

Meaning and enactment of 'person-centred' care for people in acute care living with dementia

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- ❖ Dominance of older people in the in-patient population; and high prevalence of dementia/cognitive impairment particularly among the oldest old ((Royal College of Psychiatrists 2005; Sampson et al 2009; Goldberg et al 2012)
- ❖ Complexity and multiplicity of need:
 - ❖ Expressive, emotional and communication
 - ❖ Care
 - ❖ Therapy/rehabilitation
 - ❖ Medical
- ❖ Evidence that needs are often under-recognised and inadequately addressed
- ❖ Care delivery to patients with co-incidental dementia on acute wards – litmus test of quality of hospital care
- ❖ Policy priority



Person-Centred Care?

- ‘Person-centred care’ as synonymous with care quality in policy and research
- ‘Slippery’ nature of the concept
- Varied emphasis on different domains/dimensions in social policy discourse and in research:
 - ❖ Holistic or whole person care, choice, respect, autonomy, dignity
 - ❖ Lack of consensus in the research literature (Kogan et al 2016)
- Conceptions of person-centred care in dementia:
 - ❖ Influential work of Kitwood in shaping meaning of personhood: value based approach
 - ❖ Conception of embodiment: challenging assumption of loss of agency including in severe dementia
 - ❖ And their specific application in the context of acute care?

- Research Study:
 - ❖ Data collected as part of a longitudinal, comparative case study to examine the process and outcomes of a system of care (P.I.E. (Person, Interaction, Environment))
 - ❖ Sampling: 10 acute wards in 5 NHS hospital trusts varying in size and type of catchment locality in 3 English regions
 - ❖ Wards comprised 3 medical, care of older people; 2 dementia wards; 3 orthopaedic trauma; 1 acute stroke and 1 older people's rehab ward
 - ❖ Focus on delivery of care in context of spatial, temporal and organisational setting of the hospital ward



Data Collection and Analysis

- Data Collection
 - ❖ 56 qualitative interviews with staff: different levels of seniority and disciplines; selected purposively
 - ❖ General observation of care routines, including handovers, ward rounds and MDT meetings (295 hours)
 - ❖ In-depth case studies with patients and relatives, including people unable to communicate verbally: observation and conversations, medical care records and interviews
 - ❖ Ward based data – patient profile, physical environment and staff profile
- Data Analysis
 - ❖ Interpretive, using grounded theory methods including simultaneous data collection and analysis and constant comparison within and across case studies



Ward & Patient Profile

- Size of wards: some variability (smallest 10, and largest 30) but typically 28 patients
- Physical layout (varied mixes of bays and single rooms; and access to communal spaces)
- Between half and two thirds of patients 85 years and over
- Patients with dementia (diagnosed and identified by staff as having a long term cognitive impairment): varied from 25% to 100% - more typically between a third and half of patients
- Delirium: typically around a quarter on admission; half at some point in stay

- Staff ascribed multiple meanings to the term consistent with policy and research evidence
- Elaboration of meaning revealed considerable variation across wards
- Findings organised around analytical category of ‘knowledge’: meanings, values, and ‘know-how of dementia held by staff; processes used to share and use knowledge in day to day interactions/encounters; which shape what is enacted in the real life context of acute wards.



Forms of Knowledge

- Biographical knowledge
 - ❖ Knowledge of the person:
 - Knowledge as a 'living', dynamic resource
 - Requiring valuing time with patients and legitimacy attached to it
 - Engaging in dialogue with families
- 'Knowing the person' with dementia
 - ❖ 'Knowledge of how dementia affects the person emotionally and cognitively'
 - Connecting in imagination with loss of control and uncertainty
 - Providing a 'handhold' through the acute episode
 - Interest in understanding and supporting intentional and meaningful ways people with dementia expressed themselves
 - Understanding and responding to where the person was at 'in their world'



- A distinguishing feature of wards and staff that engaged with people with dementia was:
 - ❖ the value attached to embodied knowledge in communicating with the person,
 - ❖ understanding that the body was a source of meaningful action;
 - ❖ the need to draw on multiple sources of knowledge about the person in interpreting the meaning of observational cues
 - ❖ the degree of uncertainty and unpredictability about how the person would respond such that strategies employed were built up through trial and error.
- This represented a style of working common in specialist dementia wards and greater or fewer 'pockets of practice in others

- Communicating/ relating in context of work of care
 - ❖ Binary conception of ‘task’ versus ‘person-centred’ overly simplistic: continuum of communicative practices
 - Attention on process and conduct of task: opportunity to engage in personally meaningful conversation
 - Task work –talk to facilitate conduct of task
 - Task as primary focus: process as impersonal and patient as object
 - Task as sole focus: staff unresponsive to patient’s expressed emotion – patient as object and ‘other’
- Dedicated time with patients
 - ❖ Building on forms of knowledge to engage with the patient ‘in their world’

- Anticipating need
 - ❖ Attentiveness to expressive and non-verbal cues based on person knowledge and that such cues convey meaning
 - Seeing a patient standing at the ward entrance – in context of knowledge of this patient waiting for her children to come out of school
 - More prosaically, with a puzzled expression getting up to move – wanting the toilet but disoriented
 - ❖ Affected by the physical and care environment
- Enabling approach
 - ❖ Routine care tasks as an opportunity to support rehabilitation needs. For example toileting as an opportunity to mobilise and not a chore
 - ❖ Therapy work aimed at supporting competence and sustaining residual skills



Responding to Distress

- Patients with a co-incidental dementia at high risk of experiencing distress
 - ❖ Pain and discomfort as a consequence of being ill and medical procedures carried out
 - ❖ Anxiety about recovery and ‘going home’
 - ❖ Uncertainty and loss resulting from effect of cognitive loss, including loss of competence
- Literally and metaphorically providing a ‘handhold’ to the patient
 - Sensitive use of touch and eye contact
 - Openness to embodied communication
 - Knowledge that action and interaction is imbued with meaning although it might not be immediately ‘knowable’
 - Strategies to engage the person as emergent, built up through trial and error and will likely involve creative, tailor made solutions

- Moving forward:
 - ❖ Acute care for people living with dementia not peripheral to, or disruptive of the routine work of ward staff but a central feature of it;
 - ❖ Acute care delivery as encompassing medical, therapy and support suffused with understanding of the person in context of the dementia i.e. a ‘balance of care’ to respond to the complexity of need;
 - ❖ Need for greater understanding of the precise skill-mix, training and resources to provide an appropriate ‘balance of care’ to respond to the complexity of need;
 - ❖ Knowledge and relational features of communication and practice related to, but not wholly explained by values of individualisation, dignity, compassion and respect;
 - ❖ Quality practice in real life acute settings shaped and constrained by organisational and environmental factors.

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