

Dementia Gateway: Knowing the person behind the dementia

Key messages

- Knowing the person behind the dementia is about 'personhood' (the importance of the unique identity of the person).
- Person-centred care (that is, care that is tailored around an individual's needs and preferences, values, beliefs, life history and other things that are important to a person³) helps to support personhood and, for people with dementia, may be its main benefit.⁷
- A key way for people with dementia to preserve their sense of identity is through maintaining relationships and activities.²
- It is important to understand how people with dementia see themselves and their surroundings because this can influence how they manage their condition, how they relate to others and how they might respond to different kinds of services and support.¹
- The interactions of others are extremely significant in undermining or sustaining personhood.⁵ Poor social interactions and social isolation can undermine a person's position with others, leaving them unable to assert their identity.⁶
- Life story work offers a chance for family carers to 'show' the personhood of their relative,⁹ and allows staff to get a sense of the person behind the dementia.^{9,30}

Introduction

This summary highlights key messages from the research about knowing the person with dementia. It is not intended to be a comprehensive review of the literature on this topic. The material on which this summary is based was identified through focused searching of the literature published from 2008 to 2012. Some material pre-dating 2008 has been included where reference to theory is necessary.

What is the issue?

An all-encompassing term for this summary about knowing the person would be the concept of 'personhood' (the importance of the unique identity of the person). This covers issues of self and identity, and of needs and values (spiritual, religious, cultural, physical, emotional and social). This summary introduces some of those concepts.

It is important to understand how people with dementia see themselves and their surroundings because this can influence how they manage their condition, how they relate to others and how they might respond to different kinds of services and support.¹ People with dementia say that it is important to them to preserve their sense of identity, and that a key part of doing this is through maintaining relationships and activities.² Person-centred care and support (that is, care and support that is tailored around an individual's needs and preferences, values, beliefs, life history and other things that are important to a person³) uphold this concept of personhood by focusing on self, identity, needs and values.

The status of research

Research relating to knowing the person with dementia does not neatly fit into a particular category. It is relatively limited with a mixture of studies that describe but do not evaluate interventions such as life story work; as well as narratives on the more abstract concepts of 'personhood', 'self' and 'identity'. Although direct involvement of people with dementia in research is not common, more and more researchers are recognising the importance of gaining insight into people's personal experience of living with dementia and are involving people with dementia in research.⁴

Studies about knowing the person and personhood have limitations in how they are designed and carried out. This presents a problem in bringing together findings from different studies and translating them into recommendations for good practice and how services should be improved. For example, in a systematic review of studies on interventions to support the maintenance of self and identity, studies had mixed study designs, samples of people involved and measures of the outcomes of the studies, and the quality of the studies included was generally weak.¹ A diverse range of interventions were reviewed, including art therapy, reminiscence, listening to music and life history work – all of which were said to be of particular benefit for people with dementia. Some studies did not indicate the stage of dementia of the research participants, making it impossible to assess whether any benefits seen from interventions would apply to people at all stages of the condition.¹ Positive outcomes reported in studies

included increased self-esteem; better opportunities for communication, social interaction and activity; increased awareness of identity; and reduced levels of agitation and apathy. But given the wide range of studies and interventions included in the review and limitations in methodology, there are problems with combining the results and drawing clear conclusions about how effective the interventions are.¹ The authors conclude that interventions are in the early stages of development and there is a need for more high-quality studies.

The significance of personhood or self

Personhood

'Personhood' or 'self' is a complex concept.³¹ Kitwood defined personhood as 'a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust.'⁵

There are various theories of self that refer to the importance of the person and recognition that every person is unique, with distinct needs and preferences, values and life history, and that these make up their unique identity.

It is important to recognise that these characteristics may change over time. This should inform life-history, reminiscence and personal narrative practice so that people, especially those with dementia, are not 'frozen' in time but recognised as having changing interests, opinions and preferences.

