Can We Improve Well-Being and Quality of Care for People with Dementia by Providing Person-Centred Nursing Care?

Background to the study:

With the increasing prevalence of dementia health care costs are predicted to double this decade. One of the issues faced by the health care system is how to maintain acceptable standards of care and quality of life for persons with dementia in a tight fiscal environment compounded by nursing staff shortages, inadequate dementia education for staff and increasing acuity levels in the person with dementia. Indeed, the unprecedented situation of a 200% increase of older Australians with dementia by 2024 will require major social changes in health care systems. The presence of behavioural and psychological symptoms of dementia (BPSD) is one of the main reasons why the majority of families will no longer be able to provide sufficient care in the community for persons with dementia. Consequently, an increased number of people with dementia with BPSDs are being cared for in residential aged care services.

While the causes of BPSDs are postulated to arise from multivariate causes, they contribute significantly to morbidity and mortality in the person with dementia and this impacts significantly on the health care system. The presence of severe BPSDs increases the likelihood for being physically restrained, sedated with antipsychotic medication and having emotional, and even physical needs neglected. The person displaying BPSDs may be subjected to objectification, disempowerment, and stigmatization, manifest by what Kitwood named as Malignant Social Psychology. The outcomes for the person can be serious and the use of restraint, in particular, is closely associated with falls and other injuries, resulting in increased rates of unplanned hospital admissions, surgery, loss of function and further cognitive decline.

These outcomes of care call into question the effectiveness of the aged care system for persons with dementia. As approximately 73 percent of public expenditures allocated to older Australians is for residential care, public accountability demands that care be of an acceptable if not good quality. Consequently, improving the quality of care and outcomes for aged care residents with dementia are important areas of Australian health research.

Some care delivery systems show promise in reducing BPSD and improving quality of life in dementia. Cohen-Mansfield describes how the core principle of flexibility implemented in care management strategies, within an enriched care environment, reduces the incidence and severity of BPSD in persons with dementia. One delivery system, Person-Centred Care (PCC), has many followers, for its humanity and efficacy in reducing BPSD. PCC presents a holistic alternative to the institutional ‘usual care’ (UC) still practiced by most aged care services. PCC proposes that the individual’s ‘personhood’ persists into dementia, that high care needs should not equate with dehumanisation and that flexible care can mitigate cognitive and functional deterioration.
Dementia Care Mapping (DCM) is a systematic observational methodology, to assist implementation of PCC in residential care. DCM requires expert training, is labour intensive and costly but, used correctly, provides an educational tool, identifying and reducing BPSD triggers.

Much of the evidence for the efficacy of PCC and DCM is observational with few randomised, controlled trials (RCT), and none incorporating economic evaluations. PCC and DCM have recently undergone the scrutiny of a randomised controlled trial in 15 residential dementia care sites in Sydney, Australia. This paper reports on the key resident findings and the cost-effectiveness of PCC and DCM, compared with UC. The findings relating to staff outcomes are not presented.

Research Design
The group randomized trial was conducted over one and a half years to compare the outcome of Person Centred Care (PCC), Dementia Care Mapping (DCM) which derives from PCC, and usual care (UC), in a single blind pre/post/five month follow-up design.

The Study aimed to investigate:
1. the benefits of Person Centred Care (PCC) over Dementia Care Management (DCM) and over usual care (UC) on: the residents’ behavioural disturbances and quality of life;
2. the use of psychotropic medication and physical restraints in managing behavioural disturbance, and quality of care; and
3. the cost of their care.

Research Setting:
15 similar dementia (high) care units were selected from nine research sites located in residential aged care services across the greater city of Sydney. Computer-assisted randomisation was employed by the statistician (King), who was blind to the identity of the sites, to allocate five of the 15 units each to the Dementia Care Mapping (DCM) treatment group, Person-Centred Care (PCC) treatment group, and to the Usual Care control group, according to a mixed experimental design approach that optimises the balance within the available units and sites.

