



Awareness, Self, and the Experience of Dementia

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Psychosocial Studies of the Individual's Changing Perspectives in Alzheimer's Disease

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Chapter 6

Awareness, Self, and the Experience of Dementia: Foundations of a Psychologically Minded Approach

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ABSTRACT

It is now widely acknowledged in policy and practice that the individual with dementia retains the status of a person and the essence of selfhood, has the right to be heard, and has the capacity to live well with the disabilities that dementia brings, given appropriate support. Nevertheless, negative assumptions about dementia as a 'loss of self' and a 'living death' remain influential. This chapter examines research evidence that can provide a foundation for a psychologically minded approach to dementia care and help to create a more constructive view of what it means to live with dementia. In this chapter findings are drawn from projects conducted by the Research in Ageing and Cognitive Health (REACH) group at Bangor University, UK on awareness, self-concept, identity and the experience of dementia for people across the dementia trajectory. The REACH group is now at the University of Exeter, UK.

INTRODUCTION

The stigmatisation and objectification of dementia often stems from a belief that people with dementia have lost global awareness and their whole sense of self. This chapter aims to establish the foundation for a psychologically minded approach to dementia care and create a more constructive view of what it means to live with dementia. After touching on the negative assumptions about dementia, an understanding of the nature of awareness and self will be outlined. These two frameworks will be used to discuss

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the experience of awareness and identity in early-stage, moderate and severe dementia. The evidence cited in this chapter will originate predominately from research conducted by the Research in Ageing and Cognitive Health (REACH) group at Bangor University, U.K. involving people with dementia and their caregivers. The REACH group conducts research relevant to maintaining health in later life and living well with dementia and associated conditions. This research draws on concepts, theories and methods from clinical psychology, social gerontology, neuropsychology, and neuro-rehabilitation.

Awareness can be defined as a reasonable or realistic perception or appraisal of a given aspect of one's situation, functioning or performance, or of the resulting implications. In this chapter we outline the Levels of Awareness framework, which is useful for conceptualising and understanding the nature of awareness in dementia. In the Levels of Awareness framework, awareness is considered as operating at four levels of increasing complexity: sensory registration, performance monitoring, evaluative judgement, and meta-representation. Research conducted by the REACH group has focussed on awareness in various stages of the dementia trajectory. Additionally, theories of the multifaceted nature of self will be discussed to enable dementia-related changes in self-identity to be explored.

The experience of early-stage dementia will be discussed with reference to awareness, psychological adjustment, self-concept, and maintaining a valued identity. While some researchers have argued that self and identity diminish or are lost as the disease progresses, early evidence from intervention studies suggest that there are opportunities to support self and identity in people with dementia. This has important implications for how we can improve the experience of living with dementia and tailor interventions to provide person-centred care. The experience of living with moderate-to-severe dementia will also be considered in relation to self, identity and awareness. Understanding awareness can provide a route to enhancing the experience of people with severe or end-stage dementia. In an intervention study (AwareCare), care home staff were asked about their perceptions of residents' awareness and it was found that training staff to observe and identify signs of awareness at the sensory and perceptual level can improve residents' quality of life.

This chapter will conclude by considering ways of building on retained awareness and supporting self-concept and sense of identity to illustrate how a psychological approach can assist people to live well with dementia across the disease trajectory.

BACKGROUND

Negative Assumptions about Dementia

The term dementia comes from the Latin and literally means "out of mind" or a state of having lost one's mind (Herskovits, 1995). Many negative consequences follow a diagnosis of dementia but some of those which can be overlooked include the medicalisation, stigmatisation and objectification of the person with the condition. For instance, when discussing the impact of the condition, the focus is often on the experience of caregivers, namely the burden experienced while providing care for the person with dementia. There is often little consideration of what impact this discussion has on the person with dementia. Additionally, in dementia, the self can be affected by stigma as well as by consequences of the illness, and factors such as personality and life history are often not considered when interacting with the person with dementia, which can have a negative impact on self-efficacy (Sabat, 1994). This issue has been given prominence in the theory of malignant social psychology (e.g., Kitwood & Bredin, 1992). In Kitwood's

dialectical model of dementia (see Figure 1), the experience of dementia is influenced by the interaction of biological factors (i.e., neurological impairment) and psychosocial factors (i.e., the interpersonal environment). Negative discourses direct attention away from the research evidence: People with dementia can retain substantial strengths, abilities and cognitive functions (Herskovits, 1995; Petrescu, MacFarlane, & Ranzijn, 2014). An alternative positive discourse, founded on a social interactionist perspective, can provide the foundation for social scientists to reframe and reclaim the “self” in dementia (Herskovits, 1995). It is important that such a psychologically minded approach to dementia care is taken; indeed, there is evidence that the brain’s potential for change (plasticity) is retained in dementia, although the extent of change may depend on individual factors (Fernández-Ballesteros, Zamarrón, Tàrraga, Moya, & Iñiguez, 2003). Evidence for this alternative discourse is the subject of this chapter.

Levels of Awareness Framework and Theory of Self

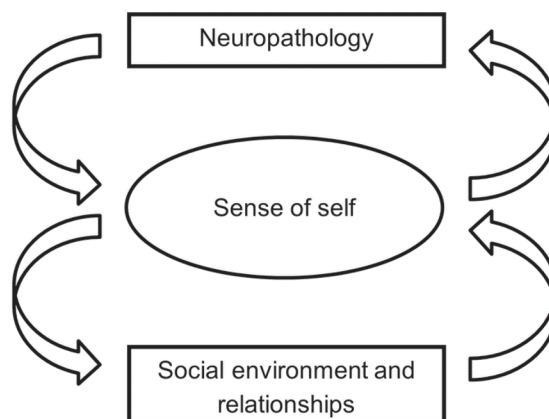
In order to reframe and reclaim the self in dementia, it is first necessary to consider the nature of awareness and the self.

Awareness

Awareness can be defined as a reasonable or realistic perception or appraisal of a given aspect of one’s situation, functioning or performance, or of the resulting implications, which may be expressed explicitly or implicitly (Clare, Rowlands, Bruce, Surr, & Downs, 2008). Awareness is not a unitary function and can be considered to operate at four levels of increasing complexity, as outlined in the Levels of Awareness framework (Clare, Marková, Roth, & Morris, 2011) described below.

Sensory registration consists of internal representations that enable attentional resources to be directed towards specific objects. These simple representations underpin more complex manifestations of awareness. The environmental and social stimuli available will determine what opportunity people have to register and express sensory behaviour (Clare, Marková et al., 2011). It is this level of awareness that is witnessed when people respond to environmental and social stimuli.

*Figure 1. Dialectical model of dementia
(Based on Kitwood, 1997)*



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Performance monitoring builds on sensory registration by involving the monitoring of ongoing task performance. This occurs when people compare expected and actual outcomes and evaluate how successful actions have been. However, this domain of awareness may still be relatively circumscribed (Clare, Marková et al., 2011). For instance, performance monitoring could be as rudimentary as lifting a cup to the mouth and realising that the cup is not heading towards the intended target, or as complex as monitoring how well one is performing on a mental arithmetic task.

