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Inhabitants of a Lost Kingdom: A Model of the Subjective Experiences of Dementia

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ABSTRACT

Current concepts of dementia often act to exclude the internal world of the dementia sufferer from consideration as a valid object of study. This paper presents a three stage model of the subjective world of dementia sufferers, drawing on ideas from both clinical and social psychology. The first stage involves the feelings engendered by the process of dementia and includes at least four discrete states: anxiety; depression; grief; and despair/terror. The second stage of the model concerns the behaviour provoked in response to the process of decline. Finally, we consider the social nature of emotional behaviour, with emotional actions falling along a continuum. The ability of an individual with dementia to engage in emotional behaviour depends upon the extent of their cognitive impairment and the social context in which they are located. This model has implications for the delivery of services, including psychotherapy, to people with dementia.

KEY WORDS – Alzheimer's Disease, dementia, subjectivity, emotions, psychotherapy, psychology.

Introduction

"*I've lost a kingdom.*" – Alzheimer Disease Sufferer.

Most people who experience most forms of emotional distress can, at least in principle, be offered some form of psychological intervention aimed either at exploring their internal world or teaching them more adaptive coping responses. By and large, this is not the case for people who suffer from a dementing illness. Those professions that we usually expect to offer treatment (for instance, clinical psychologists and occupational therapists) often do not provide much more than an assessment, most commonly of memory functions, and a consultation service. Yet in many cases, memory assessments arguably have little direct therapeutic benefit to the dementia sufferer.

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Similarly, the perspective of the dementia sufferer has been largely ignored in the clinical and research study of dementia (Lyman 1989). This can largely be attributed to the dominance of the medical model within dementia care and research, a model that has been extensively reviewed in recent years. A number of points emerge from this critical literature:

- Definitions of dementia are social constructions, imposing order upon data in a particular and selective way (Gubrium 1986). As such, these constructions act to emphasise particular ways of thinking about dementia and to ignore other viewpoints. Evidence that potentially challenges this construction is defined as irrelevant by a number of rhetorical strategies. For instance, people who initially are diagnosed as likely to be suffering from a dementing illness but who later show an improvement in their condition are retrospectively said to have suffered from a 'pseudo-dementia'.
- Neuropathological explanations (for example the involvement of genetic risk factors) cannot provide complete explanations for the development of dementia (Capstick 1995; Kitwood 1987) and are unlikely to lead to a 'miracle cure'. An over-reliance on these methods of research has meant that the wider social context in which people with dementia live their lives has, until recently, been comparatively ignored. Consequently, the behaviour of dementia sufferers is too often understood without reference to its context. For instance, the emotional and cognitive effects of relocation (Anthony *et al.* 1987) and the impact of life events (Orrell and Davies 1994) on the well-being of older people generally and, more specifically, of people with dementia (Orrell and Bebbington 1993) are important aspects of experiences that shape people's lives. Yet with respect to institutionalisation, for example, two recent texts reviewing, respectively, linguistic and neuropsychological research in older people (Maxim and Bryan 1994; Hart and Semple 1994), both with copious pages of references, do not devote a single line to the possible effects of institutionalisation on linguistic and cognitive performance.
- Alternative non-medical, non-physical explanations of a person's behaviour, therefore, tend to be marginalised. Thus, the social consequences of being old, being a woman and being physically frail, may all have a considerable impact on the way people are treated and upon the expectations that others hold for them. Hockey and James (1993) have stressed how metaphors are frequently used to describe older people with dementia that link ageing, helplessness and dependency (for example, the frequently used phrase 'he/she is

experiencing a second childhood'). These social representations can be internalised as valid self-representations throughout the lifespan. These processes – of ageist social constructions of a number of roles, and the internalisation of these negative stereotypes – are important determinants of the behaviour and feelings of older people, quite independent of the impact of a dementing process. Arguably, aspects of this linguistic world can act to restrict opportunities available for growth and even to accelerate personal decline (Giles 1991).

In this paper we will describe a model of the subjective experience of dementia that attempts to accommodate these, and other, criticisms of current formulations. This model has three main aspects:

- those feelings that are evoked within a person by the process of dementia;
- the behavioural responses of that person to this decline; and
- the social nature of these emotional behaviours.

In the second part of the paper, we will move on to consider how the model could be applied to improve the delivery of care services for people who have dementia.

Emotions and dementia

When a person either begins to suspect or is told that they suffer from a dementing illness, they are likely to experience a range of emotional responses. We would like to suggest that it may be useful to distinguish between four types of feeling: anxiety; depression; grief; and despair or terror (see Table 1). This framework should be understood as a useful heuristic based on a review of the literature, rather than being a sequential model of emotional reaction on the lines of Murray Parkes' (1986) model of emotional responses to bereavement.

