

CARING FOR OLDER PERSONS WITH DEMENTIA: THE PRINCIPLES OF PERSON-CENTRED CARE

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Introduction

Dementia is not a single disease or condition but a syndrome of multiple causes. It is usually used as an ‘umbrella’ term (Moore, 2009) for more than 200 different conditions and disorders characterised by a progressive deterioration in cognitive function, some of which are considerably rare.

Knopman *et al.* (2003) proposed different diagnostic criteria for differentiating between the most common types of dementia, namely Alzheimer’s disease (AD), Vascular Dementia, Dementia with Lewy Body and Fronto-temporal dementia. Such cognitive decline includes loss of memory and impairment in executive functions such as planning and organisational skills, accompanied by personality changes and deterioration in cognitive function sufficient to limit social activities.

Dementia: the silent epidemic

According to the latest global estimates by Alzheimer’s Disease International (Prince and Jackson, 2009), there were 35.6 million people with dementia in 2010, with the numbers nearly doubling every 20 years reaching 65.7 million in 2030 and 115.4 million in 2050. These proposed estimates are 10% higher than previously reported by Ferri *et al.* (2005).

This increase in the prevalence and incidence of dementia is mainly the result of an ageing world population, specifically in the 60+ age group. According to the World Population Ageing, 8% of the global population was aged 60 years and over in 1950. This increased to 11% in 2010 and is projected that by 2050, this figure will double. Moreover, in line with the increase in the number of older persons in developing countries, the increase in the estimated prevalence of persons with dementia will be more marked in developing countries (Ferri *et al.*, 2005).

Thus, it is estimated that over the next 20 years, there will be a 40% increase in the figures in Europe, 63% in North America, 77% in the Latin American continent and 89% in the developed Asia Pacific countries. Moreover in Asia and in North Africa, the increase in prevalence rates over the next 20 years will be over 100% (Prince and Jackson, 2009). Furthermore, Rodriguez *et al.* (2008) argued that the current prevalence of dementia in developing countries, especially in India, is underestimated due to cultural differences in defining dementia.

Personhood and selfhood in dementia

Although the medicalisation of dementia during the past years has contributed in separating dementia and AD from ageing, Kitwood (1993) suggested that the standard paradigm is marred with many contradictions. Moreover, Post (2000) asserts that this ‘hypercognitive culture’ has neglected the other more holistic aspects of the person such as the emotional, relational, aesthetic and spiritual dimensions of well-being.

As a result, Kitwood (1997) proposed a reconceptualisation of dementia that acknowledges the importance of the ‘person’ with dementia and the psychosocial milieu that will directly influence the dementia process. Thus, Kitwood (1997) defines ‘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.” (p. 8).

This conceptualisation of ‘personhood’ was derived from a moral concern for others that is critical of Cartesian ‘body-mind’ dualism. Drawing from the philosophy of Buber and Rogerian psychotherapeutic approach, Kitwood (1990) argues that the dementia process depends not only on the extent of a person’s brain damage, but also on a complex interplay of other factors including

personality, biography, neurological impairment and social psychology. He also asserts that the dementia process is dialectical; that is, it is influenced by the interaction of neurological impairment and interpersonal processes (Kitwood, 1990).

This puts responsibility on society and on caregivers that contribute to the dementia process either positively through relationships that maintain 'personhood' (described as Positive Person Work, PPW), or negatively by processes that devalue the person. He referred to these as Malignant Social Psychology (MSP). When PPW is enhanced and MSP reduced, it is possible to fulfil the patient/resident's psychological needs for attachment, comfort, identity, occupation, inclusion and love (Kitwood, 1997).

A similar term to 'personhood', and at times used interchangeably, is 'selfhood'. During the past years the concept of self in dementia has been extensively debated. Caddell and Clare (2010) carried out a systematic review of studies that sought to evaluate whether self and identity is preserved during the course of the disease. After evaluating both qualitative and quantitative studies, the authors concluded that there is some evidence that the self is retained during all stages of dementia. Nevertheless, they acknowledge the fact that aspects of self and identity may deteriorate with disease progression.

