

Developing person-centred care

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Person-centred care: 4 main elements (Brooker, 2004)

- Valuing people with dementia and those who care for them (V)
- Treating people as individuals (I)
- Looking at the world from the perspective of the person with dementia (P)
- A positive social environment in which the person living with dementia can experience relative well-being (S)
- $PCC = V + I + P + S$

Kitwood's person-centred theory

- Person with dementia V. Person with dementia
- Discovering the person meant putting neuropathology in its proper place
- $D = P + B + H + NI + SP$
 - Dementia presentation
 - P = Personality
 - B = Biography
 - H = Health
 - NI = Neuropathological Impairment
 - SP = Social Psychology

Malignant social psychology

- 'Malignant social psychology' e.g. infantilisation, intimidation, out-pacing - devalues, dehumanises, depersonalises, diminishes
- Everyday components of dementia care
- Not a result of malicious intent or (usually) frank abuse - dementia tends to elicit this reaction from those who struggle to care
- Hopeful message or attribution of blame?

The person with dementia is not:

- An object
- A child
- A vegetable
- In a state of living death (but carers may feel loss)
- In a state worse than death (but that's what many people think?)

Personhood - mark one

- Still a person *despite* loss of memory, reasoning, communication, capacity
- Does cognition underpin personhood?
 - “Life without memory is no life at all...without it we are nothing” Luis Bunuel in Sacks (1985)
- ‘Hypercognitive culture’ categorizes those with severe dementia as ‘non-persons’ (Post, 1995)
- *Autonomy* is increasingly valued – interdependency is de-emphasised

Personhood - mark two

- Abilities and capacities remain - not all is lost, and so people with dementia are still 'persons'
- Emotional sensitivity and spiritual awareness possible (Sacks, 1985)
- Aesthetic and relational aspects of well-being possible in severe dementia (Post, 1998)
- Principle of moral solidarity - weaker and vulnerable members of society worthy of care and protection - but stigma of dementia

Personhood in relationship

- Not about the person's capabilities
- Not about our ability to 'overlook' impairments
- *"Personhood is a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being."* (Kitwood, 1997)
- "I-it" vs. "I-thou" relating (cf. Martin Buber)

Personhood in relationship - 2

- Personhood product of the care-giving relationship
- 'Malignant social psychology' - care-giving relationships which devalue, dehumanise, depersonalise, diminish
- To maintain identity, biographical approach essential e.g. use of life-story books

Personhood in relationship - 3

- Indicators of relative well-being
 - e.g. expression of desire or will, helpfulness, humour
 - Self-worth, social confidence, hope and sense of agency
- Facilitated by positive care environment
- The possibility of personal growth & development in dementia care

Care-giver as facilitator

- Care-givers need skill and ease in relating warmly to others
- Not 'them' who are damaged and 'us' who are whole
- We too are 'damaged' in some way - our fears, uncertainties, insensitivities etc.
- We must ask people with dementia for forbearance as we struggle to be truly and fully human in relating to them

Iris and the friends – John Bayley (1999) pp 17

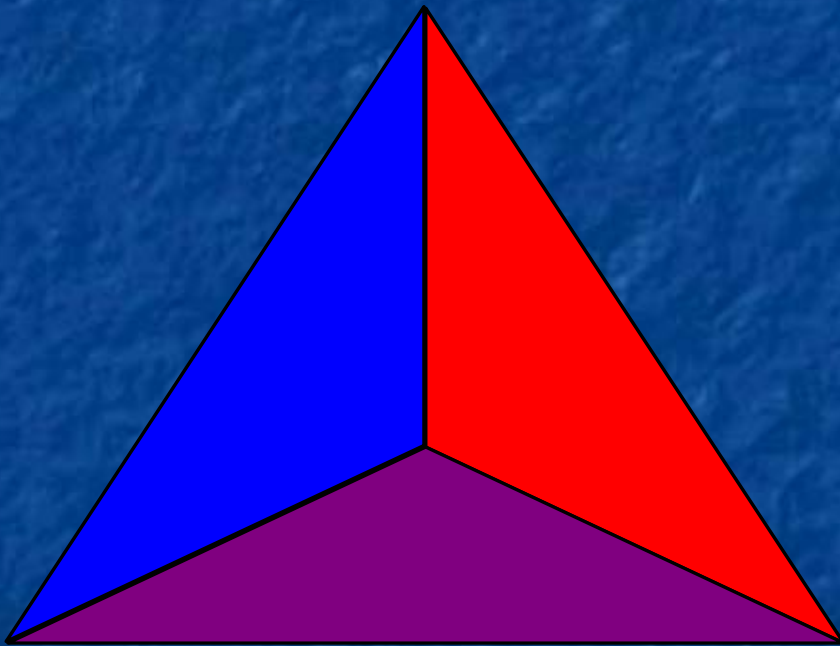
“Dr A’s rewards and compensations, even the most unexpected ones, are concerned with being alive; finding out not only how much there is in being alive, but what surprising *new* things there turn out to be; freedoms, and pleasures in constraint, which we would never have imagined or thought of, never even have considered possible.”

