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Clinical Section

USING A COGNITIVE RATIONALE TO CONCEPTUALIZE ANXIETY IN PEOPLE WITH DEMENTIA

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Abstract. Dementia is characterized by a decline in cognitive abilities that is sufficient to impair functioning in daily living. There are a number of forms of dementia (Alzheimer's, vascular, Lewy body, etc), each with its own cognitive profile and developmental course. The present paper deals with the progressive dementias, such as Dementia of the Alzheimer Type (DAT). The cognitive deterioration associated with advanced DAT is often accompanied by a decline in emotional control, social behaviour and motivation. The paper focuses particularly on the emotional features of the disorder, because this issue has a profound impact on both the sufferer and carer. A framework for conceptualizing anxiety is presented, and a model of how this conceptualization can be used effectively within a carer's training programme is discussed.

Keywords: Dementia, elderly, conceptualization, anxiety, carer.

Background

Anxiety and depressive disorders are common in dementia. However, accurate rates of prevalence are difficult to obtain owing to the confounding relationships between mood and cognitive functioning. Generally, the affective disorders are treated well with medication in this group. However, recent evidence suggests that neuroleptic agents, which are often used to treat agitated behaviours, may accelerate cognitive decline (McShane et al., 1997). Despite general efficacy, careful drug management is required both to avoid unwanted side-effects and to reduce the incidence of further confusion. Therefore, owing to the possibility of pharmacological complications, there is a strong need for the development of effective psychotherapeutic strategies that can be used both alongside or independently of pharmacological regimens. The present paper provides a conceptually driven perspective that can form the cornerstone of an effective therapeutic strategy.

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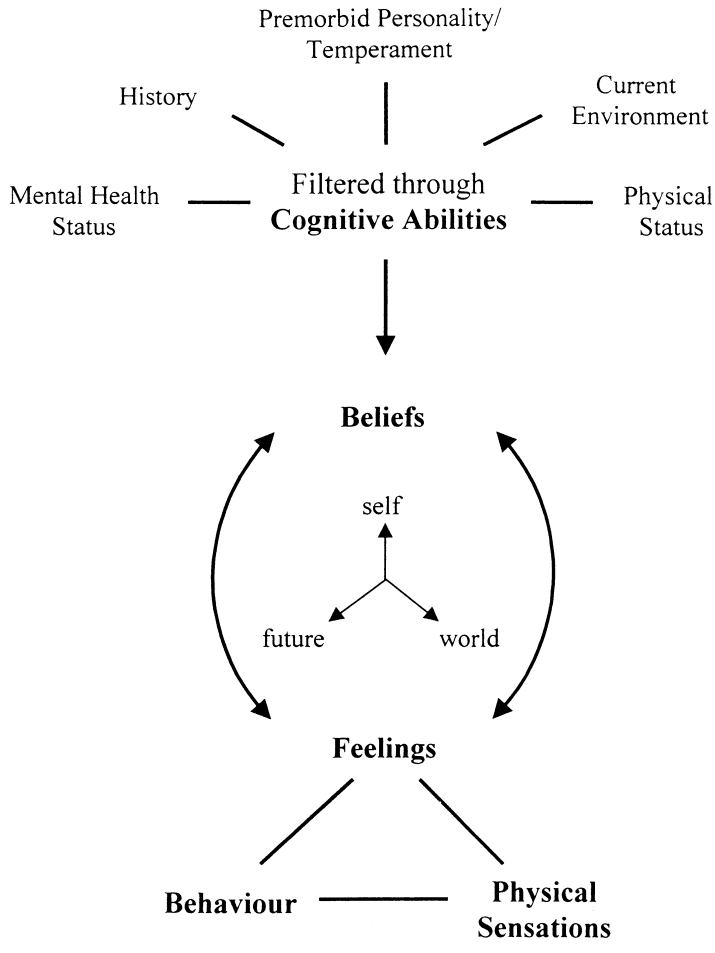