Anxiety as to what is happening and what will happen

It is, perhaps, no exaggeration to suggest that one of the greatest fears within western society is that, as we age, so may we not only become increasingly physically infirm, but also enter a personal 'hell' of progressive mental deterioration. For many, the slightest lapse in memory may thus become a cause for concern. Even when intellectual deterioration is such that a diagnosis of 'probable dementia' is reached, the same mental health professionals who make the diagnosis will not be able to predict the speed of decline or its severity, simply that decline is inevitable. The anxiety level of a person with dementia will be further

Table 1. *Major emotions and possible feeling statements of people who believe they have dementia*

Emotions	Feeling Statements
Anxiety	What will happen to me? Will (my spouse) stay with me? Or will (she/he) have me put away? Will I end up in a dementia ward? Will I end up incontinent?
Depression	I've got no energy. I'm useless. I'm not any good for anything. I don't know why he/she puts up with me. I want to die.
Grief	I'm not sure I'm safe to drive. I can't understand t.v. programmes. I'm making lots of spelling mistakes. I'm losing myself. Friends don't call any more. I can't talk to my children about what I want to tell them.
Despair or terror	I'll end up like them. This place is a living hell. I never thought I/it would end like this. I'm terrified/very scared. These people are very dangerous.

increased by the very confusing nature of some of the person's key interactions – the 'malignant social psychology' that Kitwood has described (Kitwood 1990*a*; Kitwood and Bredin 1992). This includes: the frequent unwillingness of those around that person to give him or her the diagnosis; his or her spouse being given information that is withheld from the sufferer; and being given false reasons or explanations – for example, being told that attending a Day Hospital will help them with a minor physical condition.

There are many different viewpoints about the general causes of anxiety, depending upon the author's theoretical orientation. Taking a cognitive stance, Kelly (1955: 495) defines anxiety as the recognition that one is unable to predict events: 'the recognition that the events with which one is confronted lie outside the range of convenience of one's construct system'. This definition describes much of the condition of the person with dementia.

It is hardly surprising that people who have been given a diagnosis of dementia often become suspicious and, on occasion, even paranoid. Indeed anxiety, and its associated psychiatric variants, is a frequently reported accompanying feature of dementia. Solomon and Szwarbo (1992), for instance, report that of the 86 people assessed by Solomon, 49 could be described as having a non-specific anxiety, with yet others having more specific fears and panic attacks.

Depression

There is a complex relationship between dementia and depression (Mahendra 1985). First, clinical depression may act, in psychiatric terms, as a pseudo-dementia, that is to say a condition which mimics the clinical pattern of dementia. Secondly, depression may be a risk factor for dementia. Thus Kral (1983) and Reding *et al.* (1985) report that when older people who have been diagnosed as having a depressive illness were followed up after a number of years, a higher level of dementia was found than would otherwise have been expected. Similarly Agbayewa (1986) compared 188 patients with Alzheimer's disease and 80 non-demented patients, and found that the Alzheimer's disease patients were significantly more likely to have had a psychiatric illness earlier in their lives. The two most frequent illnesses were unipolar depression and paranoid disorders.

Finally, depression has been the most commonly reported affective response of people with dementia. Thus Cummings and Victoroff (1990) estimated the prevalence of depression in Alzheimer's disease at up to 87 per cent, depending on the criteria used in different studies. Similarly, Burns *et al.* (1990) assessed 178 patients with diagnoses of either 'probable' or 'possible' Alzheimer's disease. They established that depressive symptoms were reported by almost two thirds (63 per cent) of their sample who were able to answer questions but that none of the patients satisfied DSM III R criteria for a major depressive disorder. Patients were more likely to report depression than were relatives, and the reporting of depressive symptoms was related to the severity of the dementing illness. Less severe cases of dementia, as established by levels of cognitive functioning and by cerebral damage, were likely to result in reports of higher levels of depression. The development of depression is likely to be influenced by factors such as the person's experiences of loss and their thinking style.

Grief at the loss of ability and other valued skills

Grief and depression are clearly overlapping constructs. Nevertheless, it may be useful to differentiate between them. For instance Freud noted in *Mourning and Melancholia* (1917) that the person with loss has a very negative emotional tone. The depressed person shares this experience but tends, in addition, to suffer from self-blame and lowered self-esteem. People with dementia often suffer multiple losses: the loss of cognitive functioning, the loss of particular roles and status, and changes in their relationships with those around them. Miesen has commented on the need to attend to the bereavement process in patients with dementia:

> It now appears that even demented persons experience and feel threatening losses, and it would appear that the process of dementia creates an environment which fosters uncertainty and the lack of safety. This could mean that demented persons are struggling with emotional problems, which have been hitherto underestimated. (Miesen 1992: 223)

While Miesen and others have used Bowlby's attachment theory to account for the reactions of dementia sufferers, Solomon and Szwarbo (1992) have described the experience of grief of a person with dementia as a narcissistic injury suffered through the process of psychosis. The loss is a loss of part of the self (memory, intellect and other aspects of ego functioning). As is the case with individuals without a dementing illness, these losses are seen as triggering a process of grieving in which the person concerned ideally moves through a number of stages: denial, disorganisation and finally reorganisation. Those with Alzheimer's disease or another dementia are held, however, to be unable to move to this final stage because of their limited brain functioning, which imprisons them at the stage of disorganisation. As such, Solomon and Szwarbo maintain, the subjective experience of dementia is 'not all that different from a pathological grief response. Indeed a few never get beyond the stage of denial' (1992: 300). Being unable to deal with conflict and stress, the individual finds the path of least resistance: withdrawal and depression. Again, the way in which the individual has managed previous experiences of loss will be significant.

