Abstract

Carers of people with dementia should embrace the philosophy of person-centred care and understand that social and psychological aspects of care are as important as physical care. This article discusses a three-component model that identifies the personal qualities that carers should ideally possess to deliver person-centred care to people with dementia. These qualities are empathy with the person, person-centred attitudes and a compassionate approach. The intention is that these will induce a state of cognitive security in people with dementia and enhance their sense of wellbeing. The article defines each of the personal qualities and details their component parts. It explores why person-centred care can often be difficult to achieve in practice, as well as the role of education in its promotion.

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and using that understanding to meet the person’s care needs (Stokes 2000, Brooker 2003). We propose that empathy with a person with dementia encompasses several aspects, which come under three broad headings: interpersonal sensitivity, self-awareness and knowledge.

**Cognitive security**
Central to our model is the concept of cognitive security. We define cognitive security as: the subjective feeling of a person with dementia that they perceive meaning in their experience and can respond to that experience to meet their immediate needs. Cognitive security is a subjective feeling and the meaning that the person perceives in their situation may not correspond to ‘reality’ as experienced by others. People with dementia progressively experience memory, attention and executive function difficulties that lead them to misinterpret stimuli, which may result in a view of the world that others find difficult to understand (Perrin 1997). A need for cognitive security is fundamental to all people with dementia and if individuals cannot find meaning in their experience, they will experience a state of cognitive insecurity. Carers require the ability to judge, in a given situation, where the person with dementia’s experience lies on a spectrum between cognitive security and cognitive insecurity.

Cognitive security is closely related to wellbeing. For people with dementia, the world can be a confusing place and it can be difficult for them to meet their needs or have their needs met by others. They may be hypersensitive to negative interactions with others or to the routine difficulties inherent in everyday life (Whall and Kolanowski 2004). Such difficulties would create ill-being in all people, regardless of whether or not they have dementia. However, those without dementia can use their mental abilities to compensate and restore a sense of wellbeing. People with dementia, particularly as the condition progresses, may lack such abilities and require sensitive assistance from carers to regain cognitive security and thereby enhance their wellbeing.

**Empathy with the person**
Carers must use their empathic understanding of the person to judge, in a given situation, the person’s state of cognitive security or insecurity. In the context of dementia care, empathy is defined as (Kitwood 1997): ‘Having an understanding of what another person may be experiencing, getting some glimpse of what life might be like from within their frame of reference’.

Empathy is considered essential for understanding the subjective experience of a person with dementia and using that understanding to meet the person’s care needs (Stokes 2000, Brooker 2003). We propose that empathy with a person with dementia encompasses several aspects, which come under three broad headings: interpersonal sensitivity, self-awareness and knowledge.
on the person’s situation and attempt to view the situation from the person’s internal frame of reference (Rogers 2003).

**Knowledge**
Knowledge comprises three elements: knowing the person and their life history, understanding the effects of dementia on the person, and attributing behaviour primarily to need.

**Knowing their life history**
A proper acquaintanceship with the person with dementia, both in terms of their situation and overall biography, assists carers to contextualise the person’s experience and the factors that enhance or reduce their sense of cognitive security. Kitwood (1997) observed that the manner and actions of a person with dementia sometimes reflect aspects of their past life. Therefore, knowledge of the person’s biography may help carers appreciate when the person’s frame of reference is situated in past experiences. The value of ‘life story work’ to assist acquaintanceship and thereby empathy with people with dementia is well established (Egan et al 2007, McKeown et al 2010).

**Understanding the effects**
Understanding the effects of dementia on individuals assists carers to interpret their manner, actions and communications in terms of the cognitive difficulties that are being experienced. Dementia can lead to difficulties in memory, attention, executive function, decision making and language and communication (Draper 2013). A working knowledge of these general effects may assist carers to recognise when the responses of the person are being influenced by any of them.

**Attributing behaviour to need**
People with dementia frequently behave in ways that others find challenging, and an important facet of empathic understanding is how carers attribute such behaviour (James 2011). Empathic carers recognise that behaviour most commonly has meaning for the person and so attempt to make sense of that meaning. Stokes (2000) described behaviours that challenge carers as reflecting ‘poorly communicated need’. Empathic carers recognise this and seek to identify and meet the need underlying the person’s manner and actions.

