Can we improve well-being and quality of care for people with dementia by providing person-centred care?

13th National Health Outcomes Conference

Professor Lynn Chenoweth

Presentation Outline

A. Define the theoretical foundations of Person Centred Care (PCC)
B. Describe PCC in practice
C. Outline the PCC study aims, design, measures and procedures
D. Report the PCC study outcomes for residents with dementia
E. Report the PCC study outcome for care quality

Impact of dementia on the person

- Often the social and emotional losses that occur precipitate a health event
- Characterised by disconnectedness, self-perception, awareness and response
- May lead to disorientation, apprehension, distress, anxiety, depression, ambivalence, elation, withdrawal, perseveration
- These outcomes are often labelled Behavioural & Psychological Symptoms of Dementia (BPSD)
- Nursing home placement precipitated by distress symptoms such as agitation, wandering and passivity

What triggers BPSD?

- Neurological impairment
- Poor health and physical fitness
- Life history of unique experiences/situations and their impacts
- Personality
- Social psychology of the environment

(Loveday & Kitwood, 1998; Fleming, 1999)
Socio-psychological theory of personhood in dementia (Kitwood, 1989)

- Proposes that the distinctive psychosocial environment surrounding the person leads to reduction or destruction of the person as a whole
- Promoting personhood involves understanding feelings & actions, needs for belonging & attachment to others, identity, and achieving one’s potential
- If quality of care is not good at a psychological level most persons with dementia will move downwards into some stage of enduring ill-being

Personhood

Encompasses:
- Attachment- bonds with others in immediate environment as well as from the past
- Inclusion- group membership & acceptance
- Comfort-sense of security, warmth, strength
- Occupation- meaningful activity that utilizes and supports existing strengths
- Identity- continuity with the past, a story to tell

Impact of personhood

Nurses had tried unsuccessfully to get a male resident “Ted” to sit down to eat his meals, which was frustrating and time consuming.
Ted’s wife (Rose) visited one lunch time and observed the difficulty they were having.
She approached quietly and asked the nurse to sit down to the table.
As soon as the nurses sat down Ted then sat down and without hesitation and started his meal.
Rose explained that her husband had never, and would never, sit down to a meal before a woman sat down.
Rose explained the importance of this gesture in supporting her husband’s sense of propriety – one of the marks of his “personhood”.
Person-centred care identifies and respects the unique characteristics of each person’s way of being.

Person-Centred Care

Kitwood observed that Person-Centred Care supports well-being and reduces BPSD in persons with dementia.

Four core features comprise the potential for quality of life in the person with dementia:

1. maintaining personhood
2. maintaining physical & psychosocial well-being
3. opportunities for meaningful functioning
4. living in an enriched environment
A typical scenario in residential care?

- Mr Con Soulos has reluctantly been transferred to his new "office" accommodation and is having trouble settling in because the staff are all strangers to him and seem to be quite intrusive
- Con guards his "office", refusing staff entry
- Con attacks staff who try to provide personal care, especially the younger ones who he believes have no manners, are bossy and have no right to undress him
- The staff are so afraid of his anger and aggression they tend to avoid him and his care needs are being neglected
- Con is so debilitated by his need to remain vigilant against intruders he is losing weight and in a constant state of anxiety
- How can staff meet Con's care needs while supporting his well-being and right to self-determination?

Investigators

- Prof. Lynn Chenoweth, Health & Ageing Research Unit, UTS & SESIAHS
- Prof. Henry Brodaty, Dementia CRC, UNSW
- Dr Madeleine T. King, CHERE, UTS
- Dr Yun-Hee Jeon, Australian Primary Health Care Research Institute, ANU
- Prof. Jane Stein-Parbury, UTS & SESIAHS
- A/Prof. Marion Haas, CHERE, UTS
- Dr Richard Norman, CHERE, UTS

Partner Organisations

- SESIAHS, Uniting Care Ageing, Baptist Community Services, Benevolent Society, Little Company of Mary, Thomson Health, Pacific Heights NH, Sir Joseph Banks NH, Vaucluse NH, Peakhurst NH, The Palms NH, Hornsby-Kuring-gai Assoc
**Study:** Evaluate the efficacy of PCC and DCM, compared with UC, in improving outcomes for persons with dementia living in residential care