Despair or terror at the destruction of self and the inability of others to give meaningful help

People with dementia can experience a profound, existential sense of emptiness and absence which is related to the actual or anticipated damage to their sense of self. The deep despair and terror that this sense of absence can engender may be compounded by the neglect of those around the person. Much of the behaviour of professionals they meet – the extended assessments, the frequent failure to offer emotional support and nurturance – can be seen as the avoidance behaviour of people who cannot refuse to interact with people with dementia, but who wish to avoid 'contamination'. These actions, or the sufferer's interpretation of them, mean that there are few safe places in which the person with dementia can explore the process and begin to make sense of the phenomenological reality of dementia.

Again we may, in part, reframe the poor functional performance of people with dementia in terms of an understandable, emotional reaction. Rather than resulting from some mysterious, remorseless organic process, the person's behaviour is a response to terror, a terror fuelled by memories of partly read, partly remembered, partly suppressed accounts of the treatment of people who have dementia. Their future may be unpredictable in specific detail, but their near complete social devaluation – Goffman's (1963) term 'spoilt identity' is very apposite – is highly predictable, as is the likelihood of being involved with poorly financed, poorly run services using predominantly untrained and poorly paid staff.

Because of the lack of a psychological model, we miss the 'obvious' comparisons with people being told they are HIV positive or have cancer, except that the services that people with dementia can expect are likely to be of a lower quality. What is remarkable is that a person going for an HIV test would almost automatically be offered a counselling interview; a person undergoing a course of treatment for cancer similarly might be offered a support group. A person being told they have dementia is unlikely to receive any such help.

Individuals will vary in their ability to verbalise these processes, particularly where the events that they are having to deal with are highly damaging to the self. In psychodynamic terminology, the ego-defence mechanisms of repression and suppression are very likely to be present in varying degrees for each of the four factors; and, of course, these factors will vary in strength and degree of awareness across time (Verwoerdt 1976, 1981). The variability across time which is built into this psychological model accounts for one of the difficulties facing the organic explanation of dementia: how can dead or diseased brain cells produce levels of functioning that vary from day to day, the 'good days' and the 'bad days' reported by relatives and professional carers of people with dementia?

This, then, is the first major aspect of our model – a descriptive frame which recognises that extremes of emotion are likely, indeed, common. We do not wish to suggest that this is an exhaustive list of feelings engendered by the dementing process, nor that these are the only ways to conceive of the phenomena that we will describe. What we do wish to emphasise is the necessity of developing detailed accounts of the way in which individuals with dementia experience this process and respond to these experiences.

Adapting to the process of decline

We have outlined above how the process of dementia may create emotional reactions. A range of coping strategies may be initiated to protect the self from these reactions (Keady and Nolan 1994; Cohen *et al*. 1984). In theory, it may be possible to distinguish between the primary symptoms of dementia (such as memory loss, apraxias and agnosias) that can be directly related to the neurological deficit itself and the secondary symptoms, which are those that can be attributed to the dementia sufferer's attempts to cope with the effects of neurological damage. This latter group has been variously defined but can be thought of as including: excessive self-blame; feelings of being misunderstood by families and friends; and a depressed affect (Sinason 1992; Solomon and Szwarbo 1992; Miller 1989). To paraphrase Watzlawick *et al*. (1974), at least some of the affective symptoms associated with dementia can be usefully reframed as attempted solutions to the dementing process.

We will now summarise some of these psychological processes involved within the dementia sufferer's response to the experience of neurological deterioration. Again, our purpose here is not to attempt a comprehensive review of the recent literature, but rather to indicate how dementia can be repositioned as involving psychological as well as neurological processes.

Denial or a lack of 'insight'

Denial is a relatively commonly reported aspect of dementia. Yet the development of insight or 'awareness' in people with dementia is often seen as being problematic: too much insight and they may become terrified at the thought of what may happen; too little and they may have unrealistic expectations and not co-operate with the wishes of their carers. From a conceptual point of view, however, it is not particularly useful to see denial as a fixed entity belonging to the individual. Rather, it is more productive to consider it as both functional and variable. Denial is a coping or defence mechanism that we would expect people to use when their environment is not safe enough to allow them to explore their experiences. Consequently, denial will appear at some times but not at others, and concern some aspects of cognitive loss but not others, depending on the social context and on the personal pathology of the individual dementia sufferer. Awareness itself then becomes a response that can be influenced by those around the person. For instance, by acknowledging issues of loss and grief, dementia sufferers may be able to move on and begin to make sense of their losses.