The acceptance that 'selfhood' exists in persons with dementia is a paradigm shift from the previously held beliefs that dementia results in a 'loss of self' (Cohen, 1986). The interest in the experience of persons with dementia has been given more thought lately, with a number of salient qualitative studies that used different methodologies to identify selfhood in dementia.

For example, using a social constructionist model, Sabat and Harre (1994) and Sabat (2001) suggested that all three types of self, namely Self 1 (the self of personal identity), Self 2 (represented by the person's past and present beliefs and attributes) and Self 3 (the multiple personae) persist into the later stages of AD. Although there seems to be no evidence to the contrary, Cadell and Clare (2010) argued that these conclusions may be biased since the intention of the authors was to find evidence of the preservation of the self rather than its decline. Moreover, these studies are difficult to generalise and are significantly biased towards persons with dementia who are still able to communicate verbally.

Other qualitative studies using different perspectives, such as symbolic interactionism (Hubbard *et al.*, 2002), embodied selfhood (Kontos, 2004) and narrative identity (Mills, 1997) also reached similar conclusions.

Principles of Person-Centred Care (PCC)

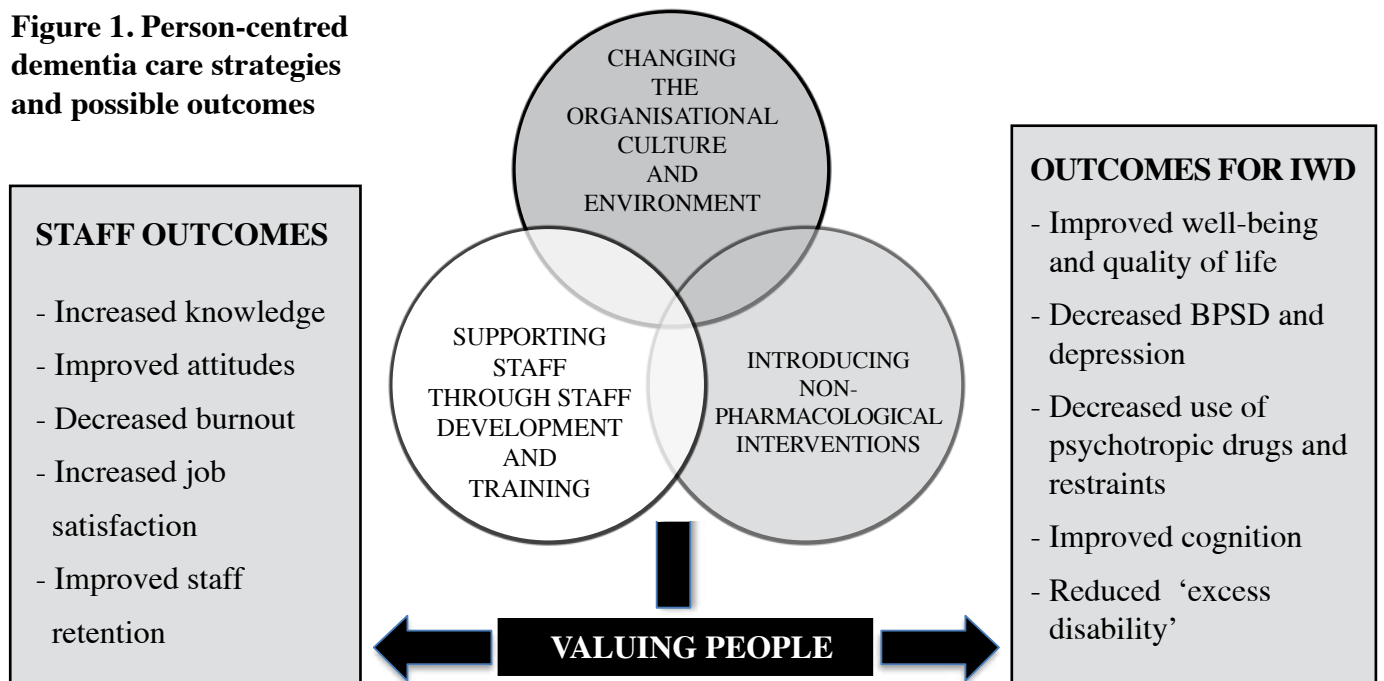
PCC is a recurring theme in the provision of high-quality dementia care (Brooker, 2004; Edvardsson, Winbald and Sandman, 2008). It has been referred to as the 'new culture of dementia that has put the living experience of the person with dementia into perspective (Kitwood and Benson, 1995).

