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# What is person-centred care in dementia?

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## Introduction

The term person-centred care has become all-pervasive on the UK dementia care scene. It has been suggested that it has become synonymous with good quality care.<sup>1</sup> It seems that any new approach in dementia care has to claim to be pc (person-centred) in order to be P.C. (politically correct). The term is used frequently in the aims and objectives for dementia care services and provision in the UK and the US, although what lies behind the rhetoric in terms of practice may be questionable.<sup>2</sup>

Although the term 'person-centred' has been used in psychotherapeutic parlance for many years, it was not used in relation to dementia care until relatively recently. The term person-centred care has its origins in the work of Carl Rogers<sup>3</sup> and client-centred psychotherapy. The term 'person-centred counselling' replaced 'client-centred' over the years, as a reflection of the importance of seeing the person seeking counselling as being the expert on themselves, and the therapist being a facilitator in their search for self-actualization. Most person-centred psychotherapy has been practised with adults who are cognitively intact. The influence of Rogerian thinking has been enormously influential, however, on the general way in which we construe therapeutic relationships and emotional difficulties.<sup>1</sup>

Despite the influence of Carl Rogers on practice, prior to the writing of the late Professor Tom Kitwood, the term was not used in the dementia care field. The first Kitwood reference to person-centred approaches in 1988 was to distinguish them from approaches that emphasized the medical and behavioural management of dementia.<sup>4</sup> Writing in the year before his death, Kitwood<sup>5</sup> wrote that he used the term to bring together ideas and ways of working that emphasized communication and relationships. The

term was intended to be a direct reference to Rogerian psychotherapy with its emphasis on authentic contact and communication.

Person-centred care, however, in relation to people with dementia has become something rather different from the application of Rogerian psychotherapy with a new client group. This is due, in part, to the fact that Rogers was only one of the influences on psychosocial models and ways of working in dementia care. Both Kitwood's view of person-centred care and Feil's validation therapy<sup>6</sup> also drew heavily on psychoanalytic as well as humanist models.<sup>1</sup> In the US, the work of Sabat<sup>7</sup> was influential in shaping thinking about people with dementia as having a selfhood. Rader's work on compassionate care<sup>8</sup> and the more radical ideas of Thomas<sup>9</sup> in describing the Eden Alternative, placed the person with dementia clearly in the centre of the care setting. Seeing the person with dementia as an individual with rights and a need for sensitive interaction also had its roots in activities such as Reality Orientation,<sup>10</sup> individualized care planning and needs assessment,<sup>11</sup> the growing dissatisfaction with institutionalized care and codes of practice<sup>12</sup> and Social Role Valorization.<sup>13</sup>

It is a mark of success that person-centred care for people with dementia has entered the accepted way in which we talk about service provision within the UK to such an extent that person-centred care for older people (not just those with dementia) is Standard 2 of the National Service Framework.<sup>14</sup> This sets out a ten-year plan for the development of health and social care services for older people. By 2004, all health and social care organizations within the UK are requested to report on their progress towards this standard. The UK Alzheimer's Society Person-Centred Care Standards for care homes<sup>15</sup> provides a comprehensive set of standards and key questions to help organizations reflect on their practice. Benchmarking of person-centred care<sup>16–18</sup> has been developed to supplement the Department of Health's Essence of Care document.<sup>19</sup>

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### Defining person-centred care

As with many terms that are frequently used, however, there is a tendency for person-centred care to mean different things to different people in different contexts. In my discussions with practitioners, researchers, people with dementia and their families, it is obvious that the concepts in person-centred care are not easy to understand or articulate in a straightforward manner. To some it means individualized care, to others it is a value base. There are people who see it as a set of techniques to work with people with dementia and to others it is a phenomenological perspective and a means of communication. In work with people outside the UK using Dementia Care Mapping (DCM),<sup>20</sup> where material often needs to be translated,<sup>21</sup> it becomes even more important to be clear about definitions of words and terminology that are not part of everyday speech. Many languages have no direct literal translation for person-centred care.

Tom Kitwood's writing on dementia is often quoted in relation to person-centred care and it is his writing that guides definitions of what constitutes person-centred care within the context of DCM. His untimely death in 1998, however, means that he cannot clarify his point of view further. Many others continue to develop ways of working with people with dementia in a humanistic context. In this article, Kitwood's work will be the backbone for helping to clarify what person-centred care now constitutes in the context of dementia care. The definition of person-centred care is not a straightforward one. Person-centred care as it relates to people with dementia has become a composite term and any definition needs to take this into consideration. The elements of the composite can become so convoluted, however, that the definition loses focus and shape.