Figure 1. Conceptual framework

Conceptualization of distress in dementia

Conceptualizations help formally to determine the features associated with the development and maintenance of people's problems. The insight gained is essential as it provides a rationale for a therapist's interventions. Indeed, by identifying the moderating and mediating features of a person's distress, one is provided with an awareness of the mechanisms associated with effective change. The conceptualization outlined in Figure 1 (James, in press) incorporates features of the cognitive model (Beck, 1976). In line with other cognitive conceptualizations, the model suggests that the person's perception of a given situation is the product of a complex set of interactive components (historical, environmental), and that cognitive processing is open to a number of personal (physiological, temperamental), societal and cultural influences. In the case of people with dementia, the processing of information will be affected by their declining cognitive abilities, resulting in some abnormal interpretations. It is important to remember,

however, that if the person with dementia is also suffering from anxiety or depression, there will be other mood consistent biases influencing his/her perception (negative thinking, catastrophizing, overgeneralizing). In the present conceptualization, it is proposed that the information processing products can be best formulated through Beck's notion of the cognitive triad (Beck, 1976). The triad suggests that a person's feelings and actions are influenced by his/her cognitions, and these are based on current beliefs the person holds about him or herself, the world and future. In accordance with the cognitive model, the product of the person's thinking will influence his/her mood, bodily sensations and behaviour. This model allows one to identify certain dysfunctional behaviours and actions as errant coping strategies – wandering, withdrawal, avoidance, aggressive acts. The reaction of carers and others to such behaviour will influence the level of distress and well-being experienced by the person with dementia. At times, some care-taking practices developed to cope with the behaviours may even serve to exacerbate the negative mood and behaviour.

The triad applied to dementia

Kitwood (1990) provided a rather haunting description of the experience of dementia:

> You are in a swirling fog, and in half darkness. You are wandering around in a place that seems vaguely familiar; and yet you do not know where you are; you cannot make out whether it is summer or winter, day or night. At times the fog clears a little, and you see a few objects really clearly; but as you try to make sense of where you are you are overpowered by a kind of dullness and stupidity; your knowledge slips away, and again you are utterly confused.
>
> (an extract from Kitwood's "Psychotherapy and dementia", 1990, pp. 40–41).

This passage attempts to illustrate the experience of dementia. As this description suggests, just like you or I, the person with dementia is continually attempting to make sense of his or her world, and is using similar sorts of cognitive processes to do so. However, in the case of the person with dementia, his or her view of the world is chaotic and incoherent; perceptions are degraded; things are no longer predictable; lifelong coping strategies are often unhelpful; situations are confusing; people act strangely towards him/her – they are sometimes aggressive and often patronizing; he or she can not remember when the problems first started, and has no idea when things are going to return to normal.

As outlined above, it is believed that this experience can be effectively conceptualized using the cognitive triad (Figure 2). As yet there is no empirical evidence to confirm this hypothesis. Nonetheless, the perspective can be supported by monitoring the spontaneous speech of people with dementia. The content of their speech often reflects a desire for security, or information associated with this desire.

> "I want to go home, I don't like it here"
> "Where is my purse . . . she's taking my money"
> "Have you seen my coat?"
> "I want my wife".

