THE PERSPECTIVES OF PEOPLE WITH DEMENTIA ON DAY AND RESPITE SERVICES: A QUALITATIVE INTERVIEW STUDY

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Introduction

- What is respite?
- Multiple models
- Effectiveness?
- Acceptability?

Tom Kitwood (1997)

Kitwood (1995) defined a new ‘person-centred’ dementia care

- Began a paradigm shift, away from the biomedical perspective, towards a more holistic perspective

- He argued that care must meet the psychosocial and ‘**personhood’*** needs of people with dementia also.

- **“a standing or status that is bestowed on one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust…” (Kitwood 1997: 8)*.

Tom Kitwood (1997)

One of Kitwood's main concerns was that person-centred care, if adopted at all, would only be done so superficially, through the strategic use of discourse and window-dressing:

"It is conceivable that most of the advances that have been made in recent years might be obliterated, and that the state of affairs in 2010 might be as bad as it was in 1970, except that it would be varnished by eloquent mission statements, and masked by fine buildings and glossy brochures".

Aim

- To explore, through the lens of personhood, how people with dementia experience respite and day services, and the care provided to them in these settings.

Methods

- Part of a larger study with 35 key stakeholders

- Convenience sampling; recruitment through service managers…

- Process consent method (Dewing, 2007)

- Qualitative semi-structured interviews (n=6) employing an empathic approach (20-65mins), spoke to carer first

- Thematic analysis as per Braun & Clarke (2006) – saturation…

Participant Characteristics

Pseudonym	Sex	Age	Diagnosis	Dementia Severity	Marital Status	Living arrangements	Ethnicity	Services used*
John	M	80	Alzheimer's disease	Mild	Married	Wife, 81; Urban	White Irish	DS, RR, IH, HH
Anna	F	68	Fronto-temporal	Moderate	Married	Husband, 71; Rural	White Irish	DS, RR, IH, HH
Adam	M	80	Alzheimer's disease	Moderate	Widowed	Son, 44; Urban	White Irish	DS, RR, HH
Cora	F	86	Alzheimer's disease	Moderate	Widowed	Friend, 76; Rural	White British	DS, RR, HH
Noelle	F	58	Alzheimer's disease	Mild	Married	Husband, 60; Urban	White Irish	None
Bill	M	74	Vascular dementia	Moderate	Divorced	Daughter, 37; Urban	White Irish	DS, RR, HH

Themes

Acceptability

Meaningful Engagement

Interpersonal Personhood

Narrative Citizenship

Acceptability

“for €12 it’s well worth it… we get our coffee and tea and a bun in the morning and then we get our lunch and a dessert and coffee or tea after that… and we get a bus… I think it’s terrific

“I can’t see why I have to… ‘you must go to day centre ’… I don’t want to… and when there’s so much to do at home… I don’t want that respite… I don’t want to go and stay anywhere… I need to have my own thing here [indicating at home, interview conducted in his sitting room]*”*

“Some people don’t speak much… I find that silence is deafening sometimes… I would like something a bit more discerning and be surrounded by people who can say we didn’t like this or that today… I come home and say to my wife.. Well I find myself complaining to her about the quality of the course [day service]*”*

Meaningful Engagement

“It was unbelievable there… I had nothing to do all day only walk around in a circle…”

“before I’d have a lot of people asking me if I’d come over and have a look at this and that in the department… I’d still have a person say to me what do you think? I used to love that actually… there are a lot of people out there actually and they would go around and they say to me please come over and I’d give them what they need… but it’s a thing that I used do outside of this thing now”

Interpersonal Personhood

"the people all the staff are terrific… the two boss ladies are fantastic… very kind and careful and helpful…"

- *"they're leading everyone up/down the pathway… it needs to be more sincere…but it's not at all… there's no real respect, it's like I don't matter…that I'm not worthwhile counting… I'm not a person"*

Narrative Citizenship

“there were two staff one day who decided to teach me a lesson… and eh… I could move my seat… so I could move it but not a certain distance because they threatened to block me… and that in a sense is threatening to block my ideas… and eh… and that turned out nasty… I got so annoyed with her... do you see this stick here? I used this with both of them [staff members]…I mean I didn’t ever think it would come to that”

“nobody asks the right questions… therefore they are all losing out on an opportunity of learning from us… what do they like… how do you know they like it… when did you last ask them? They are making a mistake of the market…”

Discussion

- **Preference for home- and community-based models**
  - Gov. spending over twice as much on residential care than on community-based care
  - Homecare is not provided on a statutory basis
- **Meaningful engagement must be individually-defined**
  - People with dementia want to experience reciprocity, have valued roles
  - How can we create opportunities for reciprocity?
  - Perhaps looking at this as ‘care’ is not helpful – a desire to be “*more than just the cared for*”
- **Personhood and Narrative Agency**
  - Clear instances of disempowerment, infantilisation, stigmatisation, invalidation, imposition, disparagement and disingenuous interactions
  - Need to tackle biomedical constructions, schema about dementia, as well as organisational and resource barriers
    - (staffing, training, high volumes of administrative work, cultural focus on the physical)

Conclusion

- Person-centred care is not care-as-usual. While many services may indeed provide consistently person-centred care, this study shows that an implementation gap may still persist in some services.