Measuring Quality and Person Centred 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

VIPS framework by Dawn Brooker

- Respecting and Valuing the individual as a full member of society.
- Providing Individualised places of care that are in tune with people’s changing needs.
- Understanding the Perspective of the person.
- Providing a Supportive social psychology in order to help people live a life where they can experience relative well-being.

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)"

Articles

Caring for Aged Dementia Care Resident Study (CADRES) of person-centred care, dementia-care mapping, and usual care in dementia: a cluster-randomised trial

Lynne Chetwynd, Madeleine T King, Yun-Hee Jeon, Henry Bradly, Jane Slein-Parbury, Richard Nimmph, Marion Hazz, Georgina Luczomer

www.thelancet.com Published online March 12, 2009 DOI:10.1016/S1474-4422(09)7006

Yun-Hee Jeon "Measuring quality and person centred dementia care" yun-hee.jeon@sydney.edu.au
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.

Yun-Hee Jeon 
Sydney Nursing School
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21 June 2013
MBI Emotional Exhaustion sub-scale by intervention group and time (N = 124)

Strategies for clinical delivery of person-centred care

- Incorporate biographical knowledge of the person with AD in clinical care
- Conduct reminiscence sessions
- Provide validation therapy
- Prioritise well-being ahead of routines and care tasks
- Simplify and personalise the environment
- Perform activities that promote a good life

(Edvardsson et al., 2008, p.364)


Two decades have passed ....

1. We have come a long way, OR Have we?
2. Has Person Centred Care moved from Rhetoric to Reality?
3. Are we there yet? If not, Why?
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)


“Translation won’t happen without dissemination and implementation: some measurement and evaluation issues”


“Studies suggest that it takes an average of 17 years for research evidence to reach clinical practice.”¹

“It takes an estimated average of 17 years for only 14% of new scientific discoveries to enter day-to-day clinical practice.”²

Research Utilisation/ Knowledge Translation

Integrated KT (CIHR 2009):

– Engaging and integrating knowledge users into the research process - collaborative, participatory, action-oriented research; co-production of knowledge
– Action research, Practice development, Quality improvement

Canadian Institute of Health Research (CIHR) 2009
http://www.cihr-irsc.gc.ca/e/39158.html#s4

Symposium - “Aged Care Reform: Advancing Quality in Dementia Care” 21 June 2013
Yun-Hee Jeon Sydney Nursing School
University of Sydney 21 June 2013

Measurement tools/Outcome measures and Quality Indicators

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.

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.

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.

• 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
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


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Person-centred Dementia Support in the Community Project (work in progress …)

- Person-centred Community Dementia Support Framework
- Organisational Self Assessment Tools

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Yun-Hee Jeon "Measuring quality and person centred dementia care" yun-hee.jeon@sydney.edu.au
• **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

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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.)
Definiton: “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.

“Not everything that counts can be counted, and not everything that can be counted counts”
—— Albert Einstein

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