Dementia and the person-centred care approach

Jessica McGreevy explores the viability of applying person-centred care to people with dementia to go beyond a purely biomedical approach and maximise their wellbeing.

Abstract

Approaches to care that focus solely on biomedical needs are still rife in dementia; however, a person-centred approach is emerging that focuses on ‘seeing the person’. This article explores the literature on person-centred dementia care to determine if it is an ideal rather than a reality. The background to the development of person-centred care is presented with reference to policies in place in the UK. Using the setting of long-term care, the journey of people with dementia is explored at diagnosis, living well and end of life.

Keywords
dementia disease trajectory, diagnosis, long-term care, person-centred care, task-orientated care

The National Institute for Health and Care Excellence (NICE) and the Social Care Institute for Excellence (SCIE) (2006) suggested that this desired level of dementia care was underpinned by the principles of person-centred care. In the UK person-centred care has been embedded in legislative policy and best practice guidance for many years (DH 2001, 2005, 2006, 2009).

Tom Kitwood was a pioneer of person-centred care. While Rogers (1961) paved the way for person-centred practices, Kitwood (1997) advanced the theory of person-centred care in the context of dementia. The use of person-centred care developed after the biomedical model was found to address the physiological needs of people with dementia, but neglect their psychosocial needs, leading to undesirable outcomes for them and their carers (Cheston and Bender 1999). Despite this, Burgess et al (2003) highlighted the continuing dominance of the biomedical model in long-term care settings. While biomedical approaches can aid people with dementia, there is support for more person-centred approaches to symptom management. For example, cognitive behavioural therapy can slow disease progression as much as NICE-approved drugs (Mitchell 2013). Also, Gubrium (1987) explained that individual stages of dementia can rarely be identified with progression not always fitting into a predefined biomedical model.

Person-centred care in the context of people living with dementia is described as a need to emphasise communication and relationships to maintain a sense of personhood, with a focus on ‘seeing the person’ (Kitwood 1995). Kitwood (1997) explained personhood as: ‘A standing or status that is bestowed upon one human being, by others, in the context of relationships and social being.'
It implies recognition, respect and trust.’ Brooker (2007) reiterated this definition, stating that care should recognise all human life, be grounded in relationships and provide an enriched social environment that compensated for impairment while encouraging personal growth. Brooker (2007) built on Kitswood’s (1997) theory of person-centred care for people living with dementia through the development of a model containing four main elements: valuing, individual, perspective and social psychology (VIPS) (Box 1).

Brooker (2007) stated that the four elements can exist independently, but brought together they create the desired outcome for people with dementia and their carers.

Although the literature highlights the need for a person-centred approach to dementia care, its introduction in health care faces many barriers, including (Innes et al 2006, McGreevy 2015, in press):

- Services being budget rather than user led.
- Poor access to or uptake of training.
- An embedded task-oriented approach to care that focuses on the illness rather than the person and is reliant on routines and use of medication.
- Staff attitudes – poor recognition that care needs to change.
- Constantly changing front-line and management staff.
- Poorly supported front-line staff.

**Person-centred care throughout the dementia trajectory**

To explore person-centred care the following discussion is based around the journey of people with dementia in long-term settings. The disease trajectory is simplified using the markers of beginning (diagnosis), middle (living well) and end (end of life).

**Diagnosis** Person-centred care should begin at diagnosis (DH 2001), but barriers to diagnosis include the misconception that dementia is a normal part of ageing, reluctance, stigma and advancing disease (Teel and Carson 2003). Reviews carried out by Bamford et al (2004), Robinson et al (2011) and Mitchell et al (2013a) highlighted the idea that although a diagnosis of dementia may be devastating initially, it opens the gateway to support networks, allows more time for person-centred activities and advance care planning. Despite this, diagnosis rates vary greatly in the UK, ranging from 42.8% in Wales to 64.8% in Northern Ireland (Alzheimer’s Society 2013).

Skilled nurses are able to provide an informal diagnosis of dementia based on symptom presentation (Page et al 2008). A formal diagnosis is often not sought (Alzheimer’s Society 2013) yet it is vital (Bamford et al 2004). It ensures that decisions can be discussed and made about treatment, services can be accessed and future planning can occur, in turn leading to a person-centred approach to care (Mitchell et al 2013b).

As Baker (2015) explained, without knowledge of the individual’s specific illness, it is challenging to understand their lived experience, to see life from their perspective and create an environment that is supportive, as required by Brooker’s (2007) VIPS model. However, for those who do receive a timely diagnosis and are given education and support, person-centred care is more of a reality with nurses being the main facilitator. The nurse’s role in creating person-centred and advance care plans at diagnosis enables people with dementia to communicate their preferences before communication and capacity are altered (Dening et al 2011). Disseminating this knowledge through the care environment allows for the development of person-centred care leading to increased wellbeing for people living with dementia, families and healthcare professionals (Loveday 1998).