Looking beyond the symptoms and to the person

Dementia leads to a gradual loss of functions, including memory, reasoning, communication skills

and the ability to carry out daily activities.^{10,11} When a person with dementia becomes less able to take part in meaningful activity and finds it increasingly difficult to interact and communicate with other people, ways of supporting the person to keep their sense of personhood need to be identified.⁴ Alongside these changes, the person with dementia may develop behavioural and psychological problems and forms of expression as they try to adapt to their situation – these may include aggression, wandering, agitation, repeated questioning, depression and psychosis – and the person may also have to contend with physical illnesses.^{11,12,13} If behaviours and conditions are the main focus of professionals' attention, the importance of the person (or personhood) behind the dementia and their needs will be overlooked.

Personhood and quality of life

In the 1990s, Kitwood strongly advocated for the respect of personhood in dementia care and its key role in promoting quality of life. He said that awareness of personhood is so fundamental to quality of life, that it can deliver better outcomes for quality of life in care settings than advances in medicine have delivered.¹⁴

Personhood and social exclusion

According to Kitwood, the interactions of others are extremely significant in undermining or sustaining personhood.⁵ Poor social interactions and social isolation can undermine a person's position with others, leaving them unable to assert their identity.⁶ In care settings, people with dementia are at risk of their personhood being undermined because they

feel excluded from 'normal' social interaction, which is often how sense of self is realised and sustained.¹⁵

Person-centred care

Person-centred care helps to support personhood. This link between personhood and person-centred care is fundamental.³² The main outcome of person-centred care for people with dementia is the maintenance of their personhood.⁷ Person-centred care should be inclusive. For example, activities should be pitched at a level that does not bore and under-stimulate a person with dementia, but also does not become so challenging that they cannot participate.¹⁶

Conflict between resident and staff views

Research shows that where resident and staff views conflict, due to time and resource constraints, person-centred care can be compromised and lead to residents feeling frustrated as their choice is taken away⁸ – for example, when care home staff favour organised group activities instead of individually tailored activity for 'easier' working, or deny residents unaccompanied access to a secure garden on dubious 'health and safety' or risk grounds.⁸

Some aspects of personhood to recognise

Kitwood's model of dementia proposes that the experience of dementia is unique to every person and depends on how physical health, life history, personality and social surroundings interrelate and shape a person.⁵ A person is also shaped by various

other things such as culture and religion. Some aspects of personhood or self are described below.

Recognising the need to maintain personhood

People with dementia living in the community need to maintain personhood against a background of losses and restrictions such as: problems with thinking, knowing and remembering (cognition); loss of everyday abilities and skills; loss of meaningful activities and meaningful relationships; and thinking that they are becoming a burden.⁴ They need to be taken seriously and understood as this influences their opinion of themselves as well as how they see themselves.⁴ Losses faced by people with dementia can lead to feelings of incompetence and worthlessness as well as loss of control, autonomy (the freedom to act, behave and so on in the way they want) and independence.¹⁷

'Self' during different stages of dementia

'Self' as a concept can be difficult to define. In research with older people with early-stage dementia, people sometimes described self as a single entity and at other times described different aspects of self such as 'role identities', 'self-recognition' and 'self-knowledge'.² Even in people with more advanced dementia, there is evidence that 'self' is not lost, as seen in research with White British, Black Caribbean and South Asian people at various stages of dementia who all described distinct roles, relationships and activities that they continued to value.¹⁷

Recognising the need for normality

In the face of the challenges of living with dementia, people with dementia living in the community take a pro-active approach to dealing with the condition by doing their best to maintain their former identity and a sense of normality.⁴ This includes trying to keep their independence around various aspects of their lives such as meaningful activity, social interactions and relationships, and a desire to remain living with their partners in their own homes.⁴ Providing the right support and information following diagnosis can help people as they go through this process.¹⁸

Recognising spirituality

Addressing a person's spiritual needs can have positive outcomes for their mental health^{19,20} and this is also true for a person with dementia.^{20,21} The need for attention to spiritual needs is recognised in guidelines from NICE and SCIE²² and in research.^{20,23}

Defining spirituality is not straightforward. A comprehensive and often used definition from the world of occupational therapy includes the importance of 'searching for a meaning and purpose in life which may or may not be connected to God or a higher being, ... and may also be experienced through connectedness to an individual's relationship with 'self', others or nature'.²⁴