**Person-centred attitudes**
Positive attitudes are crucial for effective care of people with dementia (MacDonald and Woods 2005, Sanders and Swails 2009, Stockwell-Smith et al 2011). Carers need such attitudes to help them gain empathic understanding of the people for whom they are caring and to motivate them to translate that understanding into care approaches that enhance cognitive security and wellbeing.

We propose a central role for person-centred attitudes in determining the extent that carers gain empathic understanding of those in their care and use that understanding to implement a compassionate approach to meet the needs for cognitive security. We suggest that attitudes held by carers have three facets: attitudes towards dementia, attitudes towards people with dementia, and attitudes towards their role as carers. Each facet may be regarded as occurring on a continuum between person-centred and ‘standard paradigm’ extremes.

**Disability or disease?**
The first attitude facet relates to carers’ beliefs about the nature of dementia. A ‘standard paradigm’ perspective would regard dementia as being the manifestation of neurological disease, with the implication that the person’s behaviour is random and meaningless, and should be controlled rather than understood (Kitwood 1997).

A person-centred perspective regards dementia as being multifaceted and that psychological, social and biographical factors are as important as neurological factors. Therefore, dementia should be perceived more as a disability than a disease. According to Gilliard et al (2005), taking a disability perspective promotes people’s remaining abilities and helps them compensate for their disabilities. This is in contrast to a disease perspective, which focuses on the person’s signs and symptoms and deficits. Taking a disability perspective of dementia (Gilliard et al 2005) implies that carers should make the effort to understand the person and their behaviour, and regard psychological and social care as being as important as medical or physical care.

**People or ex-people?**
Attitudes towards people with dementia can vary from them being regarded as people like ourselves (reflecting a person-centred perspective) to them being thought of as ‘ex-people’ (reflecting a standard paradigm perspective). People with dementia can be perceived to have lost, through neurological damage, specific aspects that make them human, such as personality, individuality and the ability to communicate. In general, carers who regard people with dementia as human are likely to be more motivated to regard psychological and social care as being important for the person. However, an attitude of regarding people with dementia as ex-people is associated with a task-oriented approach that prioritises physical...

The role of carer
The third facet of attitudes relates to what carers regard as their priorities when in the caring role. Professional carers, from a person-centred perspective, could put those in their care at the forefront and embrace the necessity for social and psychological care, or they could regard minimising the practical or emotional demands on themselves as their main priority. The approach of a carer who holds the latter attitude is likely to be task oriented (Stockwell-Smith et al 2011). A carer may prioritise other service users over people with dementia (Sanders and Swails 2009). In extreme circumstances, care may become neglectful and abusive (Eriksson and Saveman 2002).

A compassionate approach
A tribute paid to a unit manager by a relative who took part in a study of aggressive behaviour in care homes epitomises a ‘compassionate approach’ (Duxbury et al 2013): ‘She takes everything in her stride, she does it easily, she’s very clever is Anne [name anonymised] with all situations. She seems to have compassion… everyone seems to love her. You know you can come in here and Anne will be sat there nice and peaceful and yet when Anne ain’t on some days you come in and there’s one or two playing up. She takes it all matter of fact; nothing seems to faze her’.

A compassionate approach embraces both the skills and strategies of care delivery and the personal manner and interaction style of the carer, which we hold to be as important as the components of care. Like empathy, a compassionate approach requires: interpersonal sensitivity, self-awareness and knowledge.

Interpersonal sensitivity
Interpersonal sensitivity comprises two elements: promoting cognitive security by personal manner and interaction style; and responding to the person’s wishes and preferences.

Promoting cognitive security by personal manner and interaction style
Promoting cognitive security is the crux of a compassionate approach. It is essential that the carer uses empathy to assess the person’s state of cognitive security and adopt a personal manner and interaction style that enhances cognitive security rather than reduces it. Both verbal and non-verbal aspects are important. Overall, a calm, non-intrusive and non-threatening personal manner and a verbal interaction style that seeks to understand and respect the frame of reference of the person are most likely to engender a sense of cognitive security in people with dementia (Passalacqua and Harwood 2012).

