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# 14 Lives in Transition: Meaning Making and the Early Experience of Alzheimer's Disease

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## **Abstract**

Over the last decade the rise of the person with dementia as a legitimate focus of research, policy and practice attention has been one of the major advances in the dementia care field. Whilst such progress is to be welcomed there remains significant gaps in understanding that may impede the forging of genuine partnerships with people with dementia and their families. Using grounded theory (Glaser, 1978) and narrative interpretation as the main methodological approach, this chapter will explore the meaning of assessment for a diagnosis of Alzheimer's disease as it was lived by those in the sample (N=15) who attended a memory clinic in one health district in England.

## **Introduction**

The importance of reaching an early diagnosis of dementia was recently rehearsed in Standard 7 (Mental Health in Older People) of the National Service Framework for Older People (DoH, 2001, p.98) when it was explicitly stated, amongst other criteria, that the treatment of dementia *always* (my emphasis) involves:

- Explaining the diagnosis to the older person and any carers and where possible giving relevant information about sources of help and support.
- Giving information about the likely prognosis and options for packages of care.
- Making appropriate referrals to help with fears and worries, distress, practical and financial issues that affect the person and their carer.
- At all stages emphasising the unique qualities of the individual with dementia and recognising their personal and social needs.

To support these objectives, Standard 7 also suggested that there should be a specialist mental health service for people with dementia if, for instance, their diagnosis was uncertain, there were safety concerns or a risk assessment was necessary. Whilst this could be considered as useful advice, the standards are professionally constructed and, arguably, owned. A cursory review of the literature suggests that there has been little sociological research that explores what it feels like to be on the receiving end of an assessment for failing cognitive performance, and how the nature of this event impacts upon identity. This observation was recently reinforced by Cheston and Bender (1999) who suggested that the social context of memory assessment needs to be a central feature of the assessment process as, without its integration into routine practice, neuropsychological testing 'accentuates into {their} fears of dependency and incompetence, producing a sense of anxiety and threat' (p.200). Moreover, Cheston and Bender (1999) contend that in their extensive experience as clinical psychologists, few people with suspected dementia are told why they are being assessed. It would appear, therefore, that subjective constructions of the diagnostic process in Alzheimer's disease is important to capture if the uncertainty that so often accompanies its onset (Rolland, 1988; Aneshensel *et al.*, 1995) is to be reconstructed and placed within the person's agency.

One way to clarify the confusion surrounding primary care practice and an early diagnosis of dementia is to refer the person (and their care partner(s) as necessary) to specialist services at the point of their initial contact (Wilcock *et al.*, 1999). To this end the development of memory clinics in the USA and most European countries from the late 1970s onward appeared an ideal solution to this dilemma (Philpot and Levy, 1987; Wright and Lindesay, 1995). Indeed, studies have shown that in health districts where memory clinics exist, referral patterns and the identification of dementia is increased in community samples (Thompson *et al.*, 1997; Audit Commission, 2000; 2002a,b). This is due, in no small part, to the extensive range of tests that are available at such centres and the concentrated focus of professionals. For example, in memory clinic assessment of suspected dementia, more extensive neuropsychological tests are usually triggered by a Mini-Mental State Examination (MMSE) (Folstein *et al.*, 1975) score of 18 or above. As Bucks and Loewenstein (1999) suggest, 'best practice' indicates that such tests are conducted by members of a multi-disciplinary team which may involve the contribution of a neurologist, psychiatrist, social worker, nurse and psychologist. Writing about this intensive programme as forming part of the practice of the Bristol Memory Disorders Clinic, Bucks and Loewenstein (1999, p.111) indicated that the battery of tests that may form part of the neuropsychological assessment include:

- MMSE (Folstein *et al.*, 1975);
- National Adult Reading Test (NART) (Nelson and Willison, 1991);

- Digit Span (Wechsler Adult Intelligence Scale-Revised (WAIS-R) (Wechsler, 1981);
- Similarities (WAIS-R) (Wechsler, 1981);
- Picture Completion (WAIS-R) (Wechsler, 1981);
- Frenchay Aphasia Screening Test (FAST) (Enderby *et al.*, 1975);
- Story Recall: Immediate and Delayed (Adult Memory and Information Processing Battery (AMIPB) (Coughlan and Hollows, 1985);
- Visual Recognition (Middlesex Elderly Assessment of Mental State) (MEAMS) (Golding, 1989);
- Hopkins Verbal Learning Test - Recall and Recognition (HVLRT) (Brandt, 1991);
- FAS Benton verbal fluency (Lezak, 1995);
- Weigl Colour Form Sorting (Grewal and Haward, 1984);
- Cube Analysis (Visual Object Space Perception Battery) (VOSP) (Warrington and James, 1991);
- Digit Copying (Kendrick, 1985);
- Bristol Activities of Daily Living Scale (BADLS) (Bucks *et al.*, 1996).