Despite the frequent use of the term, there is no consensus or agreement on its definition or its components (Edvardsson, Winbald and Sandman, 2008; Brooker, 2008). Recently, Edvardsson *et al.* (2008) defined person-centred care (PCC) for people with severe AD as "supporting the rights, values and beliefs of the persons with dementia, involving them and providing unconditional positive regard, entering their world and assuming that there is meaning in all behaviour... maximising each person's potential and sharing decisions" (p. 363).

Moreover, a number of related but different conceptual frameworks and models have been developed during the past decade in order to understand what PCC means and how it could be implemented in clinical practice. Examples of these frameworks/models include the Patient-Centredness Framework (Mead and Bower, 2000), the Authentic Consciousness Framework (McCormack, 2001), the Person-centred Nursing Framework (McCormack 2006, 2010), the SENSES Framework (Nolan, 2004), the Need-Driven Dementia Compromised Behaviour Model (Algase *et al.*, 1996) and the VIPS Framework (Brooker, 2004, 2007).

Dewing (2004) suggests that these person-centred frameworks need further development and more evidence to show their usefulness in clinical practice. Moreover, the development of different frameworks could have further confused clinicians who seem reluctant to adapt them in clinical practice since they are not perceived as useful (Dewing, 2004). This has led to "tension, if not conflict, between how the practice could be and how it seems to be" (p. 43). Nevertheless, McCormack (2004) argued that staff, instead of trying to reach an 'ideal of person-

Figure 1. Person-centred dementia care strategies and possible outcomes



centredness’ need to strive for a constant state of ‘becoming more person-centred’ in their practice.

A different perspective to describe person-centred dementia care was sought by Edvardsson, Fetherstonhaugh and Nay (2010), who explored the content of PCC as experienced by various stakeholders. According to this study, persons with dementia and family caregivers characterise PCC when staff in residential care seek to promote a continuity of self and normality when they know the residents, welcome the family, provide a personalised environment and promote flexibility and continuity.

The theories of personhood and PCC, as proposed by Kitwood (1997) have dramatically contributed in developing an epistemology of dementia that is more humane and holistic as it includes the perspective of persons with dementia and the complexity of the experience. Nevertheless, his ideas have been criticised with regard to the methodology adopted in drawing his conclusions (Dewing, 2004) and the application of PCC principles in practice (Adams, 1996; Dewing, 2008). Similarly, the frameworks and models that have been developed during the past decade have not been tested empirically to indicate their effectiveness.

Dewing (2004) suggested that all these frameworks focus on two cardinal aspects, namely knowing the person and relationship-centred care. Moreover, there is a debate whether these frameworks need to be specific to a particular target group or

generalisable to different care settings and cultures. Nevertheless, others (Epp, 2003; Dewing, 2008) argued that Kitwood’s theories of PCC and the frameworks that have been subsequently developed need not necessarily be rejected but only refined. Additionally, recent evidence indicates that PCC strategies can positively influence persons with dementia and caregivers in formal care settings.

Applying person-centred care principles in formal care settings

Numerous strategies have been adopted to implement person-centred dementia care in formal care settings. These consisted of single or multi-component interventions utilising different qualitative and quantitative research designs. Person-centred dementia care strategies can be classified into three over-arching and inter-related approaches that complement each other; namely supporting staff through staff development/training, changing the organisational culture/care environment and introducing non-pharmacological interventions (Figure 1).

The ultimate aim of all these strategies is to value the person with dementia and the caring staff. Although these approaches can be used separately, studies have demonstrated that a combination provides a better and more sustained outcome than individual interventions. Furthermore, person-centred care studies have focused on different

outcomes, including staff outcomes, outcomes related to persons with dementia or both (Figure 1). The following section will appraise studies that used multi-component PCC interventions.

