



## Review Article

## Person-centred care in dementia: Philosophy and challenges in implementation

Priya T Nandimath<sup>1,\*</sup><sup>1</sup>Dept. of Public Health, Padmashree School of Public Health, Vijayanagar, Bengaluru, Karnataka, India

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## ABSTRACT

Health care concept is increasingly moving away from medical, task oriented and professional driven model towards a holistic model of health care which values the needs of the persons and centred on the needs of the patients. This shift is described as person centred care. Despite the wide availability of literature, philosophy and evidence on the outcomes of the person centred care, barely it is an ideal in reality. This present article throws light on the philosophy and challenges of person centred care and tries to raise the awareness and understanding about person centred care for people with dementia and explores on the challenges underpinning person-centred care in dementia.

Person centred care means, being “respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions”. Each individual has unique history, personality, values, right to dignity, respect and right to participation. PCC framework emphasises on the assumptions made about the people with dementia, care givers attitude, models and care practices, factors at organisational level, cultural factors as well as structural elements such as lighting and flooring. It is a holistic philosophy across the continuum of services which takes into account the specific needs of each person. The philosophy of person centred care focuses on “the abilities and strength of the person than the losses” and on “the person than on the condition”.

**Challenges Underpinning Person Centred Care:** Lack of clarity in understanding person centred care in dementia, lack of research evidence, not valuing the views and needs of people with dementia, organisational culture, task centred care culture, lack of resources.

**Conclusion:** To improve quality of life of people with dementia and for the better functioning of the people with dementia there is a need for greater implementation of person centred care. However the challenges in the implementation of person centred care are masking the achievements and positive aspects of the person centred care approach. The challenge ahead for dementia experts is to advocate and raise the awareness and understanding and to provide evidence based solutions in practically implementing person centred care and making it more real in practice than keeping it ideal in literature.

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## 1. Introduction

“The greatest challenge which is faced by our health and social care systems is to get services right for older people.”<sup>1</sup>

Report by Institute of Medicine (IOM) 2001<sup>2</sup>, drew the attention towards the concept of the health care that should be ‘centred’ on and ‘organised around’ the needs

of the persons receiving the care rather than the needs and the preferences of the caregivers and institutions. The report also considers “Patient-centeredness” as one of the six important aims in restructuring US health care system. The report stressed on defining patient centred care as being “respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions” (IOM, 2001a).<sup>2</sup> This formed the basis for the person centred care.

\* Corresponding author.

E-mail address: [priyanandimath@gmail.com](mailto:priyanandimath@gmail.com) (P. T. Nandimath).

There will be increasing pressures on health care and social services to provide effective services with a projected global increase in the economic impact of dementia. The responsibility of the care home staff increases with increase in the continuing care requirement and as the people with dementia in care home become more dependent with their advancement in disease. This in turn has a drastic impact on staffing patterns, resources, workload, training and ultimately quality of care. With the constraints on scarce resources and time, it will be extremely difficult to successfully promote person centred care.<sup>3</sup> This article philosophy of person centred care and also explores the challenges in implementation of person centred care. The article concentrated to raise the awareness and understanding about person centred care for people with dementia and explores on the challenges underpinning person-centred care in dementia.

It is very much essential that the mindsets and the paradigms of the individuals and the organisations have to significantly change in order to deliver true person centred care which at the current outset is very much essential and necessary. It is also argued that communications at the work settings are the best media to understand, construct and convey the meaning to the patients, families and caregivers.<sup>4</sup> This communication can be taken up as practice development. Communication can better be expressed when person centred care approach is applied for dementia care which allows to consider the views and needs of the people with dementia.