Personhood in dementia

- “In dementia many aspects of the psyche that had, for a long time, been individual and ‘internal’, are again made over to the interpersonal milieu. Memory may have faded, but something of the past is known; identity remains intact, because others hold it in place; thoughts may have disappeared, but there are still interpersonal processes; feelings are expressed and meet a validating response; and if there is a spirituality, it will most likely be of the kind that Buber describes, where the divine is encountered in the depth of I-thou relating.” (Kitwood, 1997 pp. 69)

Towards relationship-centred care: the Dementia Care Triangle

- The **person** with dementia
- Family care-giver
- Paid care-giver



Quality of life and quality of relationship

- Long-established findings that quality of relationship, **as rated by care-giver**, predicts level of strain / depression (e.g. Morris et al., 1988; Williamson & Schulz, 1990)
- Expressed emotion (EE) predicts strain and coping (e.g. Tarrier et al., 2002)
- Less certain whether past relationship or current relationship or the degree of change best mediates the influence of dementia symptoms on QoL

'Family functioning in the caregivers of people with dementia'

(Heru et al., 2004)

- Poor family functioning associated with greater burden and strain
- Associated with poorer communication, problem solving, intimacy and expressed emotion
- BUT more reward than burden:
 - 'I feel that she is loved and not alone'
 - 'Feeling good inside, doing for someone what you want for yourself, knowing I've done my best'

Predicting outcome for care-givers 8 months after initial contact with services (Woods et al., 2003)

- 104 family carers interviewed soon after referral and 8 months later
- General Health Questionnaire (GHQ-28)
- Overall, scores improved
- Outcome *better* where carer rated *past* communication more positively
- Outcome *worse* where *current* communication rated more positively
- Remaining close can be stressful?

Evaluating quality of relationship

- Most often based on caregiver report or on caregiver perspective (e.g. expressed emotion evaluated from critical comments during interview about the person with dementia)
- Could person with dementia also rate the relationship?
- Or can some aspects of relationship be observed?

Observing current interaction patterns

(Woods, Steele & Phibbs, 2001)

- Video-taped interactions (10-15 minutes)
 - Puzzle task
 - Planning task
- Based on Gallagher-Thompson et al., 1997 and 2001
- 22 mother-daughter dyads assessed
- Developed rating dimensions
- Inter-rater reliability ($r > 0.70$) on all dimensions

Video-taped interactions - Puzzle and Meal planning tasks: dimensions

Daughter

Engagement in task
Positive affect
Negative affect
Dominance
Depersonalization
Sensitive responsiveness
Problem solving approach

Mother

Engagement in task
Positive affect
Negative affect

Dyadic

Emotional attunement
Interactive style and communication quality

Results from video interactions

- A number of associations with dementia severity (Clinical Dementia Rating) e.g. less emotional attunement when severity greater
- Depersonalization of mother by daughter associated with Relatives Stress Scale scores independent of dementia severity
- ? Negative cycle of depersonalization and behaviour problems ?

Can people with dementia rate the quality of the relationship?

- 35 people with dementia and care-givers participated
- Mean age person with dementia 76.5 (8.7)
- Mean age care-giver 67.9 (14.4)
- 77% spouses; 91% co-resident
- 14% minimal dementia; 62% mild dementia; 23% severe dementia (Clinical Dementia Rating)
- Mean duration of memory problems 2.9 years
- 88% of carers inputting more than 20 hours per week

Three measures of relationship quality used with both carers and care recipients – level of agreement

- Bengston's Positive Affect Index $r = 0.73$ (5 items)
- QCPR (Spruytte 2002) $r = 0.70$ (14 items)
- Perceived criticism scale PCS (Hooley and Teasdale 1989)

Provides two ratings per participant
How critical do you think you are of
How critical do you think....is of you

No correspondence between carer and PWD reports!

