Measuring quality and person centred dementia care – insights from three cluster randomised trial

Associate Professor Yun-Hee Jeon, RN, PhD
Since 2003...

- “Rural-urban nursing partnership in dementia care”
- “Effective management of challenging behaviours in aged care residents with a cognitive impairment through a nursing care model” (DCM study)
- “Evaluating the efficacy of DCM, compared with PCC, in improving quality of life, well-being and quality of care in persons with dementia: a randomised-controlled study” (CADRE Study)
- “Person-centred environment and care for residents with dementia (PerCEN Study)”
- “ACFI-instructed DEmentia Learning and Information Trial Initiative (ACFIiDeLITI)”
- “Optimising leadership and management skills of the residential and community aged care workforce (CLiAC study)”
Tom Kitwood (1992) *Towards a theory of personhood in dementia care*
Person Centred Care

Person Centredness

• Much of the ill-being experienced by people with dementia is due to the attitudes and care practices by which they are surrounded

• Assumes that despite the losses experienced by people with dementia they are still left with a great capacity to enjoy life

• **Symptoms of dementia are the cumulative result of NI, PH, P, PH, P&SE, SE**


Key Principles of PCC
(Bradford Dementia Group 1997; Kitwood 1997, p.82)

• Uniqueness of each person
• Respect for the past
• See the whole person
• Focus on the positives – on abilities
• Stay in communication
• Nourish attachment
• Create a sense of community
• Maximise freedom – minimise controls
• Don’t just give, receive as well
• Maintain an environment of trust

Kitwood 1997, p.82
Determining the efficacy of Dementia Care Mapping as an outcome measure and a process for change: A pilot study

LYNN CHENOWETH¹,² & YUN-HEE JEON¹,²

¹University of Technology Sydney and ²Health & Ageing Research Unit, South Eastern Sydney and Illawarra Area Health Service
## DCM Study Results

### Table II. Mean scores for DCM and other outcome measures.

<table>
<thead>
<tr>
<th>Outcome measures</th>
<th>Pre</th>
<th>Post</th>
<th>Changes of Meana (SD)</th>
<th>t</th>
<th>Sig (2 tailed)b</th>
<th>Power</th>
</tr>
</thead>
<tbody>
<tr>
<td>DCM WIB Scores</td>
<td>0.88 (0.83)</td>
<td>0.86 (0.81)</td>
<td>0.03 (0.65)</td>
<td>0.234</td>
<td>0.82</td>
<td>0.06</td>
</tr>
<tr>
<td>CMAI</td>
<td>71.77 (23.42)</td>
<td>59.83 (19.19)</td>
<td>11.94 (23.00)</td>
<td>3.017</td>
<td>0.00*</td>
<td>0.85</td>
</tr>
<tr>
<td>RMBPC (Depression)</td>
<td>13.22 (6.13)</td>
<td>12.93 (7.29)</td>
<td>0.28 (7.11)</td>
<td>0.2354</td>
<td>0.82</td>
<td>0.06</td>
</tr>
<tr>
<td>RMBPC (Disruption)</td>
<td>14.83 (7.88)</td>
<td>12.18 (7.47)</td>
<td>2.65 (8.14)</td>
<td>1.927</td>
<td>0.06</td>
<td>0.47</td>
</tr>
<tr>
<td>QOL</td>
<td>23.65 (4.82)</td>
<td>22.71 (5.17)</td>
<td>0.94 (5.82)</td>
<td>0.944</td>
<td>0.35</td>
<td>0.15</td>
</tr>
</tbody>
</table>

### Table III. Proportion of observations of the quality of interactions between residents and staff (QUIS) pre and post intervention.

<table>
<thead>
<tr>
<th>QUIS</th>
<th>Pre (n = 504)</th>
<th>Post (n = 560)</th>
<th>Continuity correction</th>
<th>df</th>
<th>Sig.* (p)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Positive Care</td>
<td>41.9% (n = 211)</td>
<td>50.7% (n = 284)</td>
<td>8.00</td>
<td>1</td>
<td>0.005*</td>
</tr>
<tr>
<td>Positive Social</td>
<td>31.0% (n = 156)</td>
<td>42.0% (n = 235)</td>
<td>13.37</td>
<td>1</td>
<td>&lt;0.001*</td>
</tr>
<tr>
<td>Neutral</td>
<td>18.1% (n = 91)</td>
<td>5.4% (n = 30)</td>
<td>41.19</td>
<td>1</td>
<td>&lt;0.001*</td>
</tr>
<tr>
<td>Negative Protective</td>
<td>3.4% (n = 17)</td>
<td>1.4% (n = 8)</td>
<td>3.57</td>
<td>1</td>
<td>0.059</td>
</tr>
<tr>
<td>Negative Restrictive</td>
<td>5.8% (n = 29)</td>
<td>0.5% (n = 3)</td>
<td>23.01</td>
<td>1</td>
<td>&lt;0.001*</td>
</tr>
</tbody>
</table>

*Significant at p < 0.05.
Two year pre/post-test/follow-up design, 5 Dementia Care Mapping (DCM) treatment sites, 5 Person Centred Care (PCC) treatment sites and 5 control sites (Usual Care, UC)
Evaluating the effectiveness of DCM, compared with PCC, in improving quality of life, well-being and quality of care in persons with dementia