Evaluative judgement includes a person's general awareness of any symptoms, changes or impairments in his/her abilities, or of his/her functioning or situation. These judgements are more varied and composite in nature than performance monitoring, as judgements will depend on how changes are registered, personality attributes and past experience, as well as social and cultural factors (Clare, Marková et al., 2011). For example, a person might evaluate how well he/she completed a cognitive test by considering his/her score in light of how he/she recalls performing on the measure before, how well he/she believes other people perform, and his/her view of him/herself as a competent, capable individual.

Meta-representation is the most complex level of awareness and incorporates self-reflections that rely on personal knowledge and experience as well as on the perspectives of others. Again the social and environmental situation can influence how much support is provided for this reflective process (Clare, Marková et al., 2011). For instance, it will be hard to demonstrate meta-representational awareness if there is no opportunity to discuss, ponder and reflect with others.

There may be interactions between these levels of awareness and people may not operate at the same level of awareness in all domains. For example, someone may show a meta-representational awareness of his/her current emotions but only operate at the performance monitoring stage when considering how well he/she does on cognitive testing. Therefore, it may not be valid to generalise between levels or between domains of awareness (Clare, Marková et al., 2011). Consequently, the relationship between level of cognitive decline and degree of awareness is not straightforward (Clare, Rowlands, Bruce et al., 2008). Researching this field is complicated; many research designs rely on participants having sensory registration (i.e., a basic concept of their position and relationship to the environment) as this is necessary in order to interact with the researcher and study materials (Caddell & Clare, 2013).

The Self

Self can be defined as personal identity or a continuity of one's point of view, and this can be drawn from multiple public personae (Herskovits, 1995). From a social constructionist perspective the self is not unitary. Harré's (1998) theory highlighted three modes of self which, as in the case of awareness, can be considered to be operating at different levels of complexity, as described below.

Self-1 is seen when a person identifies him/herself as a unique individual with an embodied viewpoint. For instance, most people talk in terms of "I" and "my." This sense of self is less fluid than the more complex representations below. Sabat argued that people in the moderate-to-severe stages of dementia frequently use personal pronouns and demonstrate a sense of personal identity (Sabat, 2002; Sabat & Collins, 1999; Sabat & Harré, 1992).

Self-2 is evident when a person talks about his/her personal experiences and history, personal attributes and beliefs. This self is influenced by the comments of others, and a person's sense of his/her personal attributes can change over time depending on the social and environmental feedback he/she receives.

Self-3 is the social persona, the self which is presented to others at any given time point. This self can have multiple facets and will change according to the context and situation, as it is constantly recon-

structured in interactions with other people. This means that in order for a person with dementia to present a positive identity to others, the cooperation of these others is required. Work by Sabat has shown that some people with dementia do express multiple personae. For example, one participant, I.R., constructed her identity as a helper and nurturer, as well as a confused dementia sufferer (Sabat & Harré, 1992), while another participant, Dr. M., described herself as having dementia as well as being an academic and a social worker (Sabat, 2002).

It can be difficult to tease apart these different types of self because the self is experienced as a single entity (Caddell & Clare, 2013). In research, self-1 (which recognises the self as a unique embodied individual) will be exhibited by many participants even if this is not what is being explicitly tested (Caddell & Clare, 2013). However, self-2 and self-3 can only be examined if participants communicate about these to the researcher. This can be done indirectly. For instance, in order to complete many questionnaires it is necessary for participants to have a “private self” that is intact to at least some degree (Caddell & Clare, 2013).

Although some research focuses on the loss of awareness and self in people with dementia, findings from studies by the REACH group suggest that there are opportunities to support these in people with dementia. Research investigating awareness and self in people with early-stage dementia is the focus of the following section.

EARLY-STAGE DEMENTIA

Awareness

Extent of Retained Awareness

Much of current literature on awareness in early-stage dementia demonstrates inconsistent findings due to variations in the methodologies employed across studies, the conceptualisation of awareness, the object of awareness selected, and the type of assessment measurement used (Clare, Whitaker et al., 2011).

One line of investigation has been to compare self-ratings and informant ratings. Nelis et al. (2011) demonstrated that people with dementia have a tendency to rate themselves significantly higher compared to caregivers in empathetic skills, relationship skills and social behaviour. Traditionally, such a discrepancy has been taken as evidence of impaired awareness, but such studies typically have not considered either how caregivers who provide ratings are functioning socially, or how the person with dementia was considered to function in these domains premorbidly. The findings from these types of studies are also inconsistent; some comparisons of self-ratings and proxy ratings have indicated that people with early-stage dementia can have a relatively accurate appraisal of their traits (Caddell & Clare, 2012).

Another research approach has been to compare self-ratings to objective measures of performance. Self-rated functioning is associated with immediate memory performance, demonstrating that people with early-stage dementia can have a degree of functional awareness (Martyr, Nelis, & Clare, 2014). In another study, self-ratings of functioning in instrumental activities of daily living were compared to letter fluency ability (the ability to generate words beginning with a specified letter). People who had letter fluency scores in the impaired range rated themselves as experiencing greater difficulties in their daily functioning (Martyr et al., 2012). This suggests that difficulties in expressive language may contribute to better awareness.

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The Memory Impairment and Dementia Awareness Study (MIDAS) was a multimethod longitudinal exploration of awareness in people with early-stage dementia. Assessments were undertaken at baseline, and then 12 and 20 months later. In the initial phase of the study, a cross-sectional analysis was conducted using questionnaire data. It was found that the extent of participants' awareness differed in relation to the different domains considered (Clare, Whitaker et al., 2011). For instance, one method of measuring awareness involved using vignettes describing people with no, very-early-stage and more established dementia (Clare, Nelis, Martyr, Whitaker et al., 2012). Vignettes enable participants to retain some distance from the subject matter and people's responses to vignettes can provide insight into their understanding and the beliefs that underlie their conceptualisations. The majority of MIDAS participants correctly classified the established dementia vignette as reflecting either dementia or memory loss and some suggested actions that the character in the vignette could take to improve the situation. A minority (23%) self-referenced their own memory problems when responding to the vignette, and this included 36% of people who were classified as showing limited awareness on other measures. These findings suggest that the majority of people with early-stage dementia can distinguish between normal ageing and dementia and are aware of the signs of dementia in others.

Another measure used in the MIDAS study was an in-depth interview with participants in which they were asked about their experience of having memory problems. On this measure, participants' responses reflected their meta-representations in relation to themselves and their situation. Participants' performance on the vignette measure (described above) was moderately correlated with scores on this in-depth interview. However, it was participants' meta-representational capacity (as tapped in the in-depth interview) which seemed to determine what suggestions participants were able to give in response to the vignette; those rated as having limited or no meta-representational awareness were less able to offer advice to the character depicted in the vignette (Clare, Nelis, Martyr, Whitaker et al., 2012).

The findings from the MIDAS study suggest that although different awareness phenomena are inter-related, awareness should be seen as specific to a given level, domain and measurement method. Further support for this conclusion comes from studies of implicit awareness. For example, Martyr et al. (2011) found that participants with dementia had greater reaction times to dementia-related, and hence emotionally salient, words on the emotional Stroop task. This effect was not related to their degree of awareness of their diagnosis, so implicit awareness can still be elicited even when explicit awareness is diminished.