- Randomised controlled trial, two year pre/post-test/follow-up design, 5 Person Centred Care (PCC) treatment sites, 5 Dementia Care Mapping (DCM) treatment sites, 5 control sites (Usual Care, UC)

- **Aim:** to investigate the benefits of DCM over PCC and over UC for residents with dementia:
  1. reduced BPSDs, accidents, injuries, hospitalisations, dementia medicines,
  2. improved well-being/quality of life
  3. improved quality of care

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**Eligibility criteria**

1) *Aged care residents* (n=289)
   - Consented aged care residents with a diagnosis of dementia, 60 years and above, classified as High Care (Categories 1-3) based on RCS.
   - *Exclusion criteria:* serious co-morbidities which precluded the residents from engaging in normal daily activities and the social life of the care unit (such as end-stage illness, unremitting pain/distressing physical symptoms).

2) *Residential care staff and managers* (n=194)
   - Consented permanent direct care staff and managers at the 15 research sites who had been employees for at least 6 months.

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**Cluster-randomised study**

15 dementia care facilities

- 5 DCM
- 5 PCC
- 5 UC

**N=**

- 194 Staff
- 289 Residents

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**Instruments (Residents)**

- Participant demographics, clinical information
- Functional Assessment Staging (FAST) (Reisberg, 1988)
- Resident Classification Scale (Com. Dept Health & Family Services, 1997)
- Global Deterioration Scale in dementia (Reisberg 2000)
- Cohen-Mansfield Agitation Inventory (CMAI)-Long Form (Cohen-Mansfield & Billig 1986)
- Neuropsychiatric Inventory  (NPI-NH) (Cummings et.al. 1994)
- Quality of Life in Late-Stage Dementia (QUALID) (Myron et al 2000)

**Care quality:**

- Quality of Interactions Schedule (QUIS) (Dean, Proudfoot & Lindsey 1993)
- Recreation activity-type and frequency per week
- Dementia medication administration- frequency and dose
- Physical restraint type, frequency and length of time employed
**Cost of care**

- Training in DCM or Person-centred care education
- Care and management staff time spent implementing DCM or Person-centred care
- Psychiatric assessments or consultations (nb. if unrelated to outcome measurement for the research)
- Resident Incidents (including any flow-on direct costs of medical care due to incidents leading to injury, e.g. falls)
- Staff Incidents, Sick Leave, and staff turnover (e.g. recruitment costs, additional cost of locum care staff)
- Hospitalisations (only those due to psychiatric causes, or physical injuries attributed to dementia-related behaviour)

**Environment quality, safety**


**Statistical models**

Three assessment points:
- pre, post at 4 months (short-term), follow-up at 8 months (longer-term)

Random coefficient / multilevel models
- Chi-square tests – categorical variables at baseline
- Kruksal-Wallis test - continuous variables

Adjusted for covariates that differed at baseline
- Resident measures/level
  - Place of birth (Aust/not)
  - GDS – dementia severity scale Highly correlated \( r=0.70 \) with FAST
- Care quality measures
  - Quality of interactions scale (QUIS)
  - 2 scales sig diff @ baseline - positive care & positive social
- Site measures
  - Measure of environmental safety - TESS-NH

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**Intervention 1**

**Person Centred (PCC) in 5 randomly allocated sites**

- Prior to the PCC intervention JSP provided two day training to 2 staff per 5 PCC sites. Training was based on a training resource developed by Loveday & Kitwood (1998).
- PCC training was then provided to all participating staff in the five PCC care units for six hours over two weeks by the two PCC-trained staff from each of the PCC units, under the supervision of JSP.
- PCC unit staff were assisted to identify residents with BPSDs and develop residents’ care plans focusing on person centred care and resident well-being with continuing supervision by JS-P.
- Continued PCC for selected residents