- Two year pre/post-test/follow-up design, 5 Dementia Care Mapping (DCM) treatment sites, 5 Person Centred Care (PCC) treatment sites and 5 control sites (Usual Care, UC)
- Aim is to investigate the benefits of DCM over PCC and over usual UC on: well-being of aged care residents with dementia; quality of care they receive; and staff’s stress, job satisfaction and turnover rates
Methods: cluster-randomised trial

Residential Care Facilities

15 Sites

DCM

#2  N=19
#4  N=19
#8  N=18
#9  N=13
#12 N=10
#5  N=10
#6  N=12
#7  N=18
#13 N=19
#14 N=9

PCC

#1  N=5
#3  N=13
#10 N=10
#11 N=5
#15 N=14

UC

#1  N=24
#3  N=22
#10 N=21
#11 N=17
#15 N=25

194 Staff

289 Residents
RCT Results: Resident Agitation

Adjusted mean CMAI scores (with 95% CI) by intervention group, adjusted for covariates that differed at baseline.

Higher CMAI scores reflect greater agitation.

Means adjusted for: TESS-NH safety score, QUIS positive social score, RCS total score, GDS score, country of birth and number of co-morbid diseases.

Figure 2: Agitation adjusted for covariates that differed at baseline. Adjusted mean CMAI scores (95% CI) by intervention group.
## Costs of PCC and DCM

<table>
<thead>
<tr>
<th></th>
<th>CMAI change post-intervention and (follow-up)</th>
<th>Average number of residents per site</th>
<th>Total CMAI reduction for site post-intervention and (follow-up) vs. UC</th>
<th>Incremental cost of intervention (vs. UC) per site</th>
<th>Cost per CMAI point averted vs. UC at post and (follow-up)</th>
</tr>
</thead>
<tbody>
<tr>
<td>UC</td>
<td>+8.4(+7.4)</td>
<td>16.4</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>PCC</td>
<td>-5.8(-10.3)</td>
<td>19.8</td>
<td>281(350)</td>
<td>2,250</td>
<td>$8.01 ($6.43)</td>
</tr>
<tr>
<td>DCM</td>
<td>-1.0(-2.4)</td>
<td>21.8</td>
<td>205(214)</td>
<td>10,034</td>
<td>$48.95 ($46.89)</td>
</tr>
</tbody>
</table>
Staff outcomes from the Caring for Aged Dementia Care REsident Study (CADRES): A cluster randomised trial

Yun-Hee Jeon\textsuperscript{a,}\textsuperscript{*}, Georgina Luscombe\textsuperscript{b}, Lynn Chenoweth\textsuperscript{c,d}, Jane Stein-Parbury\textsuperscript{c,d}, Henry Brodaty\textsuperscript{e,f}, Madeleine King\textsuperscript{g}, Marion Haas\textsuperscript{h}

\textsuperscript{a} Sydney Nursing School, The University of Sydney, Camperdown, NSW, Australia
\textsuperscript{b} Sydney Medical School, The University of Sydney, Camperdown, NSW, Australia
\textsuperscript{c} University of Technology Sydney, Sydney, Australia
\textsuperscript{d} South Eastern Sydney Local Health District, NSW, Australia
\textsuperscript{e} Dementia Collaborative Research Centre, School of Psychiatry, University of New South Wales, Sydney, Australia
\textsuperscript{f} Academic Department for Old Age Psychiatry, Prince of Wales Hospital, Randwick, NSW, Australia
\textsuperscript{g} Psycho-oncology Co-operative Research Group School of Psychology, The University of Sydney, Sydney, Australia
\textsuperscript{h} Centre for Health Economics Research and Evaluation, University of Technology Sydney, Sydney, Australia
Results: The Maslach Burnout Inventory-Human Services Survey results showed that change over time in emotional exhaustion scores differed between the three groups. Post-hoc analyses for each group separately revealed that the only significant time effect was in the dementia care mapping group ($p = 0.006$), with emotional exhaustion scores declining over time. At baseline, more perceived support from management was associated with less emotional exhaustion ($r_s = 0.26, p = 0.004, n = 122$) and less depersonalisation ($r_s = 0.21, p = 0.023, n = 122$), but not for any of the other outcome measures.
Person-centred Environment & Care for Residents with Dementia (PerCEN Study)
NHMRC Project Grant 2008-11

Study Protocol of a Randomised Controlled Group Trial of Client and Care Outcomes in the Residential Dementia Care Setting

Lynn Chenoweth, RN, Cert Burns/Plastic Surg, Dip Leis, BA, MA(Hons), M Ad Ed, GD Tch/Lrn, PhD, Madeleine King, BSc, Dip Stats, Grad Dip Med Stats, PhD, Georgina Luscombe, BPsys(Hons), PhD, Ian Forbes, BArch, MSc, GradDipBus, Yun-Hee Jeon, RN, DN, BHScN, MN, PhD, Jane Stein-Parbury, RN, BSN, MEd, PhD, FRCNA, Henry Brodaty, AO, MB BS, MD, DSc, FRACP, FRANZCP, Richard Fleming, BTech(Hons), DCLPsy. Marion Haas, BPhy(Qld), MPH, PhD(Syd)
The effects of Person-Centred Care (PCC), Person Centred Environment Design (PCD) and the combined effect of PCC and PCD

Interventions

PCC Intervention: 5 staff attending five day off-site training workshops. The PCC on-site facilitator continues to facilitate the implementation of PCC interventions

PCE Intervention: based on a thorough environmental assessment of each site, making recommended environment changes required in each dementia care unit.
Challenges in RCTs

• Access to sites and people
• Blinding
• Fidelity and adherence
• Managing the data and the team
• Choice of measures/instruments – outcome measures and standardised tools
Lessons Learned in Research

- Good relationship with partners is the key – ownership, communication and agreement, on-going monitoring
- Preparation, flexibility and adaptation
- Acknowledging different priorities
- Control (in RCT) is almost impossible!
- Plan for additional costs and time!
- No magic portion or one size fits all!
- Good pilot study makes a difference
Three components of residential care subsidy are determined by the ACFI.