Relationship to Degree of Cognitive Impairment

There has also been substantial interest in exploring whether awareness and cognitive functioning are related. Some studies have found that people with limited awareness have more severe cognitive deficits (Hurt et al., 2010). However, psychological and social factors also significantly influence level of awareness, alongside illness-related and neuropsychological factors. Relevant factors include mood, self-concept and personality, although patterns of association may vary across the different domains of awareness (Clare, Nelis, Martyr, Roberts et al., 2012).

One study that considered the relationship between cognitive impairment and awareness in detail was conducted by Naylor and Clare (2008). They assessed 29 people with early-stage dementia on standardised measures of autobiographical memory, identity and awareness of memory functioning. Participants had a mean score of 22 out of 30 on the Mini-Mental State Examination (MMSE: Folstein,

Folstein, & McHugh, 1975), but the range of scores was 16 to 29, indicating that some participants may have been moderately impaired. The researchers found that participants' level of cognitive functioning did not significantly affect scores on measures of identity or awareness.

Self

Awareness and Self-Identity

Naylor and Clare (2008) also considered the relationship between identity and awareness. Participants who demonstrated less awareness, as indicated by ratings that were more discrepant from those of informants, had a more positive and definite sense of identity. This was not the association expected, and Naylor and Clare suggested several explanations for these findings. Perhaps people with poorer semantic (factual) memory were less able to search their episodic (event-based) memory for information with which to answer questions on an identity questionnaire. This would mean they might be responding to the questions on the basis of one or two pertinent incidents that they could still recall. There was some evidence to support this conclusion. Participants who showed higher awareness, as indicated by a lower discrepancy between self-ratings and informant ratings of current memory functioning, could recall a greater number of personal incidents from their midlife period (i.e., their more recent past). However, there are alternative explanations. For example, participants' reports might have reflected a psychological defence designed to protect themselves against distress. A final possibility is that, if participants were less able to update their episodic memory, they might have felt more definite about their identity because they would not have gone through the difficult process of trying to integrate their changed functioning into their self-concept.

Other studies have reported similar findings. The MIDAS study also employed questionnaires that included items about participants' self-concept as well as their perception of their abilities in various domains of functioning including memory, functional abilities, and social skills. Stronger self-concept was associated with higher self-ratings of memory and social functioning and with poorer awareness (Clare, Nelis, Martyr, Whitaker et al., 2012). These authors favoured the explanation that participants with less awareness had greater difficulty updating their view of themselves and their attributes (self-2) in the light of new environmental and social information. This pattern has been described as adopting a self-maintaining coping style, though sometimes the implication of this term is that participants use this style, consciously or unconsciously, as a psychological defence. Coping style is thought to lie on a continuum, with self-maintaining strategies and self-adjusting strategies as polar opposites (Clare, 2003). People who employ self-maintaining strategies aim to keep things the same as before, while people who utilise self-adjustment strategies try to integrate change into an adjusted sense of self. The negative views of others and the limited opportunities people with dementia have to present their sense of self serve as additional constraints to adopting self-adjusting strategies (Sabat, 2001).

Relationship to Degree of Cognitive Impairment

The explanation endorsed by Clare, Nelis, Martyr, Whitaker et al. (2012) regarding the relationship between self-concept and awareness has some support from an analysis of the longitudinal data from the MIDAS study (Clare, Whitaker, Nelis et al., 2013). In the time three (20-month follow-up) data, poorer memory performance was again associated with more positive self-concept ratings. However, at this

final time point, the mean cognitive screening score on the MMSE for the sample remained in the mild impairment range at 22 out of 30 and, over the 20 months of the study, participants' self-concept ratings were fairly stable and comparable to those of the general population. This suggests that self-concept does not change as a straightforward result of dementia-related memory decline. For people with dementia, lower self-concept ratings were associated with higher levels of depression and anxiety.

Characteristics of Sense of Identity

The majority of research has, however, considered what forms of identity people with early-stage dementia hold. Caddell and Clare (2011b) investigated whether people with dementia thought their identity had changed post-diagnosis and whether they believed their identity might be affected in the future by their dementia. Five women and five men took part in semi-structured interviews. Self-1, self-2 and self-3 were evident in the responses of these participants.

The interviews showed that in early-stage dementia, identity remained multifaceted: People referred to personality traits, relationships, activities, attitudes, beliefs and opinions when they talked about important aspects of their selfhood. These are some examples of how participants described themselves: "I consider myself a reasonable person you know, I get on with most people" (Caddell & Clare, 2011b, p. 384), "No problem, we still go to church on a regular basis, and er, I - no, it hasn't affected anything like that" (p. 385), and "I'm just an ordinary mum, you know, and grandmother . . . I think I haven't changed" (p. 387).

Most participants held a particular self-concept or identity and thought this was mostly unchanged since the onset of dementia. Only one respondent thought she had become a different person. None of the respondents talked about changes in their attitudes, opinions, beliefs or preferences. Some respondents did refer to changes such as symptoms and emotional reactions to dementia, but they indicated that these did not affect their identity: "The only thing that does affect me is that sometimes when I go shopping for more than one item, I tend to forget some of them" (Caddell & Clare, 2011b, p. 390).

In another interview study, Werezak and Stewart (2002) found evidence of similar sentiments expressed by participants. These authors considered how six respondents learned to live with early-stage dementia. Interviews highlighted five stages of adjustment: antecedents (recognising there is a memory problem); anticipation (expecting a diagnosis and considering future losses); appearance (becoming aware that others are noticing the memory loss); assimilation (fitting dementia into one's inner and outer world), and acceptance (coming to a position where the remainder of life can be enjoyed). During the appearance stage, respondents noticed their memory problems yet described seeing themselves as the same.

Further support for a continuing sense of identity in early-stage dementia comes from an intervention study that provided a series of poetry writing workshops for people with early-stage dementia (Petrescu et al., 2014). Four women took part and what emerged most strongly in the poetry produced was the women's insistence on their maintained sense of self; these writers portrayed a strong sense of present identity in their poems.

Finally, a study with members of the Dementia Advocacy and Support Network International (DASNI) conducted by Clare, Rowlands, and Quin (2008) used a longitudinal design to explore how identity changed and how it was supported in early-stage dementia. DASNI is an internet-based self-help and mutual support network for people with a diagnosis of dementia. Over two years, semi-structured inter-

views were conducted with seven group members about their experiences and views. Clare, Rowlands, and Quin (2008) found that part of the participants' journey postdiagnosis had been to regain a clear sense of identity. When these participants talked about their current situation, most expressed a strong sense of identity and self-acceptance:

I have always been a person who has wanted to make a difference in the world and through DASNI I feel that I have been able to change a small part of the way some people think about early-stage dementia. (Clare, Rowlands, & Quin, 2008, p. 20)

There seems, therefore, to be evidence that self-1, self-2 and self-3 continue to operate in early-stage dementia.

Changes in Identity

Caddell and Clare (2011b) did find, however, that there was tension in respondents' accounts. Although many said their daily lives continued as usual, they concurrently identified ways in which they had had to adapt: "Well, as my memory's got worse and worse, erm . . . I've - I've become less and less involved in things going on" (Caddell & Clare, 2011b, p. 309). One respondent who said she had not changed as a person also described feeling that something had changed. This may represent some dissonance in self-3, the social personae, that respondents wanted to present in the interview.

