Understanding quality of life and well-being for people living with advanced dementia

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Abstract

Aim To investigate the quality of life (QoL) and well-being of people living with advanced dementia in care homes.

Method A mixed-methods approach was taken combining participant observations, interviews with the participants' families and carers, and quantitative measurements. The quantitative measures included AwareCare assessments, QoL in Late-Stage Dementia scale ratings and semi-structured interviews with relatives and staff members. Ryff’s psychological well-being framework, the Fairness, Respect, Equality, Identity, Dignity, Autonomy principles, and Kitwood’s indicators of well-being, were examined to attempt to identify contributors to QoL for people living with advanced dementia.

Results Participants had limited verbal abilities, but used non-vocal behaviours to communicate. These behaviours influenced their QoL and well-being.

Conclusion The indicators of well-being in Kitwood’s personhood model were helpful in describing how relatives and staff perceived the QoL of the person with dementia.

Keywords advanced dementia, care homes, dementia, human rights, older people, quality of life, research, well-being

IMPROVING QUALITY of life (QoL) for people living with advanced dementia is an important goal in dementia care, and QoL is one of the main criteria of recent healthcare policies and strategies. The Dementia Action Plan for Wales 2018-2022 (Welsh Government 2018) states that care homes need to be considered as individuals’ homes and that people have the right to ‘live well’. For the World Health Organization (1995), QoL relies on ‘the individual’s perceptions of their position in life in the context of the culture and value system in which they live, and in relationship to their goals, expectations and standards’.

QoL measures are available that enable people with dementia to give a subjective view of their QoL, but cognitive impairment associated with dementia makes self-reporting QoL challenging (Logsdon et al 2002, Bowling et al 2015, Algar et al 2016).

In advanced dementia, proxy reports are used as an alternative to self-reporting. These are completed on behalf of the person with dementia by their family or by care workers (Conde-Sala et al 2010), using either direct observations or questionnaires or both (Missotten et al 2016). However, none of these approaches address the question of what constitutes QoL for people living with advanced dementia.

Several models of QoL and well-being are available that could potentially be adapted to assist in understanding what may be important for QoL among people with advanced dementia. Lawton’s framework (1997) for QoL in dementia includes four factors that each contribute to overall QoL: behavioural competence, perceived QoL, objective environment and psychological well-being (Netuveli and Blane 2008).

A person with advanced dementia may
appear to be happy, but as Ryff (1995) describes, well-being involves much more than happiness (Box 1).

It is often difficult to ascertain, or even envisage, Ryff’s (1995) six psychological aspects of well-being in a person with advanced dementia who has severe impairments in cognition and communication. Kitwood and Bredin (1992) identify 12 potential indicators of well-being that contribute to personhood in dementia, including self-respect, the assertion of desire or will, initiating social contact and humour. Box 2 summarises the global states that Kitwood and Bredin (1992) suggest underpin these indicators of well-being in people living with dementia.

A human rights view of QoL is provided by the Fairness, Respect, Equality, Identity, Dignity, Autonomy (FREIDA) principles (Box 3), which is an alternative, but complementary, perspective (Curtice and Exworthy 2010, Butchard and Kinderman 2017). The FREIDA principles build on the core value of human rights and emphasise maintaining and promoting people’s lifelong rights, development and growth, and working towards reducing ill-being (Kinderman 2007, 2017).

The principles overlap with Kitwood’s (1997) influential work on person-centred values, which are based on respecting and empowering the individual, and provide an ethical and legal framework for people with dementia in long-term care (Kelly and Innes 2013). These principles can empower nurses and others to challenge inequality and the acceptance of less-than-excellent care for people with dementia simply because it has become standard practice (Kelly and Innes 2013).

While conceptualising and measuring QoL in people with advanced dementia is challenging, some important features are emerging. These include the importance of meeting the psychological needs of the person and providing them with opportunities to take part in meaningful activities (Volcier 2007).

