

A qualitative study of healthcare workers' perceptions and experiences of using personal information documents for people with dementia



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Background



- Growing numbers of people living with dementia: often have complex co-morbidities, core hospital users
- The process of hospital care is more complicated for people with dementia:
 - **affects treatment, care and recovery in hospital (Health Foundation, 2011)**
- Hospitals must be able to effectively meet the needs of people with dementia (Oliver et al. 2014) and provide the high quality care needed (Alzheimer's Disease International, 2016).
- However, care pathways for people with dementia, the care environment, ethos and resources in hospital all need improving (Houghton et al., 2016),

Background

- Person-centred approaches: considered synonymous with best quality care for people with dementia (Edvardsson et al. 2010; Oliver et al., 2014)
- But: hospital care often task-orientated - a lack of focus on the individual (Clissett et al. 2013; Dewing & Dijk, 2016).
- Negative effects on dementia from hospitalisation due to the tensions between the prioritisation of acute care for concurrent co-morbidities, and the provision of person-centred dementia care (Dewing & Dijk, 2016).
- People with dementia may experience multiple moves in hospital, encounter numerous different staff, within an environment that lacks attention to psychosocial needs (Thompson, 2017).

Personal information documents for people with dementia



- A caregiver who gets to know a person with dementia, is better placed to initiate conversations and meaningful activities (Edvardsson et al., 2010)
- Personal information documents (or personal profiles) draw on the principles underlying life story work (getting to know the person who has dementia), by recording key information in a brief and accessible document for staff to use.
- Most life story research has been conducted in long-term settings or services, notably residential care (e.g. Berendonk & Kaine, 2016; Edvardsson et al., 2010)
- Personal information documents are not strictly life story work but may help to increase understanding of the person and improve individualised care in a simple and practical way (Thompson, 2017).
- Alzheimer's Society 'This is me' leaflet, first published 2010: an example of a tool for recording personal information about an individual with dementia

'This is me': example of a personal information documents

- Alzheimer's Society 'This is me' https://www.alzheimers.org.uk/download/downloads/id/3423/this_is_me.pdf can be used in any setting to help facilitate person-centred care and has space to record:
- Preferred name and background (family, friends),
- Current and past interests, jobs and places lived and visited,
- Routines important to the person,
- Things that may worry or upset the person, what makes the person feel better if they are anxious or upset,
- Hearing and eyesight, communication method, mobility, sleep, personal care, how the person takes their medication, eating and drinking, other information.



Use of personal information documents



- Royal College of Psychiatrists' (RCP) audits of hospital care for people with dementia: growing use of personal information documents 2011-2017
- 2017 RCP audit: 99% of hospitals reported having a system for personal information documents for people with dementia but policy-practice gap:
 - Only half the patients audited actually had such a document and there were gaps in the information collected
 - Only 60% of staff reported having access to the personal information they needed to care for individuals with dementia
- Little evidence of how they are used in practice, what optimises their use or what impact they have on care for people with dementia in hospital

Study aim and method



The aim was to analyse healthcare staff's perceptions and experiences of using personal information documents for people with dementia.

Research questions:

- What are healthcare staff's perceptions and experiences of using personal information documents for people with dementia?
- How do healthcare staff use personal information documents for people with dementia in practice?

Method: A secondary thematic analysis of data from a larger qualitative study that was based in a National Health Service Trust in England – investigated impact of a dementia awareness project 'Barbara's Story'

Barbara's story project: background

- 'Barbara's story': developed as a drama that engages staff with the experience of a woman with dementia: shows Barbara's perspective throughout – 'through her eyes'
- Goal: to improve awareness about dementia across all Trust staff
- Set in a large integrated Trust in London
- Qualitative study investigated staff perspectives of the effect of Barbara's Story on themselves, their colleagues and the organisation (Baillie et al. 2016)



Phase 1 Barbara's Story commenced
September 2012

1) Immediate written
responses

2) Focus groups conducted
August-September 2013



Phase 2: Barbara's Story second film series
shown September 2013-March 2014

Focus groups held April-September 2014

Personal information documents in the Trust and secondary analysis



- At the same time as the dementia awareness project, the Trust was implementing initiatives to improve care of people with dementia.
- One initiative was: 'This is me'
- One film featured a nursing assistant completing 'This is me' with Barbara.
- In the Phase 2 focus groups, there were detailed discussions about using personal information documents, in particular, 'This is me' – occurred in 12 of 16 focus groups, and 1 of the 3 individual interviews
- Mainly arose from focus group questions about personal experiences and observations of care delivery, and changes in the organisation.
- Secondary analysis: Phase 2 transcripts reviewed for relevant content: data extracted, then thematic analysis

