What Happens when People Living with Dementia come to Acute Care?

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Presentation

Background
Approach
Findings
Recommendations
Ongoing Work
Background

• Research Intent
• Partnerships
• Three Projects
  – RACF & Emergency Department
  – ED (observation)
  – Case study Acute Care Wards
    • Observation
    • Interviews
    • Medical records
Central Tenets of Research Approach

• Practice Development
  • Evidence base
  • Person Centred Care
  • Change Agenda
  • Critical Enquiry
• Involvement of people with living with Dementia
• Collaboration
Frightening Place
Transfer of Person Centred Information

The RACF

- Driven by management requirements
- Occurred in a reactive space
- Person centred information was prioritised in relation to other information
- Difficulty of utilising advanced care directives
- Requires more understanding of Paramedic or ambulance clinician role - as gatekeepers
Transfer of Person Centred Information

The emergency department

• Information was primarily used to facilitate medical decision making & enabling nursing task completion
• Impacted by participant understandings of the context of work role and managing care with available resources
• Preference for information fitting into culture of assessment and management priorities (reflects RACF)
• Focus on continuity of care is secondary to trajectory of moving patient through the system
What did Participants say?

• “But, so you’re not only trying to deal with the clinical situation that requires an ambulance and immediate transfer but you’re also trying to deal with the administration work as well” (RACF: RN)

• ‘…you end up sifting through 50 bits of paper to find something that says what you’re looking for… and then [pause] it’s a bit ambiguous’ (ED RN)
“We want you [GP] to let us know where to, what… I have to make a decision with a patient I’ve never met before and who’s just turned up in the Ambulance there. Tell me what to do. Cause they’re not my patient” (MO)

[The letter says] ‘assess’- well assess what?
The Angst

• Clinicians expressed
  – Frustration
  – Anger
  – Inadequacy
  – Satisfaction with the ‘good story’

• Acknowledgement that care is not ideal
  – Constrained by the systems in place
  – People with dementia don’t belong in acute care
  – Care is not aligned with best practice
As soon as we walked in, they welcomed me, they shook my hand, they shook Dad’s hand. They told me exactly what was happening. They said, ‘Don’t worry about it, we’ll look after ya’. And they were just so caring. And it wasn’t just come in for two minutes and then out. They were in there for five minutes, sometimes ten minutes. Talking to Dad, going through everything. It just, it felt really safe and at home, you know? They were absolutely brilliant. You could not fault ‘em. (CS1)
Case Study: Talking about ED

..because we were there they didn’t have to come near him, like…and they virtually left him to us.
..and down in there I think that was the part where I thought well, this isn’t very good really. If we hadn’t been there, they’d have to come and help him more.
I think it was frustrating really. And I was angry really. Because I could tell he was very sick. And it’s very hard to keep someone in the bed, of his size as well, because he’s not a small man. (CS4)
Observation in ED

- Visibility of medical equipment is minimal
- Cubicles are fitted with a bed and comfortable chair
- Clear paths are maintained to toilet and bathroom which are clearly marked
- Wall markings, hand rails, toilet seat coloured to clearly delineate position
Observation in ED

- White board in cubicle to place information and assist orientation
- Availability of multiple distraction activities to assist in settling patients
- Maintained as a quiet area, where there is no thoroughfare to other areas of ED
- Doors to unit should remain shut
Observation in ED

- Person centredness at low levels
- Focus on assessment
- Hydration and nutrition subject to individual practices
- Noisy
- High thoroughfare level
- Low levels of use of distraction
- Focus on acute presentation
Allied health team member comes and chats, tells Mrs Smith why she is here and her husband will be here soon. Mrs Smith again asks for help to ‘get out of here’ ‘put my shoes on’ ‘help me please’ refuses to eat or drink – too distracted

This scenario continues for 45 minutes and is very tiring…. 

Mr Smith arrives. Advised that they need to wait for medical review prior to discharge. Mrs Smith almost magically transformed…he helps her get dressed, gets her to have a further cup of tea, waits patiently. Mrs Smith still uses constant questions, but more settled, walking around unaided.
When I arrived Mr Brown (reportedly with advanced
dementia and # NOF) was sleeping and
comfortable, Mrs Brown was asleep in recliner. A
phone call indicated he was to be collected for
OT. No-one had time to relay this to Mrs Brown
as the orderly appeared to transfer to OT. Mr
Brown remained sleeping as he was transferred.
Mrs Brown appeared a little upset, she asked
where he would go after theatre. ED staff stated
they were not sure but he would be about an
hour, so go and have a cup of coffee we should
know which ward he is going to then. Mrs Brown
stated ‘I will do anything to help them, let them
know I am here, he needs me’. She left looking a
little bewildered
Findings

- Importance of knowledge, skill & confidence of health care providers
- Importance of family
- Importance of clear communication
- Importance of negotiating care
- Patient/ family stories are powerful
Case study

• Recruitment on wards
• Followed 8 patient journeys
• Observation
• Interviews
  – Health care professionals
  – Families
  – Individuals
• Medical Histories
Findings: Environment

Noisy, confusing
Safety considerations were paramount
Nursed in single, double, four bed rooms
Moved multiple times on occasions
Relationships to Support Care

- Multiple care providers
- Support of family
- Little history taking and sharing in this area
- Small things like knowing a person's dog's name altered care
- Kindness to family (e.g. cup of tea) improved relationships
Impacts on Environment & Relationships

• One shift at a time
• When quiet PWD were left alone
• Carers’ were the experts but were not always listened to
• Environment was the domain of health care providers and foreign to others
• Too much time for those living with dementia
• Too little time for care providers
Key Tension

• Caring for one
• Caring for many

• Essence of why it is hard to translate evidence into practice
• Impact of accepted discourse that PWD do not belong in acute care is counterproductive
What Can be done?

• Negotiate care with family
• Ask simple questions
  – What is the most important thing for you?
  – What helps this person to feel more comfortable?
• Be attentive to alleviating boredom, assisting with activity.
• Recognise that this client group will grow & will be attending acute care
‘I would like you stop asking us what we want, to stop assessing us and to actually act on what we have said’
Where to from here

Group of ED clinicians working right now to improve understanding and management at the entry point

Need to work with partners to enhance communication and understanding of needs

Keep abreast of changes
there are multiple projects addressing issues
Acknowledgements

Every single individual and group who has supported the projects so far
Those living with dementia who have given their time, allowed us to observe care, shared their experiences and provided insight into their journey.

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