Person-centred care encompasses four major elements, all of which have been defined as person-centred care in and of themselves by some writers.

These elements are:

- 1) Valuing people with dementia and those who care for them (V)
- 2) Treating people as individuals (I)
- 3) Looking at the world from the perspective of the person with dementia (P)
- 4) A positive social environment in which the person living with dementia can experience relative wellbeing (S)

Continuing the style that Kitwood had for representing complex ideas in the form of equations, this is expressed as:

$$\text{PCC (person-centred care)} = \text{V} + \text{I} + \text{P} + \text{S}$$

This equation does not suppose a pre-eminence of any element over another, nor are the elements directional, but are all contributory. They will now be explored in greater detail.

### Valuing people with dementia and those who care for them (V)

Rogers certainly had a value base of non-judgemental acceptance of the unique aspects of each individual person. This found its therapeutic expression in unconditional positive regard. An additional complexity for person-centred care within the context of dementia is the definition of the term 'person'.<sup>22</sup> The philosophers, Locke and Parfitt, whose definition of being a person depends on consciousness of thought and continuity of memory, would mean that an individual with dementia would not be seen as the same person as their dementia progressed, or indeed as a person at all in the most disabling stages of dementia. Using this definition, as dementia destroys the brain, it also destroys the person. Hughes<sup>22</sup> provides an argument for taking a view of the person that is a 'situated-embodied-agent' rather than one that defines a person by consciousness of thought. Defining the concept of a person in this way means that we should aspire to treat people with dementia at all stages of their disability, in the way in which all people would wish to be treated. Similarly, Kitwood<sup>5</sup> described the person with dementia as 'a person in the fullest sense: he or she is still an agent, one who can make things happen in the world, a sentient, relational and historical being' and 'to be a person is to have a certain status, to be worthy of respect.'<sup>23</sup>

Post<sup>24</sup> also argues for solidarity among all human beings regardless of their mental capacity. Person-centred care is also about seeing all people as valued. This may be better articulated as a value base that positively discriminates on behalf of all persons who are vulnerable. This has certainly been extended to the staff who work with people with dementia.<sup>25,26</sup> On first contact, the moral and ethical basis for person-centred care is rather like 'mom and apple-pie'. How could anyone

disagree that treating people as whole human beings is the right and civilized way to respond to people with dementia? However, a cursory look around service provision or a discussion with people with dementia and their families suggests that people with dementia are not valued by society.<sup>27–30</sup> Society places a high value on youth and intellectual capacity. Those who are elderly and particularly those with dementia are at risk of prejudice which has been called hyper-cognitivism.<sup>24</sup> This is a special type of agism, the victims of whom have cognitive impairment. My personal opinion is that this should be termed ‘dementia-ism’ to help clarify who are the main victims. It is related to other powerful prejudices such as sexism, racism and agism but it also exists independently of all of these. Within services for people who are elderly, those who have dementia often appear to have to suffer a double jeopardy of age and cognitive disability. This discrimination is evident in service provision, resource allocation, research funding, media coverage, policy priorities, professional training and status.

Dementia-ism underpins many of the shortfalls within service provision. Its eradication has to form part of the definition of person-centred care, if people with dementia are to be admitted as full members of the ‘people club’. If this part of the definition is not made explicit in value statements, training, staff selection, standards, policies and procedures, national frameworks etc., then services will not maintain a person-centred approach for long.

### Treating people as individuals (I)

The most concrete implication of person-centred care that sometimes becomes its whole definition, is about taking an individualized approach to assessing and meeting the unique needs of people with dementia. This element of the definition encompasses all those ways of working that consider men and women with all their individual strengths and vulnerabilities, and sees their dementia as part of that picture rather than as defining their identity. This approach again has resonance with the work of Carl Rogers, for whom each client was a unique and whole person. Clare *et al.*<sup>31</sup> also gives emphasis to the whole individual – ‘dementia is more than simply a matter of brain decay. People contribute a unique personality

and a set of life-experiences, coping resources and social networks’.

Likewise, Stokes<sup>32</sup> sees the uniqueness of individuals as a major part of his definition of person-centred care. He expands this model in a very practical way to work with people with dementia who are in distress. Archibald<sup>33</sup> defines person-centred care as ‘people with dementia are individual and, as such, each has a different pathway through the illness and so different care needs’.

