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Managing threats to self: awareness in early stage Alzheimer's disease

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Abstract

Lack of awareness is described as a clinical feature of Alzheimer's disease that is observed in a significant proportion of those assigned this diagnosis. There is an extensive literature emphasising biological explanations in which unawareness is viewed essentially as a symptom, but possible psychosocial factors, together with the socially constructed nature of expressed awareness, are largely neglected. The onset of dementia may be viewed as a threat to self occasioning attempts to regain control through a range of psychological strategies, which are likely to affect the ways in which people communicate an account of their experience and hence the extent to which they may be considered 'aware'. In the present study, 12 participants with a medical diagnosis of early stage Alzheimer's disease, who were described in clinical records as ranging from 'very aware' to 'unaware' of their illness, were interviewed on two occasions. Partners were also interviewed separately on each occasion. Transcripts were analysed

using Interpretative Phenomenological Analysis. In response to their memory difficulties, participants were seen as engaging in the processes of acknowledging, reacting, explaining, experiencing the emotional impact, and adjusting. All participants acknowledged memory problems, indicating a basic awareness of changes in their memory functioning, but made varying judgements about the meaning and impact of these. The resulting spectrum of responses formed a continuum running from "self-maintaining" to "self-adjusting". A self-maintaining stance related to attempts to normalise the situation and minimise the difficulties, thus maintaining continuity with prior sense of self, while a self-adjusting stance related to attempts to confront the difficulties and adapt one's sense of self accordingly. A preliminary model of the construction of awareness in early stage Alzheimer's is presented that acknowledges biological mechanisms but places the main emphasis on psychosocial factors and self-concept.



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Keywords

Alzheimer's disease; Awareness; Anosognosia; Phenomenology; Self-concept; UK

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