In a randomised, controlled, cross-over trial, the effectiveness of person-centred showering and towel baths on aggression, agitation and discomfort in residents with dementia during bathing was investigated (Sloane *et al.*, 2004). Three certified nursing aides, trained and supported by a clinical specialist, introduced the interventions over four weeks. Interventions were varied and individualised, focussing on the residents' comfort and preferences using a set of communication techniques appropriate for the level of disease severity, problem-solving approaches to identify causes and potential solutions, and changing the physical environment to maximise resident comfort.

Person-centred showering sought to individualise the experience for the resident by using a wide variety of techniques such as providing choices, covering with towels to maintain warmth, distracting attention (e.g. by providing food), using bathing products recommended by family and staff, using no-rinse soap, and modifying the shower spray.

Following the intervention period, agitation and aggression declined significantly in treatment as compared to control groups. Discomfort scores also declined significantly in both intervention groups, thus indicating that person-centred showering and the towel bath were effective in reducing agitation, aggression and discomfort when bathing residents with dementia.

Although this study provided one of the first attempts to evaluate the effectiveness of PCC interventions in practice, its focus on one specific caring task (bathing time) limited the applicability to other caring situations or settings. To overcome this limitation, Cohen-Mansfield *et al.* (2007) developed implemented and evaluated systematic algorithms that assisted residential staff to identify the most appropriate intervention during agitated behaviours of 167 nursing home residents with dementia.

The results suggested that the use of such algorithms reduced agitation and improved mood in residents with dementia. However, the short duration of the intervention time (10 days), the absence of any follow-up and the fact that both the assessment of the 'causes' of agitation and the interventions were

carried out solely by research assistants, could have limited the maintenance of the positive outcomes once the study was completed.

Such limitations were addressed by Fossey *et al.* (2006) by training and supporting nursing home staff so that they could be 'empowered' to introduce psycho-social interventions for residents with severe dementia. In a cluster randomised trial of 12 nursing homes in England (six cases and six controls), a ten-month training and support programme was introduced that focused on encouraging the staff to consider alternative interventions to the use of antipsychotics.

Training was delivered by a psychologist, an occupational therapist and a nurse and consisted of the principles of person-centred care and positive care planning, environmental redesign, the use of antecedent (A), behaviour (B) and consequence (C) model and the development of individualised interventions.

After 12 months, there was a significant decrease in the percentage of residents in the intervention group when compared to the control group even though the level of agitation or disruptive behaviour remained the same in both groups. The observed outcomes indicated that staff training and support are crucial elements in the introduction of person-centred care principles for identifying unmet needs in behavioural symptoms such as wandering, agitation, aggression, etc., thereby reducing antipsychotic use.

A possible explanation for the effectiveness of the training programme was that this managed to sensitise staff to the importance of considering alternatives to the use of drugs. The failure of the intervention programme in reducing the level of agitation and disruption can be attributed to difficulty of the research design in changing the organisational culture and, like the previous study, no follow-up was carried out so it was not possible to evaluate whether the benefits of the interventions were sustained after the trial was completed.

Another multi-component intervention that introduced person-centred dementia care is the Enriched Opportunities Programme (EOP) (Brooker *et al.*, 2007a, 2011). Conceived initially as a theoretical concept following an extensive literature review by an expert working group, this programme was implemented using an action research approach in three specialist nursing homes in the UK (Brooker

et al., 2007b). Eventually, it was further refined and evaluated in a clustered-randomised controlled trial (RCT) in 10 ‘extra care’ housing schemes (i.e. sheltered homes) (Brooker *et al.*, 2011).

This activity-based model is characterised by five inter-related elements, namely, the introduction of a new specialist role, individualised assessment and case work, an activity and occupation programme, staff training, management and leadership. In both the action research study and the RCT, there was a significant impact of the EOP in the residents’ level of well-being, depression and quality of life.

Similar to Cohen-Mansfield trial, the responsibility of implementing the interventions rested on agents that were not directly involved in providing the care. This may reduce the perceived ‘ownership’ by the staff on implementing person-centred dementia care strategies which in turn can affect long-term performance. Moreover, in both studies, the selected sites were already characterised by a good standard of care and adequate number of staff. Thus, the challenges and the impact of this programme in other settings that are not well staffed or where other priorities are present (such as in general nursing homes or hospital settings) needs to be further evaluated.

