Person-centred care for people with dementia: Kitwood reconsidered

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Abstract

There is a plethora of literature on person-centred care and its importance in health care. The principles of person-centred care are especially important for people living with dementia because of the clinical manifestations of the disease. This article intends to provide nurses with an overview of the work of Tom Kitwood and how it pertains to providing best practice in dementia care. Various person-centred theories have been developed. However, Kitwood's work is by far the most widely referred to in dementia care. An understanding of Kitwood's ideas, in particular those of malignant social psychology and positive person work, enables nurses to develop competence in delivering optimum person-centred care to people with dementia in clinical practice.

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THE CONCEPT OF person-centred care is neither new nor revolutionary. Its origins are in the work of Carl Rogers more than 50 years ago (Rogers 1961). It is an approach to care that places the person at the centre of their own care. Individuals are supported, facilitated and enabled to contribute to their care through shared decision making, equality of communication and mutual respect. Therefore, person-centred care is an approach that is considered humanistic, dignified and morally ethical (Steenbergen *et al* 2013, Perez-Merino 2014).

In the UK, person-centred care has been integral to legislative policy and best practice guidance for the past 15 years (Department of Health 2001, 2005, 2006, 2009). The ethos of person-centred care should be applied to all people in receipt of any form of health care. However, this article focuses on the provision of person-centred care for people living with dementia.

Dementia

The total number of people with dementia is difficult to determine, given the low rates of people receiving a formal diagnosis (Mitchell *et al* 2013a, 2013b). However, estimates for 2015 suggest approximately 850,000 people in the UK live with dementia. This figure is expected to increase to more than one million people by 2025, and to more than two million by 2051 (Alzheimer's Society 2014). International estimates give 36 million people living with dementia in 2010, set to increase to 66 million by 2030 and to 115 million by 2050 (Alzheimer's Disease International 2012). These increases in the number of people with dementia correlate with the number of people who are living longer. It is accepted that a significant aetiological factor of dementia is advancing age (Ballard *et al* 2011).

Dementia is an umbrella term for a group of clinical syndromes that affect multiple aspects of a person's cognitive function. In the UK, the most common forms include (Alzheimer's Society 2015):

- Alzheimer's disease (62%).
- Vascular dementia (17%).
- Mixed dementia, which is a combination of Alzheimer's disease and vascular dementia (10%).
- Dementia with Lewy bodies (4%).

The clinical manifestations of each form of dementia are similar and emphasise the importance of providing person-centred care. Clinical manifestations may include (Downs and Bowers 2008, Ballard *et al* 2011):

- Progressive loss of memory.
- Difficulty in articulating language.

- Potential changes in personality.
- Reduction in mental capacity.

Tom Kitwood was a major influence in the field of dementia care and his pioneering work provides a theoretical basis for delivering person-centred care for people with dementia (Kitwood 1993, 1995, 1997). Kitwood's work on personhood, malignant social psychology and positive person work was enterprising; 15 years after its original conception and Kitwood's death, it forms the basis of best practice in dementia care (Brooker 2007, Dewing 2008, McCormack and McCance 2010).

Personhood

The concept of personhood was first applied to people with dementia by Kitwood (1997). The concept can be complex to define, but it is used generally to describe what makes up the attributes of being a person (Dewing 2008). According to Kitwood (1997) personhood is 'a standing or status that is bestowed upon one human being, by others, it implies recognition, respect and trust'. Through this recognition, respect and trust, the personhood of an individual will be enhanced as well as their wellbeing. If the opposite occurs, then personhood will diminish, leading to 'illbeing'.

It is erroneous to suggest that people with dementia should be in a constant state of wellbeing because this is not a maintainable state for any person, well or unwell (Jones and Mitchell 2014). Despite this recognition, Kitwood (1997) asserted that people with dementia, who mostly experienced illbeing, were more likely to be exhibiting feelings of undermined personhood. Those people with dementia who experienced more frequent illbeing were often living in care environments that were not supportive of the concept of personhood (Kitwood 1997). Healthcare professionals in these care environments were not purposely undermining the personhood of the people they were caring for, but were unaware of the specialist needs required by these individuals.

Kitwood's (1997) theory sought to identify behaviours that would undermine a person's wellbeing – malignant social psychology – and behaviours that would enhance a person's wellbeing – positive person work – to enable healthcare professionals to deliver optimum levels of person-centred care that would retain and enhance personhood for people with dementia.

The theories of malignant social psychology and positive person work assist healthcare professionals in implementing person-centred practices. However, the essential psychological needs of people with dementia should also be considered and include (Kitwood 1997):

- Comfort – the feeling of trust that comes from others.
- Attachment – security and finding familiarity in unusual places.
- Inclusion – being involved in the lives of others.
- Occupation – being involved in the processes of normal life.
- Identity – what distinguishes a person from others and makes them unique.