These are:

- **Activities of Daily Living** (ratings on Nutrition, Mobility, Personal Hygiene, Toileting and Continence questions are utilised to determine the level of the basic subsidy)

- **Behaviour Supplement** (ratings on Cognitive Skills, Wandering, Verbal Behaviour, Physical Behaviour and Depression questions are utilised to determine the behaviour supplement)

- **Complex Health Care Supplement** (ratings on Medication and Complex Health Care Procedure questions are utilised to determine the complex health care supplement).
Care planning practices for behavioural and psychological symptoms of dementia in residential aged care: A pilot of an education toolkit informed by the Aged Care Funding Instrument

Yun-Hee Jeon*, Janelle Govett*, Lee-Fay Low†, Lynn Chenoweth†, Georgene McNeill‡, Anne Hoolahan**, Henry Brodaty† and Daniel O’Connor††
*Sydney Nursing School, University of Sydney, Sydney, NSW, Australia; †Dementia Collaborative Research Centre, School of Psychiatry, University of New South Wales, Sydney, NSW, Australia; ‡Faculty of Nursing and Midwifery and Health, University of Technology Sydney, Ultimo, NSW, Australia; †Alzheimer’s Australia, Ryde, NSW, Australia; **Northern Sydney Home Nursing Service, Northern Sydney Local Health District, Sydney, NSW, Australia; ††Monash Ageing Research Centre, Monash University, Melbourne, VIC, Australia

ABSTRACT: Aim: To assess the feasibility and the effects of a multi-component education toolkit that used the Aged Care Funding Instrument behaviour (ACFI-BEH) scores to trigger care planning for older people experiencing behavioural and psychological symptoms of dementia (BPSD). Method: Forty-six older people and 209 staff and managers from five Sydney metropolitan residential aged care (RAC) facilities participated in this pre–post intervention pilot study. Results: The face validity and accessibility/acceptability of the toolkit was established, but potential utility of the ACFI-BEH in informing care planning was proven to be negligible. The ACFI-informed education toolkit did not lead to statistically significant improvements in care planning practice or reduce the severity/frequency of the targeted BPSD. Care plan quality remained low post intervention, with between 31% (N = 12/39) and 65% (N = 13/20) of care plans not addressing the persons’ BPSD, nor utilising the ACFI information in relation to BPSD. Conclusion: This study has underscored the problems associated with current care planning practice in RAC settings and the need for developing strategies to ensure quality and safe care through individualised care planning practices. Our study processes, results and lessons discussed in this paper could assist future research on this type of research in RAC settings.

KEYWORDS: behavioural and psychosocial symptoms of dementia, assessment, nursing homes, care plans, aged care funding instrument
Figure 1: Resident recruitment and participation

Eligible residents invited to participate in the study (n=109)

Residents who consented to participate in study (n=56)

- Participated in pre-test (n=55)
  - Reason: Deceased

- Did not participate in pre-test (n=1)

Residents who did not consent to participate in study (n=53)

Reason:
1. Deceased (n=7)
2. Resident or family declined consent (n=16)
3. No response (n=30)

Did not participate in post-test (n=9)

Reason:
1. Deceased (n=2)
2. Moved into an area of the facility not included in the study (n=4)
3. No longer had a score greater than ‘A’ on one of the ACFI-BEH domains (n=3)
Feasibility of the education toolkit

• Face validity
• Accessibility/acceptability of the toolkit
Feasibility of the education toolkit

Limited utility of ACFI-BEH data to guide care planning

• The age of the ACFI data, including the ACFI-BEH, ranged from 2-31 months (M=12 months; SD= 8.9) at baseline, which did not change when re-audited 9 – 13 weeks after the implementation of the toolkit (M=15 months; SD= 9.4).

• Discrepancies between the behaviours recorded on the ACFI-BEH domains and those identified by the Research Nurse administered instruments measuring the same behaviours - ?? Due to the age of the ACFI or inappropriate use of the tool.

• Lack of attention to individualised care plan, limited access to care plan - ? Due to staff and managers’ non-appreciation of the ACFI’s value in planning resident care, a culture of non-individualised and limited care planning practices
Table 3. Proportion of discrepancy between participants’ ACFI-BEH data and the Research Nurse rated data (n=46)

<table>
<thead>
<tr>
<th>Types of BPSD</th>
<th>†ACFI score lower than current behaviour [n (%)]</th>
<th>‡ACFI score higher than current behaviour [n (%)]</th>
<th>Total discrepancy [n (%)]</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wandering</td>
<td>12 (26.1)</td>
<td>4 (8.7)</td>
<td>16 (34.8)</td>
</tr>
<tr>
<td>Verbal Aggression</td>
<td>2 (4.3)</td>
<td>10 (21.7)</td>
<td>12 (26.1)</td>
</tr>
<tr>
<td>Physical Aggression</td>
<td>5 (10.8)</td>
<td>5 (10.8)</td>
<td>10 (21.7)</td>
</tr>
<tr>
<td>Depression</td>
<td>10 (21.7)</td>
<td>10 (21.7)</td>
<td>20 (43.5)</td>
</tr>
</tbody>
</table>

For analysis we calculated ACFI Score ≥ B (Wandering, Verbal and Physical Aggression): B means behaviour occurs at least once a week or more; ACFI Score ≥ B: (Depression): A CSDD score of 9 or greater.