Marshall<sup>29</sup> takes a slightly different emphasis, writing that ‘(person-centred care) means, in brief, that care is tailored to meet the needs of the individual rather than the group or the needs of the staff’. Still inherent in this view is that the people with dementia are the focus, rather than the categories into which professionals and staff might place them.

The UK National Service Framework<sup>14</sup> has chosen this aspect of person-centred care on which to focus. The aim within this standard is about treating people as individuals and providing them with packages of care that meet their individual needs. Inserting a problem focus into the definition, however, can make it difficult to continue to see the whole person. It then becomes similar to the term ‘patient-centred care’ or ‘resident-focused care’, which is also sometimes used interchangeably with person-centred care.<sup>34</sup> Although this is clearly linked to the individualized element of person-centred care, it can be constraining in that the person with dementia can only express those individual needs that are covered by being a patient. There is an element of person-centred care here, but the term suggests that the person is defined by their status as patient rather than their individuality. It does, however, signify a desire to focus on the patient (or resident). This is usually done with the intent of protecting the vulnerable from being disempowered by a large bureaucratic organization and, as such, would be in accordance with the first element within the definition of person-centred care presented above.

### Looking at the world from the perspective of the person with dementia (P)

Person-centred care is part of the phenomenological school of psychology. In this, the subjective experience of the individual is seen as reality,

and hence the starting point in explaining their behaviour and therapeutic approaches to change this. Rogerian person-centred therapeutic approaches would see entering the frame of reference of the individual and understanding the world from their point of view as key to working therapeutically.

Likewise, Feil's Validation Therapy takes entering the subjective world of the person with dementia as its starting point.<sup>6</sup> Kitwood certainly recognized the centrality of understanding the individual needs of people with dementia to give a focus for interventions.<sup>35</sup> Stokes<sup>22</sup> also highlights understanding the subjective experience as key to a definition of person-centred care. Clare *et al.*<sup>31</sup> define person-centred approaches to dementia care as focusing on 'understanding the experience of dementia in terms of the person's psychological responses and social context', and aim to tailor help and support to match individual needs'. Thus they take the starting point for meeting individual needs as understanding the experience of the person with dementia.

Putting oneself in the shoes of someone with dementia is not an easy or trivial process. Kitwood<sup>36</sup> described 'seven access routes' by which dementia care practitioners could deepen their empathy toward people with dementia. Dementia Care Mapping was in part an attempt to help care practitioners put themselves in the place of people with dementia when evaluating the quality of care. Kitwood<sup>5</sup> described DCM as 'a serious attempt to take the standpoint of the person with dementia, using a combination of empathy and observational skill'. It has only really been in the past ten years or so that researchers have written seriously about the perspective of individuals with dementia.<sup>37,38</sup> In dementia research, phenomenological research into the early experience of Alzheimer's disease<sup>39,40</sup> is now well established. In quality-of-life research, self-report measures on subjective well-being<sup>41</sup> and satisfaction with care<sup>42</sup> have been developed relatively recently. Similarly, in dementia care practice, engaging directly with people with dementia in a therapeutic sense is a relatively new phenomenon.<sup>43</sup> The work of Killick and Allen<sup>44</sup> has been extremely influential in the UK in helping practitioners attend to the person with dementia in imaginative, creative and reflective ways. Without these insights that put the person with dementia in at the centre of care, how can we define any approach as person-centred?

## A positive social environment (S)

This part of the definition is about the care that promotes relationships between people. Rogers<sup>3</sup> saw relationships as key to therapeutic growth and change. He highlighted the importance of the relationship and therapeutic alliance in person-centred counselling. As verbal abilities are lost, the importance of warm, accepting human contact through non-verbal channels becomes even more important than before.<sup>1</sup> In a series of in-depth interviews in long-term care, 16 out of the 26 residents interviewed highlighted relationships, particularly friendships and reciprocity in caregivers, as being important.<sup>45</sup>

Kitwood's view of person-centred care for people with dementia was that it took place in the context of relationships – *Person to Person* was the title of Kitwood and Bredin's 1992 publication which was the first practical book on what person-centred care constituted.<sup>46</sup> Personhood is central to Kitwood's writing on person-centred care. He defined it as 'a standing or status that is bestowed on one human being by others in the context of relationship and social being. It implies recognition, respect and trust'.<sup>5</sup>

Bond<sup>47</sup> also includes the context of relationships within his description of personhood '... individuals do not function in isolation, they also have relationships with others; all human life is interconnected and interdependent'.