Living in the past

Many people with dementia seem to inhabit a world of their own, one in which memories of the past seem to be as important as the present. It is not surprising, therefore, that there has been a strong clinical and research interest in understanding the significance of these memories and reminiscences. Indeed, our understanding of the function, value and significance of the talk of older people about the past has changed significantly over the last thirty years. From being associated with the arrival of senility, and consequently discouraged, reminiscence has become reframed as an activity that is involved in the establishment of psychological integrity through formal systems of 'therapy' (Coleman 1986, 1994). Recent analysis of the significance of reminiscence suggests that the telling of stories about the past serves at least two functions for people with dementia – both of which are potentially therapeutic. First of all, telling stories about the past allows individuals to establish an identity which is significantly different to that which may be allocated to them as dementia sufferers. Stories that are told within a group setting allow dementia sufferers to establish a positive social identity: people of worth and value (Buchanan and Middleton 1994). As Crisp (1995) has written:

> …at a time when memory is being eroded and one's sense of who and where one is is falling apart, narrative provides a means of bringing the fragments together and constructing an active identity for the narrator. (p. 137)

Secondly, one of the functions of talking about the past for people with dementia is that it allows them to explore some of the subjective experiences of dementia and thus to process these experiences on an emotional level. For instance, Roy, a member of a psychotherapy group that Cheston (1996) worked with, recounted how he had been a pilot flying an aircraft in and out of a jungle. The landing strip had to be repeatedly cleared as the jungle continually re-grew. Although he clearly recognised that they were not literally similar (*i.e.* he acknowledged that he could not fly an aircraft now), Roy used this story as an illustration of how events from the past were similar to those in the present. Cheston argues that the remembered past and the present day were metaphorically similar for Roy; that is to say, there were aspects of his experience of dementia that seemed similar to finding his way in and out of the jungle.

Attachment

Miesen (1992, 1993) has attempted to find a way into the subjective world of people with Alzheimer's disease through experimental research, the results of which are mainly interpreted using Bowlby's Attachment Theory. Of particular concern for him is the frequently observed behaviour of older people with dementia calling out for, or searching for, their parents. He describes this as 'parent fixation'. Miesen suggests that the process of dementia is experienced as a 'strange situation'. The more dangerous the situation feels, the more frequently attachment behaviour occurs. At first this need for security is expressed through the person's non-verbal behaviour. As the bond with the outside world is disrupted by lowered levels of cognitive functioning, and as the sense of unease and fear heightens, however, so the person with dementia will search for some other way of maintaining a sense of emotional security. The development of parent fixation is thus represented as a means of holding onto the most fundamental attachments in one's existence.

Apathy and withdrawal

One of the most frequently reported behavioural aspects of dementia is of sufferers seeming to lose interest in the world. People with dementia are often described as apathetic and lacking in motivation. It is as if they have withdrawn from the world. Such apathy is often understood in terms of neurological damage to the brain, and in particular to the frontal areas concerned with motivation and personality. Yet it is increasingly clear that social and personal factors may also be involved.

It is a truism of social psychological research that individuals who have been labelled as in some way deviant are allocated a restricted range of social roles and that their behaviour is interpreted in terms of those prescribed roles – *cf.* Edgerton (1967) for learning disabilities; Jeffries (1977) for psychosis; Kitwood and Bredin (1992) regarding dementia. For people who are subsequently given the label of 'Alzheimer's disease' or another form of dementia, this process begins with the individual's behaviour being interpreted as in some way different from the norm. Once so identified, their behaviour and talk may be interpreted in terms of the principal features of the organic model, which would include their need to depend on others, their abnormal behaviour and their cognitive deficits. In most cases of persons diagnosed as having dementia, their social interactions do not allow them to maintain a sense of themselves as lovers, helpers, carers, teachers or whatever. It is not simply that there is no place for them to perform, even marginally, in these roles but that there is no place or permission for them to talk about themselves as occupying these roles. The ultimate result of this situation may be the fencing off of the dementia sufferer who then becomes totally displaced. Thus a self-fulfilling hypothesis is created (Sabat and Harré 1992). It may, therefore, be more useful to desist from seeing the person with dementia as withdrawn; and more accurate to say that their social roles have been withdrawn from them, leaving them only the roles of patient and dementia sufferer.

Another perspective on the cause of social withdrawal has been provided by Sinason (1992) who has described how people faced with an unbearable situation may defensively exaggerate their difficulties and thus develop a 'secondary handicap' as a defence against the trauma. Becoming the person that others take us to be may be an essential means of defending the self against further attack. In ethological terms, such fulsome compliance should halt the need of aggressors to continue their attack.

We do not wish to claim that this is an exhaustive list of the psychological explanations of the secondary symptoms of dementia; instead, it indicates how individuals manage the process of dementia. We would suggest that an increased understanding of the subjective experience of dementia and of how individuals respond to their experiences will greatly facilitate the creation of meaningful therapeutic interventions.

The social context of emotional behaviour

Emotions are not simply internal, personal and subjective feelings; they can also be understood as actions depending for their meaning upon social reaction and interpretation in a social world (Radley 1988). The relationship between emotional behaviour and the social environment is reciprocal: it is not simply that emotional behaviour occurs within a social context; emotions also provide the context through which actions and language can be understood. For instance, there is a world of difference between a friendly slap on the back between colleagues and an angry push in a bus queue, even though the behaviour itself may be very similar. Thus if we do not understand the emotional world of people with dementia, then we cannot fully understand their social behaviour; it will appear to be meaningless, or we are liable to misunderstand it.

The display of emotional behaviour

We can think of emotional behaviour as falling along a continuum (Radley 1988). At one end of the continuum, people are able to reflect upon and to recreate their experiences, for instance in the way that Cheston (1996) describes Roy as doing (see above). At the other end of the continuum, emotional behaviour is not a matter of recreating such experiences; instead, emotion is expressed physically and immediately. An example of this is that of the dementia sufferer who cries out for her (dead) mother, the behaviour that Miesen (1992, 1993) has described as parent fixation. Such emotional behaviour can be described as syncretic, that is to say one image contains a multiplicity of different emotions, an emotional package in which many different feeling states are enacted.