Findings: four themes



- Understanding the rationale for personal information documents;
- Completing personal information documents;
- Location for personal information documents and transfer between settings;
- Impact of personal information documents in practice

Understanding the rationale for personal information documents



- Personal information documents such as ‘This is me’, helped staff to focus on the person, rather than the medical condition:
 - *I think as soon as you find out someone has got dementia you relate everything back to the disease and that’s what they don’t want, to be defined by dementia, that’s the whole point of ‘This is me’, remember who I am, not the illness that I have (Nurses8)*
- The information could act as a communication tool:
 - *When you see a patient with dementia who is distressed, it could be a simple fact that they want something but they can’t effectively communicate it to you. But if you’ve got some sort of [information about them], it can help (Nurses4)*
- Essential information for caring for a person with dementia, especially as they were often not accompanied by someone who knew them (Nurses6)

Completing personal information documents



- Important to establish the best process for completing the documents: who completes the document, at what stage and in what setting? Otherwise documents might not be fully completed or indeed at all.
- Discussions revolved around the role of families and healthcare staff, involving the person with dementia at an early stage, and the feasibility of completing the documents in care homes, community or hospital settings.
 - It should be the family, friends, the people who know the individual. The individual if they still have the ability [...] The moment a person is diagnosed they should have it. (Nurses4)
- Nurses described giving the document to families to complete, or showing them how to access it from Alzheimer's Society website (Nurses1; Nurses4).
- Varied experiences of personal information documents accompanying people into hospital from care homes

Completing personal information documents (Ctd)



- There were examples of hospital staff completing the document effectively, when families were unavailable, e.g. a patient from a care home whose wife was only rarely able to visit, was on the ward for 2 weeks and the staff completed 'This is me' as a team over time:
 - Every nurse always found the time to have a little chat with him, then maybe go back a little bit, 'What did you do when you were young', and 'what's your favourite things?', and eventually over days and days they do start telling you all these important things, which then went into 'This is me', which became a great tool
- Also discussed: 'specials' giving one-to-one care could complete 'This is me':
 - really get to know your patient, enjoy being with them, what are they like, and really valuing that person. (Therapists2)

Location for personal information documents and transfer between settings

- Lengthy discussions about practical issues, e.g. where to keep completed personal information documents, so they are accessible and easily found, and how to transfer the document between settings with patients
- Should accompany patients within the hospital and between settings but who is responsible?
- Linked to a wider issue about working in a more integrated way e.g. how relevant information about care home residents could be shared and accompany patients who attend hospital in an emergency (Nurses6).
- *It's all very well us filling them out when they're here [in hospital], and then when they go home, how do we ensure that that then comes with them, because a lot of patients don't have that family network, it could get lost or is it the paramedic's responsibility for making sure they have it when they bring them here? (Therapists2)*

Impact of personal information documents in practice



- Specific examples of the difference that personal information documents could make to caring for people with dementia, through staff having immediate access to information they could use in their care e.g.
 - knowing preferences that enhanced an individual's experience in hospital,
 - how to approach a person who is distressed.
 - seemingly small details could have a significant impact on the delivery of person-centred care and indeed their safety too.
- *It's nice to know a bit more about them, what they like and don't like, even if it's just down to how they like their tea or they don't like tea. (Nurses6)*
- This is me' helped staff to know the individual as a person: assisted building a relationship and provided information they could include in their interactions (Nurses7, Nurses12).

Impact of personal information documents in practice: example (Ctd)

- A nurse described experiences with a woman with dementia whose daughter died 20 years ago:
- *There is a little box on the bottom of 'This Is me' that says, 'things that may worry or upset me'. So the husband filled it in, she was an elective patient for surgery, vascular dementia, and she'd got 'This Is me', that information was there to say 'when I get anxious I call for my daughter and she died 20 years ago'. (Nurses4)*
- The woman became distressed, started calling for her daughter. Her husband provided information for the staff about how to approach her.
- The nurse considered that being able to relieve the woman's distress alleviated any possibility of sedation, which would have affected the patient's eating and drinking and impacted on recovery. The patient recovered well from her surgery and was discharged as planned.

Conclusions

- Healthcare staff can use personal information documents in practice in ways that support person-centred care.
- Practical issues about the use of personal information documents may affect the optimal use of the documents in practice.
- Preferable to complete personal information documents at an early stage following dementia diagnosis
- Importance of embedding their use across care settings, to support communication and integrated care
- Further research: include perspectives of people with dementia and carers about personal information documents and how they affect care experiences; what processes work best for using the documents, particularly during care transitions.

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