### 1.1. *Person-centred care philosophy*

Person-centred care philosophy as stated in Guidelines for Care: Alzheimer Society of Canada, (2011)<sup>5</sup> recognises that each individual has unique history, personality, values, right to dignity, respect and right to participation. This framework also emphasises on the assumptions made about the people with dementia, care givers attitude, models and care practices, factors at organisational level, cultural factors as well as structural elements such as lighting and flooring. It is a holistic philosophy across the continuum of services which takes into account the specific needs of each person. It is grounded in mutually beneficial partnerships established between people with dementia and their caregivers. The philosophy is also about actively involving the people with dementia and their families in ensuring health and wellbeing. It also emphasizes on creating healthy partnership among care home staff, people with dementia and their families. The philosophy is also to deliver the services in a more collaborative and integrated and it should be mutually respectful to the carers, people with dementia as well as family members. This will finally account for quality of life and quality of care of the people with dementia. To summarize the philosophy of person centred care focuses on “the abilities and strength of the

person than the losses” and on “the person than on the condition”.<sup>5</sup>

### 1.2. *Origin of person centred care*

Person centred care has become synonymous with quality care.<sup>6</sup> Person centred care originally took its birth from Carl Rogers work. Person centred care was used for psychotherapeutic measure and not for dementia care until recently. Later it was introduced by Kitwood in 1988 to distinguish the approaches that emphasized medical and behavioural management of dementia. Later in US the work of Sabat influenced thinking dementia as having selfhood.

### 1.3. *Defining person centred care*

The two schools of thoughts on definition of person centred care are described below

Person centred care is often quoted with Tom Kitwood’s writing on dementia<sup>6</sup> and defines person centred care in context with Dementia Care Mapping (DCM). Untimely death of Kitwood has still left the definition unclear. However the four major components encompassed in defining person centred care 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)”

And Kitwood’s ideas can be expressed in the form of equation as,

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

Even though practically difficult to implement, person centred care is influential in acknowledging and enduring personhoods of people with dementia.<sup>3</sup> However as dementia progress the people with dementia fail to express themselves and in order to address this weakness and to understand the selfhood and wellbeing, selfhood approach can be described.<sup>7</sup> It is argued that the assumption of loss of selfhood as dementia progresses cannot be considered<sup>7</sup> and hence the approach to person centred care was extended to include three self (self1-3).<sup>8</sup>

Self 1 is described as first person pronouns-I, me, mine, or our and Sabat (2001) argued that self 1 remains intact with people with dementia.

Self-2- mainly is comprised of persons physical, mental or emotional characteristics and mostly related to the persons history, achievements etc. Sabat (2001) suggests that self 2 is intact with declining cognition but is vulnerable to damage with negative interactions with others.

Self 3 is related to the roles we take in social situations like a friend, professional, carer, etc... This self 3 should be nurtured and constructed by interaction with others. Self 3 has a potential to damage self1 and self 2.

Even with severe cognitive decline, there is persistence of self. This selfhood is considered as interplay among social, biographical and interpersonal, social context and the abilities of the persons to communicate. This ability of the person with dementia to communicate even with severe cognitive disability is missed by the care-givers as their inability to attend properly, hear or recognise.<sup>9</sup>

## 2. Challenges Underpinning Person Centred Care

Even though person centred care is considered as an ideal care approach and though considered synonymous with quality care for people with dementia, it is barely an ideal concept. The following could be some of the underpinning issues which can be addressed to make person centred care more real and practical.

### 2.1. *Lack of clarity in understanding person centred care in dementia.*

Observations amongst the practitioners, researchers and people with dementia and their families highlighted that the concepts of person centred care was difficult to understand, some of them conceived it as individualised care and others as value based care, some as means of communication and some others as phenomenological perspectives of care. Another concern in terms of barrier was the translation of language; many of the languages did not have literal translation outside UK.<sup>6</sup>

There is very little consensus on the definition of person — centeredness and that there is no widely accepted definition of person centred approach. These factors are hindering perception and understanding of the benefits and the focus of the approach. Further Person centred care is not described as guidelines to achieve quality care rather it is defined in abstract terms. It is also argued that Person centred care has both formal and informal meaning as it is both a philosophical as well as practical component of care giving which is difficult to confront. Hence it becomes necessary that a strong and a clear definition to be established so as to achieve quality care in dementia.<sup>10</sup>

Among the participants (care givers) there was variability in understanding of person-centred care — some of the participants assumed it to be with choice of services, others felt it as quality in day-to-day routines and knowledge about service users and few others felt it as shared culture at all the levels of organisation.<sup>11</sup>

Recommendation- research findings support that a clear definition with clear meaning has to be established so as to see that the concept and understanding of person centred care remains uniform.