People with dementia, then, can be thought of as moving from being able to reflect upon and to recreate their experiences (in Radley's terms, emotional gestures), towards a dependence upon the immediate display of emotions (or emotional postures). In part this movement is due to the process of cognitive decline. Additionally, and what is more important for dementia care, the degree to which this transition occurs is a function of the social environment in which these emotional displays occur.

The social control of behaviour

The extent to which people can show their emotions is regulated by the social system in which they are located. In systems where there is strong social control, the display of strong emotions may be discouraged (being seen to be in 'bad taste', people feeling uncomfortable with them). Instead, emotional behaviour is limited to the generation of emotional gestures, for instance in formalised occasions such as psychotherapy. By contrast, conditions that are receptive to the expression of strong emotional postures have been obtained in special therapeutic circumstances such as encounter groups or drama therapy, but there too they can be experienced as threatening or uncontained.

Good dementia care involves being open to all forms of emotional actions. In essence, it involves the holding and containment of the emotional content of the action, and its reflection back in a form that can be used by the patient. We need to be open both to the emotional content of the stories that we are told, and to the despairing need for reassurance shown in parent fixation and other attachment behaviours – *cf*. Winnicott's (1964) theorising that the young child needs containment of its emotions.

The most comprehensive attempt to date to define dementia care from a psychological perspective, has been Dementia Care Mapping (Kitwood and Bredin 1992, 1994). By defining good dementia care in terms of care practices that respect and value an individual's 'personhood', this sees good care as essentially therapeutic. In addition, however, our model suggests that there is a need to take this process of care one step further on, to address the issue of psychotherapeutic change with people with dementia.

Psychotherapy and dementia

> "Is there any point to which you would wish to draw my attention?"
> "To the curious incident of the dog in the night-time."
> "The dog did nothing in the night-time."
> "That was the curious incident" remarked Sherlock Holmes.
>
> Arthur Conan Doyle – "Silver Blaze"

Until recently, the dominant clinical view has been that psychotherapy is impossible for people with dementia, either because the deficits associated with this disorder are such that individuals would be unable to remember the content of a session, or because the process of dementia has been envisaged as one that deprives sufferers of the ego strength that is necessary to integrate discordant aspects of their experiences. Thus, psychotherapy and counselling for people with dementia have been the dogs that did not bark: most noticeable by their absence. However, within the last ten years or so another, broader, perspective on psychotherapeutic work with people with dementia has begun to emerge. Mackie and Bredin, for instance, write that:

> Much of what is considered essential to psychological therapies, as practised with those who are experiencing a troubled or undeveloped sense of self, seems to be perfectly relevant to psychotherapeutic care for those who have developed a dementing condition. Foremost amongst these must be an open and purposeful exploration of intersubjectivity between the carer and the patient within a safe interpersonal context. (Mackie and Bredin 1992: 14)

Similarly, Kitwood has justified psychotherapy for people with dementia by using a model of therapeutic change that is applicable across different approaches.

> It is a process that occurs in an interpersonal context, as a result of which a person is enabled to change his or her way of being in the world, or relating to others, of choosing and executing projects. In psychotherapy old wounds are healed, hidden conflicts resolved, and unfulfilled potential brought out. Hence life becomes more satisfying, secure and productive. (Kitwood 1990*b*: 43)

This recent broadening of perspectives has resulted in a steady increase in the number of reports of work with people with dementia which aims to provide them with emotional support or, more ambitiously, to help them to change psychotherapeutically. This includes both work with individuals (Sutton 1994; Sinason 1992; Hausman 1992) and with groups (Yale 1991; Hunter 1989; Krebs-Roubicek 1989). In addition, there is a much larger literature on work that adapts psychotherapeutic approaches for use with older adults without explicitly adopting the term 'psychotherapy', such as Validation Therapy (Feil 1982; Bleathman and Morton 1992) and Resolution Therapy (Goudie and Stokes 1989; Stokes and Goudie 1990).

Psychodynamic psychotherapy

The application of psychodynamic psychotherapy to people with dementia has been described in a number of case-studies (*e.g.* Hausman 1992; Sinason 1992). From a psychodynamic perspective, the process of dementia can be seen to exert a profound effect upon the dementia sufferer's ability to use defence mechanisms to protect an increasingly fragile self. As the illness progresses, so more primitive defence mechanisms are likely to emerge, such as projection and regression (Krebs-Roubicek 1989). A breakdown in the dementia victim's ego functions may be reflected in impaired memory and increased self-absorption (O'Connor 1993) and even in narcissistic regression (Unterbach 1994). This breakdown in object relations may cause splitting to occur, with some carers becoming idealised while others are consistently denigrated (Hausman 1992). The power of such splitting to affect the dynamics of residential homes and other institutions can be profound.

