for improved patient centred nursing practice. Nurses need to understand that the growing number of patients diagnosed and treated for early stage AD may have greater than expected awareness of the deficits that pose threats to their self image. This awareness is reflected in a wide range of feelings, behaviours, and communications and should not be mislabelled as denial. The 5 response processes identified (*registering, reacting, explaining, experiencing the emotional impact, and adjusting to the changes*) provide a valid framework for developing more effective, therapeutic nurse-patient responses to improve coping strategies that support personhood for patients. Counsellors can also promote the wellbeing of the patient-caregiver dyad by sensitising family caregivers to their relatives' level of awareness, feelings and fears associated with early memory loss, and the potential meanings of certain self preserving or protecting behaviours.

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