Quality of life of the person with dementia (QoL-AD rated by person with dementia)

- QoL-AD relates to Positive Affect Scale
 - $R=0.42^*$ for person with dementia's rating
 - $R=0.57^{**}$ for carer's rating
- QoL-AD relates to QCPR (warmth)
 - $R=0.49^{**}$ for person with dementia's perspective

Association between relationship scales

- For both the carer and the Person with dementia, there is a positive correlation between the positive affect scale and the warmth scale QCPR
 - Care recipient $r = .74^{**}$
 - Carer $r = .74^{**}$
- For the person with dementia, there is a negative correlation between positive affect and the level of perceived criticism from their carer $r = -0.37^*$
- and the level of criticism they direct to their carer $r = -0.34$
- For the carer : negative correlations between positive affect and both scales of the PCS:
 - Their own reported level of criticism directed to the care recipient $r = -.54^{**}$
 - and the level of perceived criticism from the person they are caring for $r = -.52^{**}$

Relative's Stress Scale

- **Levels of carer stress are positively correlated with:**

- The length of time the person with dementia has experienced memory problems;
 $r = .53^{**}$
- The levels of criticism as perceived from the carer's perspective
- Carer to person with dementia $r = .37^*$
- Person with dementia to carer $r = .40^*$

- **And negatively correlated with:**

- Person with dementia Positive affect index $r = -0.42^*$
- Carer's Positive affect index $r = -0.50^{**}$
- Person with dementia QCPR warmth subscale $r = -0.47^*$
- Carer QCPR warmth subscale $r = -0.38^*$

Association between relationship ratings and emotional attunement in video-interaction tasks

- Positive Affect Index:
 - Person with dementia $r=0.42^*$
 - Carer $r=0.54^{**}$
- QCPR
 - Person with dementia $r=0.52^{**}$
 - Carer $r=0.51^{**}$
- Criticism given
 - Person with dementia $r=-0.42^*$
- Criticism received
 - Person with dementia $r=-0.46^{**}$
 - Carer $r=-0.50^{**}$

Depersonalisation and the person with dementia

- Where depersonalisation of the person with dementia is rated more strongly in the video-taped tasks, the person with dementia is more likely to report receiving a high level of criticism from their carer ($r=0.49^{**}$)
- The carer's rating of how critical they are to the person with dementia is not significantly associated with degree of depersonalisation

Conclusions – relationship quality and quality of life

- Care-giving occurs in the context of (often) a long-standing relationship
- Many people with dementia are able to reliably and accurately rate the quality of the current relationship
- The quality of life of the person with dementia and the stress experienced by the carer are associated with the quality of the current relationship
- The quality of the relationship may be observed through observation of structured tasks
- The quality of the present relationship may prompt different reactions in different care-givers at different points in the journey – from a strength in closeness, to a strong sense of loss and grief
- Interventions must consider the relationship dynamics

Focus on relationship..

- Quality of relationship has an impact on care-giver stress
- Scope for interventions working together with person with dementia and care-giver
- E.g. Teri et al., 1997, taught care-giver to use CBT with depressed spouse with dementia; both parties showed reduced depression levels.
- Currently evaluating joint reminiscence groups for people with dementia and care-givers together, aiming to improve quality of relationship

RYCT - JOINT REMINISCENCE THERAPY

- Joint psychosocial interventions for people with dementia and their carers are more effective than interventions for carers alone (Brodaty et al, 2003)
- Small pilot suggests that Remembering Yesterday Caring Today (RYCT – joint form of RT):
 - improves quality of life of people with dementia;
&
 - reduces stress in their carers (Thorgrimsen et al, 1998)

What is RYCT?

- Active, large group approach, involving people with dementia and carers together
- Lots of materials, activity, music, dancing, laughter – refreshments & sense of occasion
- Led by 2 (local) workers, trained and supported by Age Exchange
- Involve volunteers also
- Small groups for discussion on specific topics
- Family members encouraged to facilitate not dominate!