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**Intervention 2**

**Dementia Care Mapping (DCM) in 5 randomly allocated sites**

- Dementia Care Mapping (Bradford Dementia Group, 1997) was conducted for all participating residents in 5 DCM treatment units by two DCM-trained staff from each of these units and LC & YJ.
- “Mapping” occurred continuously in 5 minute observation periods over 8 hours during the waking day for three days per resident, in accordance with the specified rules outlined in the seventh edition of the DCM manual.
- Dementia Care Mapping (DCM) Individual WIB scores were calculated for each resident and a group WIB score calculated for all residents from each DCM site
- The “mappers” fed back these findings to participating staff, to ensure they understood the identified relationship between care practices, staff-resident interactions and the residents’ expressions of well-being and ill-being.
- Staff were assisted to develop residents’ care plans which focus on person-centred care and resident well-being.
- Staff were supported by LC and YJ to continue person-centred care for residents
Table 1. Resident baseline characteristics

<table>
<thead>
<tr>
<th></th>
<th>DCM</th>
<th>PCC</th>
<th>UC</th>
<th>p value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age in years, mean (SD)</td>
<td>62.3 (7.3)</td>
<td>64.4 (6.4)</td>
<td>64.7 (6.6)</td>
<td>0.35</td>
</tr>
<tr>
<td>Gender, % female (n)</td>
<td>83.5 (16)</td>
<td>75.5 (17)</td>
<td>72.2 (18)</td>
<td>0.26</td>
</tr>
<tr>
<td>Born in Australia, % (n)</td>
<td>72.4 (48)</td>
<td>75.3 (54)</td>
<td>57.5 (46)</td>
<td>0.02</td>
</tr>
<tr>
<td>RCS Category 1, % (n)</td>
<td>22.9 (28)</td>
<td>51.0 (50)</td>
<td>20.7 (17)</td>
<td>&lt;0.0001</td>
</tr>
<tr>
<td>RCS Category 2, % (n)</td>
<td>63.3 (66)</td>
<td>43.9 (43)</td>
<td>61.0 (56)</td>
<td></td>
</tr>
<tr>
<td>RCS Category 3, % (n)</td>
<td>13.8 (13)</td>
<td>5.1 (5)</td>
<td>18.3 (15)</td>
<td></td>
</tr>
<tr>
<td>FAST</td>
<td>84.7 (46)</td>
<td>84.4 (67)</td>
<td>83.2 (76)</td>
<td>0.02</td>
</tr>
<tr>
<td>GDS</td>
<td>5.6 (1.3)</td>
<td>5.6 (1.3)</td>
<td>5.6 (1.1)</td>
<td>0.08</td>
</tr>
</tbody>
</table>

Table 2. Site-level covariates for resident outcome models

<table>
<thead>
<tr>
<th></th>
<th>DCM</th>
<th>PCC</th>
<th>UC</th>
<th>p value</th>
</tr>
</thead>
<tbody>
<tr>
<td>QUIS - NH</td>
<td>2 &gt; (1, 3)</td>
<td>4.4 (5)</td>
<td>0.72 (1.5)</td>
<td>0.327</td>
</tr>
<tr>
<td>Positive Care</td>
<td>2 &gt; (1, 3)</td>
<td>4.4 (5)</td>
<td>0.72 (1.5)</td>
<td>0.327</td>
</tr>
<tr>
<td>Positive Social</td>
<td>2 &gt; (1, 3)</td>
<td>4.4 (5)</td>
<td>0.72 (1.5)</td>
<td>0.327</td>
</tr>
<tr>
<td>Lighting</td>
<td>0.4 (1.2)</td>
<td>11.2 (11)</td>
<td>11.2 (11)</td>
<td>0.52</td>
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<tr>
<td>Comfort Safety</td>
<td>8.0 (6.2)</td>
<td>9.0 (6.2)</td>
<td>9.0 (6.2)</td>
<td>0.41</td>
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<tr>
<td>Cleanliness</td>
<td>10.0 (8)</td>
<td>9.6 (8.4)</td>
<td>9.6 (8.4)</td>
<td>0.48</td>
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<tr>
<td>Noise</td>
<td>10.0 (9.8)</td>
<td>10.2 (9.8)</td>
<td>10.2 (9.8)</td>
<td>0.53</td>
</tr>
<tr>
<td>Safety</td>
<td>0.0 (0.0)</td>
<td>0.0 (0.0)</td>
<td>0.0 (0.0)</td>
<td>0.028</td>
</tr>
</tbody>
</table>

Results - Residents

Figure 1: Effect of intervention on Agitation CMAI

Adjusted Model

Full scale range: 29-203
Obs range: 29 – 119

PCC Significant group by time interaction
F 2. Effect of intervention on BPSD NPI

