

The Negotiation of Relationships and Care: The impact of emergent age-related factors upon the experience of dementia

Edward Tolhurst

School of Social Work, Allied and Public Health, Faculty of Health Sciences, Staffordshire University

This article is an executive summary of a thesis accepted in partial fulfilment of the requirements for the degree of 'Doctor of Philosophy' from the Centre for Ageing and Mental Health, Faculty of Health Sciences at Staffordshire University

Overview

Critical analysis is undertaken of how the negotiation of relationships shapes the experience of dementia for men with the condition and their spousal carers. The manner in which age intersects with the experience of living with dementia is also explored. A sociologically-informed approach is adopted which sets out to explore how personhood (Kitwood, 1997) is shaped by complex intersections of subjective experience, interaction and broader social contexts.

Dementia is a neurodegenerative condition that is associated with disturbance of multiple functions including language, comprehension, thinking and memory (Hughes, 2011). In the UK it is estimated that about 850,000 people have dementia (Alzheimer's Society, 2014).

Context

A small number of qualitative research studies employ a joint interview approach to seek the views of couples living with dementia (e.g. Robinson, Clare & Evans 2005; Davies, 2011), but interaction has not been addressed in a methodical fashion. The literature review process highlighted that these dyadic studies tend to present data in an individualised format. In addition, the focus on age in dementia research is oriented towards those with young onset dementia (e.g. Harris & Keady, 2009), with the experience of older people presented in age-neutral terms (e.g. Caddell & Clare, 2013).

Method

Semi-structured joint interviews were undertaken with men with dementia and their carers. Each set of respondents was interviewed on two occasions, with a six-month interval between interviews. This approach was employed to ensure greater depth of data, in addition to obtaining longitudinal insights. A distinctive incremental analytical approach was adopted: this included exploration of subjective perspectives expressed by both participants, and then interrogation of how these perspectives are interwoven within dyadic exchanges. Thematic and narrative approaches were utilised to grasp how subjective experience intersects with interactional/dialogic contexts and influences (Riessman, 2008).

Sample

Recruitment was undertaken via the NHS and dementia support organisations. 14 couples were interviewed on a joint basis, and a further two carers were interviewed on a one-to-one basis. 15 couples were mixed-sex and married; one dyad was same-sex and not married. A total of 31 interviews were completed: 25 joint interviews and six one-to-one interviews. A broad age-range of respondents was recruited, with the men with dementia aged from 58 to 89; the carers were of a similar age-range, from 55 to 84. This enabled

evaluation of age-related elements of experience that extended beyond a focus on young onset dementia. One man with dementia in the sample was Afro-Caribbean, the other participants were White-British.

Results

Men with dementia

Ongoing expressions of skills and competence were of key concern to men with dementia, in addition to reflections on past achievements. While frustrations with the impact of the condition were conveyed, men often presented an account based on continuity; for example, highlighting their ability to carry on with their lives 'as normal'.

Carers

Multiple challenges and frustrations were conveyed by the carers, with caring roles being extensive in a practical sense and emotionally impactful. Guilt was also expressed by carers for feeling such frustrations. Despite encountering multiple personal challenges, a principal concern for carers related to moral dilemmas; for example, a key aim was to avoid burdening others, such as younger family members - or even society more broadly.

Interactional data

While the negotiation of relationships is intrinsically complex and varied, a collision of narrative strategies between men with dementia and their carers was identified (*see also*: Clare & Shakespeare, 2004). Men with dementia seek to present accounts based on continuity that reinforce their positive sense of self, whereas carers pursue accounts based on change that are consistent with their feelings of frustration.

Age

While younger members of the sample did encounter additional challenges, age-related impacts on experience were complex and older people also expressed intense difficulties arising from the impacts of living with dementia.

Conclusion

A key practice-based insight related to the role of cognitive function tests in diagnostic and monitoring interventions. These tests presented multiple experiential challenges to men with dementia, including threats to their sense of personal competence. It is recommended that the biomedical focus on the efficacy of these tests needs to be supplemented with social scientific research on how assessment processes impact upon well-being.

The challenge of making plans for the future was also strongly conveyed in this research. It is argued that planning for the future actually contravenes cultural principles of caring. Being a 'good carer' means caring for as long as reasonably possible; openly anticipating the point at which care will be 'relinquished' is therefore incompatible with this moral imperative. The Dementia Strategy for England (Department of Health, 2009) emphasises the requirement to help people with dementia and their families to make plans for future care. This research demonstrates that this policy goal requires much closer consideration.

Interactional insights generated by the joint interview approach demonstrate that a new model of qualitative dementia research is required that seeks a balance of perspectives from people with the condition and their carers. Relational contexts of experience should be evaluated in a more methodical manner to elucidate how subjective perspectives are expressed and challenged within interactional settings. The link between this interactional order and broader socio-cultural impacts must also be addressed. Enhancements to the understanding of socially-framed interaction has clear practice-related implications, as professionals must negotiate family dynamics during clinical interventions. In addition, a more credible notion of how social location shapes personhood should be developed that can address the impact of status characteristics such as age and gender in a more cogent

manner (Bartlett & O'Connor, 2010). An approach to dementia research informed by *the sociological imagination* (Wright-Mills, 1959) can place the understanding of personhood on more credible relational foundations.

References

Alzheimer's Society (2014) "*Dementia UK: update*" (2nd ed), Available from: http://www.alzheimers.org.uk/site/scripts/download_info.php?downloadID=1491

Bartlett R & O'Connor D (2010) *Broadening the dementia debate: towards social citizenship*, Bristol: The Policy Press.

Caddell L & Clare L (2013) A profile of identity in early-stage dementia and a comparison with healthy older people, *Aging and Mental Health*, vol.17, no.3, pp.319-327.

Clare L & Shakespeare P (2004) Negotiating the impact of forgetting: dimensions of resistance in task-oriented conversations between people with early-stage dementia and their partners, *Dementia*, vol.3, no.2, pp.211-232.

Davies JC (2011) Preserving the 'us identity' through marriage commitment while living with early-stage dementia, *Dementia*, vol.10, no.2, pp.217-234.

Department of Health (2009) *Living well with dementia: a national dementia strategy*, London: DH Publications.

Harris PB & Keady J (2009) Selfhood in younger onset dementia: transitions and testimonies, *Aging & Mental Health*, vol.13, no.3, pp.437-444.

Hughes JC (2011) *Alzheimer's and other dementias*, Oxford: Oxford University Press.

Kitwood T (1997) *Dementia reconsidered: the person comes first*, Buckingham, Open University Press.

Riessman CK (2008) *Narrative methods for the human sciences*, London: Sage.

Robinson L, Clare L & Evans K (2005) Making sense of dementia and adjusting to loss: psychological reactions to a diagnosis of dementia in couples, *Aging & Mental Health*, vol.9, no.4, pp.337-347.

Wright-Mills C (1959) *The sociological imagination*, Oxford: Oxford University Press.