Communicating with patients who have dementia

**AUTHOR** Tony Bush, CertEd, RMN, DipN, is staff nurse, County Hospital, Pontypool, Gwent.


It was not until the 1980s that significant research was carried out on brain disorders. Lack of understanding of dementia has perhaps been the reason for the over-emphasis on physical care, and a failure to see these patients as people with feelings, beliefs and values. Three therapeutic techniques to help practitioners increase and improve communication with people who have dementia are described. It may be that communication is the key to understanding and resolving behaviour disturbances.

Recent research suggests that simply defining dementia in terms of organic brain disease and linking the process with ageing may not be as straightforward as was once thought. Stokes and Holden (1990) adopted the view that dementia was not a disease in its own right but, rather, a collection of signs and symptoms requiring further investigation.

There is confusion over what constitutes the disease process termed Alzheimer’s (Gilleard, 2000). Neurofibrillary tangles and senile plaques, initially thought to be the main neuropathological phenomena resulting in a diagnosis of Alzheimer’s disease, have now been found to occur independently of each other in the brains of older people with dementia as well as in those who do not have it.

Social, genetic and toxicological research has likewise proved inconclusive. Essentially, the true aetiology of the illness remains a mystery. Even the distinction between senile and pre-senile dementia is decidedly blurred, the same types of atrophy (shrinkage) and destruction of individual nerve cells in the brain occurring in both (Cheston and Bender, 2000).

**Approaches to care**

Delieu and Keady (1996) felt that understanding the physical biology of Alzheimer’s disease and other dementias was the bedrock from which all informed care should flow. However, it would seem that such theories, combined with an ensuing preoccupation with the biomedical aspects, might well have contributed to an overemphasis on the physical side of caring for people with dementia.

Nurses are perceived as being at the heart of the professional care response to the challenges set by the prevalence of dementia in our society. Yet Walsh (1998) raised the question: why, after so many years of using the nursing process and acknowledging the ethic of taking a holistic approach to care, were nurses apparently failing to assess and treat patients properly?

Psychological and social aspects of care are still found to be largely neglected, despite intrinsic physiological links in a holistic sense. The explanation for this neglect may lie in a failure to perceive the individual as anything more than a conglomeration of signs, symptoms and physical problems. It is also possible that nurses, universally restricted by time constraints, all too easily become entrenched in caring for individuals in purely physical terms. This is undeniably time-consuming and can often leave limited scope for considering other aspects of care.

**Background**

The Alzheimer’s Disease Society (2002) estimates that there are over 700,000 people in the UK today with dementia, over 55 per cent of whom have been diagnosed with Alzheimer’s disease. In global terms, it is estimated that there are 18 million people in the world with dementia, a figure that could rise to around 34 million by 2025.

Cheston and Bender (2000) established that from the outset of the First World War until the 1970s, there was almost no research into Alzheimer’s disease. It was not until the 1980s, when the profile of the condition was raised sufficiently for funding for biomedical research into brain disorders to be granted, that it became more familiar in the public domain. Perhaps this long-term lack of prominence in the collective consciousness of the general public may go some way to explaining the apparent dearth of understanding of the condition and the often benign yet basic and functional approaches of caregivers, both lay and professional, towards the care and treatment of people with dementia.

Shifts in cultural emphasis have also been influential. The gradual erosion of the extended family, which began in the late 1950s and accelerated through the 1960s to the present day, combined with greater social mobility, has contributed to an increased burden of care upon professional services. Maintaining an elderly grandparent within the auspices of a close-knit and extended family unit has now become a practice of the past. The care in the community coda of Margaret Thatcher’s Conservative government (1979–1990) may have sought a return to this type of value but, ultimately, has resulted in under-funded community services being deluged with patients as a result of a serious underestimation of demand. In addition, the philosophy fostered the creation of an overcrowded private nursing home culture that replaced, to a
large extent, long-term NHS care. Treating people in bulk with limited resources does little to nurture an enlightened and humanistic approach to care, to which the psychiatric institutions of the past are perhaps a telling historical testament.

**Communication**

The act of communication comprises all of the ways that people send and receive messages (Rao, 1993). We all need to communicate – it is an essential skill if we are to function effectively in society in the course of our everyday lives. If the process becomes impaired, our social capacity is reduced and we run the risk of alienation and diminished function.

Those who cannot communicate, or who communicate inappropriately, are often marginalised by society. Challenging behaviour and behavioural disturbances often occur as a result of frustration at being unable to communicate effectively and make needs and feelings understood by others.

The perpetuation of inappropriate attitudes and approaches in the treatment of people with dementia can, to some extent, be attributed to the way in which the symptomatic aspects of the condition are exhibited. There is general agreement that dementia has an impact on an individual in physical, psychological and social terms. The activities of living (Roper et al, 1983) are disrupted by the illness almost as a matter of course, and physical dependency on others for the meeting of basic daily tasks (bathing, dressing, washing, eating), is increased. Psychological, behavioural and social disturbances are major accompanying factors.