The 15 care units were similar in the following respects: provided high-care residential service to persons with dementia (Categories 1-3 as determined by the Resident Classification Scale (RCS)); funded by the Commonwealth Government; held three year accreditation status granted in the previous 12 months by the Residential Care Accreditation Agency; had similar management structures, staffing ratios (1 nurse to 8-10 residents) and staff mix; serviced by General Practitioners (GPs) and other specialist health staff; and employed nursing care, therapy provision and recreation programs for residents.

Study Sample:
289 consented Aged care residents with a diagnosed dementia were included in the study. Eligibility criteria included: diagnosis of dementia, 60 years and above, classified as High Care (Categories 1-3) according to questions 8 to 17 on the Resident Classification Scale (RCS) (questions relating to cognition and behavioural disturbance), as assessed by the Aged Care Assessment Team (ACAT), or relevant nursing care staff.
Exclusion criteria included: serious co-morbidities which preclude the residents from engaging in normal daily activities and the social life of the care unit (such as cardiac or respiratory failure, end-stage illness, unremitting pain/distressing physical symptoms).

Research Instruments
1) Baseline measures (Covariates)
- **Demographics and Clinical Information** – age, gender, previous occupation, marital status, number of children, length of time in high care service, family and other visitors; past psychiatric and alcohol and drug history; diagnosis of dementia, date of diagnosis, other diagnoses/co-morbidities and prescribed dementia medications.
- **Functional Assessment Staging (FAST)** resident’s stage of dementia and associated functional abilities and changes in 7 major stages (total of 16 successive stages and substages). Reliability is demonstrated with intra-class correlations of above 0.85.
- **Global Deterioration Rating Scale** for Assessment of Primary Degenerative Dementia (GDS) – measures severity of dementia (range Stage 1 to 7); higher scores reflect more severe stages of dementia.

2) Resident Outcome Measures (pre/post/follow-up): were assessed longitudinally: at pre-intervention (pre-test), at the conclusion of the DCM and PCC interventions (post-test) and at three months later (follow-up).
- **Cohen-Mansfield Agitation Inventory (CMAI)-Long Form** assessing the frequency with which patients manifest up to 29 behaviours associated with agitation, as observed by care staff over the past week on a 7 point rating scale (1-never observed to 7-observed a few times in an hour). The tool evaluates unique aspects of behaviour and the effects of cognitive enhancers and other types of psychotropic drugs on behaviour. Higher scores indicate worse BPSD.
- **Neuropsychiatric Inventory for the Nursing Home (NPI-NH)** — measures frequency and severity of 12 domains of BPSD in previous seven days (range for each domain = 0 to 12, for total = 0 to 144). Higher scores indicate worse BPSD.
- **Quality of Life in Late Stage Dementia (QUAL-ID)** - measures 11 observable behaviours in affective states: discomfort, activity engagement and interactions with others in the previous 7 days. It is a five-point scale capturing the frequency of each item (range 11 to 55). Lower scores reflect a higher quality of life.
- **Resident Classification Scale (RCS)** Standard assessment employed in all residential aged care services to determine residents’ physical, social, emotional, cultural and spiritual abilities, their disabilities, level of care required to support these 22 aspects of functioning. RCS completed twice only (pre/post-intervention) on all participating residents to determine the forms and levels of care they require for the domains relating to cognition and behaviour (items 8-17). Residents with a high proportion of Cs, Ds & Es are rated as category of 1 or 2, and require a high level of care.

3) Care Delivery Outcomes
- **Quality of Interactions Schedule (QUIS)** Number and quality of interactions between residents with a dementia and care staff, during four 15 minute observation times each day over two days (8 hours per unit). Interactions are coded in one of five categories: positive social, positive care, neutral, negative protective, negative restrictive.
- **Resident Recreation Activities**: Descriptors, rates, length of time involved and satisfaction levels of residents in recreation and social activities.
- **Resident Incidents**: Nature, frequency, treatments and outcomes of incidences and injuries sustained by residents related to BPSD.
- **Physical restraint** Type, frequency and duration.
• **Hospitalisations:** Number of resident transfers to hospital, reasons, and duration of hospitalisation.
• **Dementia Medications:** Up to five dementia medicines administered in the past one month. Antipsychotic and benzodiazepine doses were converted into chlorpromazine (CPZ) and diazepam (DPZ) equivalents respectively.

