

Person-centred care: the emperor's new clothes?

Despite the concept being widely discussed and promoted, it is still hard to find true person-centred care in practice. Are we fooling ourselves, just like the emperor? asks David Sheard.

"They're frightened of making a fool of themselves."

– Member of staff (see interviews below)

In the tale of the emperor's new clothes, the emperor is sold a suit made of 'invisible' cloth by a couple of weavers, who assure the emperor that only the wise can see it. When the emperor reveals his magnificent suit, no one admits that all they can see is a naked man for fear of looking a fool. It is left to a young child to point out the reality that everyone else shies away from. Does this tale have relevance in the world of dementia care and person-centred care as it currently stands?

The national picture

The current national picture in the UK is one where the words and the concepts behind person-centred care are widely talked about and promoted by services for people with dementia at conferences, in literature and in training. The words 'person-centred' feature prominently in brochures and statements of philosophy throughout health and social care services. Yet across the UK, other than in small pockets, it is hard to find significant large scale evidence of people with dementia receiving truly person-centred care.

So has there really been a change from the old culture of care, or are we fooling ourselves, just like the emperor? Is 'The Emperor's New Clothes' a perfect metaphor for person-centred care? Is it a myth, an illusion, an unattainable and impossible dream?

Has dementia care been camouflaged in professional ideologies? We have person-centred care, design and disability issues, life history and meaningful occupation, standards, dementia specific training and a plethora of DSDCs and organisations such as my own Dementia Care Matters, all committed to increasing the 'industry' of dementia care, which dazzles with middle-class professionalism, distracts with overblown concepts and creates dismay in those who believe person-centred care is not based in reality. Where does the truth lie?

Professor Tom Kitwood (1997) created a revolution in care cultures by demonstrating the need to focus on certain key ingredients in providing person-centred care:

- biography and identity
- autonomy and agency
- communication and interaction
- inclusion and occupation
- comfort and attachment.

Through his and others' work, more and more services are fighting to change the old culture of care. They are trying out different pieces of the person-centred jigsaw, struggling to connect all of the elements involved. So what continues to block the full picture on the jigsaw appearing?

Many services would identify certain traditional blocks to achieving person-centred care, as shown in Box 1.

Equally many services would identify a wide range of essential ingredients to succeeding in implementing this approach (Box 2).

However, is this the whole tale?

A philosophy for life

Maybe to prevent person-centred care becoming the 'The Emperor's New Clothes' we need to revisit the concept, and see that it is not just about people with dementia but actually concerns each one of us. The need is to understand that person-centred care is a life philosophy – an aspiration about being human, about pursuing the meaning of self, respecting difference, valuing equality, facing the anxieties, threats and guilt in our own lives, emphasising the strengths in others and celebrating uniqueness and our own 'personhood'.

1: Traditional barriers to person-centred care

- No dementia-specific philosophy of care
- Too much focus on losses and dependency
- Overemphasis on staff hierarchies
- Fixed care ideologies
- Lack of link between beliefs, training and care delivery
- Low pay
- Professional self-distance
- Care based on tasks and physical needs alone
- No continuous learning culture
- Obsession with risk prevention.

How can we expect those who support people with dementia to understand a person with dementia's life history and feelings if they have never had an opportunity in their life to explore their own? How can we expect those who support people with dementia to keep giving so much of themselves to people with dementia if they themselves do not receive person-centred care – if they are not helped to mirror this philosophy in their own life? How can we recognise well-being and ill-being in people with dementia if we do not even recognise it in ourselves?

Training needs to empower staff, to help them feel pride in the work they do and in the knowledge they have, to emphasise the importance of using individual initiative, instincts and passion as well as the need for professional knowledge, concepts and standards.

If those people who support people with dementia are going to start working truly together and so provide person-centred care, the training that is provided needs to work with the strengths of each individual staff member – and it also needs to help individuals acquire skills that may not come naturally to them.

Instinctive feelings and skills

Some people's strengths include an ability to be able to use and understand the jargon and terminology used in person-centred care and its application to people with dementia. However, the terms and words used about person-centred care have become more visible and important than the real, 'invisible' meaning of how to achieve this approach.

We all know many staff who are 'instinctive' rather than 'theoretical'. We all know

Why is person-centred care so difficult to achieve? Why do staff highly trained in this approach struggle to implement it? What is it about some untrained staff who are just 'naturals' – who appear to have 'the knack'...?

staff who have never worked with people with dementia, have very few if any qualifications and yet they are 'naturals'. They do not need training in person-centred care. They see things as they are, what's really visible, they have developed themselves into people who instinctively live their lives with the ability to connect to another's feelings, who use their instincts and gut feelings, who *feel* person-centred care rather than just practise it. In many cases such people cannot talk the talk – they don't have the words to describe that this is person-centred care. They are working from the heart rather than the mind.

Inspiration from untrained staff

Dementia Care Matters has been appraising a number of key questions. Why is person-centred care so difficult to achieve? Why do staff highly trained in this approach struggle to implement it? What is it about staff who are just 'naturals' and appear to have, in Bell & Troxel's word (2003), the 'knack'? What makes it so difficult to replicate 'feeling' through training?

We undertook a number of interviews with untrained staff which demonstrate true inspiration – two are presented on the next page. These interviews leave us wondering how far person-centred care and the care 'industry' which has developed around it have come in the last 15 years when staff who have never heard of person-centred care are feeling and demonstrating it every day. The interviews highlight how these staff clearly articulate everything we would want them to know about supporting people with dementia without any knowledge of the term person-centred care or the jargon used in this field. They have not needed training to help them 'feel' what people with dementia 'feel'.

These staff need training that enables them to see that there is a theoretical framework behind the things they are

doing naturally. They need help to understand the words and the theory to the practice they are instinctively using. Once they have this they may have an even greater understanding and realisation that person-centred care is coming from their heart while the concepts around this approach are being learned by others in the head. They will then stand a better chance of holding their own and not being put down by staff with outdated beliefs, professional qualifications and training.

Joining up the visible and invisible

Given the difference in two types of staff engaged in the battle against the old culture of care – the instinctive and the theoretical – we need to find a way to join both together. Each group has different needs, each can learn from the other and services need to recognise this. People who have a strong theoretical understanding need to learn how to apply person-centred care to themselves and to 'feel' it. Those who find it easy to work with their instincts need to acquire knowledge about the terms behind person-centred care and how these apply to people with dementia.

Through specific training both groups need to acquire opposite skills that do not come naturally to them; to relearn, re-apply and renew understanding. The best way for them to achieve this is through support and training which enables both types of people to train and lead each other, to work together, to learn from each other, to model person-centred care to each other, to empower each other and draw out the best from each other.

This will not be achieved by training alone. Training is only one piece of the puzzle. Many staff go on courses, feel inspired and have renewed hope, only to find that it disappears when they return to a service still practising the old culture of care. If person-centred care is going to work then it is not just about individual change but a whole culture change.

The future for person-centred care

As a member of staff in one of these interviews states, "It's no bother, it's not such trouble, it's so simple." Is this our inspiration for the future: getting the simplicity of person-centred care back into organisations, managers and staff?

I would suggest the key ingredients of person-centred care are essentially:

- recognising it as a life philosophy that benefits all of us
- a belief that this work is rewarding and is a process of two-way giving
- a culture that celebrates working with people with dementia and loves each individual for who they are
- a manager that models person-centred care with staff and provides leadership rather than management



David Sheard is director of Dementia Care Matters and visiting senior fellow, European Institute of Health and Medical Sciences, University of Surrey.