Again, ensuring that people with dementia have the opportunity for social and loving relationships with those around them seems so obvious that surely we do not need a definition of care to tell us this? However, again, even a cursory examination of care provision shows that this is not the norm. Kitwood's writing on 'malignant social psychology' and the importance of interpersonal process in dementia clarify why this seems so difficult to achieve in practice.<sup>48,49,5</sup>

With the onset of dementia, individuals are very vulnerable to their psychological defences being radically attacked and broken down. As the sense of self breaks down, it becomes increasingly important that the sense of self is held within the relationships that the person with dementia experiences. These relationships cannot be developed through the traditional therapy hour as in person-centred psychotherapy. Rather the development of relationship occurs through the day-to-day interactions. The psychological needs

are identified as comfort, attachment, occupation, identity and inclusion.<sup>5</sup> Although these needs can be seen as universal, the disabilities associated with dementia mean that they have to become the main foci of person-centred care in this context, if personhood is to be maintained. Kitwood described what a positive social psychology might look like for people with dementia rather than the negative malignant social psychology which prevailed in his earlier writing. He used the term 'positive person work' to describe ten different forms of interaction that would maintain personhood.<sup>5</sup>

Although some of his writing and ideas may have been difficult to grasp by those providing direct care, the creation of Dementia Care Mapping (DCM) provided a means of very concrete feedback on the quality of person-centred care in this respect. DCM provides staff with feedback about how the people in their care are experiencing daily life. This information can be used to plan more person-centred care on an individual, group and organizational level.<sup>36,50,51</sup> DCM has been used extensively for driving organizational change towards person-centred care both in the UK and increasingly around the world. DCM is currently being revised and the new version will undoubtedly place a much greater emphasis on evaluating the positive social psychology as the current version does in eliminating the malignant one.<sup>52</sup>

The practice of caring for very vulnerable people with dementia in large groups with low staffing levels, however, can place care workers in an intolerable bind when trying to provide a positive social psychological milieu. How to balance the needs of one individual who requires lots of attention against the needs of the wider group, who may be equally needy but make less show of it, is one that faces dementia care practitioners day in, day out. Case-studies<sup>53,54</sup> pay testament to the imaginative and committed work of many care practitioners in this field.

A number of ways of working with people with dementia can be captured under the umbrella term of person-centred care. The British dementia care scene has been described as having gone through a renaissance in the past ten years.<sup>1,55</sup> Certainly the amazing wealth of innovative practice presented in the pages of the *Journal of Dementia Care* would have been just as mind-boggling to a dementia care practitioner in the mid-1980s as telecommunications would have been to a scientist from 1780. Life-story work, reminiscence,

creativity, play, doll therapy, pet therapy, sensory therapies, psychotherapy have all been written about with people with dementia. Central to these ways of working is the facilitation of social confidence and communication at an emotional level.<sup>26</sup>

Rather than seeing people with dementia as the ones having problems and those who are caring having none, Kitwood<sup>25</sup> suggested that many of the problems experienced in dementia care are interpersonal. They occur in the communication. He suggests we need to view the relationships between 'carers' and 'cared-for' as a psychotherapeutic relationship and, in this respect just as in psychotherapeutic work, the helpers need to be aware of their own issues around caring for others.

In person-centred care, the relationships between all people in the care environment should be nurtured.

#### Towards a model of person-centred care

The term 'person-centred approach' to care was first used by Kitwood to differentiate ways of working with people with dementia that was not framed within a biological or technical model. Understanding and expertise in the provision of person-centred care has developed enormously since the term was first used. Different elements of person-centred care have been articulated. If this definition also works as a model, it should facilitate some predictions of what might happen if only certain elements of person-centred care are in place whilst others are neglected. The following observations are based on the experience of working with many care facilities for people with dementia. They are summarized diagrammatically in Figure 1. The first part of the model (V) is anti-discriminatory practice for people with dementia and those who work with them. The rights of people with dementia are certainly more recognized than they were even five years ago due, in large part, to the work of Alzheimer's Associations around the world. Also, people are being diagnosed earlier in greater numbers and the current cohort of people in their seventies feel more empowered to speak out against authority than previous cohorts. The push for anti-dementia-ism, however, has largely come from people with dementia themselves. It is not explicit in the value statements of many care organizations or in government policy. The danger in not making it explicit is that the

