The CADRES study: Making a difference for the person with dementia through Person-Centred Care

Presenter
Lynn Chenoweth

Professor of Aged & Extended Care Nursing
UTS & SESIAHS
Presentation Outline

A. Impetus for the CADRES project

B. Principles and practices of Person Centred Care (Kitwood, 1997)

C. Implementation of the CADRES project and evaluation of project outcomes for residents with dementia

D. Lessons learned in researching PCC

E. Recommended Person-Centered dementia Care approaches
Acknowledgements

Funding:
Australian Health Ministers Priority Research Grant, administered by the NHMRC

In-Kind support:
UTS, UNSW, SESIAHS, 15 aged care services across Sydney, NSW

Research Team:
Lynn Chenoweth- and Jane Stein-Parbury-UTS/SESIAHS
Yun-Hee Jeon-ANU
Madeleine King-USyd
Henry Brodaty-UNSW/POWH
Marion Haas and Richard Norman -UTS-CHERE

Research Team Assistants:
Chanel Burke, Dr. Teri Merlyn, Gloria Holland

Statisticians:
Dr Georgina Luscombe, Dr Patsy Kenny
A. IMPETUS for the CADRES Project

- The presence of unmet-need behaviour in persons with dementia increases the likelihood of transfer to a residential care service when families are unable to provide the complex level of care required.

- Up to 80% of persons with dementia living in residential care present with:
  - Agitation
  - Aggression
  - Resistance to care
  - Significant social withdrawal
  - Presence of psychiatric symptoms (hallucinations & delusions)

Consequences of this change in accommodation and care delivery

- There is Insufficient funding for:
  - individualised care
  - skilled, dementia trained staff
  - ready access to specialist dementia services, eg. psychogeriatricians, geriatricians, physio and occupational therapists.

- Reliance on task-oriented care when staff numbers are low, and regular staff are replaced by agency

- Staff’s knowledge of how to prevent or reduce unmet need behaviour in dementia is generally lacking

- Staff are often unable to care for residents with unmet-needs behaviour without use of physical and chemical restraint

- Outcomes for residents with unmet-need behaviours include distress, injuries, falls, hospitalisation, and reduction in function, cognition and well-being

- Staff burden and stress occur, with high staff turnover
The authors conducted a series of studies to investigate the effectiveness of different models of dementia care, including Person-Centred Care and Dementia Care Mapping, aimed at improving quality of care and quality of life in persons with dementia.

What we found:
The most common ways of managing behaviours in residents with dementia were attempts to DISTRRACT them.

There was little evidence that staff attempted to ENGAGE with residents’ feelings and needs.

Staff did not believe that their care practices contributed to either resident well-being, or to resident distress and unmet-need behaviours.
Person-Centred Care principles

Based on the Psychosocial theory of Personhood in Dementia
(Ref: Kitwood, 1997, p.8)

**Personhood** is the standing or status that is bestowed upon one human being by others in the context of relationships and social being

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
How does Person-Centred Care improve the well-being of persons with dementia?

- Person-Centred Care upholds personhood to foster well-being

- The distinctive psychosocial environment surrounding the person can either support or reduce personhood

- Promoting personhood through PCC involves understanding feelings & actions, needs for belonging & attachment to others, personal identity, and achieving one’s potential
What is Dementia Care Mapping?

• Documenting observations of residents going about their daily life over three days:
  Articulation, Borderline, Cool, Distress, Expression, Food, Games, Handicraft, Intellectual, Joints, Kum and go, Labour, Media, Nod, Own care, Physical care, Religion, Sex, Timalation, Unresponded to, Withstanding, X-cretion, Yourself, Zero option

• Rating levels of Well-being and ill-being (WIB score): +5, +3, +1, -1, -3, -5

• Feeding back observations and WIB ratings to all staff for each resident observed

• Working with staff to develop PCC approaches for each resident and monitor care improvements
• Both Dementia Care Mapping and Person-Centred Care improved resident well-being and reduced ill-being and incidence and severity of unmet need behaviours

• PCC will occur when there is
  1. Strong management support
  2. Inspiring leadership
  3. Staff are open to new ideas
  4. Staff self-identify a need to improve care and communication with residents with dementia
  5. Staff are provided with education about what PCC means in practice
  6. Staff have respected role models

Previous positive study findings for PCC
The problem: Was it the DCM process or the PCC approach that led to these positive findings?

The study team decided that we needed to investigate this by comparing DCM and PCC and Usual Care through:

- recruiting a larger sample size
- greater preparation of staff in both DCM and PCC
- targeted selection of residents with unmet-need behaviours
- employing the most robust measurements
- using a pre/post/follow-up design
- keeping data collectors blind to the interventions
- ensuring strongly collaborative effort
- structured times for resident/staff observations (feeding time, recreation time and early evening)
- undertake a cost analysis of both interventions
CADRES Study design, implementation and evaluation

- 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)

- Investigated the benefits of DCM over PCC and over UC for residents with dementia:
  1. reduced behaviours, accidents, injuries, hospitalisations, dementia medicines
  2. improved well-being/quality of life
  3. improved quality of care
  4. cost effectiveness of interventions
Study sample

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.
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)
- Accidents & injuries & hospital admissions related to BPSDs
- WIB scores, PE and PD scores for DCM sites

Care quality:
- Quality of Interactions Schedule (QUIS) (Dean, Proudfoot & Lindesay 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

Person Centred Care (PCC) Intervention in 5 randomly allocated sites

- JSP provided two day training to 2 staff per 5 PCC sites, based on a training resource developed by Loveday & Kitwood (1998).