### 2.2. *Lack of research evidence*

Although lot of anecdotal evidences are available to suffice that person centred care can improve the quality of life and well being of people for the person with dementia, it is argued that little research is carried out in the area of implementation of person centred care among the individuals at all the stages of illness, age, gender, and ethnicity. It is also argued that very fewer studies have been carried out in implementing person centred care in services and programs and less evidence on how person centred care is incorporated into practice.<sup>10–12</sup>

Recommendations: Extensive research can be carried out to in these areas so as to provide evidence based results in the outcomes of implementation of person centred care.

### 2.3. *Valuing the views and needs of people with dementia*

Even though valuing the views and needs of the people with dementia is central to the person centred care, in reality the need for understanding the needs and views of the people with dementia among the care givers is poor. As to suffice this, it is found that most of the participants (care givers) did not reflect on the role of people with dementia in deciding care delivery. This strongly reflects that no sufficient attention is paid to the views of the people with dementia. And the attitudes of the care giver have still not shifted from task oriented care and still being stuck with the medical model.<sup>12</sup>

Recommendations: it is very much essential to sensitise the care givers to consider the values and needs of the people with dementia, and considering their preferences in care a treatment

### 2.4. *Organisational culture*

It is found that the care givers consider organisational culture as both barriers and facilitators to person centred care. Bureaucratic structures are a strong challenge to any innovation where as sympathetic managers are able to understand the benefits and outweigh them against the benefits of implementing person centred care.<sup>11</sup> The emphasis of policy on person centred care also makes the managers to describe the services as person centred without any shift towards the concept and culture of person centred care. This clearly emphasises that organisational culture also plays a pivotal role in implementing person centred care.

Recommendations-: Hence it can be strongly recommended that the organisations need to be flexible and adoptive to the new culture and to provide genuine care rather than providing fake care.

### 2.5. Task centred care culture

One of the major barriers in delivering person centred care is the commitment and the ability of the staff to understand the values, philosophy of the organisation and this highlights the importance of appointing the staff with appropriate qualities.<sup>11</sup> Still dementia care is in the stage of task centred care culture, staffs come and deliver their services as a task rather than making it more meaningful and need based.

Recommendation: at this juncture it can be recommended that the staff selection and recruitment should be based on the abilities to deliver care with respect to philosophy and values and needs of the people and not merely to perform the care task. Recruiting skilled, enthusiastic and person with good communication skills will surely impact the outcomes of the care.

### 2.6. Lack of resources

Scarcity of resources is also a major barrier for implementation of person centred care. The skilled personnel are also lacking in providing the care delivery to the people with dementia.<sup>11</sup>

Recommendations: Identifying and proper training resources and materials and ways to access them should be established for the carers. In house training and sensitization of carers to recent research findings will also help in developing skilled professionals in dementia care.

### 2.7. Person-centred dementia care outcomes

It is argued that the large number of measurement tools which are demonstrated are not been tested in actual research and this stresses on conducting more empirical studies in this light. These studies might help in understanding and exploring to what extent the person centred care can bring in improvement and outcomes.<sup>13</sup>

## 3. Conclusion

To improve quality of life of people with dementia and for the better functioning of the people with dementia there is a need for greater availability of person centred care. However lack of clear understanding about the person centred care philosophy, its practical implementation in day-to-day practice, scarcity of resources, lack of empirical evidence about the outcomes, inflexible organisation culture, and lack of evidence on measurement tools for person centred care are all masking the achievements and positive aspects of the person centred care approach. The challenge ahead for dementia experts is to advocate and raise the awareness and understanding and to provide evidence based solutions in practically implementing person centred care and making

it more real in practice than keeping it ideal in literature.

## 4. Source of funding

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## 5. Conflict of Interest

None.

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## Author biography

Priya T Nandimath, Associate Professor

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