The Caring for Age Dementia Care Resident Study (CADRES) (Chenoweth *et al.*, 2009; Jeon *et al.*, 2011) was another clustered randomised trial, composed of 289 residents living in 15 Australian long-term care facilities who had dementia with BPSD. Sites were randomly assigned to PCC interventions, dementia care mapping (DCM) and usual care.

The PCC interventions consisted of “participating staff working together to identify the causes for resident behavioural disturbances by reconceptualising them as communication of unmet need, develop person-centred care plans aimed at reducing these behavioural disturbances in various ways, and provide care that was based on attempts to understand and acknowledge the residents’ feelings, thus requiring a sensitivity to the residents’ psychosocial responses to the care context.” (Jeon *et al.*, 2011, p.8).

In sites where DCM was introduced, the interactions of staff were mapped for 12 hours and feedback passed on to their colleagues. The primary outcome was agitation as measured by the Cohen-Mansfield Agitation Inventory (CMAI) and

measured across sites at baseline, after four months of intervention and after four months’ follow-up. In addition, staff outcomes (consisting of level of burnout, staff attitudes and reactions to behavioural disturbances) were measured over time across all participating sites. The study found that both PCC and DCM reduced agitation while DCM also decreased the level of staff burnout.

Although this study has provided further evidence on the importance of person-centred dementia care strategies, Ballard and Aarsland (2009) suggested that any intervention can result in non-specific benefits as compared to usual care. Moreover, the authors remarked that the intervention period was too short and the results failed to show evidence of the effectiveness on quality of life or on reducing other BPSD other than agitation. Nevertheless, unlike the RCTs by Cohen-Mansfield (2007) and Brooker (2011), the direct involvement of staff in implementing PCC strategies could have positively influenced staff outcomes, especially in decreasing burnout.

Although the CADRES study pointed out that PCC strategies significantly reduced BPSD episodes over time, it was unable to show that these interventions successfully improved the quality of life of dementia residents. Consequently, another multi-component RCT was designed with the aim of evaluating the effect of PCC interventions on the quality of life (QOL) of persons with dementia in 38 accredited Australian residential care homes (601 residents) and 378 full-time care staff (Chenoweth *et al.*, 2011).

In addition, the effect (including cost-effectiveness) of changing the dementia care environment and the combined outcome on the residents’ QOL was also investigated. Residents were randomised and compared between four intervention groups, namely Person-Centred Care (PCC), Person-Centred Care Environment (PCE), their joint effects (PCC+PCE), and the Usual Care and Environment (UC/UE). PCC interventions consisted of staff training and support while PCE intervention consisted of an environmental assessment and the implementation of these changes following negotiation with the care facility management.

Preliminary findings from this ongoing study indicate that PCC strategies significantly decreased BPSD and improved QOL over time. Additionally, PCE significantly reduced BPSD (especially agitation) and resident depression. There were no

significant changes in the control wards (i.e. UE/UC facilities) in BPSD, QOL and depression.

This study further shows the importance of PCC interventions, not only in reducing behavioural symptoms such as agitation, but also in improving the residents' quality of life. The authors suggested that a number of lessons could be learnt with regard to the process of implementing PCC strategies. Similar to what was found in other investigations (Jeon *et al.*, 2011), management and staff commitment is crucial for successful implementation of these interventions. These also need to be acceptable to all the stakeholders concerned, including persons with dementia and their family and appropriate to the cultural context in which they are introduced.

Conclusion: the way forward

There is increasing evidence that multi-component PCC strategies can positively contribute to reducing behavioural symptoms and improve the quality of life of individuals with dementia. Nevertheless, it is still unclear which component of PCC is effective or at

what stage and type of dementia these strategies become useful (Edvardsson, Winbald and Sandman, 2010).

Other confounding factors are not always considered, such as the effect of co-morbidities, consequences of medications and organisational issues such as type of staff available. Consequently, there is a need for further investigations that seek to measure the effectiveness of PCC interventions in residential homes. A Cochrane Review of Randomised Controlled Trials focusing on the effectiveness of psycho-social interventions in reducing anti-psychotic use in long-term wards is being currently prepared (Richter *et al.*, 2010). This will provide further evidence on how to deliver care in a more humane way to older persons with dementia residing in formal care settings.

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