† Total number of participants who were identified on the RAWS, CMAI, or CSDD as displaying the behaviour but scored an A (meaning ‘behaviour does not occur or occurs less than once a week) on the related ACFI-BEH domain

‡ Total number of participants who were identified on the RAWS, CMAI or CSDD as not displaying the behaviour but scored ≥ B on the related ACFI-BEH domain
No significant effect on reducing BPSD & No change in individualised care plan quality

- Due to small sample size, confounding factors, length of intervention and timing of evaluation, staffing, a culture of oral handover, care planning policy, perception of care planning only as accreditation purpose.

**Table 4. Analysis of change in pre and post CMAI, RAWS and CSDD**

<table>
<thead>
<tr>
<th>BPSD Measures</th>
<th>t value</th>
<th>df</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td>CMAI Verbal (BLOMS correction)</td>
<td>-0.496</td>
<td>45</td>
<td>0.622</td>
</tr>
<tr>
<td>CMAI Physical (BLOMS correction)</td>
<td>-0.362</td>
<td>45</td>
<td>0.719</td>
</tr>
<tr>
<td>RAWS Average (BLOMS correction)</td>
<td>0.468</td>
<td>45</td>
<td>0.642</td>
</tr>
<tr>
<td>CSDD</td>
<td>1.165</td>
<td>45</td>
<td>0.250</td>
</tr>
<tr>
<td>Behaviour present</td>
<td>Wandering n (%)</td>
<td>Verbal Aggression n (%)</td>
<td>Physical Aggression n (%)</td>
</tr>
<tr>
<td>-------------------</td>
<td>------------------</td>
<td>-------------------------</td>
<td>---------------------------</td>
</tr>
<tr>
<td></td>
<td>RAWS†</td>
<td>CMAI‡</td>
<td>CMAI£</td>
</tr>
<tr>
<td>Pre</td>
<td>Post</td>
<td>Pre</td>
<td>Post</td>
</tr>
<tr>
<td>Pre</td>
<td>32 (69.6)</td>
<td>24 (52.2)</td>
<td>34 (73.9)</td>
</tr>
<tr>
<td>Missing/ Not Written</td>
<td>16 (50)</td>
<td>10 (41.7)</td>
<td>10 (29.4)</td>
</tr>
<tr>
<td>Inappropriately Addressed</td>
<td>2 (6.3)</td>
<td>1 (4.2)</td>
<td>4 (11.8)</td>
</tr>
<tr>
<td>Inappropriately/Partially Addressed</td>
<td>4 (12.5)</td>
<td>4 (16.7)</td>
<td>1 (2.9)</td>
</tr>
<tr>
<td>Partially Addressed</td>
<td>9 (28.1)</td>
<td>9 (37.5)</td>
<td>18 (52.9)</td>
</tr>
<tr>
<td>Fully Addressed</td>
<td>1 (3.1)</td>
<td>0 (0)</td>
<td>1 (2.9)</td>
</tr>
</tbody>
</table>

† The Revised Algase Wandering Scale (RAWS)-Long-Term Care version: 20 cut off score was used.
‡ Cohen Mansfield Agitation Inventory (CMAI) – Verbal behaviours: 9 cut off score was used.
£ Cohen Mansfield Agitation Inventory (CMAI) – Physical behaviours: 22 cut off score was used.
§ Cornell Scale for Depression in Dementia (CSDD): 9 cut off score was used.

NB: Percentages were calculated as in the following example from the table: of 32 residents with wandering behaviours in the pre assessment, 9 (28.1%) had partially addressed care plans. Of 24 residents in the post assessment with wandering behaviours, 9 (37.5%) had partially addressed care plans.
Key issues

- Culture – Leadership (both organisational and individual)
- Measurements – quality of life, person centred care & quality of care
  - Psychometric properties
  - Generalisability
  - Objectivity
  - Practicality/feasibility
  - Benchmarking
  - Routine use
  - Workforce and organisational characteristics
Aims:

1. to develop and promote evidence-based tools for improving leadership and management in the aged care sector including a clinical leadership qualities framework (ACLQF) and a clinical leadership program in aged care (CLiAC); and

2. to determine the feasibility and the effectiveness of CLiAC in improving workforce recruitment and retention and care safety and quality, which have not been previously researched in the aged care sector.