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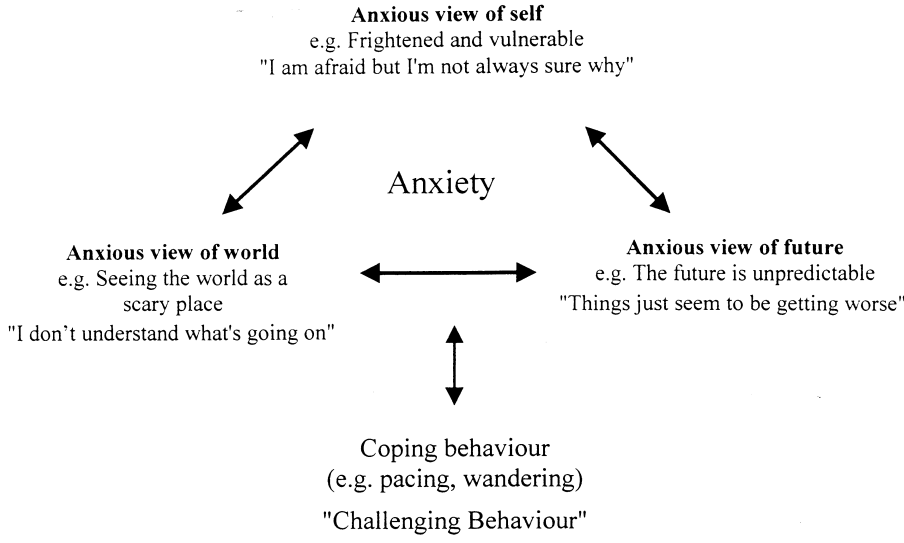

Figure 2. Anxiety triad for the person with dementia

Some of the distressing behaviours that are observed in people with dementia (sometimes termed as "challenging behaviours") can result from the high levels of anxiety being experienced – see Box 1, case example.

Utilization of the model

The triadic model is currently being incorporated within a teaching package for carers. The aim of the model is to provide carers with insight into the "world" of the person with dementia. Through this insight, it is envisaged that they will be more able to understand the background to the behaviours being displayed, and also to be able to respond to them more appropriately. The package is composed of six two-hourly sessions and is designed to help carers cope with challenging behaviours. The goals of each session are outlined in Box 2.

Within the first two sessions, the carers are socialized to the triadic relationship with respect to themselves and to the person with dementia (Figure 3). They are required to empathize with the person's situation using the cognitive perspective, and helped to problem-solve to determine why certain challenging behaviours occur at specific times. They are asked to reflect on their own thought processes, identifying biases and misinterpretations. The teaching is supported by an educational pack, containing handouts from the teaching, information about DAT and homework tasks. This is particularly important as many of the carer's dysfunctional biases result from causal misinterpretations of behaviour. For example, while carers can often appreciate that memory difficulties are common in dementia, and thus make allowances for lapses, they are less aware that many of the other features (lack of motivation, sequencing problems, soiling, problems of affect) are also common features of dementia. Hence, through a process of monitoring, thought re-evaluation and education, the carers gradually learn

Box 1: Case example

Mrs J – Mrs J had advanced Alzheimer's disease, characterized by severe memory impairment and communication difficulties.

I was asked to see Mrs J because of her "aggressive" behaviour, which she displayed within a residential home. During my assessment, which included discussions with the staff, a number of important points emerged: (i) the "aggression" took the form of shouting and crying; (ii) the shouting occurred when she was prevented from walking up and down the main hallway of the home; (iii) the behaviour had escalated since she was required to move rooms – from a 2nd floor room to one on the ground floor; (iv) the staff had tried numerous ways of dealing with the behaviour, but to no avail. They were concerned with health and safety issues (e.g., walking into a food or drug trolley). They also found the behaviour disruptive, especially late in the evening when they were trying to settle the other residents for bed; (v) Mrs J walked the corridor hourly; (vi) prior to her wandering she often appeared agitated; (vii) the greatest amount of anxiety, and conflict, occurred when the staff tried to either block her route or lock her in her room. As part of the assessment, I also spoke to Mrs J's family. These conversations helped to complete, and also direct, the formulation. I was particularly interested in her fears, and descriptions of any situations likely to make her feel vulnerable. It appeared that one of her main fears was her safety, which stemmed from a burglary and assault that had happened five years ago. The burglar had entered through a window in her ground floor flat. After the assault she had become very anxious and sold her flat for another one situated on the first floor. She felt much more secure in her new home. Mrs J's daughter also provided valuable information regarding the sorts of coping strategies used by her mother in the past. "She was a great pacer", said her daughter. Mrs J's daughter said that whenever her mother was worried "... she would sort her head out by going for a walk".

