

Working with people, making sense of dementia

Clare Morris describes how she has found Personal Construct Psychology an invaluable framework for making sense of the experience of dementia from the person's point of view, as well as that of professional and family carers. This article concludes her series on communication with the person with dementia.

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It is a source of great surprise to me that I have never found any reference to George Kelly's Personal Construct Psychology (1955, 1991) in literature which discusses 'person-centred' care.

'Person-centred' care is recognised as the critical shift in philosophy required in the development of the 'new culture of dementia care' but it has proved hard to define (Packer 2000). There are now many and diverse examples of good practice, ranging from re-designing the environment to creative and innovative ways to interact with people with dementia. Morton (2000) draws on Carl Rogers' work in tracing the origins of the therapeutic process in dementia care, and points out the difficulties in describing the process of therapy with someone who barely acknowledges our presence. Rogerian principles have been critical to the development of a variety of therapeutic approaches (for example Resolution therapy, Validation therapy, Pre-therapy) along with the valuable contributions of social psychology, disability rights, reminiscence, creative therapies and others.

In this issue Packer (2000) describes a 'real life' scenario of the difficult and stressful task care staff face in their work. The critics of 'person-centred' care have good reason to question its practicality in the real world. Staff recruitment and retention crises, low morale and 'burn-out' are the 'weakest link' and therefore the problems we need to address in the evolution of a truly person-centred service.

How do we all go about the task of living? What motivates us? How does dementia affect each and every one of us? In my view we need a model of the person that can be applied equally to the person with dementia at all stages of the disease; family and formal caregivers; and you and me. A framework to describe the process of therapy, and which integrates the eclectic influences of the cultural revolution in dementia care.

Personal Construct Psychology (PCP) is such a framework. PCP describes how people go about the task of living, adapting and changing; it is used in a wide range of clinical, organisational and research contexts. This framework has been invaluable to me personally as a meta-theory for making sense of the experience of dementia, intervention and care from the perspective of the person

with dementia, their carers and relatives, and professional service providers. It has huge implications for care-giving and therapeutic intervention, and for understanding the needs of people employed to care for people with dementia. Should we not be applying the principles of person-centred care to staff as well as 'clients'? This approach is very relevant to service managers in addition to those who provide 'hands-on' intervention.

The person as a scientist

Central to PCP is the concept of people as personal scientists. Behaviour is seen as an experiment to test out our theory of the world (people, events, objects, their environment, etc). In every action and interaction we are making predictions and testing them out, as I am in writing this article. The results of our experiment, or the outcome of our behaviour, either validate or invalidate our theory of the world. Our responses to the evidence from our experiments determine whether and how we adapt and change in relation to events.

Validation

If we are right in our prediction, then we are validated, and will repeat our 'experiment' – continue with the behaviour – and even make more elaborate experiments along the same theme to develop our understanding of the world. This in 'Kellyan' terms is known as *aggression*.

I have given many talks on this subject on CANDID study days, in other hospitals, and to audiences of professionals and carers. My 'experiments' were validated on those occasions by people's questions and comments, hence the more elaborate experiment to write this series of articles. I am testing out my theory of the needs of both people living with dementia and those of us trying to provide an appropriate and effective service. My prediction and experiment is that this approach will make sense of something for you.

I have found some of the important sources of validation for a person with dementia in my role as a counsellor to be: successful communication; feeling understood; and exercising choice. These are areas of validation for all of us, and they are seriously compromised by the experience of dementia. →

Invalidation

Should our prediction turn out to be wrong then we are invalidated, as I would be if I found that what I am trying to express in this article is meaningless to you.

Life is full of ups and downs for all of us. We experience invalidation at regular intervals, but when we are coping well this is balanced by validation in other ways, and we can always change the way we do things. A younger person with dementia will be invalidated in their sense of competence much of the time through having to give up work and finding 'busybodies' interfering in their life by providing 'help'. Care staff are invalidated by not being able to provide person-centred care through resource constraints or because people do not respond to their interventions.

So what can we do in the face of invalidation? Each of the following alternatives are fully adaptive responses, and serve to help us maintain control when we are invalidated.

1. We can try again. Maybe there is something 'in the weather', or we are having an 'off day'.

2. We can re-evaluate our theory, generate an alternative hypothesis, and so conduct a different experiment by behaving differently. I could write this article differently for a different journal.

Albert (Packer 2000 - see pp30-33 of this issue) lost his temper after repeated invalidated attempts to discover his circumstances. It could be argued that the person with brain injury may be limited in their ability to re-evaluate their theory for a variety of reasons. However I have witnessed this (*reconstruction* in PCP terms) in some of my clients.

Gina reconstructed Alzheimer's disease, as did her husband. This was achieved through giving her time to talk in a confidential environment, and helping her to 'put her cards on the table' in order to problem-solve the issues arising as a result of her condition. She discovered that by being more open about her disability with family, friends and some but not all acquaintances, the task of living with dementia was less of a burden.