The Study: 2010-2013

Action research project conducted in four stages
The Study: 2010-2013

Stage 1 (Oct – Nov 2010): Establishing a National Aged Care Clinical Leadership Consortium


The framework (ACLQF) & the program (CLiAC), delivery and evaluation methods

Stage 3 (May 2011 - Jun 2013): A cluster randomised trial

- **Time 1** data collection: before the intervention, baseline **Jul 2011**
- **Intervention/CLiAC implementation** (over 12 months) **Sep 2011-Aug 2012**
- **Time 2** data collection: 9 months after **Time 1** **Apr 2012**
- **Time 3** Data collection: 9 months after **Time 2** **Feb 2013**

Stage 4 (Jul – Sep 2013): Developing policy options, strategies and directions to improve clinical leadership skills of the aged care workforce
Stage 2: Developing a Toolkit

Aged care-specific Clinical Leadership Qualities Framework (ACLQF): CLINICAL

<table>
<thead>
<tr>
<th>Key Quality and Descriptors of the Quality for Aged Care Middle Managers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Committed to and facilitates the delivery of clinical care that is underpinned by person-centred care</td>
</tr>
<tr>
<td>- Has a sound understanding of person-centred care as a philosophy for care procedure and organisational aspiration in aged care.</td>
</tr>
<tr>
<td>- Embeds strategies to support the older person through their personal experience of ageing in ways that demonstrate valuing of the person within a person-centred, social, spiritual and humanistic approach to care, recognising that the person’s illness or functional/cognitive limitations are not the only aspect of care.</td>
</tr>
<tr>
<td>- Promotes the rights of older people, their families and carers to be valued participate in decision-making.</td>
</tr>
<tr>
<td>- Demonstrates effective role modelling of person-centred care to staff and customers.</td>
</tr>
<tr>
<td>- Translates the vision of person-centred care to practice through collaborative implementation of person-centred care for older people.</td>
</tr>
<tr>
<td>Links personal leadership and management behaviours to improved outcomes</td>
</tr>
<tr>
<td>- Can identify and describe personal leadership and management style and strengths.</td>
</tr>
<tr>
<td>- Uses a range of indicators of quality outcomes and feedback mechanisms to monitor and evaluate performance.</td>
</tr>
<tr>
<td>- Understands and works with the diverse interests and views of internal and external stakeholders to contribute to positive outcomes for older people in their care.</td>
</tr>
<tr>
<td>- Takes responsibility and accepts accountability for decision-making including the development and delivery of services.</td>
</tr>
<tr>
<td>- Is accessible and visible to older people, their families and carers and staff.</td>
</tr>
<tr>
<td>Initiates, monitors and leads improvements in the quality and safety of care</td>
</tr>
<tr>
<td>- Is motivated to improve the quality and safety of care for older people with a focus on continuous improvement.</td>
</tr>
<tr>
<td>- Uses organisational ‘quality systems’ and information, and when necessary in person-centred care.</td>
</tr>
<tr>
<td>- Consists with a range of internal and external stakeholders in determining improvement priorities.</td>
</tr>
<tr>
<td>- Engages older people, their family members and staff to work effectively and in partnership to improve the quality of care in the delivery of aged care.</td>
</tr>
<tr>
<td>- Supports and promotes the development and review of operational, clinical and governance processes.</td>
</tr>
<tr>
<td>Nest/situates decision-making in ethical, legal, regulatory, professional and organisational context</td>
</tr>
<tr>
<td>- Is aware of and operates within ethical, legal, regulatory and professional frameworks.</td>
</tr>
</tbody>
</table>

- Leads and manages staff and others including volunteers in accordance with frameworks specific to the aged care context. |
- Operates within these frameworks to direct and effect change. |
- Influences and participates in the effective management and deployment of staff and other resources |
- Identifies and justifies resources to optimise care as necessary, advocating for optimum staffing and resources if quality and safety are being compromised. |
- Uses organisational systems and processes to effectively manage staff and other resources. |
- Integrates knowledge, skills and acumen of clinical practice and aged care specific business processes when making management decisions. |
- Contributes to recruiting, selecting and retaining staff who can develop and maintain a person-centred approach to care, and the resources to facilitate the development and maintenance of person-centred care of older people. |
- Promotes valuing of equity and diversity, safety, security and well being within the workforce. |
- Coordinates and delegates work and participates in the review of individual and team performance. |
- Collaborates with stakeholders in care processes to optimise clinical outcomes |
- Is self-aware and has a diverse repertoire to respond to and engage staff and others in addressing a range of complex management issues. |
- Works collaboratively and effectively within and across systems and sectors (i.e., health and social care, and primary, secondary, and tertiary settings) to optimise quality aged care. |
- Demonstrates effective interpersonal skills with a range of people in the aged care setting. |
- Works in ways that facilitate collaborative action through applying team building, emotional intelligence, negotiation, conflict resolution and problem solving skills effectively. |
- Leads staff and others through directive decision taking when necessary. |
- Accesses and uses evidence to guide self and staff to implement person-centred care |
- Accesses and retrieves relevant clinical and managerial information and research to guide effective performance in role and organisational goals. |
- Uses evidence to optimise quality and safety of person-centred practice in aged care. |
- Is familiar with a range of practice, policy and research issues in aged care. |
- Works within organisational and professional systems to contribute to the implementation of evidence based policy and practice. |
- Encourages and supports staff to use a range of evidence to guide their practice. |
- Learns and develops both self and others involved in the care of the older person |
- Identifies own strengths and limitations and leads by example. |
- Uses self-reflection and feedback on own performance as opportunity for further development. |
- Actively seeks and engages in professional development opportunities. |
- Demonstrates confidence and professional expertise when educating or supervising others. |
- Encourages and supports staff to use a range of evidence to guide their practice. |

©Copyright Jeon & Conway 2011
Stage 2: Developing a Toolkit
Stage 3: A Cluster Randomised Controlled Trial

Sites (Unit of randomisation): 6 RACFs and 6 CACSs to the CLiAC Intervention group (n=12); and 6 RACFs and 6 CACSs to NP group (n=12).