Similarly, in the DASNI study (Clare, Rowlands, & Quin, 2008), respondents did report some changes occurring in their identity. Compared to their sense of self and identity before the onset of dementia, respondents commented that they believed part of themselves had indeed been lost. This was especially the case if respondents had retired because of dementia: "I had to give up my job, this was a devastating loss. It was essentially how I had defined myself" (Clare, Rowlands, & Quin, 2008, p. 17). The difference in emphasis from Caddell and Clare (2011b) may be due to the fact that the participants in the DASNI study were relatively young (age range: 48-66 years) and at this life stage the changes necessitated by declining cognition, such as retirement or changed family commitments, might have been particularly pertinent to their sense of identity.

Some of the differences in participant reports may also be related to respondents being at different stages in the process of adjusting to and accepting a dementia diagnosis. Werezak and Stewart (2002) highlighted the five stages of adjustment: antecedents, anticipation, appearance, assimilation, and acceptance. In particular, assimilation was an important stage of the process. Assimilation referred to the continual process that respondents described of fitting dementia into daily life. This included assimilating their thoughts and feelings about the disease. All of the respondents in the study by Werezak and Stewart described achieving some degree of acceptance of their dementia and stated that they were able to focus on enjoying the remainder of their lives. This suggests that the end result of changes to identity need not be negative.

Maintaining Sense of Identity

In the interviews conducted by Caddell and Clare (2011b), respondents were also asked about what they believed would happen to their sense of identity in the future. The majority of respondents did not think they would change in the future and expressed a desire not to change: "If I haven't changed since

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(childhood), I'm not likely to change again now am I?" (Caddell & Clare, 2011b, p. 389). However, most respondents also described uncertainty about what to expect. Participants did fear losing abilities that contributed to their current sense of identity, and several linked this threat to a potential deterioration of their dementia: "I'm hoping they'll find something that will stop it deteriorating . . . I dread the thought of it getting worse . . . you know, if I couldn't communicate" (Caddell & Clare, 2011b, p. 388).

Steeman, Tournoy, Grypdonck, Godderis, and Dierckx De Casterlé (2013) utilised a longitudinal design to explore how identity was maintained in early-stage dementia. They interviewed 20 people with early-stage dementia four times over a period of 13.5 months. Stage of dementia was determined using the Clinical Dementia Rating (CDR) and at baseline participants had a CDR of either 0.5 (*questionable dementia*) or 1 (*mild dementia*). In the initial interviews participants spoke about being valued for what they did, and their current functioning was an important element in this identity construction: "Yes, that is vanity, that is vanity, is it not. I still work for a firm in N. and now and then I still play a little bit the role of consultant, adviser" (Steeman et al., 2013, p. 225).

At the final interview 11 participants remained in the questionable or mild dementia range. At this time, participants talked more about being valued for who they were and reflected this with stories about their personal characteristics, although they could still base their current sense of value on past achievements. This pattern of shifting focus for identity was evident in 13 participants and seemed to be triggered by cognitive decline and increased dependency. Steeman et al. (2013) provided two case studies to demonstrate this pattern. These are briefly described below.

Liza had a baseline MMSE score of 25 and talked of how she was able to function and manage: "I always have a notebook here, in which I write down everything, if I need something in the kitchen or so. And then it is not so difficult to do the shopping" (Steeman et al., 2013, p. 229). At the final interview Liza maintained a CDR of 0.5 but was much more dependent on the help of others. In this interview she linked her positive identity to her view that she still had control over who she was, what she wanted and what she felt: "I believe I still have sound wisdom" (Steeman et al., 2013, p. 230).

Another participant was Terry. She had a baseline MMSE score of 21 and a CDR score of 0.5. In the initial interviews she emphasised her autonomy, which she related to her continued ability to drive:

I'm not a valetudinarian yet. And I still drive the car well. My daughter told me I'd better sell the car. . . . But if I don't have a car, then I'll feel hey hey (grumbling). Then I'm a mere nobody. That's what I think of it. (Steeman et al., 2013, p. 233)

At her third interview Terry had maintained her CDR and MMSE scores but her doctor had advised her to stop driving. Despite Terry's concern that such an occurrence would negatively impact her identity, this was not actually the case as instead she emphasised her soundness of mind in taking no risks and in saving money:

Yes, that's what he said. But I was going to get rid of the car anyway. My son gave it to me and it stands still a lot, losing value each day. It's too stupid that I [would] still [have a car]. . . . It's gone now; I guess it has been 14 days or three weeks. But I really don't notice it. No, I'm still, uh, I'm still very careful. I don't believe that it, uh. The doctor maybe does it because he has to, if they ever would say something. They can probably determine it precisely how I was, should I have an accident. It would be too stupid, wouldn't it? And also, for the little bit that I was driving. No, no, I'm not going to lose any sleep over it. (Steeman et al., 2013, p. 234)

Obviously in early-stage dementia, in particular, people often have identities as part of a married couple as well as single identities. Davies (2011) explored this in joint interviews with couples where one spouse had been diagnosed with early-stage dementia. These respondents did not expect that their marriage commitment would be disrupted by the process of dementia, but they did understand that changes might arise in their roles and responsibilities.

Having an identity as a couple meant that participants talked in terms of living with and responding to the changes dementia brought as a couple. This was illustrated by one caregiver who, although he had to take on more of a supporting role, still described himself and his wife as doing things together:

But we had to do a couple of chores in the morning so we did it together and then I sort of say, "Okay, we're going to bring the car in for a tune-up. We have to go to the bank," and "I'll write it down for the day, and then you do the laundry." So we cross out the other day before 'cause that's all she needs to do is focus on that day. And that's what she does. She took the laundry down. She washed it. She ironed it. (Davies, 2011, p. 228)

This identity of "couplehood" was also evident in a third theme in the interviews conducted by Davies (2011) that focused on resilience. Couples reported a continuing caring relationship that was resilient to the problems of early-stage dementia, and thus they maintained continuity in their marital relationship and maintained the "married" identity.

Psychological Adjustment

From the proceeding discussion it is evident that many people with early-stage dementia need to adjust and compensate for changes in their identity. This can have psychological consequences and there has been interest in how people with early-stage dementia manage and cope and how this relates to their awareness and sense of self. This research will be briefly reviewed before the moderate and severe stages of dementia are considered.

Self

The changes and strategies people employ to maintain a valued identity underscore how important identity is to psychological well-being. Caddell and Clare (2012) explored how different aspects of identity related to mood and quality of life in early-stage dementia. Using a cross-sectional analysis of questionnaire measures, they found that higher scores on identity-related variables were associated with fewer anxiety and depression symptoms, as well as better quality of life.

The analysis of the longitudinal MIDAS data also demonstrated that self-concept was an independent predictor of quality of life in early-stage dementia. However, this relationship was partially mediated by participants' depression and anxiety scores (Clare, Whitaker, Nelis et al., 2013). A recent analysis of the overall MIDAS data used bivariate correlation and regression analyses (Woods et al., 2014) and found that self-concept made a strong, independent contribution to quality of life.

However, the association between psychological well-being and identity may be mediated by additional factors. For instance, it could be that the participants showing this pattern had less severe cognitive problems, as autobiographical and personal semantic memory are thought to play a part in the formation

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of identity (Massimi et al., 2008). Additionally, the MIDAS study data (Clare, Nelis, Martyr, Whitaker et al., 2012) and findings from the study by Naylor and Clare (2008) would suggest that awareness may also be a mediating factor.

