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

Mary Godfrey, Rosie Shannon, Anne Skingley, Rosie Woolley & John Young

Academic Unit of Elderly Care and Rehabilitation, University of Leeds
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?
What is Quality Care in Practice?

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.”
Communication

- 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’
Enactment in Care Work

• 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
Conclusion

• 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.
This paper and the research on which it is based was funded by the National Institute for Health Research (NIHR), Health Services and Delivery Research Programme (HS&DR). The views and opinions expressed by the authors are those of the authors and do not necessarily reflect those of the NHS, the NIHR, NETSCC, the HS&DR programme or the Department of Health.

m.godfrey@leeds.ac.uk