Responding to wishes and preferences
A compassionate approach behoves staff to find ways of helping people express their wishes and preferences and respond to those wishes and preferences, if it is possible for them to do so. That may not be easy. Carers may have to do things that people dislike, such as personal care, or prevent them from doing things that they want to do, such as going out alone (Duxbury et al 2013). Perceived non-empathic actions should be justified as being in the person’s best interests and carers must recognise and attempt to minimise the diminution of cognitive security that they entail (Duxbury et al 2013).

Self-awareness
Self-awareness involves overcoming personal constraints to create a positive relationship with the person with dementia. Compassionate caring occurs in the context of a positive relationship between the carer and the person with dementia. Our view of caring relationships focuses on the fact that people with dementia may find relationships difficult to initiate and sustain because memory, attention and language difficulties can lead to problems interacting with others (Ericsson et al 2011). Carers need the self-awareness to recognise that they must reach out to the person with dementia more than would be required to create a relationship with someone who does not have dementia. Tom Kitwood promoted the value of a less inhibited (and thereby more compassionate) approach to interacting with people with dementia. In discussing the nature of positive person work, he stated that the ‘quality of interaction is warmer, more rich in feeling, than that of (British) everyday life’ (Kitwood 1997). Therefore, carers should be proactive and adopt a warm, outgoing and welcoming manner, including the use of touch.

Knowledge
Knowledge is composed of three elements: finding creative care solutions based on empathic understanding of the person; knowing when to direct and when to facilitate; and using empathy to judge the appropriateness of care interventions.

Creative care solutions based on empathy
When carers recognise that a person with dementia is experiencing cognitive insecurity and is, for example, agitated or distressed, it is vital that they use their empathic understanding of the person
to find an individual creative care solution that will enhance the person’s cognitive security and wellbeing (Stokes 2000, James 2011). This involves identifying the underlying need that is making the person feel insecure and finding an appropriate way to meet that need. The source of a person’s needs may be in their immediate situation, for example a woman who takes pride in her appearance may find it difficult to dress herself properly and requires tactful assistance with getting ready in the morning. In such a situation, carers could lay out clothes in the correct order that they need to be put on. Alternatively, the source of cognitive insecurity could be in the person’s life history, for example a former postman living in a care home may have a need to be out of doors on his rounds and is frustrated by the home’s locked doors. In this case, the person could be helped to feel useful by taking the mail around in the care home and his need for fresh air met by regular escorted walks outside.

Knowing when to direct and when to facilitate
When caring for people with dementia, carers should know when to be directive and when to be facilitative, for example when to take the lead and guide the person and when to assist the person to manage things for themselves (Tranvåg et al 2013). This aspect of decision making requires empathic understanding of the person’s capabilities and wishes. It also requires positive attitudes, since facilitating people with dementia to do things for themselves, such as going out on their own, cooking and continuing to drive, may be more demanding on carers’ time and may require them to tolerate greater degrees of risk.

Using empathy to judge the appropriateness of care interventions
The final component of a compassionate approach is the requirement for carers to monitor continually the person’s verbal and non-verbal cues to assess the success or otherwise of attempts to enhance the person’s sense of cognitive security and modify their care strategies accordingly. Empathy remains central to this process. At the same time, gaining feedback from people in more advanced stages of dementia with limited verbal and non-verbal abilities may be difficult (Hughes 2013). Carers sometimes have to trust that their judgement of the person’s state of cognitive security is accurate and that their care strategies are meeting the goal of enhancing wellbeing.

Discussion
We believe that our three-component model of the qualities required by carers of people with dementia offers a credible and potentially useful account of the personal qualities, skills, attitudes and knowledge that professional and family carers require to enhance cognitive security, and thereby contribute to wellbeing in people with dementia. The model provides clues as to why good, person-centred care may be difficult to achieve in practice (Clissett et al 2013). One factor is the relative complexity of the mental processes that carers need to apply to empathise with people with dementia and to implement a compassionate approach. These qualities require high levels of interpersonal sensitivity and self-awareness. In addition, an underpinning knowledge of how dementia affects the individual is essential for carers to establish an accurate understanding of the person’s often fluctuating state of cognitive security. Biographical knowledge is required so that the effects of dementia on the individual can be more readily understood. However, such information may not be available in many formal care settings.