In people with advanced dementia, indicators of well-being include social contact, interactions and communication at a fundamental level. These can include touch (Brooker et al 1997) and elicited responses, such as smiling, babbling, laughter, eye gaze and reciprocity, all of which have been termed ‘happy behaviour’ (Astell and Ellis 2006, Ellis and Astell 2017).

People with dementia often need to move into care homes as the condition progresses. Purposely designed and adapted care homes enable carers to provide relaxation for people with advanced dementia and opportunities for personal contact that can enhance QoL (Reimer et al 2004). However, the transition into long-term care means that the person with dementia must leave their home, which they may have shared with loved ones, for a communal environment shared with strangers. This is also a transition for the family who might have previously been providing the care.

It is important to continue to involve the family and understand the triangle of care which includes the person with dementia, their family and the care home staff working together for the best QoL for all (Carers Trust 2016).

Aim
The aim of this study was to investigate the QoL and well-being of people with advanced dementia living in care homes. It explored residents’ lived experiences in the care homes, and their relatives’ and staff members’ perspectives of residents’ QoL.

The research investigated how the human rights of residents were upheld, and how
families and staff members dealt with surrogate decision-making. The study drew on two in-depth case studies of care home residents living with advanced dementia, Graham (case study 1) and Martha (case study 2), both pseudonyms. They were living in two different homes run by the same organisation. The study examined how helpful the different approaches to understanding QoL, well-being and human rights in advanced dementia are in practice to identify features that may be helpful in supporting these important outcomes.

Case study 1. Graham

Graham was 88 and had been diagnosed with dementia six years previously. He had been living at the care home for 12 months. He was immobile and it was common to see him holding a cup to his mouth. He was brought to join the other residents in the lounge.

During the observations he appeared busy, often picking up objects to explore with his eyes and hands. He stopped to interact with Graham when he was delighted, waving at them and blowing raspberries, and eliciting laughs in response. When there was no response, he would reach out and pinch the researcher's nose and gasp when she laughed. He also gestured with his hand to his own nose and, when the researcher touched the tip of his nose, smiled, nodded and clapped.

The AwareCare tool assessment indicated that Graham showed a wide range of responses to his social environment. His most frequent responses were movements of the eyes or head and he smiled in response to more than three quarters of attempts to interact. Speech was almost absent, although he often appeared to mumble. He was most responsive to being touched or his hand being taken or having an object introduced to him. Food and drink also often elicited a response, but he was less responsive to his name being called or other things happening in his vicinity.

Graham's wife, Lorna, arrived every day around lunchtime, bringing in different magazines and newspapers to read to him. He was a sports fan and she would flick through the sports pages with him. Graham was observed to study the newspaper and run his fingers across the photos, and sometimes to laugh at Lorna while she read. He pulled on the bottom of the newspaper and laughed when Lorna told him off playfully.

Quality of life

Lorna believed that becoming immobile had affected Graham's quality of life (QoL) and human rights. He was previously active, sociable and enjoyed going out every day. His mobility had deteriorated after a fall, and he had not been encouraged to walk during a three-month hospital stay before coming to the care home.

She explained that, irrespective of the request made of him, he would often respond with 'No', which had been interpreted as a refusal. Lorna thought that, with encouragement and support, Graham could have remained mobile.

When Graham moved into the care home, Lorna was keen for him to receive physical therapy, but the home considered his condition was now too advanced for it.

She explained that, when Graham threw objects, it was not aggressive behaviour. Lorna explained Graham's attempts to interact: 'Oh, he likes attention you know, he's known to throw objects at times. He'll throw and he smiles, you can tell. He's got that cheeky twinkle in his eye.'

To Stephanie, Graham's behaviour was his way of saying 'look at me', drawing attention to himself and initiating interaction with others, perhaps to reduce boredom.

Stephanie had also noticed that, late in the day when families had left, it would be quiet in the household, with staff assisting residents to eat. At these times, while Graham was alone, he would throw his food, drink and any object nearby and become agitated.