As Bucks and Loewenstein (1999) go on to explain, this extensive battery of tests usually takes about one hour to complete and is performed during one appointment at the memory clinic, with a further appointment necessary to explain the results and/or to conduct more tests. Whilst the venue was different, such extensive assessment procedures were familiar to each participant in the reported study.

## **Study Design**

### *Sample Characteristics*

The samples for both parts of the study were gained via contact with a respected memory clinic in the UK and profile screening for the interviews were undertaken by the clinics' medical and neuropsychology staff. Briefly, each interview was tape recorded and conducted in the person's own home and non-participant observations were made during the person's clinic appointment. Field notes were kept and all tapes were transcribed and analysed on the day of the interview. To maintain qualitative rigour, all research participants included in this chapter had a diagnosis of mild Alzheimer's disease using standard *DSM-IV* criteria (American Psychiatric Association, 1994). On all but one occasion, the care partner of the person with Alzheimer's disease wanted to be present during the home interview. This resulted in a complete data set of 15 people with Alzheimer's disease (12 women and 3

men, age range 72 - 84 and 67 - 86 years respectively) and, on 14 occasions, their care partners.

The study followed a grounded theory approach with the data subject to constant comparative analysis (Glaser and Strauss, 1967; Glaser, 1978). As Glaser (1978) goes on to explain, in grounded theory, theory and theory development are grounded in empirical data and acts of everyday social life with the aim of generating a theory that:

... accounts for a pattern of behavior which is relevant and problematic for those involved and that this goal is not reached by voluminous description, but by clever verification. (Glaser, 1978, p.39)

With the author having a practice background (community mental health nursing) with people with dementia and their families, theoretical sensitivity to the data analysis and the study aims was heightened further in the process of theory and conceptual development. Table 1 sets out the study findings in diagrammatic form and the remainder of the text will focus on the narratives and supporting components that underpin the 'seeking help' dimension.