The conceptualization of Mrs J's difficulties revealed a woman who was frightened of living on the ground floor, owing to a traumatic incident in her recent past. She was attempting to cope with her anxiety by pacing, but this was causing disruption in her current environment. The staffs' attempts to deal with the behaviour were exacerbating the situation, resulting in conflict and frustration in both parties. This conflict was leading to Mrs J's "challenging behaviour".

The interventions devised for Mrs J were both practical. Firstly, she was moved to a room on the 2nd floor of the home, and secondly she was encouraged to walk in the garden of the residential home. She was provided with appropriate clothing to deal with the vagaries of the British weather.

to distinguish factual information from inaccurate/unrealistic expectations and misinterpretations.

Summary

This work has conceptualized the experience of anxiety in dementia. As outlined above, the conceptualization is currently being used with a group of carers in Newcastle. Using this cognitive template, it is hypothesized that the carers will be protected from being overwhelmed by the difficult situation they are in. If successful, this training will allow carers to move into a zone of healthy coping. In this zone there will be times when they feel sad, down, or angry, but it is hoped that they will be buffered from being

Box 2: Goals of carers' teaching sessions

Session 1

To discuss:

- The nature, and course, of the different forms of dementia
- Highlight the different forms of treatment, including use of medication
- The role of coping – coping with difficult situations and strong emotions

Session 2

To discuss:

- Unusual behaviours are a common feature of dementia
- The emotional impact of the behaviours
- What carers think about distressing behaviours (i.e., the meaning attached to the behaviours)
- The role of thoughts – applying the cognitive triad to both the person with dementia and the carer

Session 3

To discuss:

- Dealing with the distressing thoughts
- The notion that thinking styles can be both realistic and unrealistic
- The action of unrealistic/inaccurate thoughts on mood
- Methods of monitoring unrealistic, distressing thoughts

Session 4

To discuss:

- How to identify thought biases
- Dealing with biases by establishing the facts behind the behaviours
- Obtaining a greater understanding of the behaviours as a result of the new perspective

Session 5

To discuss:

- How to deal with practical difficulties (dressing, bathing, incontinence and pressure sores)
- Legal and financial issues to do with dementia
- Reviewing the facts about dementia and relating these to carers' experiences

Session 6

- Reviewing and consolidating the work done on the course

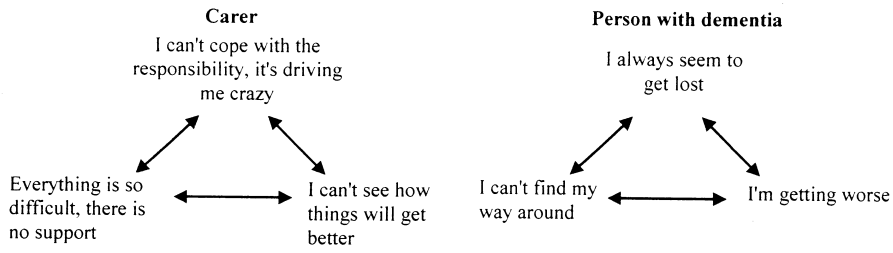

Figure 3. The anxiety triad for the carer and person with dementia

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overcome by clinical states of anxiety and depression. Although this paper has focused on anxiety, in keeping with Beck's cognitive specificity model, feelings of depression and anger can also be effectively conceptualized using the triadic framework (James, in press).

Finally, the above work has suggested that negative affect is an inevitable consequence of dementia, but this is not necessarily the case. Indeed, it is important to remember that these dementias are progressive and have a variable course. As such, there may come a time when, owing to cognitive changes, the environment appears to be safer and less threatening (i.e., the person with dementia may no longer be able to perceive real threats as threats). If such a situation arises, the person's level of anxiety may be even lower than the levels experienced prior to the onset of dementia.

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