Stephanie thought that Graham was responding to a lack of stimulation in the environment: 'It's too quiet in here, it seems, and maybe there's not enough going on tea time.'

Interactions

The staff recognised Graham's actions at these times as attempts to initiate interaction with others. Accordingly, the staff kept food aside until they could sit with Graham and encourage him to eat independently.

Making adjustments such as these means meal times can be enjoyed, providing physical benefits and adding to overall QoL (Biernacki and Barratt 2001). Nourishment is important for physical and psychological QoL, and removing strict routines to allow people to eat out of the ‘set time zones’ and responding to their preferences increases their autonomy. In Graham's case it enabled him to eat independently.

In summary, although Graham had little verbal communication, he used non-verbal communication extensively and, with the support of his wife and the understanding of staff, his personhood was evident.

On the QUALID scale, his wife and care staff rated his QoL at the same level (21), despite Lorna's concern that no attempt had been made to reduce his immobility.

'I don't see him the same way as the others you know. He's different, isn't he?'. She observed that other residents were often sleeping while Graham would be wide awake, calling out to others desparate to interact. This made leaving him even more difficult.

Stephanie, a senior care assistant, explained that when Graham threw objects, it was not aggressive behaviour. She said: 'He'll throw and he smiles, you can tell. He's got that cheeky twinkle in his eye.'

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Method
The study took place in two specialist dementia care homes operated by an independent company in North Wales. The homes are divided into households of 8–12 residents, with each household caring for people in different stages of dementia.

Case study 2. Martha
Martha was 86 and had been diagnosed with dementia four years previously. Martha had lived at the care home for 14 months. Her first language was Welsh. Jo, Martha was observed to sit up and smile broadly when greeted by staff members. She would initiate conversation with others, often mumbling but occasionally pronouncing clear words. Martha would call triggers, although her most frequent responses were movements of the eyes and head and reciting names of her family. Martha was introduced to her, and the least when speaking to or called by her name.

At one mealtime, Martha gestured at others nearby her to eat, tapping the table and pointing towards their plates or pushing their plates towards them, as if taking on a mothering role. On other occasions, Martha’s behaviour changed significantly and she appeared distressed.

She was observed shouting in response to others or sitting alone in a separate room with her arms folded and her head on her chest. During such times, she would refuse assistance from the care staff, shouting: ‘Shoo, shoo’ and throw her hands up in the air. Staff attributed these changes to recurrent urinary infections.

Communication tool
The researcher, a Welsh speaker, used the Talking Mats communication tool with Martha, presented on a tablet. Initially, she was interested in the screen, inspecting it closely and leaning over it. She let the researcher guide her hand over the screen to place different cards in different places, and would say: ‘Ooo’ and laugh.

During the AwareCare tool assessment, Martha took great interest in personal objects from her home that were presented to her. Martha would point at people in photographs from her home that were presented to her. Martha was even more responsive than Graham according to the AwareCare tool assessment. She produced single word responses to more than two thirds of the triggers, although her most frequent responses were movements of the eyes and head and mumbling. She also smiled in response to most of the triggers. She showed the greatest range of responses when touched or when an object was introduced to her, and the least when spoken to or called by her name.

Martha’s family visited every day and would speak with her in Welsh. During such a conversation in Welsh with her daughter, Jo, Martha was observed to sit up and smile broadly, her eyes open wide, fully immersed in the interaction. She made direct eye contact and nodded while Jo spoke with her, reciprocating vocally and non-vocally, and reciting names of her family.

Jo explained that care staff had taken the time to understand Martha’s personal history: ‘The staff know her, you know. They can walk in now and tell you how she is, what kind of person she is. They do know her and that helps us as well.’

Jo described her mother’s character, laughing: ‘What she said went, you would not dare disagree.’ She enjoyed seeing that aspects of Martha’s personality were still evident. Jo said: ‘It is important for us to make the most of it now while she is chatty like this, because there will come a time when there will be no communication.’

