From professional to the personal: dementia care practitioners as family carers

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Context of the study

- Evidem- MCA - 5 year research programme to explore implementation and practice of Mental Capacity Act 2005 by dementia care practitioners
- 123 interviews with range of social care & primary care practitioners in England about MCA
- 70/123 had personal experience of dementia caring (57%)
- Risk of bias but personal experiences not part of recruitment
At end of qualitative interview... we asked

1. Have you had experiences of looking after someone with dementia in your own family or network e.g. partner/friend? Have these affected any of the matters we have been talking about?

2. Finally, have you been thinking of making any plans yourself or for a person you know (e.g. discussion with parents or partner) about this area? If yes, please outline.
<table>
<thead>
<tr>
<th>JOB ROLE AND PERSONAL CHARACTERISTICS</th>
<th>BY GROUP PARTICIPANTS</th>
<th>BY GENDER</th>
<th>BY AGE (IN YEARS)</th>
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</thead>
</table>
| Specialist community nurses (dementia) | 19 (13 had personal experience of dementia/caring) | Male = 3  
Female = 12 | Range = 35–68  
Average = 51 |
| Care home managers and senior care staff | 28 (18 had personal experience of dementia/caring) | Male = 3  
Female = 25 | Range = 28–68  
Average = 45 |
| Care home workers | 17 (2 had personal experience of dementia/caring) | Male = 0  
Female = 17 | Range = 20–68  
Average = 45 |
| Safeguarding adult coordinators (social workers) | 17 (12 had personal experience of dementia/caring) | Male = 2  
Female = 11 | Range = 29–57  
Average = 49 |
| Local Alzheimer’s Society staff | 10 (6 had personal experience of dementia/caring) | Male = 4  
Female = 6 | Range = 30–63  
Average = 41 |
| Other voluntary sector staff (including carer centers and voluntary associations) | 22 (13 had personal experience of dementia/caring) | Male = 7  
Female = 15 | Range = 22–76  
Average = 46 |
| Social services staff | 10 (6 had personal experience of dementia/caring) | Male = 1  
Female = 9 | Range = 28–61  
Average = 44 |
| **Total** | **123** (70 had personal experience of dementia/caring) | Male = 20  
Female = 95 | Range = 20–76  
Average = 46 |
Four Themes

• Considering care profession (I can do this work)

• Informing practice (I know how difficult it is)

• Greater empathy (I know what it’s like)

• Personal agency (I need to prepare...)
“because of my experience of my parent, therefore, I now feel more focused having personal experience to have an idea of how to help people”. (Specialist Nurse 6).

“It definitely made me realize what it’s like to be on the other side of the fence, because I couldn’t fathom my way around the services and I worked in them! I don’t know what it’s like for carers who don’t know the system . . . it was a nightmare.” (Specialist Nurse 4)
‘I need to prepare’

“Yes, as a matter of fact I said to my kids I am going to do my own care plan . . . and then one day if ever they need it they can have it, but would like to write my own care plan ...because they don’t live with you . . . they don’t know your likes and dislikes, they know you as Mum, but they forget because they are getting on with their own life and so they forget you don’t like two sugars in your tea anymore, do you know what I mean?”

(Care Home Manager 2)

• “Own plans? Yes, as a result of this [difficulty], myself and my partner, we will make plans. There’s nothing like personal experience to sharpen the focus. We’re in the process of the Lasting Power of Attorney and Court of Protection [for a relative].”

(Safeguarding Adult Coordinator 1)
Implications

• Are dementia services carer friendly places to work?
• Are practitioners’ experiences valued?
• Are practitioners able to make changes?

• Picture: Carers UK Summit London 2013
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