Awareness

There have been mixed findings about the relationship between awareness and psychological adjustment. Initial studies found that health-related quality of life did not differ according to level of awareness in people with mild dementia. This was taken as evidence that limited awareness might not always function as a protective factor (Hurt et al., 2010). For instance, Werezak and Stewart (2002) considered that awareness impacted on the antecedent stage of adjusting to a dementia diagnosis, as participants had to become aware of their memory problems to start the acceptance trajectory. However, recent studies have not always supported these initial ideas.

Participants in the MIDAS study who had low levels of awareness reported significantly less anxiety than those with higher awareness scores (Clare, Whitaker et al., 2011). The relationship between awareness and emotional well-being was explored further in a recent secondary analysis of the MIDAS data (Woods et al., 2014). Few of the awareness measures emerged as significant predictors of quality of life. However, the discrepancy between how the person with dementia evaluated his/her memory and the caregiver's ratings did have a small-to-medium significant correlation with quality of life. This association was mediated by depression (which decreased the strength that awareness had in the regression model) and self-concept, which made a strong, independent contribution to the model (i.e., more positive views of self were associated with higher quality of life).

In moderate dementia, which is considered next, a similar relationship has been found between health-related quality of life and awareness. Hurt et al. (2010) found that people with more limited awareness rated themselves as having higher quality of life.

MODERATE-TO-SEVERE DEMENTIA

Awareness

Moderate-to-Severe Dementia

Clare, Rowlands, Bruce et al. (2008) explored the differing degrees of awareness that were manifested in the interactions and conversations of 81 people with dementia living in 10 different residential homes. On the MMSE more than half of the participants scored below 11 and the modal score was 0. However, all participants had some speech. The final dataset of unstructured interactions included 304 conversations with 80 participants and these were analysed using a grounded theory approach.

All participants demonstrated some degree of retained awareness. This awareness was expressed in relation to the self, relationships and the environment. In terms of the environment, respondents made comments about the weather and the home routine. For example, one participant stated, "But it's wet really, out there, you know, now" (Clare, Rowlands, Bruce et al., 2008, p. 2372). However, a more

complex awareness was also demonstrated, with respondents expressing awareness both in relation to the present and past and in relation to changes that had occurred over time. One participant showed this awareness by saying:

Don't do anything now . . . I used to do a lot of walking at one time, but . . . I've just . . . nothing's right now . . . I'm not a bit like I used to be . . . not a bit like I was . . . when I first came here. (Clare, Rowlands, Bruce et al., 2008, p. 2374)

In terms of self, awareness was shown in relation to the body, mind, emotions and actions. For example, a female participant said, "But the pain now and again, the arm swells here and the fingers kill, but otherwise I'm alright" (Clare, Rowlands, Bruce et al., 2008, p. 2371). Some participants demonstrated this awareness through presenting themselves in particular ways or using coping strategies that attempted to cover up their diminished functioning, as one participant said:

Well, perhaps err . . . things have gone wrong, but I'm not gonna let on . . . They think, they think everything's OK, but it isn't, I've made a right mess of it . . . [Interviewer: And so sometimes you cover up when you make a mess?] Yes, I'm not honest enough, when I know I'm wrong. (Clare, Rowlands, Bruce et al., 2008, pp. 2373-2374)

Participants also talked about their relationships with others and showed an awareness of other people's feelings and needs. Therefore, these interviews provide substantial evidence that considerable awareness is retained in the moderate-to-severe stages of dementia. However, there were also, as would be expected, some examples of unawareness and this often related to inaccurate appraisals or to difficulties in making sense of the current situation (Clare, Rowlands, Bruce et al., 2008). Some participants confused past and present experience:

And of course I don't know at the moment whether both my parents are living . . . I would think if anything disastrous had happened I would have been told, but . . . whether they're here or not I don't know. Mystery. (Clare, Rowlands, Bruce et al., 2008, p. 2375)

When respondents' appraisals were considered, some made inaccurate judgements about their capabilities: "I'm going to get, well, I sold the other [car], I shouldn't, don't think I should have done, but I did, so I'm going to buy another one" (Clare, Rowlands, Bruce et al., 2008, p. 2374). Others had difficulty understanding the perspectives of others:

I shall, I shall get shot if I don't, if I let them know what I've been doing . . . not getting on my way. I should be getting on with my work, with my work . . . I'd better go and wash up. (Clare, Rowlands, Bruce et al., 2008, p. 2374)

Severe Dementia

In a study by Magai, Cohen, Gomberg, Malatesta, and Culver (1996), 43 nursing home residents participated in observational sessions. All participants had a significant level of impairment and were con-

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sidered to have severe dementia. However, even in the most impaired participants, 29% showed sadness that was context-dependent, that is, in very-late-stage Alzheimer's disease, people behaved in a way that showed some awareness of the environment and were able to react and respond to relevant stimuli. Other participants were observed to express interest, happiness, fear and anger, demonstrating that emotional responsiveness can also be preserved in severe dementia.

Focusing on severe dementia, the AwareCare measure (Clare, Whitaker et al., 2012) was developed through a review of existing measures and focus groups held with staff and informal caregivers. The measure was refined through observations of 21 women and 19 men with severe dementia. The resulting responsiveness index is based on seven spontaneously occurring stimuli (such as someone being nearby) and three introduced stimuli (such as the person being called by name). An accompanying response index has 14 categories which are subdivided into movements in the eyes, face, head, arms, body and sounds. This measure has demonstrated face, construct and concurrent validity and there is some initial evidence of test retest reliability (Clare, Whitaker et al., 2012).

Observations of participants with severe dementia using the AwareCare measure have shown that people demonstrate the greatest responsiveness when someone is nearby or an object is introduced (Clare, Whitaker, Woods et al., 2013). An example provided by a care home staff member was, "Well, when I was giving [resident] her breakfast the other morning, she didn't like it . . . her facial expression, I could tell she wasn't keen" (Clare, Whitaker, Woods et al., 2013, p. 134). This indicates that social stimuli are most engaging for people with severe dementia. Participants with less severe dementia showed greater responsiveness, as did those with better self-care ability and greater mobility (Clare, Whitaker et al., 2012). That participants with severe dementia were able to demonstrate retained awareness and interact to some extent with their environment also suggests that self-1 may be preserved into the late stages of dementia. Other studies have considered self-2 and self-3 towards the end of the dementia trajectory.

Self

The interviews conducted by Clare, Rowlands, Bruce et al. (2008) provide some evidence that self-2 and self-3 can still be preserved in moderate-to-severe dementia. For instance, participants talked about their personal characteristics, expressed how they were feeling and what they were thinking, and talked about their increased dependence and lack of agency. For example, "Basically I'm a happy person, get worried and a bit uptight sometimes, but on the whole I enjoy life" (Clare, Rowlands, Bruce et al., 2008, p. 2371), and:

I say, "Well, that's what we've come here for . . ." We don't like to think of it that way, do we . . . we haven't come to die, we've just come, we've got to that stage, haven't we . . . And we need more help, we can't help ourselves so much. (pp. 2371-2372)

Other studies support this conclusion that self-2 and self-3 can be preserved. Crichton and Koch (2007) presented a case study of a participant named Laura who had dementia. Unfortunately, they do not provide Laura's MMSE score or any information about stage of dementia, but the suggestion is that Laura had moderate-to-severe dementia. This is based on the information that Laura had limited vocabulary, required a lot of assistance with activities of daily living and towards the end of the study she had moved to a residential home. For Laura, it seemed that it was her identity as someone who was in relationships with others that was important to her, as she said, "Well we've always got on very

well” (Crichton & Koch, 2007, p. 367). Laura remained aware of her previous occupational role as a midwife: “I used to just love delivering the babies and I did general nursing as well even though I did so many years of midwifery” (Crichton & Koch, 2007, p. 367). Additionally, Laura was able to identify previous hobbies and changes that had occurred over time: “It is annoying! Well, I used to play bowls, I’m not well enough to play anything or do anything much now, I just sort of sit around” (Crichton & Koch, 2007, p. 367).