## **Findings**

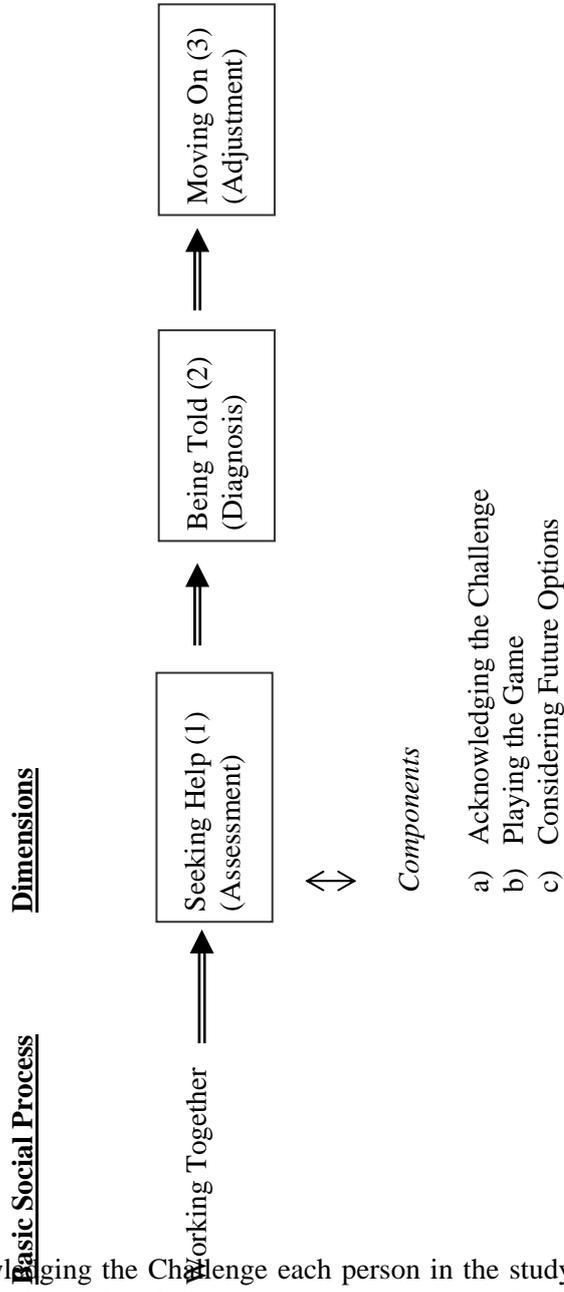
### *Dimension (1): 'Seeking Help'*

As Table 1 illustrates, the first dimension of '*seeking help*' reveals the early contact with professional service providers and a journey that led the person with (undiagnosed) Alzheimer's disease (and their care partner) through an increasing number of psychological assessments and screening procedures that varied in their intensity and level of sophistication. On each occasion this journey was initiated by the person's attendance at a GP surgery and, from there, a relatively quick decision by the GP to refer the person to the memory clinic for further assessment. As it emerged from the narratives through constant comparative analysis, Seeking Help contained three supporting components, and these were identified as: a) 'Acknowledging the Challenge'; b) 'Playing the Game'; and c) 'Considering Future Options'.

#### *a) Acknowledging the Challenge*

For each person in the sample, their decision to seek help was initiated by a growing awareness that something quite serious was happening to them, and that this experience could no longer be discounted. One person on the study likened this process to 'getting more and more frustrated' about his inability to 'remember simple things', fearful that, in his words, he was 'losing it big time'.

**Table 1: Working Together: Linking the Experience of Dementia from Onset to Early Adjustment**



In acknowledging the Challenge each person in the study recounted this first contact with his or her GP in a variety of ways, but the dominant expressions were ones of support and of being taken seriously, as one participant recounted:

I felt she {the GP} listened to me and knew I had some sort of trouble ... she asked me some questions from a list and then spoke to us saying I had a memory problem. I was told I would need more help and that I should go to the centre {memory clinic} to find out more about it. So I went on from there.

At one level this first contact was a relief as it validated the person's right to be concerned about themselves and their level of social and/or psychological functioning. However, at another level, following this first contact and mention of a referral 'to the memory clinic', there was a sudden realisation that something really serious was happening and that further investigations would be necessary. This sudden realisation resulted in a variety of responses:

- After coming home {from the GP} I got worried that I would need more tests to find out what was wrong with me. I didn't know then if I would get any better ;
- I turned to my husband after we got back here {person's home} and we just held each other, somehow we both knew that things had changed for good;
- After hearing I needed to go to ... {names the memory clinic} I remember coming home and crying. I needed some time to think about things. Something was wrong with me and I had a problem - but I didn't know what.

Moreover, the time-lag between a GP referral and an appointment to the memory clinic was also seen as important as it gave people with (undiagnosed) Alzheimer's disease time to dwell upon their anxieties and 'figure out' a strategy for managing, and perhaps more importantly reconstructing, their experiences. Equally, this 'time-lag' applied to other family members, giving them an opportunity to explore their own emotions and motivations for continuing with the referral, an issue that is picked up in the second component of the model.

*b) Playing the Game*

In Playing the Game the purpose of assessment is constructed as predominantly controlling, with correct moves in the process symbolising a game of chance and second-guessing. As already mentioned, a delay in attending the memory clinic instilled in the person feelings of uncertainty and anxiety, providing people with time-out to consider - and at times plan - their future response. Whereas the first encounter in the community with the GP was relatively brief, and acted to confirm initial fears and suspicions, the next steps in assessment were approached more cautiously.

In discussing this next phase of the assessment process, participants spoke about the need to be 'more prepared' and ready to anticipate 'what might happen to me'. Those in the sample certainly knew that their mental functioning would be probed and tested {a referral to a 'memory clinic' simply reinforced this} and that, therefore, a decision was needed over how to handle this turn of events. Moreover, whilst the environment, purpose of the visit {to the memory clinic} and the nature of the condition blended together to paint a confused picture for the person concerned, it also raised anxiety for the care partner, particularly over their anticipated role in the process. As one care partner stated:

Before that first visit I had heard all sorts of things about the place. Mostly good mind you, but I was more worried about ... {names her husband} and how he would cope if he had something bad. I must be honest and tell you that I was worried about that first visit there too. I didn't want to tell them too much about how he was getting on because it might have looked bad for him. I didn't want everyone to know our business.

For staff working at the clinic such protective behaviour meant that a delicate balance had to be struck between maintaining a person's sense of integrity and undertaking an assessment that, as the chapter highlighted earlier, is predominantly structured around proving poor performance through the discourse and quantitative evidence of loss. Whilst staff at the memory clinic undoubtedly did their best in the opening part of the interaction to allay such tensions, the start of the more formal testing procedures confirmed (to both partners) the seriousness of what was happening, as these experiences attest:

- I was asked questions which I should have known but didn't. I knew they knew I wasn't doing so well so I stopped giving out answers and said 'I don't know' to most things. It was easier then to get through it that way;
- The first thing that happened was that they asked me questions on numbers and things. Adding up I think. I have never been good at that type of thing but I just did the best I could;

- I had to draw a few shapes down and I had trouble doing it. I got a bit scared then.

