Person-centred Dementia Care: A Vision to be Refined

Healthcare professionals have increasingly been moving away from a task-oriented, professional-driven model of healthcare, towards a more holistic model of care which emphasizes patients' perspectives and their subjectively defined experiences and needs. In the field of dementia care, this shift has been described most often as a move towards "person-centred care." Despite a wealth of literature describing the philosophy of person-centred care, we know very little about the current definition and implementation of this philosophy in dementia-care settings. This article will provide an overview of the literature to date.

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The concept of the "person" is at the centre of current debates on the beginning and end of life,[1] the assessment of competency,[2,3] and human suffering.[4] Promoted as a shift in the "culture" of care, holistic dementia care is referred to most often as "person-centred" (although terms such as "individualized," "resident-focused," and "patient-centred" also are utilized), and is based on various sources, including the social psychology of professor Tom Kitwood.[5]

Person-centred dementia care (PCC) has emerged as a response to an old culture of care[6,7] which: 1) reduced dementia to a strictly biomedical phenomenon;[8] 2) was task-driven; 3) relied on control techniques including chemical and physical restraints,[9] warehousing and unnecessary medication; and 4) devalued the agency and individuality of persons with dementia. In contrast, PCC is value-driven, focuses on independence, well-being and empowerment of individuals and families,[10] and "enables the person to feel supported, valued and socially confident."[11] Promotion of PCC also is a response to the lack of attention in dementia research, and to the agency and subjectivity of persons with dementia.[12]

Personhood

According to Kitwood,[5] personhood is "a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being... impl[ying] recognition, respect and trust." The aim of good dementia care is "to maintain personhood in the face of the failing of mental powers."[5] Attention to personhood includes recognition of "the centrality of relationship, the uniqueness of persons, [and] the fact of our embodiment."[5] Dementia care which focuses only on the disease and its treatment does not attend to a patient's personhood, treats the patient as a passive object, and is damaging to the patient.

PCC is founded on the ethic that all human beings are of absolute value and worthy of respect, no matter their disability, and on a conviction that people with dementia can live fulfilling lives[8] (Table 1). Central to PCC is the principle that an individual's life experience, unique personality and network of relationships should be valued and taken into account by staff in care settings. This perspective is founded on the observation that the presentation of dementia cannot be reduced to the effects of neuropathologic damage, but is instead a combination of factors, including personality, biography, physical health, neurologic impairment and social psychology. In contrast, focusing on a patient's losses or deterioration may reinforce negative perceptions and treatment of individuals with dementia, and also may have a significant impact on the progression of dementia.

Several studies have identified the importance of self-esteem for the overall well-being of persons with Alzheimer's disease (AD).[13,14] PCC involves the establishment and maintenance of positive, supportive, social environments for persons with dementia (Table 2). In these contexts, personhood of individuals with dementia may be enhanced by strengthening the person's positive feelings, nurturing the person's abilities or skills and helping the healing of a psychic wound.[15]

Through the generation and/or sustenance of positive interactions, stability and secure relationships, the personhood of individuals with dementia is replenished continually. Specific psychotherapeutic techniques (Table 2) to facilitate these relationships include the following:

1) ***Validation*** – the acceptance of reality, and feelings of being alive, connected and real.
2) ***Holding*** – the provision of a safe psychological space where tension and vulnerability may be exposed. Holding may be both psychological and physical.
3) ***Facilitation*** – "enabling a person to do what otherwise he or she would not be able to do, by providing those parts of the action... that are missing."[5]

Table 1

Person-centred Dementia Care Defined

1. Care that is centred on:
   a. the whole person, not on the diseased brain;
   b. remaining abilities, emotions and cognitive abilities—not on losses;
   c. the person within the context of family, marriage, culture, ethnicity, gender.
2. Care that is centred within a wide society and its values.

Adapted from: Cheston R, Bender M. *Understanding Dementia: The Man with the Worried Eyes.* Jessica Kingsley Publishers Ltd., London 1999, p.12.

Table 2

Positive Interactions in Person-centred Dementia Care

Social interactions	
Recognition:	individual known as a unique person by name; involves verbal communication and eye contact
Negotiation:	individual consulted about preferences, choices, needs
Collaboration:	caregiver aligns him/herself with care recipient to engage in a task
Play:	encouraging expressions of spontaneity and of self
Stimulation:	engaging in interactions using senses
Celebration:	celebrating anything the individual finds enjoyable
Relaxation:	providing close personal comfort (*e.g.*, holding hands)
Psychotherapeutic interactions	
Validation:	acknowledging person's emotions and feelings and responding to them; empathy
Holding:	providing a space where the individual feels comfortable in self-revelation
Facilitation:	enabling person to use their remaining abilities; not emphasizing errors
People with dementia can take a leading role in:	
Creation:	individual spontaneously offers something to the interaction; affirmation of this
Giving:	individual offers him/herself in a positive emotional or helpful way

Adapted from reference 15.

Signs of Personhood

PCC has been encouraged by first-hand accounts of the experience with dementia[16,17] and by a wealth of recent studies revealing qualities of personhood in individuals suffering from dementia.