Another study that included at least some participants with severe dementia (mean MMSE score of 8.7) was an interview study with 38 nursing home residents (Cohen-Mansfield, Golander, & Arnheim, 2000). Participants were asked about their occupational and family roles, what activities they liked and wanted to do, and what activities they could no longer do. Only 27% of respondents could not identify a previous occupational role (self-2) and the majority (47%) reported having been homemakers. Participants were able to talk about a range of previous activities and personal attributes they were proud of. For instance, one resident spoke of pride in “speaking three languages” (Cohen-Mansfield et al., 2000, p. 386). However, some also talked about roles they had now lost: “I used to be a famous teacher, a psychologist, now I am nothing” (Cohen-Mansfield et al., 2000, p. 386). When asked about family relationships (which could draw on self-3), 62% of participants talked about being a parent and 54% talked about being a son or a daughter. Additionally, 42% said being a spouse was important to them, 31% identified themselves as grandparents, and 27% reported being a sibling.

However, Cohen-Mansfield et al. (2000) found that when they talked to staff and family members, it appeared that four of the residents they interviewed had provided the researcher with imaginary identities. For instance, one family member was surprised by his mother’s claim that she was a successful businesswoman as he remembered her as a housewife and mother. This could suggest that self-2 and self-3 are not always preserved as dementia progresses. Furthermore, in terms of interpreting this study’s findings, it should be noted that the MMSE of participants ranged from 0 to 22, so all stages of dementia were included and it was not possible to distinguish which responses had been made by participants with more moderate and severe dementia.

Improving Caregiver Perceptions of Quality of Life

During the AwareCare intervention, care staff trained in the AwareCare observation method learned that it was possible to detect a range of responses in residents whom they had viewed as non-responsive (Clare, Whitaker, Woods et al., 2013). Before the training had commenced, a typical response from a staff member was, “Oh no, I’ve got to observe [resident] but she doesn’t do *anything*, that’s gonna be well boring” (Clare, Whitaker, Woods et al., 2013, p. 134). However, at the end of the intervention the perception of specific residents had changed and a more typical reflection was, “She does respond . . . A lot of eye movements and turning her head, and if you suddenly touch her and she hasn’t seen you she jumps . . . She is very aware” (Clare, Whitaker, Woods et al., 2013, p. 134).

Researcher observations also suggested that care staff who had received the training made some positive changes in their working practices. For instance, they seemed to spend more time having conversations with residents than they had done before the training. A researcher noted that in one of the homes, “[Resident] was given a textured cushion and a soft toy to hold . . . [resident] was given a magazine to hold and look through . . . when she had the magazine she was more alert” (Clare, Whitaker, Woods et al., 2013, p. 136). Family caregivers thought that their relatives’ quality of life improved when staff had been trained with the AwareCare tool (Clare, Whitaker, Woods et al., 2013).

SUPPORTING RETAINED AWARENESS AND SENSE OF SELF

How the findings discussed above can inform a person-centred and empowering care approach will now be explored.

Retained Awareness

So far, little work has been done to increase awareness in people with dementia and to inform caregivers about how to support retained awareness. While it may not be appropriate to ask the person with dementia to reflect on having memory difficulties, it may be beneficial to support awareness in other ways. Implications for care and treatment could be addressed at the various levels of awareness described earlier (Clare, Marková et al., 2011).

There are a number of different approaches to measuring awareness and these elicit different aspects of awareness. Consequently, researchers and clinicians should consider taking a multidimensional approach to assessment in order to obtain a comprehensive understanding of the person's level of awareness (Clare, Whitaker et al., 2011). As previously described in this chapter, vignettes enable the person with dementia to demonstrate his/her knowledge and understanding of the condition and its implications, and can be a useful approach when evaluating individuals who experience limited explicit awareness on direct questioning (Clare, Nelis, Martyr, Whitaker et al., 2012). Furthermore, it is important that researchers outline a clear conceptual framework, provide clear operational definitions of awareness, and specify the object in relation to which awareness is assessed (Clare, Whitaker et al., 2011).

Sensory Registration

At the sensory registration level of awareness there needs to be sensitivity to signs of preserved processing and the provision of an appropriate context in which to express these. The AwareCare studies have demonstrated the importance of appropriate interaction and environmental stimulation, as well as the essential role care staff play in engaging residents with severe dementia (Clare, Whitaker et al., 2012). A facilitating environment can be provided through sensory stimulation, postural change or environmental adaptation (Clare, Marková et al., 2011). A review by Day, Carreon, and Stump (2000) found that research recommendations have included providing tactile stimulation in surfaces and wall hangings. Different spatial configurations have also been trialled to enhance the engagement of people with dementia in activities.

Specific multisensory interventions seem to have some limitations. Baker et al. (2003) compared a 30-minute individual multisensory stimulation session with a 30-minute individual activity session in a randomised controlled trial. There were 136 participants who had moderate-to-severe dementia. Multisensory stimulation was no more effective than activity in changing behaviour, mood or cognition in the short or long term. However, the impression was gained that participants who were less cognitively able enjoyed the multisensory sessions more and those who were more able had a preference for the activity sessions. This highlights the importance of matching sensory stimulation to the needs and functioning of the person with dementia.

Other formats have had greater success. Gigliotti, Jarrott, and Yorgason (2004) selected horticultural activities designed to stimulate all five senses. For example, in one activity participants made herbal heat pads. Participants were attendees at a day centre and had a mean MMSE score of 17 (score range:

2-27) and attended an average of 16 horticultural therapy activity sessions. Compared to traditional activities, horticultural tasks generated more positive affect and participants were engaged in productive behaviours for more of the time.

Finally, some interventions have targeted a specific sense. Topo et al. (2004) trialled a picture gramophone multimedia program that worked in a similar way to a karaoke machine. While the music played, users saw the names of the songs and photographs associated with the music. Twenty-three participants were involved in the intervention evaluation. Unfortunately, MMSE scores were not available for 35% of participants. In the remainder of the sample, the majority of participants had mild symptoms of dementia, 22% were in the moderate stage, and 9% in the severe range. Staff evaluations suggested the intervention had a positive effect on participant mood and social interaction. For instance, some participants appeared “visibly pleased” (Topo et al., 2004, p. 343) when using the picture gramophone and in group sessions some participants “sang together and swayed in time” (p. 344).