RYCT Sessions

- Introductions – names and places
- Childhood and family life
- School days
- Starting work
- Going out and having fun
- Courting & marriage
- Homes, gardens & animals
- Food & cooking
- The next generation – babies & children
- Holidays and journeys
- Festivals & special days
- Rounding up & evaluation

RYCT essentials

- Value each person's contribution
- Make people welcome and appreciated
- Use a rich array of memory triggers – stimulate all the senses
- Use non-verbal communication
- Give people plenty of time to respond
- Use creative ways to explore memories
- Use failure-free activities
- Divide time: large group / small group / feedback small to large group
- Make connections between people
- Celebrate differences, achievements, individual stories, shared experience

Remembering Yesterday, Caring Today (RYCT) projects





Gertie (aged 93) sees a blow-up photo of her family at the seaside in the 1930s. She recognises all of them from their legs!

She tells Pat, a carer, their names and what she remembers about them all and Pat writes it all down to refer back to later



Dennis remembers his wedding tie and what happened on the occasion, when presented with a blow-up photo of his wedding day. His wife cannot believe this, as he has not given her any indication that he remembers any of it.



MRC Trial Platform April 2004 – March 2006 (Bangor, Bradford and UCL)

To refine RYCT intervention and develop treatment manual (12 sessions)

- To develop and validate outcome measures
 - Autobiographical memory
 - Quality of communication
- To identify and test feasibility of control groups
- To resolve design issues