Change is difficult at the best of times, and with neurological deficits that affect flexibility and organisation of your thinking, it could be expected to be much more difficult. While people in the earlier stages of dementia can and do reconstruct their circumstances, the onus is likely to be on



It is always important (but not always easy) to assume the person is aware. To reconstruct "unaware of my presence" is to free yourself from the invalidation of caring for someone who does not acknowledge your existence. Photo from *Openings* (John Killick & Carl Cordonnier) - see p35.

caregivers to change their own behaviour to accommodate the neurological deficits of the person with dementia, in order to enable reconstruction.

3. We can refuse to accept the outcome of our 'experiment' and cling to our original prediction. Theories very dear to a person's heart are very resistant to change. If we don't like the evidence we can choose to interfere with it. 'Denial' may manifest itself in anger, aggression, and the tendency to blame others or find excuses because to acknowledge the 'truth' is untenable. I would be hostile if I continued to expound an approach that held no meaning for anyone else, as would be a caregiver who does not appreciate the nature of language disorder in neurological disease, and insists the person with aphasia access the 'right' word, eg 'meat' is wrong when you mean 'beef'. The importance of the pursuit of meaning can be lost when we are faced with communicating with people whose language is affected (Morris 2000b).

Hostility, as it is known in PCP terms, is a label that requires caution; does the person actually know they are wrong? There is always a very good reason for hostility, and it plays an important part in protecting the core of our being. It is frequently seen in the early stages of dementia, perhaps because acknowledging that your faculties are slipping is likely to be very threatening to one's sense of being a person, and according to more than one of my clients, worse than death itself.

For Rebecca (Morris 1999b) and many other people with dementia, it is just too threatening to face up to what she *knows* is happening. 'Confabulation', angry or aggressive behaviour, refusing to cooperate and blaming others are all possible signs of hostility in a person who *needs* to distort the evidence in order to

maintain some degree of control or composure.

4. We may choose to withdraw from 'experimentation' in order to avoid putting our 'faulty' theory to the test.

This can manifest itself either passively or actively, as in physical withdrawal from the environment, or obsessive-compulsive behaviour which attempts to increase predictability of the world. *Constriction* is enforced to a great extent in neurological disease; difficulty expressing yourself will tend to restrict conversation; visual and perceptual deficits will mean you miss out on information or it

is distorted. Further constriction takes place with repeated invalidation, illustrated by the way people with Alzheimer's gradually withdraw from interaction with their environment; people may often take to their bed for very long periods; and people with frontal lobe degeneration such as Pick's disease often develop 'obsessional' routines to cope with their anxiety. One gentleman, when he attended clinic, would at regular intervals leave the interview and march out of the hospital, up to a lamp post, touch it and march back. When asked why he did this, he said because it made him "feel lucky, unlike this Pick's thing". Perhaps it was a way of creating a small island of validation for himself, as the lamp post was always there to be touched. Likewise, Bill (Packer 2000), who created a 'no-go' area around himself, was perhaps constricting in response to the perceptual problems common in Lewy body disease. If events fail to make sense and people's actions do not appear as they are intended, but are frightening and unpredictable, or if you are responding to hallucinations, then creating a 'no-go' zone is a practical solution to the problem. (Morris 1999a, 2000a).

Sociality

People not only require social interaction for their well-being, but it is through trying to predict the way *others* make sense of events that we enter into a relationship. Our predictions and therefore theory may be wrong, but the attempt to do so is what, in PCP terms, is *sociality*, and the way we achieve relationship, and therefore psychological contact. It feels good when someone accurately subsumes your experience; it feels less good when your needs and feelings are not understood; but it helps when you can sense that the attempt is made.

In PCP, any prediction made about another's experience is *propositional* (ten-

tative and seeking clarification). This is a very useful platform from which to plan person-centred dementia care, as it frees us to try things out, evaluate their benefit and change or develop the approach. In the case of the person with dementia who is 'unaware' of our presence: are they really unaware, or so *constricted* that they are unable or unwilling to respond? Is response delayed so long that we are already involved in something else? I would maintain it is always important (but not necessarily easy) to assume the person is aware. To reconstrue "unaware of my presence" is to free yourself from the invalidation of caring for someone who does not acknowledge your existence.

Careful observation of the person's behaviour *may* provide clues to a way to make contact sometimes. If we don't have training and most importantly supervision, reconstruing situations such as these is far more difficult. Add to this the time-pressured reality of continuing care, and we might be tempted to *constrict* by withdrawing and focusing on other residents, or we might be *hostile* and punitive. This stance provides us with a more validating path to follow, a hopeful one in which we might be able to make a difference.

Levels of awareness

Another important concept crucial to the description of the experience of dementia is that our theories and therefore experiments do not exist purely in conscious awareness. We 'construe' or experiment and change with our whole bodies and we may never notice or articulate the process. An illustration of this is to be found in sitting down. We make a prediction as to how hard or soft a chair is by glancing at it, then the whole of our body is tuned into the experiment of sitting in that chair without falling on the floor. The experience of invalidation is felt when it is harder or softer than expected, or when it breaks or wobbles.