Performance Monitoring

It is important that people with dementia are able to evaluate their own performance accurately so that they can undertake their daily tasks safely and maintain their independence (West, Dennehy-Basile, & Norris, 1996). This also has implications for psychological well-being, as an overestimation of ability may result in task failure while underestimation may result in task avoidance. This can lead to a further loss of skills and confidence. Interventions can provide training designed to improve the accuracy of awareness at the performance monitoring level as a means to support effective coping (Clare, Marková et al., 2011). This could be a focus for cognitive rehabilitation interventions. The ongoing GREAT study (Clare, Bayer et al., 2013) aims to establish whether cognitive rehabilitation is effective for people with early-stage dementia. After goal identification, participants meet with the therapist for 10 weekly sessions and then receive four maintenance sessions over the following six months. In these sessions participants and their caregivers work with a therapist to devise and implement strategies for achieving personally relevant goals. The therapist introduces and models strategies, and the participant and caregiver work on the selected goal during the following week according to the agreed schedule of activities. This schedule helps participants monitor their performance and their progress towards their goal. On a weekly basis strategies are adapted and adjusted as necessary.

Evaluative Judgements

A similar approach can be taken for evaluative judgements. Inaccurate evaluative judgements, for example, in which the person with dementia attributes forgetfulness to normal aging, are likely to cause caregivers concern and create practical difficulties. However, for the person with dementia this may be a way of coping and it would not be appropriate to confront these beliefs (Clare, Marková et al., 2011). Interventions can assist couples to negotiate common understandings which might facilitate the development of effective coping styles. Evaluative judgements may change over time and so an effective strategy might be to provide support that facilitates developments in coping style. Support groups for people with early-stage dementia might be valuable in this process (Lodgson et al., 2010).

In the moderate-to-severe stages of dementia, when people are struggling to a greater degree with evaluative judgements and are becoming confused by situations, contextual cues and environmental support may be beneficial (Clare, Marková et al., 2011). A review by Day et al. (2000) contained several

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examples of how physical environments have been adapted to enhance the functioning of people with dementia. How buildings are configured can assist people with dementia to orient and navigate, as can the use of landmarks and signage. Enabling people to see outdoor areas can help orient to time of day and season. For example, in one study cited by Day et al. (2000) the frequency of toilet use increased when toilets were visibly accessible (i.e., they could be seen to be vacant). Another study described in this review found that specially designed clothes closets that presented clothing in the appropriate sequential order increased autonomy in dressing. More recently, an investigation of 50 nursing homes found that with advancing dementia, people became increasingly dependent on a compensatory environment. One design recommendation was to ensure nursing homes had a circulation system with a straight layout so that residents were not required to change direction en-route (Marquardt & Schmiege, 2009).

Meta-Representations

As previously discussed, for some people with dementia it may not be appropriate to force them to reflect upon their experience of having the condition and discuss its implications; however, for others, it may be useful to have this opportunity in order to support meta-representations. This might be done through attendance at support or psychotherapy groups. Cheston, Jones, and Gilliard (2004) have explored how the narratives people with dementia share in therapy groups help them assimilate difficulties into their current self-representation. They provided a case study of a gentleman attending a 10-week psychotherapy group. Over the sessions, this gentleman was able to move from a representation (or awareness) of his memory difficulties as temporary to appraising his memory problems more accurately, and this transition was undoubtedly accompanied by increased feelings of hopelessness: “Well I do think that, that they’re going to get better. I know that it’s always been like that, that things look bad for you and then they get better” (Cheston, Jones, & Gilliard, 2004, p. 102; early session), and, “Today’s been the worst day of my life. I can’t do anything for myself at all” (p. 103; a later session).

Retained Sense of Self

A relatively recent review (Caddell & Clare, 2011a) found 10 intervention studies that aimed to improve or explored ways to support self and/or identity in dementia. Several of these interventions were based on the premise that stimulating memory would support a person’s identity. All of these studies reported some beneficial outcomes; for instance, participants had, in some cases, become more aware of their identity. None of the interventions resulted in deterioration in well-being, and most participants expressed interest, pleasure and involvement in the intervention, suggesting they enjoyed taking part. However, it was not possible to draw firm conclusions about intervention efficacy as little attention has been focused on how to target self-image or identity, or on how to measure such outcomes.

Self-1: The I

Throughout the journey of dementia people need to be acknowledged as autonomous individuals with their own views and preferences. This will validate self-1. Sensitively designed technologies may help compensate for identity loss by providing external memory and conversation aids (Massimi et al., 2008). Providing a social context in which the self is valued is particularly important because in dementia

the relational self may supersede the individual self (Herskovits, 1995). This means that people may be able to exhibit and retain more of their selves when interacting with others than when engaging in independent self-reflection.

Although self-1 can be considered a less complex and fluid representation of self than self-2 and self-3, it still has relevance in early-stage dementia. People with early-stage dementia are often very aware of the stigma about memory problems (Toms, Quinn, Anderson, & Clare, in press), and as noted in the introduction, this stigma can direct attention away from the fact that people remain unique individuals (self-1) with retained strengths and abilities (Herskovits, 1995).

The ongoing SMART study (Quinn et al., 2014) is a pilot randomised controlled trial of a group-based self-management intervention for people with early-stage dementia. The intervention is based on Social Cognitive Theory (Bandura, 1986; 1997) which suggests that people's adaptive behaviour is partly determined by their feelings of self-efficacy. Self-efficacy refers to an individual's belief that he/she can successfully perform a specific action in a particular situation. Participants randomised to the intervention are invited to attend eight weekly sessions, and facilitation techniques include enabling people with dementia to exchange ideas and coping strategies, participate in joint problem-solving, and share successes. Although caregivers are present at the first and last sessions, for the remainder of the meetings people with dementia attend alone. Integral to the SMART intervention is the acknowledgement that people with early-stage dementia remain autonomous individuals with their own views and preferences.

Self-2: Attributes and Beliefs

Cohen-Mansfield, Parpura-Gill, and Golander (2006) explored ways of tailoring interventions according to the roles that participants considered to be part of their identity. They randomised 262 people with moderate-to-severe dementia (the mean MMSE score for the sample was 11) to either a control group that received regular social activities or an intervention group where interventions were designed to engage participants in interactions related to their role identities. For example, a male participant with a strong identity as a family man was encouraged to create a family tree using family photographs. Another man who had been an aviation engineer and had a strong professional identity was engaged in constructing a model plane. Cohen-Mansfield and colleagues found that participants allocated to the intervention group manifested more pleasure and interest during activities than those in the control group. They also seemed more involved in the activities and demonstrated less disorientation and agitation. During the intervention phase these participants also showed greater awareness of their identity.