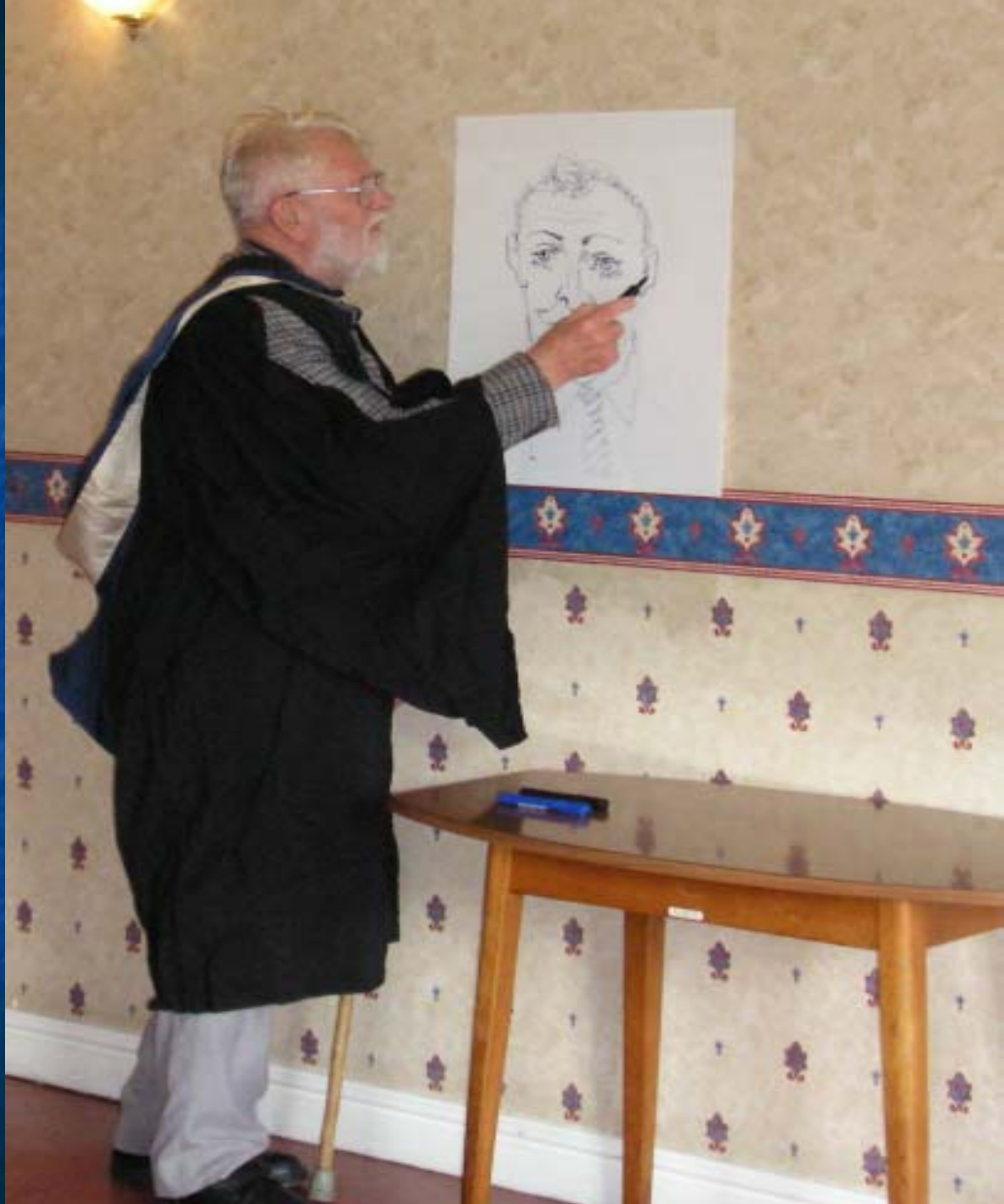
DESIGN

- Pragmatic randomised trial with 1 experimental group per centre & 1 or 2 control groups – either 'active' or 'passive' (treatment as usual)
- In each of the 3 centres experimental groups contribute to training of 2 facilitators plus:
 - London – develop RYCT & 'active' control manuals
 - Bradford – refine both manuals
 - Bangor – test refined RYCT manual

Outcome Measures

- For the person with dementia
 - Mood (Cornell, RAID)
 - Quality of life (QOL-AD)
 - Autobiographical memory
- For the care-giver
 - Mood - GHQ
 - Care-giving stress (Relative's Stress Scale)
 - Positive aspects of care-giving
- For both
 - Communication and quality of relationship between the carer and patient:
 - semi-structured interviews
 - videos of: non-verbal task eg jigsaw puzzle;
& verbal task eg planning family meal









Battlers and Warriors

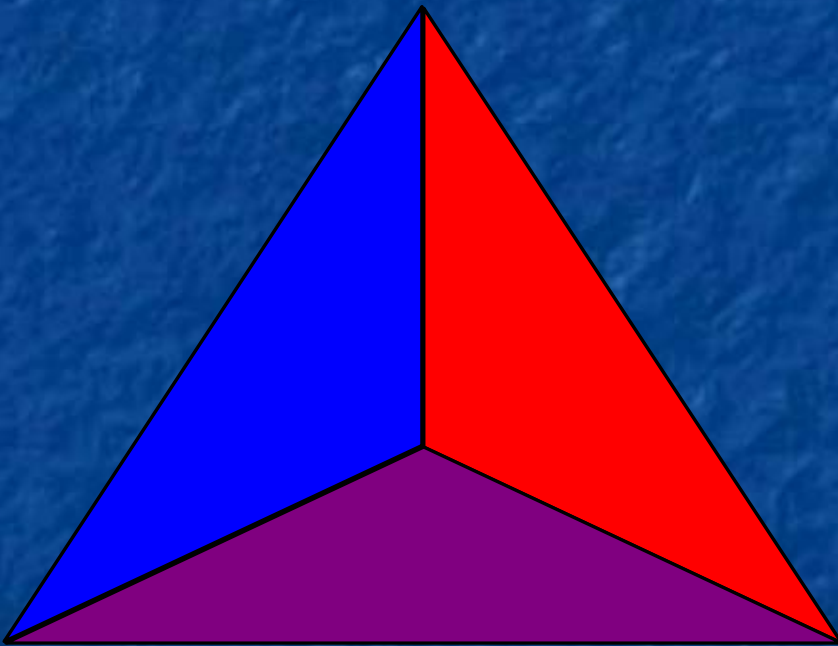
We are the broken and damaged,
but with the help of the great fraternity,
the fraternity of the warriors of the blue elephant
and the battlers from Llandygai

We may not fly like eagles but we will keep our
dignity.

When the great Amen has sounded,
we will have kept our dignity
When the knell has sounded,
we will have kept our dignity.

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Partners in care?

- Staff: Relatives are more trouble than the residents?
- Relatives: The staff are always changing and they don't have time to talk – they never tell us what is happening.

Relationship-centred care

- Maintaining and supporting relationships between person with dementia and family members
 - Do relatives feel welcome?
 - Do they feel able to continue to include the person with dementia in family activities?
 - Do they feel their visits have a meaning and a purpose?
 - Can they find support when distressed?

Relationship-centred care - 2

- Developing positive relationships between care home staff and family members
 - Sharing information
 - Sharing the care
 - Valuing each other's contribution

Dementia Services
Development Centre Wales

Canolfan Datblygu
Gwasanaethau Dementia
Cymru

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