- PCC training then provided to all staff in the 5 PCC care units for six hours over two weeks by the two PCC-trained staff from each of the PCC units, supervised by JSP.

- PCC unit staff were assisted to identify residents with unmet-need behaviours and develop residents’ care plans focusing on PCC and resident well-being, supervised by JS-P.

- Staff continued PCC for selected residents for 4 months

“Improving Dementia Care: A Resource for Training and Professional Development. (1998).”
Loveday, B., Bowe, B. and Kitwood, T.
Dementia Care Mapping (DCM) Intervention in 5 randomly allocated sites

- DCM (Bradford Dementia Group, 1997) conducted for participating residents in 5 DCM treatment units by two DCM trained staff from each of these units and by LC & Y-HJ.

- “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.

- DCM 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 by LC, Y-HJ and DCM-trained staff to develop residents’ PCC plans.

- Staff were supported by LC and YJ to continue person-centred care for all residents.
How was Person-Centred Care implemented by care staff?
1. Attending to the person’s feelings, experiences and perceptions of their own reality
2. Attending to the resident’s emotional, social, physical and spiritual needs and establishing positive relationships
3. Assisting and encouraging the resident to maintain function and engage in meaningful life experiences
4. Creating an enriched environment

- make safe & secure
- make simple & domestic (familiar)
- provide good visual access to caregivers
- reduce levels of unwanted stimulation (noise, light, breeze, clutter, people)
- enhanced levels of wanted stimulation (affection, touch, tactile objects, enjoyable music)
- allow wandering & exploring with interesting signposts
- Provide opportunity for privacy & personal interaction
- Encourage links to the community
5. Avoiding triggers for distress

1. Setting realistic goals
2. Learning to use Active Listening
3. Allowing & encouraging choices
4. Using praise, compliments and acknowledgement
5. Avoiding own negative behaviours
6. Avoiding negative reactions
7. Avoiding distressing situations
Analysis of PERCEN study findings

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
Effect of PCC on Agitation CMAI
29 symptoms/signs of agitation

Adjusted Model

CMAI
higher is worse

<table>
<thead>
<tr>
<th></th>
<th>PRE</th>
<th>POST</th>
<th>FU</th>
</tr>
</thead>
<tbody>
<tr>
<td>DCM</td>
<td>49.9</td>
<td>47.9</td>
<td>46.5</td>
</tr>
<tr>
<td>PCC</td>
<td>49.5</td>
<td>43</td>
<td>38.6</td>
</tr>
<tr>
<td>UC</td>
<td>47</td>
<td>55.5</td>
<td>54.5</td>
</tr>
</tbody>
</table>

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

P values
Tm’t x tm 0.0013
Time trends
PCC 0.0037
DCM 0.026

SE (means) ~ 5.2, CI +/- ~10

PCC Significant group by time interaction
Effect of PCC on psychiatric symptoms

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

Adjusted Model

<table>
<thead>
<tr>
<th></th>
<th>PRE</th>
<th>POST</th>
<th>FU</th>
</tr>
</thead>
<tbody>
<tr>
<td>DCM</td>
<td>13.1</td>
<td>16.1</td>
<td>12.6</td>
</tr>
<tr>
<td>PCC</td>
<td>25.5</td>
<td>17.3</td>
<td>15.4</td>
</tr>
<tr>
<td>UC</td>
<td>17</td>
<td>19.7</td>
<td>15</td>
</tr>
</tbody>
</table>

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

P values
(Time 0.12)
(Tm’t x time 0.14)
Time trend
PCC 0.015

No significant group or time effects overall, but...
Psychiatric symptoms—summary of 12 domains

Statistically significant effects for 3 domains in PCC group (0.015)
- Appetite & eating disorders, disinhibitions, sleep

Borderline significance 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 statistically significant for 4 domains:
- hallucinations, agitation/aggression, depression/dysphoria, aberrant motor behaviour
Effect of PCC on quality of life

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

Adjusted Model

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),
Effect of DCM on Well-being

Significant overall time effect (F(2,85) = 19.78, p < 0.001), WIB scores changed significantly over time. Interaction between time and group was not significant (F(8,172) = 1.53, p = 0.150), facilities did not differ significantly in how their WIB scores changed over time.