Another intervention intended to support identity through technology has been trialled with Mr. H., a gentleman with moderate-stage dementia (Massimi et al., 2008). An automated, computerised biography of his life presented in both sound and images was shown in his kitchen. This intervention was continued for four weeks. Mr. H. was said to have exhibited a stronger sense of identity following the intervention, and the computerised biography seemed to give Mr. H. a voice with which to assert his identity to others. Mr. H.'s daughter commented:

The fact that he's enjoyed seeing his past and remembered it, and he feels quite proud of what he's done. I think he feels he's got a sense of pride in the past, which he had forgotten before. He's reminded himself, in a way, of what he's achieved, I think. (Massimi et al., 2008, p. 756)

Self-3: Social Persona

Hedman, Hellström, Ternstedt, Hansebo, and Norberg (2014) explored how people with dementia positioned themselves by observing support group sessions and interviewing participants. The group they observed contained five people, all with moderate dementia. They found that the group predominantly affirmed how members represented themselves to the group and this strengthened sense of self. Group members were observed to present themselves in a variety of ways. All the participants told stories about their lives and other group members listened attentively to these and asked questions, thereby validating the person speaking in the assumed role of storyteller. Participants also presented themselves as morally concerned and supported each other as having such characteristics. One such exchange was:

Mr. L: *It's important to help the next guy.*

Facilitator: *We should all help each other - that's important!*

Ms. A: *Yes, people need to help each other.*

Mr. L: *Yes, that's Rule Number One. In any situation.*

Ms. A: *It's good to help those in need, for there will come a day when we're there ourselves, and no one will care about us. I'm not there myself yet, but even so.*

Ms. G: *And to listen to one another - that's extremely important, I think. (Hedman et al., 2014, p. 16)*

Other self-representations that were shared and then supported by other group members included the person burdened with dementia and the coping person. In representing themselves as a coping person, people positioned themselves as managing to live a good life despite having dementia:

Ms. A: *For me, it has come on gradually, so I think, "Ok, so this is how it starts. I'll just put it aside for the time being, and go out and do something nice." [Laughter.]*

Facilitator: *Right on!*

Ms. A: *There's no point trying to delve into a subject you really don't understand.*

Ms. M: *No, better to just go for a walk.*

Ms. A: *Exactly.*

Ms. M: *Get some fresh air.*

Facilitator: *Get some fresh air.*

Ms. M. and Mr. L: *Yeah! (Hedman et al., 2014, p. 17)*

Support groups do not necessarily need to meet face-to-face. Rodriquez (2013) looked at the postings of respondents on an internet forum. Although the resource was sometimes used by caregivers, Rodriquez only considered the postings of people who self-identified as having dementia and inductively coded their messages into themes. He considered a total of 354 posts from 32 respondents. He found that respondents used the forum to seek solace from the online community:

When I come to these message boards I find such hope and understanding that I am not alone in what I am going through. Robert you are an inspiration to me. Mary, Joyce, Robyn thank you so much for all your sharing. No one knows how it is, and what I am going thru. I have been to support groups and that helps some but this better. (Rodriquez, 2013, p. 1220)

Rodriquez (2013) found that some people used the forum to recover components of themselves that had seemed lost. The most pertinent example was the routine conversations that people were able to have online in comparison to the social isolation they reported experiencing offline. However, Rodriquez also provided the example of Henry, who had expressed a fear of going out alone. This received many postings from other users who made suggestions and provided encouragement. With this support, Henry did manage a shopping trip out, and posted, “It was good to find out that I can still do ‘normal’ things like a shopping trip” (Rodriquez, 2013, p. 1223).

The chance to maintain and perhaps develop new positive social personae can also be provided by self-help and advocacy groups, such as DASNI. Such forums can provide a context for interactions through which selfhood can be constructed and maintained. In such groups, participants have the opportunity to enhance key aspects of themselves that they can present in social situations and this can strengthen their self-efficacy and self-esteem (Clare, Rowlands, & Quin, 2008). As respondents from DASNI commented, “I could not do what I do or feel as I feel or lecture or even have accepted the disease if it were not for my DASNI family” (Clare, Rowlands, & Quin, p. 18), and,

I have gotten real down two times in the last four months. At that time it seems as though my failure in things I do is exaggerated many times. I feel as though my power has been lost to do anything about it. I feel helpless and hopeless. Thank God for my chat group DASNI sticking with me and helping me to crawl out. (p. 18)

SUMMARY AND CONCLUSION

This chapter started by presenting multicomponent models of awareness and self which provide the basis for a detailed and nuanced understanding of these phenomena across the dementia trajectory. In early-stage dementia the extent to which awareness is maintained was emphasised and the association between cognitive decline and awareness was considered. The self in early-stage dementia was similarly considered. This incorporated an understanding of how awareness and identity are related and the impact of cognitive impairment on sense of self. However, the majority of the evidence suggests that people in the early stages of dementia retain a strong sense of self even though they perceive some changes occurring, and there are many ways through which individuals and couples work to maintain sense of self. This section concluded by considering how awareness and identity impact psychological adjustment.

In the section on moderate-to-severe dementia, evidence was again presented that emphasised the degree to which elements and domains of awareness and identity can be preserved. This concluded with a consideration of how such understandings can improve caregivers’ perceptions of quality of life. The final section expanded on this theme of promoting well-being by providing an overview of the range of interventions that have promoted self and awareness across the dementia trajectory. This section also briefly noted considerations for future research.

In conclusion, we have reviewed evidence for retained awareness and sense of self and identity across the dementia trajectory. We have presented evidence that even in the severe stages of dementia people retain some awareness in specific domains, and some sense of self. There is substantial evidence that aspects of awareness and identity can be maintained across the dementia trajectory. This understanding

is important to consider when developing person-centred care; interventions need to promote the use of retained abilities and skills as these contribute to psychological well-being. One key challenge for clinicians is to identify when it is appropriate to promote awareness and how to support caregivers so that they understand the extent of awareness of the person with dementia (Clare, Marková et al., 2011). Research can continue to support and guide these clinical endeavours by adopting and continuing to explore a multifaceted model of awareness and self.

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KEY TERMS AND DEFINITIONS

AwareCare Trial: A trial funded by the U.K. Medical Research Council to use detailed observations to develop a tool that can be used to assess the degree of awareness shown by people with severe dementia, and to train care staff in the use of the AwareCare measure.

Awareness: A reasonable or realistic perception or appraisal of a given aspect of one's situation, functioning or performance, or of the resulting implications.

Evaluative Judgement: The ability to evaluate symptoms, changes or impairments, performance, situation, or functioning (e.g., memory).

GREAT Trial: A large-scale randomised controlled trial, funded by the U.K. National Institute of Health Research Health Technology Assessment Programme, evaluating the efficacy and cost-effectiveness of cognitive rehabilitation for people with early-stage dementia. The full title of this study is *Goal-oriented cognitive rehabilitation in early-stage dementia: multi-centre single-blind randomised controlled trial*.

Meta-Representation: Complex reflection on one's situation and the changes experienced (e.g., deterioration of cognitive ability in dementia), self-reflection, and consideration of the perspective of others.

Performance Monitoring: The ability to monitor ongoing task performance on a specific task (e.g., a memory test) as it occurs, and identify errors.

REACH Group: The Research in Ageing and Cognitive Health (REACH) group is based at the School of Psychology, Bangor University, U.K. Group members work with people in midlife to later life, with people who have dementia, and with caregivers. Their work focuses on maintaining cognitive health in later life and living well with cognitive impairment and dementia.

Self: Personal identity, attributes, life history, roles, and characteristics.

Sensory Registration: The most basic level of awareness, which involves the registration of basic sensory and perceptual information, reflecting the capacity for attentional resources to be directed towards an object, leading to appraisal and/or behaviour response.

SMART Trial: A trial funded by the Welsh National Institute for Social Care and Health Research (NISCHR) that aims to find out how best to support people in developing the capacity for self-management in the early stages of dementia. The full title of this study is *Self-management in early-stage dementia: a pilot randomised controlled trial of the efficacy and cost-effectiveness of a self-management group intervention*.