**Cost of Care**

Cost of care for participating residents in relation to care activities and episodes were measured in terms of (a) their impact on the use of expensive resource types - such as staff time - or (b) because they are expected to occur at different rates between the three arms of the study, including staff training in DCM or Person-centred care education; care and management staff time spent implementing DCM or Person-Centred Care; Resident Incidents (including any flow-on direct costs of medical care due to incidents leading to injury, e.g. falls); resident hospitalisations attributed to dementia-related behaviour.

**Interventions:**

1) **Person-Centred Care (PCC)** education and training using Kitwood’s 4 PCC principles was provided to 2 care staff from each of the five PCC care units by one PCC-Trained CI (Stein-Parbury) over 4 full days. The PCC trained staff were then supported by the CI to identify residents who would benefit from PCC intervention and to develop selected resident care plans and care strategies from a PCC perspective over a two week period. PCC unit staff were then encouraged and assisted to continue supporting the implementation of person-centred care practices in the PCC sites by PCC trained staff till study completion.

2) **Dementia Care Mapping (DCM)** education and training was provided to 2 care staff from each of the five DCM sites for 4 full days by DCM accredited trainers. DCM was then conducted for all participating residents in the 5 DCM treatment units by two DCM trained CIs (Chenoweth & Jeon) and the two DCM trained staff from each of these 5 units. “Mapping” occurred continuously in 5 minute observation periods over eight hours during the waking day for two days per resident, in accordance with the specified rules outlined in the 7th edition of the DCM manual. The “mappers” calculated the Well-Ill-Being score for each resident and the number and type of positive and negative care events occurring for selected residents over the observation period. These data were fed back to participating staff within 24 hours, so that they could consider the identified relationship between care practices, staff-resident interactions and the residents’ expressions of well-being and ill-being. Staff were assisted by the “mappers” to develop residents’ care plans focusing on person-centred care and resident well-being. DCM trained staff were encouraged and assisted to continue supporting the implementation of person-centred care practices till study completion.

3) **Usual Care (UC)** continued uninterrupted at five control sites.

**Study Procedures**

Each of three Research Assistants was assigned to be responsible for each of the three intervention groups (5 sites per group) pre, post and follow-up. Prior to this the RAs were trained to implement all measures at an uninvolved dementia unit. The emphasis was given to ensure observational data were obtained consistently amongst the RAs. The outcomes of PCC, DCM and UC were assessed at the beginning and end of the three-month intervention period and again five months later.
Data Analysis:

The statistical significance of differences between the intervention groups in resident and site characteristics at baseline were tested with chi-square tests for categorical variables and Kruksal-Wallis test for continuous variables (all distributions were skewed). The study hypotheses were tested with general linear models all three time points were included as outcomes for the primary analysis. As a secondary analysis, the baseline outcome was included as a covariate for the remaining two time points. In both of these modelling approaches, main effects and an interaction term were estimated for intervention and time, and characteristics of site and residents that differed between the intervention groups at baseline (p<0.10) were included as covariates. Hierarchical linear models were estimated for the continuous outcome variables (CMAI, NPI, QALID), using SAS Proc Mixed and hierarchical logistic models were estimated for the dichotomised medication variables, using SAS Proc Glimmix.

Study Findings

Results from primary analysis of three of the resident outcome measures are presented in Table 1; there were no substantive differences between these models and the secondary analysis models.

Table 1. Sample size, participation and retention rates, and baseline characteristics for sites and residents in the three intervention groups: dementia care mapping (DCM), person-centred care (PCC), usual care (UC).