This introduction of the more formal part of the assessment process was an important time, a point that was not lost on those taking part. From their experiences, participants were asked to do tasks for which there was little information on their purpose, or, just as importantly, on their outcome. Usually, requests for response were read from 'charts' and one gentleman in the study likened the question and answer session to 'being back at school'. As he went on to explain, 'that's the last time anyone asked me to count out loud'. From the data such perceived levels of threat evoked a number of coping responses, examples of which included:

- Taking time-out during the assessment;
- Being confrontative;
- Making excuses;
- Avoiding awkward questions;
- Relying on others for clarification;
- Strategic resistance.

Such responses allowed participants to 'step back' from the assessment process, giving them time to figure out the meaning (and rules) of what was happening and, perhaps more importantly, to reflect upon the consequences of poor performance.

From the study data it appears that *Playing the Game* continues until the formal testing process comes to an end, a period of time short in its duration but vast in its implications. Closing the encounter left those engaged in the process with a further opportunity to interpret their experience and prepare for the follow-up visit. This period of reflection led to the third component in the dimension, *Considering Future Options*.

### *c) Considering Future Options*

After completing the battery of neuropsychological tests, people attending the memory clinic received a second appointment around a month later. During this time, people with (undiagnosed) Alzheimer's disease and their care partners had time to reflect upon their performance and motivation for attending the clinic. For care partners the feeling was generally positive as the diagnostic process acted to 'sort things out' and help to clarify future options. However, for people undergoing the diagnostic process, anxiety levels were undoubtedly raised during and after this time as the seriousness of what they had been through began to sink in.

In the phase of Considering Future Options, couples whose inter-personal relationships were close were more likely to construct some sense of value and meaning out of their experience, building a partnership whereby ‘they faced the future together’; an act that formed a joint protective barrier against external threats. From the provided narratives it would appear that a continuation of ‘strategic resistance’ (to the assessment process and/or their own experience of memory loss) from the time of engaging in the battery of neuropsychological tests had a crucial impact upon shaping future transitions and decision-making. Indeed, instead of bringing people closer together, ‘strategic resistance’ acted to drive a couple further apart. In many ways this dynamic added an extra layer of stress upon an already stressful situation, with the external assessment procedure confirming the seriousness of the situation for one partner in the process, whilst, for the other, the person with dementia him or herself, it was simply an irrelevance. Thus in relationships where ‘strategic resistance’ was the over-riding coping style for the person with Alzheimer’s disease, the seeds were sown for a culture of recrimination to grow and germinate. Undoubtedly, this experience was not helped by the limited explanatory information provided by the assessor at the time of the neuropsychological test(s).

In Considering Future Options, therefore, different outcomes were available to each participant in the study, including, of course, an option not to return to the memory clinic and proceed with further tests and/or to receive the results. Indeed, to varying degrees, all participants in the study shared a feeling of reluctance about returning again to the memory clinic, although such an outcome was necessary if the results of the tests were to be shared and acted upon - a paradox that was not lost on those taking part and one which formed the cornerstone of the basic social process ‘Working Together’ (see: Table 1).

## **Conclusion**

With such issues in mind, how can the balance of control/power in assessment be more equally distributed, with the person being assessed actually having a meaningful voice in the act itself? To alter the threatening nature of the discourses rehearsed in this study, it would seem sensible to apply a biographical approach to the assessment process and reduce the power of the assessor from one of expert to enabler. Whilst this would be a more time-consuming process, the integration of biography into the assessment discourse would make an important ‘statement of intent’ amongst professional groups towards respecting the personhood of people with (suspected and eventually confirmed) dementia. It may also be necessary to think carefully about the physical environment and what a memory clinic actually looks like through the eyes of those that use the service - one person in the study likened it to ‘a

waiting room in a hospital'. Perhaps what is needed to further lessen the threat to personal identity is simply to provide alternative, community-based methods of assessment where people are offered a real choice about service location. I have little doubt that if such choices were available, then some people would want the security that 'a waiting room in a hospital' could bring, whilst others would prefer the intimacy and security that an assessment in their own home would afford. Diagnosis of dementia is not an end in itself, just one step along a new road of discovery. However, how this initial step is approached, taken and supported will have a profound impact upon the person's future adjustment, identity and sense of agency.

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Harris, Phyllis Braudy (ed) *The Person with Alzheimer's disease: Pathways to understanding the experience*, pp.3-28 © 2002 [copyright holder]. Adapted and reprinted with the permission of John Hopkins University Press.

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