Underemphasis	Element	Overemphasis
Discrimination within care organizations and policy agenda against people with dementia and those who care for them	<b>V</b> Valuing people with dementia and those who care for them	Care evangelism. Platitudes that people agree with but don't know how to put into practice.
Chaotic and inappropriate assessments and care plans of people with complex needs and life histories.	<b>I</b> Treating people as <b>individuals</b>	Lots of paperwork. Care plans are all different from each other but meet individual needs only within a narrow range
Care will not meet the priorities of the individual. High levels of challenging behaviour and learned helplessness.	<b>P</b> Looking at the world from the <b>perspective</b> of the person with dementia	Lots of information collected but never used appropriately.
Poor communication and lack of dementia-aware interpersonal skills by staff. Organisational emphasis on safety and aesthetics.	<b>S</b> A positive <b>social</b> environment	Slavish following of techniques. Frequent changes in direction as latest techniques are tried and discarded.

Figure 1 Towards a model of person-centred care for people with dementia

pressures of dementia-ism are so powerful in society that they will erode attempts at person-centred care that are not firmly built on a strategy of positively valuing individuals with dementia within the context of care. Standard One of the UK National Service Framework is about rooting out age discrimination. This is entirely laudable. However, it only addresses part of the prejudice for people with dementia. If their services are to be person-centred along with everybody else's, then dementia-ism needs to be rooted out with equal energy.

On the other hand, if person-centred care is seen only as a value base, then it can quickly become seen as a group of empty words, or evangelism without a practical application and a body of knowledge. There are some people who can extrapolate practice very easily from a value base, but many others need the implications to be spelt out in rather more concrete terms.

The second element (I) is the focus on the individual. If person-centred care is just taken to mean individualized care without the other elements of the definition, then care can quickly deteriorate into serving needs within a very narrow frame that makes very little difference to the lived experience of dementia. Taking an individualized approach to care will usually entail trying to see the world from the perspective

of the person with dementia. However, it is possible to do individualized assessments and care, without considering the viewpoint of the person with dementia at all. In these cases, the assessment would generally focus on constructs entirely determined by the professional perspective. All the residents in a facility can have individual care plans that are different from each other, but may not prioritize the things that are important for each individual at all. On the other hand, if the practicalities of complex individual needs are not assessed and catered for, then the provision of person-centred care becomes too chaotic to be deliverable.

The third element (P) is about taking the perspective of the person with dementia as the starting point. If this is all that person-centred care is taken to mean, then a lot of information is generated which never makes a difference to people's lives. Filing cabinets in care facilities around the world are full of information about people's lives but still care staff will not know even the rudimentary facts. The individual's perspectives need to be used if they are to be part of person-centred care. On the other hand, without the personal perspective, care becomes little more than guesswork. The level of challenging behaviour is likely to be high as people with dementia struggle to make themselves heard. Alternatively,

people may have burnt out in their attempts and a situation of learned helplessness develops.

The fourth element (S) is the positive social environment. These are the interpersonal skills and the individual and organizational wherewithal to make an impact on the lives of people with dementia. If this is all that person-centred care consists of, however, then there is a danger that care becomes mechanistic without reference to individual needs and perspectives. Without a strong value base, the reason for using these tools in the first place becomes obscured and a slavish following of technique can occur. On the other hand, if care workers, family members and organizations do not have the skills and techniques to provide a positive social environment for people with dementia, then confusion and distress will reign. The organization is likely to place an emphasis on care practices that promote the safety of property and residents and on the aesthetics of the physical care environment.

### Conclusions

Fundamental improvements in person-centred care for people living with dementia will not occur until the policy agenda is aligned with the agenda for people with dementia. In clinical gerontology, in the fields of practice and research, we need to be able to articulate what it is we mean by person-centred care if we are to influence that agenda. Person-centred care for people with dementia does not equate with person-centred counselling any more than it equates just to individualized care. It has become a shorthand term for encompassing a whole movement in dementia care which is more far-reaching than either of these things. It is easy to be woolly with such an over-used term. By understanding the different elements of a tentative model of person-centred care, it is hoped that some light can be shed on why it is often so difficult to achieve in practice. Of course, the acronym VIPS also stands for Very Important Persons, which is an easier way of defining the outcome of person-centred care for people with dementia.

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