AWARE: exploring awareness in early-stage dementia

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Awareness is an area of growing interest for dementia researchers, but to date research in this area has produced little conclusive evidence that can serve as a guide for improving services and care practices. Adding the perspective of people with dementia and their carers, and providing a cross-cultural dimension, seems to be an important next step in order to strengthen the value of research in this area. The AWARE project, currently in progress, aims to share ideas about awareness in dementia and prepare a plan for future research on awareness that includes the perspectives of people who are living with dementia. Associated aims are providing information for people with dementia, caregivers, and clinicians throughout Europe, and making suggestions for enhancing care practices.

The AWARE project, funded by the European Commission, was initiated by researchers from the Interdem network, who all share an interest in psychosocial approaches to timely intervention for people with dementia and their families. The project brings together people who are living with dementia, their representatives, clinicians and researchers from various EU member states and beyond. It takes the form of two workshops, of which the first was held in Cambridge in May 2003.

At the Cambridge meeting we were fortunate to have a number of Alzheimer's Society representatives from the UK, including people with a dementia diagnosis, caregivers, and Society staff. It was especially good to have a strong contingent from the Cambridge branch, arranged via their Link Group, as well as participants in the Living with Dementia network. We were also joined by Alzheimer's Society representatives from Spain and the Netherlands, and a representative of For Dementia in the UK. Other participants included researchers and clinicians from the UK, Ireland, Germany, Italy, Netherlands, Portugal and Poland, some of whom gave short presentations which served as a stimulus to the wide-ranging discussions that followed.

Rachel Canning, who has vascular dementia, was very pleased to be able to participate in the meeting. She considers it very important that researchers and those involved in service planning and dementia care provide a gateway for the views of people with dementia and carers to influence and be reflected in research, policy and evaluation. The learning environment of the AWARE meeting made her optimistic that research can be conducted in partnership with people with dementia and carers.

The meeting provided a great opportunity to think about a concept that is often discussed in the negative, describing a *lack* of awareness as a symptom of dementia.

Research on awareness in dementia has tended to focus on identifying an absence of awareness in the person with dementia, often in a rather narrow and deficit-focused way. This might mean investigating whether or not the person acknowledges that s/he has an illness, or whether it is possible to identify impairments in awareness of changes in memory or other skills. Awareness is often described as if it is a fixed entity, something that exists or does not exist, rather than something that varies depending on a range of factors, for example who one is talking to and in what context, or the amount of information one has. People with dementia are therefore faced with an uphill challenge if they are to prove the presence of awareness. Yet in many respects it is other people who hold the key to increasing awareness, through giving a diagnosis, providing information, and offering support. It is hard to see how someone with dementia can have full awareness if they have not been given a diagnosis and gone through the process of coping and coming to terms with that diagnosis, and making sense of what is happening. It was suggested that researchers and clinicians should start with the assumption that the person with dementia is aware, and look for evidence of this, rather than focusing narrowly on identifying impairments.

The discussion also emphasised that when we do try to explore how aware the person with dementia is, it is important to consider that person's experience as a whole, in the context of his/her life history and current situation, and to listen to what s/he has to say. There is sometimes a tension between the need to simplify and streamline assessments for research purposes and the need to capture the complexity of experience.

One of the important points to emerge at the meeting was that awareness may be viewed by clinicians and carers quite differently from how it is seen by the person who is living with dementia. We need to think about awareness at several different levels: the awareness the individual has, the awareness the carer has, and the awareness that society has. These have to be considered together, because they are on a continuum and they interact with one another. Changing societal awareness about dementia, for example, is likely to affect the awareness that individuals have about the implications of changes they experience. Our understanding of awareness should not focus just on the individual, but needs to be broadened out to consider the social context and the network of relationships that surround the person with dementia, and the way in which these may change over time.

Generally, knowledge about dementia and Alzheimer's disease is increasing, helped by the availability of new treatments. Increased awareness is likely to mean there is a greater demand for good quality service provision. An ongoing, trusting relationship with a professional helper could be a central component of this, but there is a need to bring about a shift in the power-balance between people with dementia, carers and professionals so that there is more of an equal exchange and a genuine dialogue.

Cross-cultural perspectives help to highlight the possible danger of ignoring contextual factors. Views about dementia, and perceptions of shame or stigma, vary in different European countries, and between different kinds of settings, for example rural versus urban contexts. Similarly, socially acceptable responses to change also vary, for example the extent to which it is felt appropriate to be open about difficulties, or deemed preferable to try to cover up any problems.

Given this complexity, we might well ask how important awareness really is. It was noted that people with dementia may not give much consideration to 'awareness' in the course of their day-to-day life, and the concept may therefore seem to them to have limited relevance. People concentrate on getting on with life, rather than reflecting on how aware they are of their difficulties. Researchers and clinicians, on the other hand, have their own definitions of awareness and their own reasons for wanting to measure awareness in people with dementia. A challenge will be to define awareness in a way that is appropriate, relevant and meaningful for people with dementia and their families as well as clinicians and researchers. For example, we might think about awareness in terms of how someone appraises his/her situation, abilities, and needs. We are beginning to gather evidence showing that the way a person with dementia appraises his/her difficulties can make a difference to the kinds of interventions that are helpful, and that differences in perspective between the person with dementia and his/her carer, whereby the person with dementia underestimates his/her difficulties or the family member overestimates them, can place a great deal of strain on the relationship. An example was given by a person with dementia of his acceptance of limitations placed on him by his carer in order to avoid conflict and limit strain on the carer, but he consequently felt this was a limitation on him.

Awareness of the changes dementia brings can facilitate some of the decision-making that needs to be done, for example with regard to limiting or giving up driving, financial and legal issues, and planning where to live. People with a diagnosis of dementia and their family members may well have different concerns; for example, the person with dementia may aim not to become a burden, while the family member may want to provide as much care and support as possible. Open communication that makes it possible to talk about changes and about what the future holds is crucial here.

‘Awareness’ brings with it consequences, and ultimately a responsibility. For example, being aware can result in people with dementia feeling scared and anxious. However, it can also hold the key to acceptance (e.g. of a diagnosis). It also gives other people a responsibility to take action if it is acknowledged that the person with dementia is 'aware’. Maybe sometimes it is preferable to think that people with dementia are not aware, and then we do not have to take action or accept emotion.

We should not, however, attempt to prescribe what constitutes a 'good' level of awareness. Indeed, this is likely to be a very individual matter. In thinking about raising awareness, therefore, we need to ask not just how we can do it, but also why we should attempt it and for whom it might or might not be beneficial. Some of the ethical debates about the appropriateness of giving a dementia diagnosis are also relevant here, in that individuals have the right to know their diagnosis, but they also have the right to choose not to know. The same is true with regard to other aspects of the experience of dementia. The goal, therefore, may not necessarily be one of raising individuals' awareness, but rather one of supporting the level of awareness that works for each person and helping manage differences in perspective.

The real experts on what it is like to experience memory problems and dementia are people living with dementia. We had several most moving accounts from people in the early stages of dementia who know from the inside and want to tell how it is. Rachel Canning actually thinks she is becoming *more* aware since her diagnosis. She has learnt as much as she can about her condition and is dedicated to raising awareness about it. Her diagnosis is a ‘face saving’ device, giving her a reason for forgetting, for example. It lets her off the hook!

From whatever perspective we are in contact with people who have dementia, it is essential to listen to them and value their experience. This was the central and powerful message from the meeting, which, in the words of one participant, 'combined knowledge with humanity'.

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