A psychodynamic perspective also draws attention to the therapist's own emotional world. Working with people with dementia is uniquely challenging in that it involves carers in having to face the loss of what makes each of us uniquely human (Kaplan 1990). The implications of our own emotional reactions to the people who force us to address these issues stretch far away from formal psychotherapy to all patterns of interaction and care. With no other client group are carers, health professionals and therapists forced to confront so many issues that potentially involve such enormous personal power. For instance, we may come to infantilise or to 'parentify' our relationship with dementia sufferers and their partners – to treat our clients as if they were small children, incapable of making even the smallest decision – or we may come to place them in the position of idealised parents and compete with others to become the 'ideal child' ourselves. Counter-transference issues may become especially acute when long-term decisions about residential care need to be made, involving fundamental issues about the caring relationship (Sebastian-Moyer 1990).

Behavioural interventions

Given the popularity and ubiquity of cognitive-behavioural therapy, it is perhaps not surprising that a number of clinicians have attempted to show how these techniques can be adopted for this client group (*e.g.* Teri and Gallagher-Thompson 1991). Haggerty (1990) has described an 'early-stage Alzheimer's patient reassurance group' that used conventional group therapy principles together with therapeutic relaxation, cognitive therapy and positive suggestions concerning the illness. This group focused on the reduction of anxiety and depression and involved between six and eight patients in the early or middle stages of dementia. Patients were said to readily form close, mutually supportive relationships in which they considered themselves to be members of 'a little family'. Similarly Welden and Yesavage (1982) used relaxation training and found that this reduced anxiety and improved the memory of older patients with dementia, including some patients with Alzheimer's disease.

Humanistic therapy

Humanistic ideas have had a wide influence on care practices for people with dementia. For instance, Resolution Therapy (Stokes and Goudie 1990) stresses the importance of carers empathising with individuals and attending to the emotional content underlying the apparently confused behaviour of the person with dementia. Stokes and Goudie see Resolution Therapy as part of more general care schemes rather than being restricted to a formal programme.

Preventive and maintenance strategies

Working with a model similar to those currently being used to understand schizophrenia (*e.g.* Zurbin and Spring 1977), and using such concepts as vulnerability factors, stressors and support systems (Bowling 1994), we can move away from specific behavioural or cognitive changes, and look instead at increasing emotional resilience and reducing anxiety and depression. A modest goal for psychotherapeutic work with people with dementia may be to attempt to maintain clients at the top of their range of variability.

Non-verbal therapies

So far, we have been considering 'talking' therapies. It may, however, be that the future of therapy is with non-verbal therapies such as art and music (*e.g.* Pollack and Namazi 1992). Certainly, if the linguistic systems are so much at risk in dementia (*cf.* Maxim and Bryan 1994), then we may do better in attempting to help people with dementia feel secure and in control, if we use non-verbal means to achieve these ends.

Although we have focused on explicitly psychotherapeutic and counselling interventions, we recognise that these approaches need to be adapted for use with people with dementia and that, perhaps most importantly of all, the insights offered by psychotherapeutic theories need to be integrated into wider forms of dementia care. While good dementia care should be therapeutic (Kitwood 1990*b*), it does not necessarily have to draw upon formal psychotherapeutic techniques. Novel techniques have been developed to communicate with the dementia sufferer. Woods and Ashley (1995), for instance, report using tape-recordings of relatives' voices played to dementia sufferers using personal stereos. They argue that the therapeutic impact of this intervention is due to meeting the attachment needs of the dementia sufferers.

More particularly, we would argue that services that attend to the emotional needs of dementia sufferers would allow a range of psychotherapeutic interventions to be available as early as possible. This extends to understanding the emotional impact of psychometric testing upon individuals. In order for these people to be able to give meaningful consent to such testing then, before any cognitive assessment is undertaken, the individuals concerned and their families should have the implications of such testing fully explained to them. Similarly, after the assessment, if a diagnosis, however provisional, of dementia were to be reached, then all people so diagnosed should have access to support groups or other fora within which the implications could be explored. Such emotional work needs to be available to dementia sufferers throughout their illness, taking different forms as appropriate.

Conclusions

The efforts of mental health professionals and others who work with people with dementia have been restricted because of their almost exclusive use of the organic model. As a result, little work has gone into developing adequate psycho-social frameworks of the experience of dementia.

In this paper, we have proposed a three-part model with which to understand the subjective experience of dementia. We have summarised the evidence showing the likely presence, in varying degrees of strength and awareness, of four feeling states and the range of different responses within each of these states. We argue that the ability of individuals to express their emotions is contingent both upon the social context within which they are placed and their level of cognitive functioning. These two aspects are related. Thus Kitwood has described a dialectical interaction between the 'malignant social psychology' surrounding the individual and their internal cognitive decline. We have also summarised evidence that the individual's reaction to the diagnosis of dementia, and their awareness of changes in themselves and their abilities, may have larger, clearer and more important effects on their behaviour and feelings than the actual cognitive changes themselves.

The framework that we have described here indicates the need for changes in practice. It focuses on the sufferer as the primary reason for intervention and attempts to separate the delivery of services to them from those required by relatives and carers. This framework would allow for the development of ways of working with individual sufferers through expanded notions of psychotherapy, both verbal and non-verbal.

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References

Agbayewa, M. O. 1986. Earlier psychiatric morbidity in patients with Alzheimer's disease. *Journal of American Geriatric Society*, **34** (8), 561–4.