<table>
<thead>
<tr>
<th>Interventions</th>
<th>DCM</th>
<th>PCC</th>
<th>UC</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sites</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Number (#) of sites</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>0.86</td>
</tr>
<tr>
<td>Mean # beds/site (range)</td>
<td>52 (38-75)</td>
<td>47 (24-70)</td>
<td>53 (21-75)</td>
<td></td>
</tr>
<tr>
<td>Resident/staff ratio/site, mean (range)</td>
<td>0.73 (0.46-0.92)</td>
<td>0.92 (0.41-1.7)</td>
<td>0.86 (0.57-1.36)</td>
<td></td>
</tr>
<tr>
<td>Quality of Interactions (QUIS)²</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Positive Care</td>
<td>1.6</td>
<td>3.3</td>
<td>1.6</td>
<td>0.03</td>
</tr>
</tbody>
</table>
Resident Outcomes

For the primary outcome measure, agitation as measured by the CMAI, there was a significant group by time interaction. As Figure 2 shows, agitation increased in the UC sites during the study period and persisted at follow-up (p=0.03 for time trend within UC), while it decreased in the PCC group during the study period with a further drop at follow-up (p=0.01 for time trend within PCC). The slight reduction in agitation in DCM sites was not statistically significant.

Figure 2.  Resident agitation: Adjusted mean CMAI scores (with 95% confidence intervals) by intervention group at each time point, adjusted for covariates that differed at baseline

1. Higher CMAI scores reflect greater agitation. Means adjusted for: TESS safety score, QUIS positive social score, RCS total score, GDS score, country of birth and number of co-morbid diseases.

For the secondary measure of BSPD, neuropsychological distress as measured by the NPI (Table 2), there was a significant time effect, which was driven by the PCC sites, in which there was a significant time trend (p=0.04). Time trends in NPI in the other two intervention groups

1. Differences between groups at baseline were tested for with ANOVA for continuous variables (due to skewness in the Global Deterioration Scale, Kruskal Wallis was used) and chi-squared tests for categorical variables.
2. QUIS scores were measured for staff members; site-level averages were entered as covariates in the generalized linear models.
were not statistically significant. There were no statistically significant effects for quality of life (Table 2), resident incidents or medications, except that falls were less prevalent in DCM (p=0.02) and PCC (p=0.03) sites than in usual care sites.

Table 2. Resident mean (SE) scores for agitation\(^1\), neuropsychological status\(^2\) and quality of life\(^3\), by intervention group\(^4\) at each time point\(^5\), adjusted for covariates that differed at baseline\(^6\).

<table>
<thead>
<tr>
<th></th>
<th>Pre</th>
<th>Post</th>
<th>Follow-up</th>
<th>P values(^6,7)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Agitation (CMAI)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>DCM</td>
<td>46.1 (6.5)</td>
<td>45.1 (6.6)</td>
<td>43.7 (6.5)</td>
<td>P(Group) = 0.33</td>
</tr>
<tr>
<td>PCC</td>
<td>47.5 (9.1)</td>
<td>41.7 (9.2)</td>
<td>37.2 (9.1)</td>
<td>P(Time) = 0.47</td>
</tr>
<tr>
<td>UC</td>
<td>50.3 (6.8)</td>
<td>58.7 (6.9)</td>
<td>57.7 (6.8)</td>
<td>P(G x T) = 0.005</td>
</tr>
<tr>
<td><strong>Neuropsychological status (NPI)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>DCM</td>
<td>12.7 (5.1)</td>
<td>16.8 (5.1)</td>
<td>13.5 (5.1)</td>
<td>P(Group) = 0.68</td>
</tr>
<tr>
<td>PCC</td>
<td>21.3 (6.8)</td>
<td>14.5 (6.9)</td>
<td>12.6 (6.9)</td>
<td>P(Time) = 0.05</td>
</tr>
<tr>
<td>UC</td>
<td>16.9 (5.3)</td>
<td>20.2 (5.4)</td>
<td>15.3 (5.3)</td>
<td>P(G x T) = 0.30</td>
</tr>
<tr>
<td><strong>Quality of life (QUALID)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>DCM</td>
<td>23.5 (1.6)</td>
<td>23.4 (1.6)</td>
<td>24.5 (1.6)</td>
<td>P(Group) = 0.78</td>
</tr>
<tr>
<td>PCC</td>
<td>22.7 (2.2)</td>
<td>21.5 (2.2)</td>
<td>20.8 (2.2)</td>
<td>P(Time) = 0.80</td>
</tr>
<tr>
<td>UC</td>
<td>23.2 (1.7)</td>
<td>23.7 (1.7)</td>
<td>24.4 (1.7)</td>
<td>P(G x T) = 0.33</td>
</tr>
</tbody>
</table>