Recruitment of Managers and Staff in the Survey: Eligible participants are willing permanent direct care staff and managers at the 24 research sites who have been employees for at least 6 months.

Blinding: Staff and researchers (data entries and analysis) have been blind to the groups.

CLiAC program implementation

- **Facilitator**: BCS facilitator working with Dr Jane Conway
- **Participants** – ECMs and CCMs, Middle managers
Stage 3: A Cluster Randomised Controlled Trial

The feasibility and the effectiveness of CLiAC being examined at three different time points against a no program control group (NP).

**Hypotheses:** The CLiAC group will have the following significant benefits over the NP group.

- **HP1** – enhanced work environment for aged care staff
- **HP2** – improved care quality and safety for aged care recipients
- **HP3** – reduced staff turnover rates
- **HP4** – reduced staff absenteeism
- **HP5** – improved staff ‘intention to stay’ & ‘decreased intention to leave’
- **HP6** – increased job satisfaction for staff
- **HP7** – reduced cost of retaining and recruiting staff, as well as cost of care
- **HP8** – improved managers’ knowledge and skills in leadership and management
Outcome Measures (1)

- **Work Environmental Scale-R (WES-R)** - actual work environment under three domains: relationship; goal orientation; and system maintenance and change dimensions

- **Workforce Dynamics Questionnaire (WDQ)** - overall staff satisfaction, autonomy, role perception/flexibility, team working, care quality, management structures and styles, access to technology and equipment, training and career progression opportunities, uncertainty

- **Multi-factor Leadership Questionnaire (MLQ)** – a broad range of leadership types and differentiating effective and non-effective leaders at all organisational levels

- **Person-centred Care Assessment Tool (P-CAT)**: *the extent to which* staff rate their aged care setting to be person-centred with best quality care for people with dementia.

- **Approaches to Dementia Questionnaire (ADQ)**: *staff attitude towards dementia* care that reflects their understanding of the need to provide person centred care
**Outcome Measures (2)**

- **Document reviews (March 2011-April 2013):** 1) *Human resource records* to measure staff absenteeism and turnover; 2) *Care-recipient incident reports* to measure safety and quality of care performance indicators

  1) **Monthly collection of HR data:** staffing, turnover and movement
  2) **Monthly collection of clinical indicators:** of a total Number of Clients per month, how many had: Unplanned Hospital Admissions; Fall with Injury; New Urinary Tract Infection; New Pressure Areas; Unintentional Weight loss >2kg over the Month.

  6 Month Incidence Rate *(new cases per 100 clients in time period)*
  
  \( \frac{\sum \text{new events over 6 months}}{\sum \text{mean clients over 6 months}} \times 100 \)

- **NHS Leadership Centre Evaluation Questionnaire** – Managers’ perceptions of the study intervention, perceived effects on care quality, changes to practices and procedures, sustainability of change, improvements to and valued aspects of the program
Has it been successful?

Qualitative results - 
**YouTube** -
[http://www.youtube.com/watch?v=0HrPBHgBaAQ](http://www.youtube.com/watch?v=0HrPBHgBaAQ)

Results of the RCT ... working in progress
Quality indicators in dementia care – building an international, interdisciplinary research programme
THERE was a time, not too long ago, when this question could not have been asked. The quality of care was considered to be something of a mystery: real, capable of being perceived and appreciated, but not subject to measurement.

The very attempt to define and measure quality seemed, then, to denature and belittle it. Now, we may have moved too far in the opposite direction. Those who have not experienced the intricacies of clinical practice demand measures that are easy, precise, and complete—as if a sack of potatoes was being weighed.

True, some elements in the quality of care are easy to define and measure, but there are also profundities that still elude us. We must not allow anyone to belittle or ignore them; they are the secret and glory of our art. Therefore, we should avoid claiming for our capacity to assess quality either too little or too much. I shall try to steer this middle course.

Measuring Person-centered Care: A Critical Comparative Review of Published Tools

David Edvardsson, PhD,*,1,2 and Anthea Innes, BA (Hons), MSc, PhD3

1Department of Nursing, University of Umea, Sweden.
2Australian Centre for Evidence Based Aged Care, La Trobe University, Bundoora Victoria, Australia.
3Department of Applied Social Science, Dementia Services Development Centre, University of Stirling, UK.

- Dementia Care Mapping 8th edition (DCM8)
- The person-directed care measure
- The person-centered care assessment tool (P-CAT)
- Measures of individualized care
- Family involvement in care
- The English language person-centered climate questionnaire—patient version & staff version
- The person-centered inpatient scale
- The client-centered care questionnaire
Research Paper

The CARES® Observational Tool: A valid and reliable instrument to assess person-centered dementia care

Joseph E. Gaugler a,⁎, John V. Hobday b, Kay Savik a

a School of Nursing, University of Minnesota, 6-153 Weaver-Densford Hall, 1331, 308 Harvard Street SE, Minneapolis, MN 55455, USA
b HealthCare Interactive, Edina, MN, USA
Person-Centred Environment & Care Assessment Tool (PCECAT)

- Characteristics of the home
- Organisational culture, care & activities; Interpersonal relationships and interactions; Physical layout and design of the home
- New quality strategies

VIPS Dementia Toolkit

Values

V1 Vision
V2 Human Resources
V3 Management Ethos
V4 Training & Practice Development
V5 The Service Environments
V6 Quality Assurance