**REFERENCES**


**KEYWORDS** Mental health, Dementia, Communication

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**BOX 1. SEVENTEEN ELEMENTS OF MALIGNANT SOCIAL PSYCHOLOGY (KITWOOD, 1997)**

<table>
<thead>
<tr>
<th>Element</th>
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<tr>
<td>Treachery – using forms of deception to distract or manipulate and therefore force a person into compliance.</td>
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<td>Disempowerment – not allowing somebody to use his or her abilities, or failing to help that person complete an action once it has been initiated.</td>
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<td>Infantilisation – patronising somebody in the way an insensitive parent may treat a young child.</td>
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<td>Labelling – using a category such as dementia as the main basis for interacting with somebody and for explaining that person’s behaviour.</td>
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<td>Stigmatisation – treating a person as a diseased object, alien or outcast.</td>
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<td>Outpacing – providing information or presenting choices too quickly for somebody to understand, putting a person under pressure to do things more rapidly than he or she is able.</td>
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<td>Invalidisation – not acknowledging the subjective reality of a person’s experience and feelings.</td>
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<td>Banishment – sending a person away, or excluding that person physically or psychologically.</td>
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<td>Objectification – treating somebody like a lump of dead matter to be pushed, lifted, filled, pumped or drained, without reference to the fact that the person is a sentient being.</td>
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<td>Ignoring – carrying on a conversation or action in somebody’s presence as if that person was not there.</td>
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<tr>
<td>Imposition – forcing somebody to do something, overriding desire or denying that person choice.</td>
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<tr>
<td>Withholding – refusing to give requested attention or to meet evident needs.</td>
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<td>Accusation – blaming somebody for actions or failure of actions that arise from that person’s lack of ability or understanding of the situation.</td>
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<td>Disruption – intruding suddenly or disturbingly upon a person’s action or reflection, crudely breaking that person’s frame of reference.</td>
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<td>Mockery – making fun of somebody’s ‘strange’ actions or remarks, teasing, humiliating or making jokes at that person’s expense.</td>
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<td>Disparagement – telling a person that he or she is incompetent, useless or worthless, giving that person messages that damage self-esteem.</td>
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<td>Intimidation – using power threats that cause anxiety and fear.</td>
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social function during their stay, they did not significantly deteriorate. It was concluded that nursing care might have helped prevent the generally expected deterioration normally associated with Alzheimer’s disease and related dementias. The follow-on question should perhaps have been: ‘is this care outcome really good enough and, if considered not to be, what can we as nurses do to improve upon it?’

The person-focused approach

Kitwood (1997) acknowledged the apparently ‘overwhelming organicity’ of dementia, and although understanding the medical profession’s reasons for taking a technical approach to treatment as a result, felt that it was to the detriment of ‘personhood’ – ‘the standing or status bestowed upon one human being by others’. It seems counterproductive in a humanistic sense that care and treatment are largely focused on signs and symptoms rather than the individual and the fact that there is a person with feelings, beliefs and values somewhere beyond the perceived surface dysfunction.

This approach of reducing individuals to objects upon which treatments are routinely performed (either with or without their participation or affording them due consideration as people), was summed up by Kitwood (1997), who produced a list of 17 elements of ‘malignant social psychology’ from which nurses and carers should dissociate themselves (Box 1),

It was the formulation of these concepts that led to the introduction of the patient-focused approach to dementia care in the UK. The primary aim of person-centred nursing in dementia care is to maintain personhood in the face of failing mental powers (Kitwood, 1997). We define our own ‘personhood’ in terms of specific psychological needs (Dewing, 1999) such as:

- Love;
- Attachment;
- Inclusion;
- Comfort;
- Identity;
- Occupation.

The situation is no different for the person with dementia, and nurses need to be mindful and understanding of this fact if personhood and the reduction of ‘ill-being’ are to be achieved on an individual basis.

Certain key elements need to be considered in the person-centred approach. These include valuing and respecting the person, giving consideration to the person’s perspective in terms of meaning and impact and frames of reference. Core conditions in successfully implementing this approach include:

- Congruence (genuineness);
- Unconditional positive regard;
- Empathic understanding.

The focus should be on the person with dementia, not his or her diseased brain; on the person’s emotions and understandings, not memory losses, and on the person within the context of a marriage or family and within a wider society and its values (Cheston and Bender, 2000).

Resolution therapy

Carl Rogers (1902–1987) emerged as a prominent figure in the humanistic psychology movement in the 1950s. He pioneered the idea of client-centred therapy and assisted people to take responsibility for themselves. He believed that the experience of being understood and valued gives people the freedom to grow as human beings (Dickson, 1997).