1. Higher CMAI scores reflect greater agitation.
2. Higher NPI scores reflect greater neuropsychological distress; means and SE from analysis of untransformed data; p values from analysis of square-root transformed data, significant covariates were GDS (p=0.01) and RCS (p=0.02).
3. Higher QUALID scores reflect better quality of life; significant covariates were GDS (p=0.006) and RCS (p=0.0003).
4. Dementia Care Mapping (DCM), patient centered care (PCC), usual care (UC).
5. Prior to intervention (Pre), immediately after X month intervention period (Post), X months after end of intervention period (Follow-up).
6. Six covariates differed at baseline: TESS environment safety score, QUIS positive social score, RCS total score, GDS score, country of birth and number of co-morbid diseases.
7. P values from hierarchical linear models with all three time points included as outcomes: P(Group) is for main effect of intervention, P(Time) is for main effect of time (over three time points) and P(GxT) is for the interaction between group and time.

While quality of Life as measured by the QUALID showed no statistically significant improvements in either PCC or DCM sites, residents in the DCM sites showed improved Well-Being Scores (WIB) at Post-test and Follow-up. There remained a significant overall time effect (F(2,85) = 19.78, p < 0.001), indicating that WIB scores changed significantly over time. However, the interaction between time and group was not significant (F(8,172) = 1.53, p = 0.150), meaning that the 5 DCM facilities did not differ significantly in how their WIB scores changed over time.

**Cost-Effectiveness**

There was no significant difference between the groups in terms of dementia medication costs per resident at either of the three time periods. QUIS-Positive Social scale, highest in PCC sites, was a significant co-variate (p=0.01) for falls. Falls at post-test and follow-up were less prevalent in DCM (p=0.02) and PCC (p=0.03) sites than in UC sites. There were no differences in resident hospitalisation rates and restraint use associated with BPSD across PCC, DCM and
The per-site cost of DCM was higher than that of PCC. Since PCC lead to a greater reduction from baseline in CMAI scores, PCC was the more cost-effective option of the two.

**Conclusions**

The PCC intervention was successful, with the decease in CMAI score reflecting significant reductions in agitation and anxiety, and improvements in the quality of participants’ sleep, eating and other activities. Nevertheless, the failure of PCC and DCM to improve resident quality of life, compared to Usual Care, suggests the QUAL-ID measure may have floor effects that do not register some subtleties. The significant improvement in DCM site well-being over time, as measured by the WIB scores, may support this conclusion. The outcomes data, combined with the cost data, confirm our postulation that PCC provides the benefits of DCM without the expense and time consuming implementation of DCM.

The superiority of the PCC intervention, compared with the DCM intervention, which derives from PCC, may be explained by the characteristically different intervention approached. For PCC sites the PCC –trained staff selected residents on the basis of BPSDs creating problems for care delivery. They directly applied PCC training, engaging in identification of issues for care planning and greater ownership of the processes. Whereas, while the DCM intervention followed the same PCC principles, this intervention was expert-driven, providing information and support to the trained DCM and site staff, but possibly with less ownership, which may have affected receptiveness of staff to change.

This is the first cluster-RCT of sufficient size to test Kitwood’s (1987) theory of personhood rigorously. Our results exceeded our expectation, with PCC providing greater benefit than DCM. Whilst changes in other resident outcomes were not significant overall, we consider Kitwood’s theory of ‘personhood’ supported.

**References**