**Living with dementia** With the right understanding, support and person-centred approach, living with dementia can be a positive experience (Baker 2015). Healthcare staff are central in providing meaningful relationships, which Edvardsson et al (2008) explained are an intrinsic part of person-centred care. However, in long-term care settings where a task-orientated approach still exists, people with dementia are often left feeling isolated, disempowered and worthless (Innes et al 2006). While their physiological needs are considered, this task-orientated or biomedical approach often does not adequately address their psychosocial needs (Innes et al 2006). If we fail to recognise people’s psychosocial needs, in addition to their biological needs, this can lead to them feeling devalued and exhibiting behaviours such as

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**Box 1 VIPS model of person-centred care**

- **Valuing** Valuing human lives regardless of age or cognitive impairment
- **Individual** Treating people as unique individuals, appreciating their history, personality, preferences, physical and mental health
- **Perspective** Understanding the world from the perspective of the person in care
- **Social psychology** Social environment is needed that compensates for any impairment and provides opportunities for personal growth, taking into account relationships and surroundings

(Brooker 2007)
shouting, hitting, refusing care and becoming withdrawn (Kitwood 1997, Brooker 2007). People with dementia who display these behaviours are often unfairly labelled as ‘challenging’. This negative label was described by Kitwood (1997) as malignant social psychology, taking away from personhood while further creating a barrier to person-centred care.

Overuse of antipsychotic medications, such as chlorpromazine, haloperidol, quetiapine and risperidone, to reduce the occurrence of ‘challenging behaviours’ can also be a barrier to person-centred care. The Banerjee report (2009) concluded that use of antipsychotics for people with dementia should be reduced and good practice adopted when they were needed. Common side effects of antipsychotic medications include drowsiness, parkinsonism and personality changes, causing the person to become withdrawn and isolated (Alzheimer’s Society 2011), in turn preventing the development of meaningful communication and therapeutic relationships (McCormack 2004). Feil and de Klerk-Rubin (2012) explained that by using non-pharmacological approaches (Table 1), behaviours can be understood, triggers identified and further episodes of distress avoided. The behaviours are no longer labelled as ‘challenging’, but a way of communicating (Alzheimer’s Society 2011). By default, such interventions are person led (Feil and de Klerk-Rubin 2012), resulting in the natural development of person-centred care.

Although a person-centred and collaborative approach to care is best practice, McCormack (2004) suggested that nurses continue to retain control over a person’s care decisions with the absence of collaboration because they lack skill in balancing conflicting demands and choices. However, in long-term care settings, where these barriers have been overcome, person-centred care becomes the ‘norm’ with staff unable to comprehend care that is not person-centred (Baker 2015). To break down these barriers, education is required with a focus on time management, communication, leadership and understanding of dementia and the importance of person-centred care (McGrevey 2015, in press).

Communication and memory are also important when discussing person-centred care, which relies on (Kitwood 1997):

- Knowing the person.
- Where they have come from.
- Their personal preferences.
- Personal goals.
- Daily concerns.

As dementia progresses, communication alters and memories become more disordered, making information gathering challenging for healthcare professionals (James 2011). If this information has not been obtained in the earlier stages of dementia, it can act as a barrier, which is often frustrating for staff and people with dementia. However, Baker (2015) suggested that person-centred care can still occur if family members are consulted about life history, preferences and decisions. NICE and SCIE (2006) stated that families who are informed, involved and have open lines of communication with those providing care will be more supportive of person-centred care assisting in making it a reality for the person with dementia. This is a less ‘pure’ form of person-centred care, as it is reliant on the input of others rather than the person with dementia (Mitchell et al. 2013b).

**End of life**

It is a basic human right to die with dignity. The Department of Health, Social Services and Public Safety (2010) stated that palliative care requires a philosophy that is person-centred, enabling people to maintain control, choice and dignity until the end of life. However, a review of end of life interventions showed that in 84 studies, where 135 person-centred outcomes were assessed by 97 different measures, only 80 measures were used once and only eight were used in more than two studies, suggesting that although person-centred