Anthony, K., Proctor, A. W., Silverman, A. M. and Murphy, E. 1987. Mood and behaviour problems following the relocation of elderly patients with mental illness. *Age and Ageing*, **16**, 355–365.

Bleathman, C. and Morton, I. 1992. Validation therapy: extracts from 20 groups with dementia sufferers. *Journal of Advanced Nursing*, **17**, 658–666.

Bowling, A. 1994. Social networks and social support among older people and implications for emotional well-being and psychiatric morbidity. *International Review of Psychiatry*, **6**, 41–58.

Buchanan, K. and Middleton, D. 1994. Reminiscence reviewed: a discourse perspective. In Bornat, J. (ed.), *Reminiscence Reviewed*. Open University, Buckingham.

Burns, A., Jacoby, R. and Levy, R. 1990. Psychiatric phenomena in Alzheimer's disease III: disorders of mood. *British Journal of Psychiatry*, **157**, 81–86.

Capstick, A. 1995. The genetics of Alzheimer's disease: rethinking the questions. In Kitwood, T. and Benson, S. (eds), *The New Culture of Dementia Care*. Hawker Publications, London.

Cheston, R. 1996. Stories and metaphors: talking about the past in a psychotherapy group for people with dementia. *Ageing and Society*, **16**, 579–602.

Cohen, D., Kennedy, G. and Eisdorfer, C. 1984. Phases of change in the patient with Alzheimer's dementia. *Journal of American Geriatrics Society*, **32**, 11–15.

Coleman, P. 1986. Issues in the therapeutic use of reminiscence with elderly people. In Hanley, I. and Gilhooly, M. (eds), *Psychological Therapies for the Elderly*. Croom Helm, London.

Coleman, P. G. 1994. *Ageing and Reminiscence Processes*. Wiley, Chichester.

Crisp, J. 1995. Making sense of the stories that people with Alzheimer's tell: a journey with my mother. *Nursing Inquiry*, **2**, 133–140.

Cummings, J. L. and Victoroff, J. L. 1990. Noncognitive neuropsychiatric syndromes in Alzheimer's disease. *Neuropsychiatry, Neuropsychology and Behavioral Neurology*, **3**, 140–158.

Edgerton, R. B. 1967. *The Cloak of Competence: stigma in the lives of the Mentally Retarded*. University of California Press, Berkeley.

Feil, N. 1982. *Validation – the Feil method*. Edward Feil Productions, Cleveland.

Freud, S. 1917. Mourning and Melancholia. In Strachey, J. (ed.), *The standard edition of the complete psychological works of Sigmund Freud*, **14**, 239–258. Hogarth, London.

Giles, H. 1991. "Gosh, you don't look it!": a sociolinguistic construction of ageing. *The Psychologist*, **3**, 99–106.

Goffman, E. 1963. *Stigma: notes on the management of spoiled identity*. Prentice-Hall, Englewood Cliffs, NJ.

Goudie, F. and Stokes, G. 1989. Dealing with confusion. *Nursing Times*, September 20, 38.

Gubrium, J. 1986. *Oldtimer's and Alzheimer's: the Descriptive Organisation of Senility*. JAI Press Inc., Connecticut.

Haggerty, A. D. 1990. Psychotherapy for patients with Alzheimer's Disease. *Advances*, **7**, 1, 55–60.

Hart, S. and Semple, J. M. 1994. *Neuropsychology and the dementias*. Lawrence Erlbaum, Hove.

Hausman, C. 1992. Dynamic psychotherapy with elderly demented patients. In Jones, G. M. M. and Miesen, B. M. L. (eds), *Care-giving in Dementia*. Tavistock/Routledge, London.

Hockey, J. and James, A. 1993. *Growing up and Growing Old: Ageing and Dependency in the Life Course*. Sage, London.

Hunter, A. J. G. 1989. Reflections on psychotherapy with ageing people, individually and in groups. *British Journal of Psychiatry*, **154**, 250–252.

Jeffries, J. J. 1977. The trauma of being psychotic: a neglected element in the management of chronic schizophrenia. *Canadian Psychiatric Association Journal*, **22**, 5, 199–205.

Kaplan, E. 1990. Facing the loss of what makes us uniquely human: working with dementia patients. In Genevay, B. and Katz, R. S. (eds), *Countertransference and Older Clients*. Sage Publications, California.

Keady, J. and Nolan, M. 1994. Younger onset dementia: developing a longitudinal model as a basis for a research agenda and as a guide to interventions with sufferers and carers. *Journal of Advanced Nursing*, **19**, 659–669.

Kelly, G. 1955. *The Psychology of Personal Constructs* (2 vols). Norton, New York.

Kitwood, T. 1987. Explaining senile dementia: the limits of neuropsychological research. *Free Associations*, **10**, 117–140.

Kitwood, T. 1990*a*. The dialectics of dementia: with particular reference to Alzheimer's Disease. *Ageing and Society*, **10**, 177–196.

Kitwood, T. 1990*b*. Psychotherapy and dementia. *BPS Psychotherapy Newsletter*, **8**, 40–56.

Kitwood, T. and Bredin, K. 1992. Toward a theory of dementia care: personhood and well-being. *Ageing and Society*, **12**, 269–287.