Kitwood (1997) theorised that these psychological needs are present in all human beings, but are likely to be heightened for people with dementia because they are usually more vulnerable and less likely to be able to take action to satisfy these needs. Essentially, these five psychological needs contribute to the expression of love.

Retaining and enhancing personhood is important for people with dementia because of the anticipated decline in their cognitive functioning. For people with advanced dementia, it is likely that the nurse or other health and social care professionals will be responsible for meeting these psychological needs, especially given the large number of people with dementia in long-term care facilities.

The care staff and care environment determine whether the psychological needs of people with dementia are met and if personhood is maintained or enhanced subsequently. This depends largely on whether care staff behaviour corresponds more with malignant social psychology or positive person work.

Malignant social psychology

Malignant social psychology is a term for a range of behaviours that undermine the personhood and wellbeing of people with dementia (Kitwood 1997). Kitwood (1997) described many ways that the personhood of people with dementia may be undermined in care settings, following his direct observation of practice (Table 1). He acknowledged that these depersonalising tendencies often occur because of a lack of specialised education among healthcare professionals rather than through malicious intent.

Kitwood (1997) explained that malignant social psychology arises because people with dementia are seldom visible or acknowledged in society, which undermines the personhood of these individuals. Therefore, these people are treated as less-than-human as a result of this depersonalisation. Kitwood (1997) first postulated that nurses have to act as role models so that others – family and members of the public – who come into contact with the person with dementia will be able to replicate

person-centred practices. It is beyond the scope of this article to explore all aspects of malignant social psychology fully, but a case study is presented to illustrate the concept.

Case study

David is 85 years old and has dementia. He has been living in a care home for almost four years and needs some degree of assistance with most of his activities of daily living, such as washing and dressing, elimination, eating and drinking, and maintaining a safe environment (Roper *et al* 2000). David came to the care home when his wife Jean died.

Ray, a nurse, is assisting David with his lunchtime meal in the dining room when the following conversation takes place:

Ray: 'Come on, David, you haven't even eaten any of your vegetables yet.'

David: 'I don't want any more. I am finished.'

Ray: 'Well you won't get any pudding unless you finish that up. Come on, the vegetables are good for you.'

David: 'No thanks. I have to go now and get ready – Jean is collecting me in 15 minutes.'

Ray: 'Jean just called before dinner and told me to tell you she was running a bit late, so you still have some time. Won't you just finish off your vegetables?'

David: 'I don't like those vegetables.'

Ray: 'Of course you do. Here, let me help. Open your mouth. Good man. That wasn't so bad. Now I can get you some pudding.'

There is no obvious malicious intent or abuse in this scenario. The nurse is trying to encourage David to maximise his daily intake of food, which is an advocated practice. However, this interaction contains multiple examples of malignant social psychology that served to undermine David's personhood, such as:

- Treachery – Ray told David that his wife Jean, who is deceased, was running late, therefore meaning David had more time to finish his meal.
- Disempowerment – David is normally able to eat and drink unassisted, however this scenario involves Ray feeding David.
- Infantilisation – Ray treated David like a child, asking him to open his mouth and then offering to reward him with pudding.
- Ignoring – Ray did not acknowledge that David did not like the vegetables on his plate.
- Imposition – Ray imposed that David would eat his vegetables.

Positive person work

Positive person work is in contrast to malignant social psychology. It intends to fulfil the psychological needs of people living with dementia

TABLE 1

Malignant social psychology

Malignancy (concepts developed by Kitwood (1997))	Definition
Treachery	The use of deception to distract or manipulate behaviour.
Disempowerment	Not allowing or enabling a person to use the abilities they still have.
Infantilisation	Treating the person like a child.
Intimidation	Causing the person to feel fearful as a result of threat or physical power.
Labelling	Referring to people inappropriately, for example 'elderly mentally infirm'.
Stigmatisation	Treating the person as if they were an outcast.
Outpacing	Providing information or choices too quickly thus potentially making information difficult to understand.
Invalidation	Not acknowledging the reality of the person.
Banishment	Excluding the person either physically or emotionally.
Objectification	Treating the person as an object, for example during washing or dressing.
Ignoring	Conversing with others in the presence of the person as if they are not present.
Imposition	Forcing the person to do something.
Withholding	Failure to provide attention or meet an obvious need.
Accusation	Blaming a person for their misunderstanding or inability.
Disruption	Suddenly disturbing a person and interrupting their activity or thoughts.
Mockery	Making fun or joking at the expense of the person.
Disparagement	Telling the person that they are worthless.

that Kitwood (1997) identified, thereby retaining or enhancing their personhood and wellbeing. Kitwood (1997) listed a number of behaviours that were perceived as enabling good dementia care (Table 2), some of which are illustrated in the following case study.