Descriptive Statistics

<table>
<thead>
<tr>
<th></th>
<th>N</th>
<th>Minimum</th>
<th>Maximum</th>
<th>Mean</th>
<th>Std. Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>WIB.1: INDIV</td>
<td>91</td>
<td>.056</td>
<td>2.778</td>
<td>.06592</td>
<td>.479459</td>
</tr>
<tr>
<td>WIB SCORE</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>WIB.2: INDIV</td>
<td>91</td>
<td>-.444</td>
<td>2.944</td>
<td>.22027</td>
<td>.467774</td>
</tr>
<tr>
<td>WIB SCORE</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>WIB.3: INDIV</td>
<td>91</td>
<td>.111</td>
<td>2.611</td>
<td>.47924</td>
<td>.537637</td>
</tr>
<tr>
<td>WIB SCORE</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Valid N (listw)</td>
<td>91</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

a.timepoints = 3
CARE QUALITY

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).
QUIS Positive Care ratings by group and time

(significant contrast only between pre and post-test for UC group)
DCM SITES-POSITIVE EVENTS

Significant overall time effect (F(2,85) = 48.61, p < 0.001), frequency of positive events changed significantly over time. Interaction between time and group was significant (F(8,172) = 2.98, p = 0.004 or p < 0.005), Facilities differed significantly in how the frequency of positive events changed over time.
DCM SITES - NEGATIVE EVENTS

No significant overall time effect ($F(2,85) = 2.04, p = 0.137$), Frequency of negative events did not change significantly over time. Interaction between time and group was not significant ($F(8,172) = 1.55, p = 0.145$), Facilities did not differ significantly in how the frequency of negative events changed over time. Possible floor effects of the DCM measurement?
Medications – ‘raw’ % usage
regardless of duration or regularity?
no adjustment for clustering

Anti-depressants

Anti-psychotics

Anxyol

Other

PRE  POST  FU
Resident incidences, accidents and hospitalisation related to behaviour

- 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
Major outcomes of PCC

Statistically significant improvements in:
1. Incidence and severity of agitation, anxiety, sleep, eating problems and disinhibition
2. Incidence of falls
3. Well-being in DCM sites
4. Aspects of care quality, ie. social conversation, positive communication in care events

No statistically significant improvement in
1. Overall quality of life
2. Recreation activity opportunities
3. Psychiatric symptoms, eg hallucinations, severe violence
4. Dementia medication use
5. Physical restraint use
6. Hospitalisation rates
How can staff employ PCC principles in practical ways for residents in a state of ill-being?

Case Study- aggressive behaviour to staff and others

- Con Soulos has reluctantly been transferred to his new “office” accommodation and is having trouble settling in because the staff are strangers and intrude on his space
- **Con guards his office, refusing staff entry**
- Con attacks staff who try to provide personal care, especially the younger ones whom he believes have no manners, are bossy and exert their right to undress, bathe and toilet 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 these staff he is losing weight, looks disheveled, and is in a constant state of anxiety

**Question**: How can staff meet Con’s care needs, support his well-being and respect his rights?
Approaches which helped to reduce Con’s anger, aggression and anxiety

1. Greeting Con by his title and last name at all times
2. Explaining who staff were and their roles in “Con’s workplace”
3. Requesting Con’s permission to enter his corridor “workplace” and room-“office”
4. Supporting Con’s belief that he was the manager of the “workplace’ and therefore, having the right to demand staff respect and be instructed by him
5. Requesting Con receive care in order to be clean and well groomed for his wife’s visit and “business meetings”
6. Encouraging Con to choose the time care occurred and how this would happen, usually with his wife’s supervision and sometimes her support
7. Encouraging Con to assist with his own care as much as possible, and allowing him to guide how this occurred
8. Encouraging Con and his wife to meet with other residents and families at pleasant events, so he had others to communicate with
9. Providing opportunities for Con to engage in activities that he enjoyed and could master, such as wiping the window sills and table tops, arranging decorative objects, singing along to the pianola and joining other men to hold “business meetings”
Case study - refusing to cooperate

Nurses had tried unsuccessfully to get Ted Smith to sit down to eat his meals, which was frustrating and time consuming for staff, and distressing for Ted. No matter what staff tried Ted would not eat his meals unless given to him in his bedroom, thereby he was missing out on this social opportunity.

This dilemma was resolved by supporting Ted’s personhood

Ted’s wife Rose arrived one lunchtime when Ted was refusing to sit down to eat

Rose approached quietly and asked the nurse to sit down at the table

As soon as the nurse sat down Ted then sat down and without hesitation happily 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”
Case study- The person who is constantly upset

Olive Beach cries frequently, is negative about most things and refuses to communicate with other residents. Both staff and residents shy away from her. Staff are unable to cheer her up despite many attempts to draw her into activity and friendship groups.

Helping Olive to enjoy her life through PCC

The nurse manager sat with Olive and acknowledged Olive’s feelings of sadness and asked if there was anything she would like to do that she enjoyed. Olive explained why she felt upset most of the time and stated she would like to get her poetry bound. The AINs and DT helped Olive to create an attractive folder of her poetry using plastic sleeves, transfers and cut outs from birthday cards. Olive enjoyed showing other residents and visitors her prized poetry folder, started to join some group activity and made one friend who also enjoyed poetry.
CONCLUSION

Research demonstrates the value of Person-Centred Care in reducing unmet need behaviours and enhancing the well-being of persons with dementia.

There are particular benefits including:

- retaining or improving a sense of self (personhood)
- Increasing staff’s capacity to care
- forming attachments
- improving physical and psycho-social functioning