Individuals

i1 Individual Support & Care
i2 Recognising & responding to change
i3 Personal Possessions
i4 Individual Preferences
i5 Life Histories
i6 Activity & Occupation

Perspective

P1 Communication
P2 Empathy & Acceptable Risk
P3 Physical Environment
P4 Physical Health Needs
P5 Challenging Behaviour As Communication
P6 Advocacy

Social

S1 Inclusion
S2 Respect
S3 Warmth
S4 Validation
S5 Enabling
S6 Part Of The Community
S7 Partners, Families, Friends & Relatives
The development of quality indicators to improve psychosocial care in dementia

Emmelyne Vasse,1 Esme Moniz-Cook,2 Marcel Olde Rikkert,3 Inge Cantegreil,4 Kevin Charras,5 Pascale Dorenlot,6 Georgina Fumero,7,8 Manuel Franco,8 Bob Woods9 and Myrra Vernooij-Dassen1,10

• **Diagnosis and assessment:** Dx being discussed with Person; Assessment of depression & anxiety; records of life history, social family circumstances and needs & preferences

• **Care plan and treatment:** Tailored psychosocial interventions; personalised care plan shared; content of care plan (ADL, social, structured activities); regular contacts between staff, person, family

• **Behavioral problems:** Tailored care plan based on assessment of behaviours; psychosocial interventions prioritised

• **Caregivers:** Respite care offered; psychosocial interventions; assessment for mood and coping; staff training
Table 1. Quality Indicators for psychosocial care in dementia

<table>
<thead>
<tr>
<th>NUMERATOR</th>
<th>DENOMINATOR</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Diagnosis and assessment</strong></td>
<td></td>
</tr>
<tr>
<td>1. Number of people with dementia whose patient file records that diagnosis</td>
<td>Total number of people with dementia who are assessed for depression and/or</td>
</tr>
<tr>
<td>was discussed with the person with dementia.</td>
<td>anxiety.</td>
</tr>
<tr>
<td>2. Number of people with dementia who are assessed(^a) periodically(^b)</td>
<td>Total number of people with dementia who are assessed for depression and/or</td>
</tr>
<tr>
<td>for depression and/or anxiety.</td>
<td>anxiety.</td>
</tr>
<tr>
<td>3. Number of people with dementia with registration in patient file and/or</td>
<td>Total number of people with dementia who are assessed for depression and/or</td>
</tr>
<tr>
<td>care plan of:</td>
<td>anxiety.</td>
</tr>
<tr>
<td>• Life history</td>
<td></td>
</tr>
<tr>
<td>• Social and family circumstances</td>
<td></td>
</tr>
<tr>
<td>• Needs and preferences(^a)</td>
<td></td>
</tr>
<tr>
<td><strong>Care plan and treatment</strong></td>
<td></td>
</tr>
<tr>
<td>4. Number of people with dementia whose patient file records that they</td>
<td>Total number of people with dementia who are assessed for depression and/or</td>
</tr>
<tr>
<td>are currently receiving psychosocial interventions, tailored to the person's:</td>
<td>anxiety.</td>
</tr>
<tr>
<td>• Needs and preferences(^a)</td>
<td></td>
</tr>
<tr>
<td>• Cognitive and physical abilities</td>
<td></td>
</tr>
<tr>
<td>5. Number of people with dementia with a registered personalized care plan,</td>
<td>Total number of people with dementia who are assessed for depression and/or</td>
</tr>
<tr>
<td>shared between the person with dementia, informal caregiver and care</td>
<td>anxiety.</td>
</tr>
<tr>
<td>professional, that is periodically(^b) updated. This means that:</td>
<td></td>
</tr>
<tr>
<td>• At least two types of interventions were discussed with and offered to</td>
<td></td>
</tr>
<tr>
<td>the person with dementia.</td>
<td></td>
</tr>
<tr>
<td>• The care plan is drawn up in agreement with person with dementia,</td>
<td></td>
</tr>
<tr>
<td>informal caregiver and professional at the service.</td>
<td></td>
</tr>
<tr>
<td>• Response to initiated interventions has been monitored less than one</td>
<td></td>
</tr>
<tr>
<td>year ago.</td>
<td></td>
</tr>
<tr>
<td>6. Number of people with dementia whose care plan includes:</td>
<td>Total number of people with dementia who are assessed for depression and/or</td>
</tr>
<tr>
<td>• ADL activities</td>
<td>anxiety.</td>
</tr>
<tr>
<td>• Recreational and social activities</td>
<td></td>
</tr>
<tr>
<td>• Structured day activities</td>
<td></td>
</tr>
<tr>
<td>7. Number of people with dementia who have an assigned professional who</td>
<td>Total number of people with dementia who are assessed for depression and/or</td>
</tr>
<tr>
<td>maintains regular contact with the patient and the main caregiver and</td>
<td>anxiety.</td>
</tr>
<tr>
<td>ensures coordinated delivery of health and social care services.</td>
<td></td>
</tr>
<tr>
<td><strong>Behavioral problems</strong></td>
<td></td>
</tr>
<tr>
<td>8. Number of people with dementia who have behavioral problems with</td>
<td>Total number of people with dementia who have behavioral problems at service.</td>
</tr>
<tr>
<td>registration of a tailored care plan that:</td>
<td></td>
</tr>
<tr>
<td>• Is based on an assessment(^a) to establish factors likely to cause</td>
<td></td>
</tr>
<tr>
<td>the behavior</td>
<td></td>
</tr>
<tr>
<td>• Includes registration of its frequency of review agreed on by the</td>
<td></td>
</tr>
<tr>
<td>informal caregiver and staff involved</td>
<td></td>
</tr>
<tr>
<td>9. Number of people with dementia who have behavioral problems that are</td>
<td>Total number of people with dementia who have behavioral problems at service.</td>
</tr>
<tr>
<td>treated with a psychosocial intervention first before pharmacological</td>
<td></td>
</tr>
<tr>
<td>treatment is started.</td>
<td></td>
</tr>
<tr>
<td><strong>Caregivers</strong></td>
<td></td>
</tr>
<tr>
<td>10. Number of caregivers of people with dementia for whom it is registered</td>
<td>Total number of caregivers of people with dementia.</td>
</tr>
<tr>
<td>that:</td>
<td></td>
</tr>
<tr>
<td>• Respite or short-break care is offered to them</td>
<td></td>
</tr>
<tr>
<td>• Other psychosocial interventions, tailored to their needs and</td>
<td></td>
</tr>
<tr>
<td>preferences are offered to them</td>
<td></td>
</tr>
<tr>
<td>11. Number of caregivers of people with dementia who are periodically(^b)</td>
<td>Total number of caregivers of people with dementia who are periodically(^b)</td>
</tr>
<tr>
<td>assessed(^a) for mood and coping.</td>
<td>assessed(^a) for mood and coping.</td>
</tr>
<tr>
<td>12. Number of staff at care service/facility that receive specific dementia-care</td>
<td>Total number of staff at care service/facility.</td>
</tr>
</tbody>
</table>
Existing tools/indicators suffer from limitations …