Case study

David, who featured in the earlier case study, is in his bedroom at the care home. He has just sat down and his TV is on. The nurse, Ray, joins David and the following conversation takes place:
Ray (knocks on the door): 'Hi, David, do you mind if I come in?'
David: 'No problem, come in.'
Ray: 'I am just getting the menus ready for dinner tonight and wondered if you would like Irish stew or omelette?'
David: 'I don't really like either of those… maybe the stew.'
Ray: 'That's okay. What are you in the mood for? We will see what we can do for you.'
David: 'Maybe something like baked beans on toast. I really don't have much of an appetite.'
Ray: 'No problem, I am sure we can manage that. Is there anything else you need?'
David: 'No thank you. I think I just might watch TV here until something good comes on.'
Ray: 'Janet is just setting up for bingo if you want to join us, or I can put one of your videos on for you.'
David: 'Thanks, bingo would be good.'
This scenario is markedly different from that which took place in the earlier case study. It demonstrates examples of what Kitwood noted as positive person work. The behaviours associated with positive person work (Table 2) are important in personalising care for people with dementia. Examples that occurred in the scenario include:

- Recognition – Ray knocked on the door and asked if he could enter David's room.
- Collaboration – David did not want either of the two meals that were on offer for dinner, so Ray and David came up with an acceptable alternative.

TABLE 2

Positive person work	
Positive person work (concepts developed by Kitwood (1997))	**Definition**
Recognition	A person who is recognised by name and acknowledged as a person with unique thoughts, feelings and preferences, for example greeting a person by their preferred name.
Negotiation	Facilitated through consultation with the person about their preferences in care and their daily lives. Where possible, they are supported to be involved in the decision-making process, for example serving residents food that they enjoy.
Collaboration	Partnership between the healthcare professional and the person to carry out an activity or task, for example having a bath or getting dressed in ways that are comfortable for the person.
Play	The provision of appropriate activity and enablement of self-expression, for example rolling a ball, sharing a joke or playing a game.
Giving	Accepting whatever kindness the person with dementia gives, for example the person with dementia may want to give a nurse a flower from the garden.
Timalation	A form of interaction, such as aromatherapy, which stimulates the senses.
Celebration	Not just during celebratory occasions, such as birthdays or anniversaries, but the person should see their achievements celebrated. For example, joining the person who is happy and celebrating, irrespective of the reason, by clapping, whistling, singing or smiling.
Relaxation	Low level of intensity and recognition that some people may like to relax in solitude, for example listening to music or spending time in the garden.
Validation	Connected to the work of Feil (1993), this is about accepting the reality of another even if it is as a result of hallucinations or misperceptions.
Holding	Providing a safe psychological space or environment to enable people to truly express themselves. For example, if a person with dementia is experiencing distress do not isolate them, stay beside them and validate their experiences without trying to stop or ignore them.
Creation	Encouraging the person to be creative, because this can be therapeutic. For example, spontaneous singing or dancing, or horticultural therapy.
Facilitation	Enabling the person to do what otherwise they would be unable to do. This is similar to collaboration, for example accompanying a person to go for a walk outside of the unit.

- Play – David decided to play bingo.
- Facilitation – Ray had offered to put on one of David's videos.

Alternatives to Kitwood's theory

Undoubtedly, the basis of person-centred care in people with dementia arose from Kitwood's work. His work on personhood, the psychological needs of people living with dementia, malignant social psychology and positive person work remain important today. Kitwood's work forms the basis of a range of other person-centred theories, such as the VIPS model (Brooker 2007), the Senses Framework (Nolan *et al* 2006) and the person-centred nursing framework (McCormack and McCance 2006, 2010). These theories provide nurses with evidence-based alternatives when considering person-centred dementia care. Kitwood's theories on person-centred care are often a favoured starting point for practising clinicians. This is because they provide an overview of clinical practices, defining those that are advocated, as positive person work, or discouraged as malignant social psychology. Kitwood's work remains relevant 15 years after publication, indicating that practice remains unsatisfactory for many people with dementia.

Conclusion

There is increasing provision of person-centred practices in dementia care, however there is still scope for improvement. Nurses working in dementia care units have a responsibility to learn and disseminate best practice in person-centred care. Kitwood's work is important because it provides a template that is easy to relate to, defining what can be good – or inadvertently bad – about practices. Moreover, it forms the basis of any theory on person-centred care for people with dementia. The essential message of Kitwood's work is that all people are equal, regardless of their cognitive ability. The task for care providers is to maintain and enhance the personhood of people in their care. This care should recognise that all people are unique and individual, irrespective of their diagnosis **NS**

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