Kitwood, T. and Bredin, K. 1994. Charting the course of dementia care. *Journal of Dementia Care*, May/June 22–23.

Kral, V. 1983. The relationship between senile dementia (Alzheimer type) and depression. *Canadian Journal of Psychiatry*, **28**, 304–6.

Krebs-Roubicek, E. M. 1989. Group therapy with demented elderly. *Alzheimer's Disease and related Disorders*, 1261–1272.

Lyman, K. A. 1989. Bringing the social back in: a critique of the biomedicalisation of dementia. *The Gerontologist*, **29**, 5, 597–605.

Mackie, I. and Bredin, K. 1992. Psychotherapeutic care of dementia sufferers. *Elders: the Journal of Care and Practice*, **1**, (3), 13–19.

Mahendra, B. 1985. Depression and dementia: the multifaceted relationship. *Psychological Medicine*, **15**, 227–236.

Maxim, J. and Bryan, K. 1994. *Language of the Elderly*. Whurr, London.

Miesen, B. 1992. Attachment theory and dementia. In Jones, G. M. M. and Miesen, B. (eds), *Care Giving in Dementia*. Routledge, London.

Miesen, B. 1993. Alzheimer's disease, the phenomenon of parent fixation and Bowlby's attachment theory. *International Journal of Geriatric Psychiatry*, **8**, 147–153.

Miller, M. D. 1989. Opportunities for psychotherapy in the management of dementia. *Journal of Geriatric Psychiatry and Neurology*, **2**, 11–17.

O'Connor, D. 1993. The impact of dementia: a self-psychological perspective. *Journal of Gerontological Social Work*, **20** (3/4), 113–128.

Orrell, M. and Bebbington, P. 1993. Life events and senile dementia. *British Journal of Psychiatry*, **166**, 613–620.

Orrell, M. W. and Davies, A. D. M. 1994. Life events in the elderly. *International Review of Psychiatry*, **6**, 59–71.

Parkes, C. M. 1986. *Bereavement*. Penguin, 2nd Edition, Harmondsworth, Middlesex.

Pollack, N. J. and Namazi, K. H. 1992. The effect of music participation on the social behaviour of Alzheimer's Disease patients. *Journal of Music Therapy*, **29** (1), 54–67.

Radley, A. 1988. The social form of feeling. *British Journal of Social Psychology*, **27** (1), 5–18.

Reding, M. M., Haycox, J. and Blass, J. 1985. Depression in patients referred to a dementia clinic. *Archives of Neurology*, **42**, 894–896.

Sabat, S. R. and Harré, R. 1992. The construction and deconstruction of self in Alzheimer's disease. *Ageing and Society*, **12**, 443–461.

Sebastian-Moyer, R. B. 1990. Recognising countertransference: a key to good nursing home placement. In Genevay, B. and Katz, R. (eds), *Countertransference and Older Clients*. Sage Publications, California.

Sinason, V. 1992. *Mental handicap and the human condition*. Free Association, London.

Solomon, K. and Szwarbo, P. 1992. Psychotherapy for patients with dementia. In Morley, J. E., Coe, R., Strong, R. and Grossberg, G. (eds), *Memory Function and Aging-Related Disorders*. Springer, New York.

Stokes, G. and Goudie, F. 1990. Counselling confused elderly people. In Stokes, G. and Goudie, F. (eds), *Working with Dementia*. Winslow, Bicester, Oxon.

Sutton, L. 1994. *What is it like to lose one's mind?* paper presented at the 10th International Conference of Alzheimer's Disease International, University of Edinburgh.

Teri, L. and Gallagher-Thompson, D. 1991. Cognitive-behavioural interventions for the treatment of depression in Alzheimer's patients. *The Gerontologist*, **31**, 413–416.

Unterbach, D. 1994. An ego function analysis for working with dementia clients. *Journal of Gerontological Social Work*, **22** (3/4), 83–94.

Verwoerdt, A. 1976. *Clinical Gereopsychiatry*. The Williams and Wilkins Co: Baltimore.

Verwoerdt, A. 1981. Individual psychotherapy in senile dementia. In Miller, N. and Cohen, G. (eds), *Clinical Aspects of Alzheimer's Disease and Senile Dementia*. Raven Press, New York.

Watzlawick, P., Weakland, J. H. and Fisch, R. 1974. *Change: Principles of Problem Formation*. Norton, New York.

Welden, S. and Yesavage, J. 1982. Behavioural improvement with relaxation training in senile dementia. *Clinical Gerontologist*, **1**, 45–49.

Winnicott, D. W. 1964. *The Child, the Family and the Outside World*. Penguin, Harmondsworth, Middlesex.

Woods, P. and Ashley, J. 1995. Simulated presence therapy: using selected memories to manage problem behaviors in Alzheimer's disease patients. *Geriatric Nursing*, **16** (1), 9–14.

Yale, R. 1991. *A Guide to facilitating Support Groups for Newly Diagnosed Alzheimer's Patients*. The Alzheimer's Association, Greater San Francisco Bay Area.

Zurbin, J. and Spring, B. 1977. Vulnerability – a new view of schizophrenia. *Journal of Abnormal Psychology*, **86**, 260–266.