

“You would think that you were the only person in the world.”

What Person-Centred Care means to Family Carers of People Living with Dementia in the UK.

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The Presentation

- Reflections on the methodology, and methods used in collecting the data - the successes and challenges
- Begin to illuminate what person-centred care means to the family carers
- Consider how such accounts can be shared to improve practice

Dementia

- There are 820,000 in the UK with dementia; this is projected to reach one million by 2020, doubling by 2040 (Alzheimer's Society 2014).
- Worldwide in 2013, 44.4 million people are estimated to be living with dementia, with this number expected to increase to 75.6 million in 2030, and 135.5 million in 2050 (Alzheimer's Disease International (ADI) 2014).

Person-Centred Care

- National and international policy supports a person-centred care approach to providing care for people with dementia

(National Collaborating Centre for Mental Health 2006 UK; The Swedish National Board of Health and Welfare 2010; Dalhousie University 2012; National Dementia Strategy, Malta 2015-2023).

Perspectives on Person – Centred Care

- Person / relationship –centred care is achieved through consistent long-term relationships with caregivers (Clissett *et al.* 2013, Nolan *et al.* 2006)



The Project

- Gap in understanding the perspectives of carers of people with dementia about person-centred care across the care and condition trajectory
- Building on methods and approaches of engaging with people with dementia and family carers
- Funding from patient and public involvement (PPI) monies from Sheffield Hospitals Charity
- Developing the PPI element for future research and service developments

Family Carer Participants

- 5 interviews with family carers of people with dementia (2 male spouses, 2 female spouses and 1 daughter) – a range of experiences of primary care, outpatient care, acute hospital care and specialist mental health care
- 2 groups – one with 4 couples speaking together and one of 12 family carers speaking alone

An Invitation to tell their story



Person-Centred Methods

- Having a conduit person who knows the people
- Sensitivity and flexibility
- Being cautious of paternalism
- It takes time!
- Reciprocity
- Demonstrating empathy and understanding
- Creating a safe atmosphere – helped by knowing the person
- Valuing all that is said
- Pacing
- Humour

Person-Centredness across the trajectory of the condition

- *Being Attentive*
- *Support in maintaining relationships*
- *Respect*
- *Understanding and awareness of dementia*

Being Attentive

“They are such lovely girls, I could not fault one of them, they always say ring anytime, I rang them out of hours over the weekend and you would think you were the only person in the world.”

“The ward manager spent time with me on more than one occasion, but I could just tell that he had other people, other things on his mind.”

Support in maintaining Relationships

Staff can assume that care involves the carer spending time alone, some couples want to continue to spend time together and good care involves supporting them to do activities or going out together. Carers want options and not assumptions.

“The homecare support really helps – it saves us getting fraught, it makes a big difference the carer can come and help him get dressed and I can be more like his wife.”

Respect

- Respecting the 'person' with dementia / family carer
- 'Knowing' the person with dementia and their family carer
- Communication with the person with dementia and their carer
- Instilling confidence in the person with dementia and their family carer

Understanding and awareness

“My wife experienced pain during a cataract operation due to insufficient anaesthetic eye drops; the doctor did not understand that he needed to keep reminding her that she should squeeze his hand if she was uncomfortable”

“People don’t know what you do as a carer, the effort you have to put in to get (name) turned out. Getting (name) showered isn’t easy and we start going to bed at 9am as it takes at least an hour - no-body sees all the effort.”

Next Steps

- Building on these accounts to make the case for a research proposal
- Making a difference to care – how can we ensure that accounts from people with dementia and from family carers makes a difference to practice?
- Start with some case studies in some specific clinical areas – the eye clinic, an older persons medical ward
- How can we use these accounts in health care professional's education?