A person-centred approach would acknowledge that people's spiritual needs should be identified throughout all stages of dementia. A formal assessment of people's spiritual needs is one way of doing this by identifying what activities they find meaningful.²⁰ A literature review on this topic

concluded that people living with dementia strive to maintain their spirituality within the challenges of dealing their dementia.²³

Recognising culture

Care staff may need to pay special attention to aspects of the life history of black and minority ethnic people, especially for people who are not born in the UK.²⁵ These aspects include: country of origin; migration history and reasons for migration; and the cultural experiences of people and their communities in the UK and their country of birth.²⁶ This helps care staff to avoid stereotyping people and to get to know them on the basis of their own individual understandings of their identity.²⁵

Collecting information about the person

The abilities and behaviour of people with dementia are influenced by personal histories, social interactions and social contexts.²⁷ This is where life story and reminiscence therapy are valuable. The process of gathering information about a person and their situation should involve the individual as well as family and carers.⁹

Life story and reminiscence

Assessment and care plans frequently fail to identify the individual histories and characteristics of people with dementia, and this can compromise the quality of person-centred care provided.¹⁰ Life story work helps to address this gap because getting to know the person and supporting the delivery of person-centred care are central elements of its approach.^{9,28,29} Events and occupations that a

person experienced in the past often influence what they do and say as well as influencing needs they have in the present. Through an understanding of life history, people can be supported and helped to keep their sense of identity intact. Life story work can enable the voice of the person with dementia to be heard, verbally and non-verbally, by giving them an opportunity to express their wishes and preferences, using for example life story books and memory boxes.⁹

Life story work offers a chance for family carers to 'show' the personhood of their relative;⁹ and allows staff to get a sense of the person behind the dementia and make links between the person's past and the present, so helping them respond more sensitively to need.^{9,30} The depth and richness of knowledge that staff can gain about the person with dementia is greater than carrying out standard assessment procedures alone.⁹ Life story work is also about acknowledging that people change and that hobbies, interests, likes, dislikes and other aspects of the person from the past may no longer have meaning in the present.

Personal narratives

Some authors have pointed to the importance of the personal 'narrative' or story as a way of helping people with dementia to get their sense of themselves and their identity back and to keep this sense. This is seen in a paper analysing 13 memoirs of people with dementia, which are powerful accounts of their experiences and concerns.⁶ The people whose memoirs were analysed were in the early to moderate stages of dementia, and used

different ways of 'writing' their memoirs, such as on a computer or speaking into a tape-recorder and the speech then being written down. All of them had support from carers to record their feelings and ideas. This review of the memoirs found that problems associated with dementia can create issues in social situations. For example, language and memory problems can create feelings of embarrassment, a feeling of being a burden to others, or feeling overwhelmed in social situations, all which can lead to people withdrawing from social situations or feeling despair and depression. The authors of the study argue that writing can provide a powerful medium through which people with dementia can manage these social effects, by helping them to assert their identity and express themselves on paper. Very often the expectations of others mean that the voice of the person with dementia has been taken away from them. Writing helps the individual to take part in positive social interaction with others and this encourages a social identity to be developed.⁶

Implications from the research

The research on supporting personhood in people with dementia is growing but still limited. Many studies have weaknesses in the way they are designed and how they are carried out. This presents a problem in bringing together findings from studies and drawing conclusions that can be used to make recommendations for how services can be improved.

Services that support a person's sense of themselves and their identity are still in the early stages of development.¹ What is clearly evident is

that person-centred care should be at the heart of services that promote personhood, self and identity. For care staff, this also means emphasising people's individual strengths and avoiding drawing attention to people's failing abilities.² The need to recognise the importance of providing opportunities for meaningful social interaction, positive verbal and even written communication, and meaningful relationships between staff, people with dementia and their families is important. In care settings, life story approaches and activities tailored to the person with dementia are clear examples of where this can be promoted. More conclusive evaluative research is needed in this area.

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