### Table 1 Non-pharmacological approaches

<table>
<thead>
<tr>
<th>Intervention</th>
<th>Explanation</th>
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<tr>
<td>Drama</td>
<td>Focuses on the use of movement, mirroring, puppets, storytelling and play in a structured manner</td>
</tr>
<tr>
<td>Art</td>
<td>Focuses on work such as drawing, painting, sketching, collage and photography</td>
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<tr>
<td>Music</td>
<td>Seen as a sensory therapy, can be group or one-on-one, receptive and participatory</td>
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<tr>
<td>Dance and movement</td>
<td>Focuses on movement alongside music</td>
</tr>
<tr>
<td>Reminiscence</td>
<td>Focuses on reliving past positive experiences – can be organised or occur through natural conversation</td>
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<tr>
<td>Life story work</td>
<td>A gathering of life history through communication between the person and their family</td>
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<tr>
<td>Doll therapy</td>
<td>The use of an empathy doll, usually led by the person with dementia and often unstructured</td>
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<tr>
<td>Pet therapy</td>
<td>The use of animals – can be organised or unorganised, focuses on the importance of relationships</td>
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<tr>
<td>Horticultural therapy</td>
<td>Making use of outdoor space, working or being in or around a garden</td>
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<tr>
<td>Validation therapy</td>
<td>Focuses on being accepting of another’s reality</td>
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Table 2 The 7Cs of the Gold Standards Framework

| Communication | Healthcare professionals to communicate openly with person living with dementia, family and the multidisciplinary team – for example, the GP or specialist palliative care services |
| Co-ordination | A named co-ordinator to lead the person’s palliative care. In a long-term nursing care setting this should be the person’s named nurse or key worker in long-term residential settings |
| Control of symptoms | An important aspect of palliative and end of life care is symptom control so the person experiences the least amount of pain/distress as possible. Also, consideration should be given to the person’s psychological, social and spiritual needs, that is, holistic or person-centred care |
| Continuity of care | The healthcare professional should inform the person’s GP and secondary care teams in advance so they can provide collaborative care at an early point |
| Continued learning | As identified, there is limited knowledge around provision of palliative care. It is everybody’s responsibility to ensure that education around palliative care is to an acceptable level |
| Carer support | This places onus on the emotional and practical care of advocates, family and friends of the person living with dementia. It is also important to note that palliative care continues after death, that is, into bereavement care for the resident’s family |
| Care in dying phase | The final ‘C’ gives consideration to the death of the person. Previously the GSF advocated use of a protocol for the last 48-72 hours of life, such as the now defunct Liverpool Care Pathway (LCP). With the discontinuation of the LCP and no obvious recommended alternative, the onus is on all healthcare staff to provide an individual approach to care in the dying phase – for example, stopping non-essential interventions, considering comfort measures, psychological and religious/spiritual support |

(Mitchell et al, 2015, in press)

References


Alzheimer’s Society (2013) Dementia Diagnosis Rates. tinyurl.com/n7oasjv (Last accessed: August 27 2015.)


Care approaches exist, in reality they are not fully used (Wilcock et al, 2008).

Healthcare professionals do not always associate dementia with palliative care, even though the World Health Organization (WHO) (2012) stated that palliative care is appropriate for all people living with progressive chronic illness. As a result of this lack of recognition, timely planning is poor with discussion about end of life choices often happening in a moment of crisis when physical symptoms take priority, communication diminishes and capacity is altered (Wilcock et al, 2008).
Murtagh et al (2004) suggested that healthcare professionals are poor at recognising when people are reaching the end of life, with many only associating palliative care with the ‘dying phase’ (Mitchell et al 2015, in press).

Palliative care is: ‘An approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual’ (WHO 2012). End of life care is: ‘Care for those who are approaching death, with a key goal being to make the person comfortable and attend to their needs and wishes as the end of their life approaches’ (Kelly and Innes 2010). Palliative care is preparation for end of life care; lack of understanding about this denies the person living with dementia the opportunity to prepare for death, in turn preventing delivery of person-centred end of life care (Morris 2012).

A number of tools are available to assist in the delivery of palliative and end of life care for people with dementia. The most widely used is the Gold Standards Framework (GSF), which can be adapted to local needs and resources (Thomas 2011). Its primary aim is to develop a practice-based approach that allows people to ‘die well’. The GSF identifies seven steps of palliative care, referred to as the 7Cs (Table 2), which enable healthcare professionals to improve the planning of palliative and end of life care.

Using this framework ensures that the person living with dementia is identified as needing palliative care, with timely assessments and better forward planning, allowing care to be person centred.

Conclusion

Person-centred care is a prerequisite to maximising wellbeing for people with dementia, which cannot be achieved by addressing biomedical needs alone. However, there are barriers to embedding person-centred care in practice. Making person-centred care a reality should begin with a timely diagnosis once the person states it is their preference to know. As the literature demonstrates, diagnosis is not always timely; however, with some people living with dementia but never receiving a formal diagnosis. For those who do receive a diagnosis, person-centred care can be achieved as time allows for planning and input from the person before capacity is altered.

However, the literature has shown that throughout the dementia disease trajectory there are many barriers to person-centred care, including: poor education, poor planning, ineffective communication and too many demands on nurses. There should be more education on what person-centred care is, which in turn can be disseminated throughout long-term dementia care settings for the benefit of all.