The relationship-forming and solution-finding requirements of a compassionate approach to care may overstretch carers and they may find it difficult to reach out to people with dementia to the extent that is required, even if their attitudes are positive (Sung et al 2011). Finding appropriate care strategies often requires cognitive sophistication and creativity. Stokes (2000) and James (2011) discussed behaviour that challenges and provided examples of imaginative approaches to individual care needs. However, not all carers will have the necessary levels of creativity.

Caring for people with dementia places cognitive and emotional demands on carers that they may struggle to fulfil, particularly since many lack specific training in dementia care (All-Party Parliamentary Group on Dementia 2009). Lack of knowledge about dementia might result in unqualified care staff having lower levels of empathy than qualified nurses (Aström et al 1990). At the same time, it would be wrong to assume that untrained or uneducated care staff cannot demonstrate the qualities of empathy and compassion, or that educated carers are universally empathic and compassionate. Some unqualified staff appear to be ‘naturals’ at empathy, even without background knowledge or the ability to articulate how they come by their empathic insights (Sheard 2004). Person-centred attitudes are crucial. Even when carers possess empathic understanding, if they do not value the enhancement of wellbeing for people with dementia, they will not be motivated to empathise with the person or to learn the complex cognitive and emotional skills of a compassionate approach to care (Mullan and Sullivan 2016).
Carers sometimes show empathic awareness of a person’s state of cognitive insecurity and understanding of an appropriate compassionate care approach. However, for a variety of reasons, they do not implement that approach, opting instead for an easier course of action. Sometimes that is because of practical or resource constraints or the culture of care being insufficiently person-centred (Growther et al. 2013, Spencer et al. 2014). Determining how to instil person-centred attitudes in carers is the ultimate challenge of dementia care and one that has been achieved only partially to date (Sheard 2004).

Our model emphasises that both professional and family carers require knowledge and understanding of dementia to fulfil their caring role, starting with an appreciation of the central place of cognitive security as a main goal of care. Education about the effects of dementia on individuals and the value of seeing the person in the context of their life history, assists carers to empathise with those in their care. Carers may be educated to recognise and interpret the person’s behavioural cues and to appreciate that their sense of meaning may be different to that of the person with dementia.

Principles of cognitive-security enhancing communication can be learned, and carers can be introduced to strategies for finding creative care solutions in a range of situations. For example, carers should speak clearly in plain language, avoid asking the person open questions and respond to the person’s feelings when they are unable to express their meaning clearly. Education and training initiatives that seek to address these or similar issues have been described and evaluated (Broughton et al. 2011, Passalacqua and Harwood 2012, Elvish et al. 2014, Smythe et al. 2014). At the same time, research has indicated that, while necessary, education and training are not sufficient to enhance practice (Lintern et al. 2000, Hope and Waterman 2004). Stokes (2010) remarked that: ‘My feeling… is that people do not learn person-centred ways of engaging with people with dementia: it is something you feel, it’s something you do because your heart and mind is in the right place, it’s something you get — or possibly some people don’t.’

With increasing numbers of people developing dementia worldwide (Alzheimer’s Disease International 2011), improving the quality of care is urgent. The need for professional and family carers with the ability to empathise and with person-centred attitudes that motivate them to give compassionate care has never been greater.

Conclusion

Our three-component model relating to the personal qualities that carers should possess to deliver person-centred care to people with dementia has relevance as a means of conceptualising and analysing dementia care and as a framework for education and training. At the same time, it identifies some of the challenges to enhancing care for people with dementia. It shows that quality care requires carers to possess sophisticated cognitive, emotional and interpersonal qualities specific to dementia care settings and positive attitudes and motivation. While some professional and family carers are naturals, others struggle with the interpersonal aspects of the caring role.

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