Although Jo had reservations about her mother living at the care home, she talked about visiting and explained: ‘It’s nice to see her in good spirits, displaying the ways she used to be – the way she was at home, mischievous.’ Jo considered that the care her mother received at the home contributed to their family’s well-being and that the relationship with the care staff had made the journey easier for them.

Martha’s staff nurse, Gaynor, described her as charming and compliant with care, and said Martha ate and drank when she was physically well. She was vulnerable to urine infections, however, and during these times she would sometimes be awake at night, and would refuse medication, food and fluids, inevitably prolonging her ill-being.

Family involvement
Gaynor explained that, at these times, Martha would ‘become frustrated, as a result of being unable to verbalise how she’s feeling’. Gaynor thought that Martha’s family’s involvement was fundamental to her QoL: they could speak with her in her first language, and encouraged her to take her medications, eat and drink. Overall, Martha could communicate her feelings through vocal and non-vocal behaviours, and could verbalise more when she was with a person who could speak Welsh. Having a close family nearby, especially when she was unwell, was important to her well-being.

On the QUALID scale Martha’s daughter rated her QoL much more positively (17) than did the staff (41). Martha’s daughter explained how important it was to see her mother as the individual she had always been, but that this could be difficult for the staff. She added that Martha’s recurrent physical problems may have influenced the staff’s lower estimate of Martha’s QoL.
Participants were observed in public areas of the care home on five occasions of 30 minutes each. For each participant, in-depth, semi-structured interviews were conducted with care staff and a member of the participant’s family. In these interviews the researcher asked staff and relatives about the resident’s well-being, how it was monitored and how their human rights were being maintained and promoted in the homes. The interviews also covered surrogate decision-making, that is, how decisions were being made in the best interests of residents who were unable to make their own decisions.

The quantitative measurements used were the Quality of Life in Late-Stage Dementia (QUALID) scale (Weiner et al 2000) and the AwareCare tool (Clare et al 2012). The QUALID scale comprises 11 items reflecting positive and negative components of observable mood and behaviour. Each item is rated on a five-point scale with lower scores indicating a higher QoL (Weiner et al 2000). The scale was completed by one family member and one staff member independently for each participant, indicating the descriptor that best described the individual over the previous week (Clare et al 2014).

The AwareCare tool (Clare et al 2012) is an observational tool that evaluates signs of awareness in residents living with advanced dementia. It examines responsiveness to various triggers in the social environment including the presence of other people, touch, nearby objects and the person’s name being used. Responses to these triggers, such as movements of the eyes, head and body, facial expressions and vocalisations including mumbles, single words and shouts or moans, were noted during each observation session.

A digital application, Talking Mats (Murphy and Oliver 2013), was also used to assist communication with participants. It consists of picture communication symbols presented on a tablet, which can support individuals with limited verbal ability to communicate and express their feelings.

Ethical considerations
Consent was obtained from relatives and care staff, but because the participants could not give consent, a personal consultee was approached to advise on their inclusion in the study.

Ten residents participated in the study, but this article focuses on one resident from each home.

Results
In constructing the two in-depth case studies presented in this article the whole range of data gathered has been drawn on. In each case we first present observations made by the researcher during the formal observation periods and more generally from her time in the home. This is followed by the perspective of the relative taken from the qualitative semi-structured interview, before presenting care staff perspectives also from the qualitative interviews. Finally, findings from the quantitative measures used are noted.

Discussion
The case studies focus on two people with their own personalities who had different ways of expressing happiness, affection, humour and distress.

Ryff’s well-being framework
Using Ryff’s (1995) well-being framework to consider Graham and Martha, it is evident that both were seeking to exert control over their environment through their behaviour, a process known as environmental mastery, and that positive relationships were important to them. However, it is more difficult to judge Graham and Martha’s feelings of acceptance, sense of purpose and self-growth.