I often refer to construing at lower levels of awareness as 'gut' construing. How is it people with memory impairment can benefit from therapeutic work when they can't remember what has been said? Margaret has moderately severe vascular dementia and was part of a validation group for two years. It was a shock to the nurses to discover she could speak, although she was unable to contribute fully to the conversation in the group. However she used to join in songs and make occasional comments such as "it is better to have loved and lost than never to have loved at all" and "my brain is going up the wall". After 18 months in the group, she was able to tell me what she liked about the group, while not actually in the group or the group room. She said what she liked about the group was to "see what everyone is wear-

ing". She had to be cued in to the fact it was time for the 'meeting', however once cued she could 'remember' the good feelings that had taken place over time. People with dementia often recognise and remember people who have very pleasant or very unpleasant associations. Oliver Sacks' (1985) report of the 'experiment' to shake hands with a man with amnesia when he had a drawing pin in his hand demonstrated this 'gut memory'; the man refused to ever shake hands with him again but could not remember what had happened nor explain why.

Contrasts

In PCP terms, one of the most important properties of a construct (our theory is made up of many linked constructs) is that it is bipolar. We only know exactly what someone means, when we know what they don't mean. Bill's construing of mealtimes was very different to other aspects of his day, and the following hypothesis emerges:

Validated	Invalidated
eating	? all other situations - no trust
permits interaction	creates no-go zone

By observing behaviour it is possible to build up a profile of situations where he permits interaction and allows proximity and situations where he does not. Predictions can be made about how he is seeing, hearing, feeling in relation to our theories of how this could be distorted from our perception of events. With these predictions we can plan intervention and try alternative strategies. By creating a 'no-go' zone, Bill is constricting his world to make it more manageable in light of the way *he perceives events*. The more elaborate the theory we have of his likely perceptual difficulties, the more specifically we can design intervention strategies that compensate for them. (Morris 1999c, 2000a) To what problem is a given behaviour the solution? (Morris 1999a). There will be times when we are unable to find ways to validate, but there is therapeutic value in the stance we take towards it.

Ways to validate people

- * subsuming the experience (standing in the shoes) of clients and staff
- * non managerial clinical supervision for staff
- * anticipating and compensating where possible for neurological deficits
- * through communication and advocacy
- * through activity
- * through environmental design
- * facilitate communication of the message rather than accuracy of expression or apparent appropriateness in time.

People with dementia are first and foremost *people* struggling to make sense of events and their environment with a wide range of cognitive disabilities. Disabilities can be subtle or severe, may fluctuate, and may or may not be recognised by the person experiencing them. This represents a challenge to anyone working with people with dementia. How can we validate both staff and people with dementia? This is the challenge we face in the evolution of the 'new culture of dementia care'. The syndrome of dementia is experienced in different ways by the affected person, their relatives, friends and neighbours, and professional care-givers. Personal Construct Psychology is an approach which links these experiences.

Conclusion

I hope you found it made sense of something for you and I hope the philosophy behind the previous articles is made more explicit. This is just a taste of what PCP has to offer the field of dementia care. If you are interested in finding out more about Personal Construct Psychology and Dementia, CANDID is hosting a Foundation Course which includes a period of clinical casework supervision. If you have already completed an equivalent course and would like to develop your work and hear what other people are doing, you might be interested in taking part or contributing to a day of information exchange on December 8. It is a good way to meet others and so develop the peer supervision and support networks critical to good practice. Contact me or Katy Judd at CANDID on 020 7829 8772 or e-mail to c.morris@candid.ion.ucl.ac.uk.

References

Kelly GA (1955, 1991) *The Psychology of Personal Constructs, Volumes I and II*. Norton, New York.
 Morris C (1999a) Building up a Toolbox of Strategies for Communication. *Journal of Dementia Care*, 7(4) 28-30.
 Morris C (1999b) How denial can lead to anger and aggression. *Journal of Dementia Care* 7(5) 25-27.
 Morris C (1999c) Visual impairments and problems with perception. *Journal of Dementia Care* 7(6) 26-28.
 Morris C (2000a) Hallucinations and delusions: What you see is real for you. *Journal of Dementia Care* 8(1) 28-30.
 Morris C (2000b) Understanding difficulties with speech and language. *Journal of Dementia Care* 8(2) 24-26.
 Morris C (2000c) Understanding specific memory disorders. *Journal of Dementia Care*, 8(3) 26-28.
 Morton (2000) Just What is Person-Centred Dementia Care? *Journal of Dementia Care*, 8(3) 28-29.
 Packer T (2000) Does Person-Centred Care Exist? *Journal of Dementia Care*, 8(3) 19-21.
 Sacks O (1985) *The Man Who Mistook His Wife for a Hat*. Duckworth, London.