The qualities of personhood include self-awareness,[18] subjectivity,[19,20] meaning-making,[21,22] meaningful talk,[23] sexuality,[24] expressive behavior,[25] autonomy,[26] social and cognitive abilities,[27] an intact sense of social and personal identity,[28] humor and individuality,[29] and agency and the capacity to value.[30] Although persons with dementia experience diminishing linguistic ability as the disease progresses, they often are able to compensate with extralinguistic communication (*e.g.*, gesture).[31] The individual with dementia is not simply a passive victim, but rather "seeks actively to make sense of and cope with what is happening."[12] Discussions on dementia care in bioethics literature also promote treatment and care based on personhood[28] and "ethics of the everyday,"[32] focused on an "embodied personhood expressed within a context, and through relationships."[33]

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There also is evidence that individuals with dementia, who are given appropriate support, sometimes can experience "rementia"—learning and experiencing cognitive clarity despite degenerative neurologic impairment.[6,34] This work points to the significant potential of persons with dementia and the important roles they can play in their own care and in decisions affecting their lives, when provided with appropriate support and services.

Benefits of PCC

Several studies have revealed positive results from the implementation of PCC.

Quality of life. Burgener et al[35] found that a person-centred approach, including the maintenance of social activities, past pleasures and activities, was associated with positive quality-of-life outcomes in individuals with AD. They also found that the quality of the relationship between caregivers and individuals with dementia was associated with the care recipient's level of depression, psychological well-being, and productive behaviors.

Decreased agitation. Matthews et al[36] found that a client-oriented intervention for agitation and sleep patterns of persons with dementia, emphasizing freedom of client choice for activity scheduling (*e.g.*, meals, toileting, ward activities, bed times), resulted in decreased verbal agitation levels and staff feeling less rushed and more tolerant of residents' behaviors.

Improved sleep patterns. Richards et al[37] found that an intervention to individualize activities, with respect to each participant's past interests and current capabilities, led to improvements in nocturnal sleep and reduction in daytime napping.

Maintenance of self-esteem. Sabat et al[13] found that, when the positive attributes of dementia sufferers' selves are attended to by others in their social milieu, and when the opportunity for self-expression is provided, persons with dementia are better able to maintain self-esteem while minimizing anxiety, grief, anger, and the feeling of being a burden to others.

Specific strategies for the professional practice of PCC also have been discussed in the literature. These include:

- assessments which involve and recognize the choices of care recipients and family caregivers;[38,39]
- assessments which are non-judgmental and build trust and rapport;[38,39]
- the provision of alternate bathing methods, such as the towel bath;[40]
- activities which are appropriate with respect to the remaining cognitive abilities of the person with dementia;[26]
- culturally sensitive services;[41,42]
- continual assessment of the person with dementia and involvement of relatives in care planning;[25]
- recognizing vocalizations as attempts to communicate;[43] and
- the use of resident biographies and personal profiles.[44]

Central to these techniques is the development of positive relationships between all those involved in the caring process. In fact, high-quality care is dependent on understanding the care recipient's life and identity, and on the fostering of these relationships.

Barriers

Despite the positive findings with respect to implementation of PCC, several problems confront its promotion. First, there is little consensus on the definition of "person-centredness."[45,46] Schwartz et al[45] write, "... despite the ubiquitous promotion of these principles, practitioners of person-centred approaches are confronted with a paradox that hinders perception and understanding of its particular benefits, and obscures its focus; there is no broadly accepted definition of the person-centred approach itself."

PCC most often is described in abstract terms of quality, rather than in guidelines for how that quality may be achieved.[47] PCC is both a philosophical approach and a practical component of patient care, having formal and informal meanings and implications for practice—a dynamic concept which changes with a patient's physical condition and the environment of care.[48] Studies to date, however, have not explored the definition and implementation of PCC within a range of care programs and services, or how the philosophical approach is incorporated into practice. Furthermore, although PCC has been promoted for individuals at all stages of AD,[49] little research has been conducted to explore the meaning of PCC for individuals at different stages of dementing illness, or for individuals varying by gender, age or ethnicity. The absence of a clear definition of PCC places limitations on our understanding of its benefits for individuals with dementia, as well as for program administration, nursing staff, and caregiving families.

We have only a minimal understanding of the factors supporting or impeding the implementation and practice of PCC.[50] While PCC may focus on the needs of individuals, it still may be guided by the values of professionals, as opposed to the care recipient and the caregiving family.[32] Issues of institutional power, and of staff roles and responsibilities, may place professional staff in conflict with the very essence of "person-centredness."[51]

It becomes more difficult to implement PCC when the families of care recipients are not present at the time of admission to long-term care, or when care recipients have no family members to provide critical personal information.[52] There also is a scarcity of research on successful strategies for PCC.

It is impossible to further develop the practice of PCC without an understanding of the ways in which the philosophy of PCC has successfully been implemented by administration and nursing staff.

Next Steps

The future practice and development of PCC depends on several requirements. Care providers must be aware of the values forming their own definition of "personhood," how these values form the practice of caring, and the fact that definitions of PCC vary between administrative personnel, front-line nursing staff, family caregivers and individuals with dementia. Care providers also must carefully assess the factors which promote and impede PCC, and share their success stories with other care providers. Academic research also can support these goals—particularly qualitative research, which applies to the experiences of dementia and caring, and to the perspectives of all involved in the caring process.

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