Exploring stress as experienced by people with dementia: a contribution to understanding the potential for recovery.

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Why this area of research?
Methodology

Interpretative Phenomenological Analysis

- Persons – making sense of experience
- Subjective domain
- Understanding the particular
- Systematic, depth and rigour

Smith, Flowers, et al. (2009)
Method

- 5 focus groups
- across Scotland
- 21 participants with dementia
Themes

- Something’s torn – your life’s torn.
- Families can bring stress.
- The stress of living with dementia.
- A whole new set of rules.
- It’s our lives and we’re going to get under control ourselves.
‘Something’s torn – your life’s torn’

‘I’m not able so far to accept … that I’m not the person that I was – because I’m not’.

Sandra
‘Families can bring stress’

'I know in there (points to head) she means well, I know she does what she does for my benefit... a lot of people try to tell me she's just trying to help - which she is...'
"We all experience it. It’s like shutters going down’

‘Not knowing is worse than knowing’
A whole new set of rules

‘I think I can go a wee bit further and I don't see any time that I would be told start again - everything will be alright.’

Fred
It's our lives and we are going to get it under control ourselves

'I think you’ve got to look for a balance in yourself … having your carer’s fine … but you’ve still got to find your own answers.'

Ian
Conclusions

- Grief experienced by people with dementia is poorly understood and misinterpretation may prolong stress and undermine recovery potential.
- Attention to stress and coping can play a positive part in supporting the person with dementia to exercise control over key aspects on their lives.
References


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