Resolution therapy (Box 2) is a form of therapeutic intervention specifically developed for work with people with dementia (Stokes and Goudie, 1990). Based on Roger’s humanistic ideas of counselling, it is a means by which the often hidden emotional message underlying the actions and language used by people with dementia are sensitively reflected back to them. The aim is to encourage carers to empathise with the concealed meanings and feelings of people with dementia that are underlying their confused verbal and behavioural actions, reactions and responses. It is suggested that these techniques provide the helper with increased understanding of the person’s feelings and apparently confused, incongruous behaviours. These behaviours are likely to have value to the individual – to have a meaning and relevance – and if we learn to listen, observe and accurately interpret we may be able to elicit what the meaning is and, if necessary, act to improve the situation (Morton, 1999).

Resolution therapy can be an effective way of helping people with dementia to make sense of what has been happening to them (Cheston, 1998). It was developed in response to the reappraisal, and consequent discounting, of reality orientation. The latter is thought to be a less therapeutic intervention because of its mechanised implementation and its tendency to dismiss the emotions and perceptions of people who have dementia. Resolution therapy, on the other hand, is based on the proposition that while people with dementia may be losing their cognitive powers, their capacity to experience and feel as human beings is largely unaffected, therefore a psychological approach that incorporates Rogerian reflective counselling techniques is considered to be more appropriate.

Strong anecdotal evidence suggests that resolution therapy has a significant level of therapeutic value, yet compelling research-based evidence is lacking. Nevertheless, this did not prevent Stokes and Goudie (1989) concluding that the therapeutic potential for resolution therapy is enormous if it is used by nurses who are in daily contact and communication with patients with dementia.

Validation therapy

Feil (1996) used validation therapy extensively with older people with dementia as far back as 1963. Validation is defined as a method of communicating based on understanding individual behaviour with respect and empathy (Box 2). Or, as ventured by Pritchard (1998), communicating with a person in terms of that person’s perceptions of reality as opposed to

REFERENCES


Box 2. Three Therapeutic Techniques: A Summary

Resolution Therapy

Rogers (1902–1987)

Resolution therapy is based on Rogers’ humanistic ideas of counselling. The emotional message, which is often hidden, but which underlies the actions and language used by people with dementia, is sensitively reflected back to them. The aim is to encourage carers to empathise with the concealed meanings and feelings that are underlying patients’ confused verbal and behavioural actions, reactions and responses.

Validation Therapy

Feil (1996)

Validation is a method of communicating based on understanding individual behaviour with an attitude of respect and empathy. It involves communicating with people in terms of their perceptions of reality as opposed to attempting to orientate them to what we perceive as being real.

Pre-therapy

Prouty (1990s)

Pre-therapy consists of the application of four contact reflections: situational reflection, facial reflection, word-for-word reflection and body reflection, and the principle of reiteration, which involves the repetition of earlier reflections that have made contact. It was initially conceived as a method of facilitating psychological contact with psychotic clients as a pre-condition of therapy and aims to strengthen the person’s contact functions (Morton, 1999).

Application of Therapy

Prouty (1990s)

Pre-therapy, a technique developed by Garry Prouty in 1990, is strongly based on Rogerian counselling principles and the person-centred approach (Morton, 1999). It was initially conceived as a method of facilitating psychological contact with psychotic clients as a pre-condition of therapy.

The technique consists of the application of four contact reflections and one principle, which aim to strengthen the person’s contact functions. The four reflections are as follows:

- Situational reflections: used to attempt to strengthen contact with the world, and relating to facts, situations, people, environment and events;
- Facial reflections: the nurse or therapist states the emotion that is apparent in the client’s facial expressions;
- Word-for-word reflections: coherent communication or meaningful sounds are repeated by the nurse or therapist in an attempt to support communicative contact;
- Body reflections: the nurse or therapist mirrors the posture or movements of the patient or reflects them via verbal description.

The reflections are supported by the principle of reiteration. This involves repeating earlier reflections that have made contact, ‘evidenced by their eliciting contact behaviours’ (Morton, 1999).

While none of Prouty’s published work relates specifically to people with dementia, Morton (1997) felt that pre-therapy clearly has the potential to be adapted for use in this area.

Conclusion

Communication is a social skill of paramount importance for maintaining meaningful social contact with others. Both verbal and non-verbal modes of communication can be severely disrupted by dementia. Disinhibition, aggressive behaviour, lack of motivation with regard to initiating social contact and participating in recreational pursuits may all result in social isolation. Compounding this can be physical factors such as overall frailty. Diminished sensory ability, auditory impairment and visual impairment, are also highly influential concerns.

It has been suggested by Lliffe and Drennan (2001) that communication with the patient with dementia may be the key both to understanding and resolving behavioural disturbances.

The art of initiating and sustaining meaningful contact and interaction with confused, older people who are physically challenged by the rigours of old age has never been easy or straightforward. Yet, as nurses in the 21st century, it is up to us to consider and critically reflect upon our practices and approaches and modify these accordingly, in order to contribute to taking the treatment of patients with dementia forward in the name of good quality health care.

References