- 12 domains: delusions, hallucinations, agitation/aggression, depression/dysphoria, anxiety, elation/euphoria, apathy/indifference, disinhibition, aberrant motor behavior, sleep, appetite & eating disorders

Adjusted Model

- Full scale range: 0-144
- Obs range: 29 – 102

P values

<table>
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<tr>
<th>Time</th>
<th>Value</th>
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<tbody>
<tr>
<td>PRE</td>
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</tr>
<tr>
<td>POST</td>
<td>16.1</td>
</tr>
<tr>
<td>FU</td>
<td>12.6</td>
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</table>

Time trend: PCC 0.015

SE ~ 4.5 (adj), CI +/- ~ 9

No significant group or time effects overall, but...

NPI – summary of 12 domains

Statistically significant effects for 3 domains in PCC group (p < 0.05)
- Appetite & eating disorders, disinhibitions, sleep

Borderline for 5 domains
- NS for Group, Time & Grp-by-Time, but p < 0.1 for time trends
- PCC improved over time
  - Delusions (p=0.04), anxiety (p=0.07), irritability/lability (p=0.09)
- DCM improved at POST, but declined again
  - Elation/euphoria (p=0.02)
- UC improved over time
  - Apathy/indifference (p=0.09)

Not stat sig for 4 domains:
- Hallucinations, agitation/aggression, depression/dysphoria, aberrant motor behaviour

F 3. Effect of intervention on quality of life

QUALID

13 items: smiles, sad, cries, facial signs of discomfort, physically uncomfortable, sounds of discontent, irritability/aggressiveness, enjoys eating, enjoys touching/being touched, enjoys interacting, emotionally calm

Adjusted Model

- Full scale range: 11-55
- Obs range: 15 – 35

P values

<table>
<thead>
<tr>
<th>Time</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>PRE</td>
<td>23.4</td>
</tr>
<tr>
<td>POST</td>
<td>23.0</td>
</tr>
<tr>
<td>FU</td>
<td>24.1</td>
</tr>
</tbody>
</table>

No stat sig treatment or time effects, or interaction

No stat sig time trends

SE ~ 1.5, CI +/- ~ 3

Note: GDS score is a significant covariate for QOL (p < 0.001)
**CARE QUALITY**

Figure 5: QUIS Positive Social ratings by group and time.  
(significant overall effect of group (p = 0.001) but not of time (p = 0.56), nor group by time interaction (p = 0.08).)

**DCM SITES only**

Fig. 10: POSITIVE EVENTS

There is a significant overall time effect (F(2,85) = 48.61, p < 0.001), indicating that the frequency of positive events changed significantly over time. The interaction between time and group was also significant (F(8,172) = 3.46, p = 0.002 or p < 0.005), meaning that the facilities differed significantly in how the frequency of positive events changed over time. On the graph, you can see that all facilities except SJB2 increased dramatically from pre to post intervention.

**DCM SITES only**

Fig. 11: NEGATIVE EVENTS

There was not a significant overall time effect (F(2,85) = 2.04, p = 0.137), indicating that the frequency of negative events did not change significantly over time. The interaction between time and group was not significant (F(8,172) = 1.55, p = 0.145), meaning that the facilities did not differ significantly in how the frequency of negative events changed over time.

[mention possible floor effect in discussion]
Resident incidences, accidents and hospitalisation related to BPSDs

- There were no differences in resident incidences across groups
- Rate of hospitalisation was minimal for all groups
- 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
- QUIS-Positive Social scale was a significant co-variate (p=0.01) for falls

CONCLUSION-outcomes of PCC

This research demonstrated statistically significant improvement in:
1. Incidence of some BPSDs, eg agitation, anxiety, sleep, eating, disinhibition
2. Incidence of resident falls
3. Enhanced well-being in DCM sites
4. Some aspects of care quality, ie. social conversation, positive communication in care events

There was no statistically significant improvement identified in:
1. Overall quality of life
2. Recreation activities
3. Severe forms of BPSD, eg hallucinations, violence
4. Dementia medication use
5. Physical restraint use
6. Hospitalisation rates

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Dr Georgina Luscombe