- Psychometric properties
- Generalisability
- Objectivity
- Practicality/feasibility
- Benchmarking
- Routine use
- **Workforce and organisational characteristics** (RN staffing ratios, Skill-mix, Worker stability & high agency staff, Facility size, Resource model, Management structure, Organisational culture, Total RN nursing hours, Wage and Client case-mix, etc.)
To measure and ensure Quality Dementia Care, do we need Revolution or Evolution?
Definition: “indicators are explicitly defined and measurable items, which act as building blocks in the assessment of care. They are a statement about the structure, process (interpersonal or clinical), or outcomes of care and are used to generate subsequent review criteria and standards, which help to operationalise quality indicators.”

For quality indicators to be effectively and reliably used for ongoing monitoring and quality improvement ...

Measurement of care quality should
1. be harmonised or accord with what constitutes quality care
2. be inclusive of multidimensional factors influencing that care such as organisational and environmental features
3. therefore, contain elements of: Structure or characteristics of each care setting; Process or actions/activities of care and how they are provided; Outcome or consequences of care to the health and well being of clients.
Change of Culture through Quality Improvement using Quality Indicators

- Structure
- Person
- Process
- Care
- Outcome
- Dementia Care Standards
If a measurement matters at all, it is because it must have some conceivable effect on decisions and behaviour. If we can't identify a decision that could be affected by a proposed measurement and how it could change those decisions, then the measurement simply has no value.”

— Douglas W. Hubbard, *How to Measure Anything: Finding the Value of "Intangibles" in Business*

Methodologically sound, measurable and objective indicators of person centred dementia care consisting of all key domains of quality assessment is urgently needed
Relevance to policy in Australia
Dementia

- Worldwide, 35.6 million people with dementia today .... nearly double every 20 years to 65.7 million in 2030 and 115.4 million in 2050 (Alzheimer’s Disease International 2009)

- In 2011, estimated 298,000 people with dementia in Australia ... reaching 400,000 by 2020 and 900,000 by 2050. Dementia is a leading cause of death, accounting for 6% of all deaths in 2010. Total direct health and aged care services expenditure on people with dementia was at least $4.9 billion in 2009-10. (AIHW 2012: Dementia in Australia)
Tackling Dementia

- Supporting people with dementia across the health system ($41.3 million)
  - Support for more timely diagnosis
  - New Dementia Supplement
- Better care for older Australians with behavioural problems associated with severe dementia in residential care ($41.0 million)
- Better care for older Australians with dementia in Home Care packages ($123.3 million)
- Improving acute care services for people with dementia ($39.2 million)
- Improved support for people with younger onset dementia ($23.6 million)
The Use of Indicators in Australian Residential Care Homes
A National Perspective, Future Directions & Public Reporting

Ian Yates AM, Chief Executive,
Pat Sparrow, Director, Aged Care Reform, COTA Australia
NACA Secretariat-Aged Care Reform

DEVELOPMENT CONSIDERATIONS

- Insight into quality of care and life
- Existing evidence & work
- Promote quality improvement for service providers
- Recognise resident experience as a valid and important indicator
- Built upon reliable, consistent and valid data

DEVELOPMENT CONSIDERATIONS

- Easily understood and meaningful
- Value add to providers rather than an additional compliance burden
- Complimentary to standards and accreditation
- Aspirational indicators
Is knowing enough good enough?

“We knew enough about scurvy 263 years before the British Merchant Navy introduced citrus as a routine dietary supplement to shipboard diets. If knowing enough were all it took, a goodly number of the diseases and social plagues of contemporary society would have been eradicated, and far greater resources would be dedicated to addressing the fundamental and social determinants of health than is currently the case.”

(Estabrooks, 2001, p.292)

THANK YOU

yun-hee.jeon@sydney.edu.au