FREIDA principles
When applying the FREIDA principles’ (Curtice and Exworthy 2010, Butchard and Kinderman 2017) human rights’ perspective with Graham and Martha it became apparent that ‘identity’ was a positive factor for both. However, Graham’s right to autonomy had been reduced by his immobility. The relative lack of Welsh speakers among the care home staff may be seen as a lack of fairness in meeting Martha’s needs and affected her identity as a Welsh speaker.

Kitwood’s indicators of well-being
In terms of Kitwood’s indicators of well-being, Graham and Martha showed agency (Kitwood and Bredin 1992, Kitwood 1997). Graham threw objects to achieve a response, Martha encouraged her fellow residents to eat. They were both socially confident, especially with their relatives. When Martha had a urine infection or was unwell, she showed less hope and self-worth, and became distressed.

Graham’s sense of self-worth was evident in the warmth of his relationships with other people and lack of distress. He and Martha both demonstrated several of Kitwood’s indicators of well-being, including initiating social contact, humour, self-expression, affectionate warmth, social sensitivity and the ability to express a range of emotions.
Kitwood’s (1997) personhood theory suggests that personhood lies not only in the individual, but is supported by the presence of others. This was clear for Martha and Graham, whose personalities remained evident to their families and to the staff who had made an effort to get to know them well.

**Behaviour as a result of unmet needs**
Cohen-Mansfield et al’s (2007, 2015) theory that the distressed behaviours displayed by people with dementia can be a result of unmet needs is also relevant to the care of people such as Graham and Martha. People with advanced dementia are often less able to communicate their needs, meaning that these needs can be unrecognised and unmet.

For Graham, calling out and throwing may have alleviated boredom, or be a way of communicating his need for interaction and affirmation. For Martha, distress may have been unable to recognise her family, having the opportunity to converse in Welsh supported her sense of safety, familiarity and comfort, which contributed to her overall QoL. Martha’s difficulty in communicating in her second language, coupled with her illness, may have increased her psychological distress, which adversely affected her well-being (Hamilton 2008).

**Restorative potential in people with advanced dementia**
There is a negative, and incorrect, perception that people at a late stage of their dementia journeys have no restorative potential. However, promoting and maintaining the functional abilities of care home residents for as long as possible contributes to their QoL, and decreases the burden on caregivers (Sandberg et al 2002). In this study, Lorna clearly expressed her feelings of distress about Graham’s immobility and the lack of intervention he had received.

**Non-verbal communication is important**
Communication goes beyond the spoken word, as was evident in much of Graham’s and Martha’s daily behaviour. Discussing Graham’s refusal to comply with physiotherapy in hospital, Lorna expressed her view that Graham’s ‘No’ was not a refusal, but a way of contributing to the conversation. Decision-making could be improved by considering the congruence between an individual’s behaviour and their verbal communication. Communication research has placed emphasis on non-verbal behavioural cues, which often supplement verbalisation. Non-verbal behaviours are used across a lifetime and form part of the individual’s identity. They are an important form of communicating and provide comfort for families in the absence of verbal communication (Hamilton 2008). Ignatieff (1999) wrote the following about his mother: ‘My mother’s disease changed my view of what a person is... It taught me to be less sentimental about memory as a carrier of human continuity. My mother had no memory whatever, but she was the same person.’ Martha’s daughter Jo also emphasised the importance of cherishing the moments she had with her mother now.

**Conclusion**
The QoL and well-being of people living with advanced dementia are important aspects of their lives that have received little attention or innovation. These observations of Graham and Martha have added to the evidence base on the QoL and well-being of people living with advanced dementia.
This study found that Kitwood’s indicators of well-being were helpful in describing how relatives and staff perceived the QoL of the person with dementia. Even with limited verbal communication, the person with dementia remains an individual and, with the support of others, can experience QoL and well-being.
References


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