Poking and prying with a purpose.

Research on family caregiving in dementia.

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Why the focus on family caregivers?

- Demographic trends and prevalence of dementia
- Older people want to stay at home and ‘age in place’
- Family support is necessary for this to happen
- Benefits and costs ........for whom?
- Recognising the expertise of family caregivers
Caregiving as a series of transitions

- Role acquisition
- Role enactment
- Role disengagement (Aneshensel et al, 1995)

- Recognising the need
- Taking it on
- Working through it
- Reaching the end
- A new beginning (Keady, 1999)
Physical Impact

“I did it all myself. I knew that he wouldn't want anyone else. It was me he wanted. He didn’t know it but it was me” (wife)

“He can be very aggressive.....that’s very hard” (daughter)

“When it’s time to get up, I’m exhausted. I’ve only been asleep for about an hour but I have to get up...no choice” (wife)

“I would get up in the morning and she would be soiled and she would have to have a shower. I would be sick after it” (son)
Psychological Impact

“Kyle (son) would say that I wasn’t there for him. I have really neglected him in the years that I shouldn’t have...those teenage years. I just wasn’t there for him” (daughter)

“Things are really bad now because he doesn’t know me, It is the toughest things...me there 24 hours a day, no sleep and he doesn’t even know me” (wife)

“I look back and see how I have neglected my own family over the years. Help was needed and there was nobody else to provide it. You were left in the middle trying to balance everything. It has its effects” (daughter)

“I’m both a wife and a widow”
Social Impact

“You just feel abandoned....you feel that there is nobody out there” (daughter)

“It’s only when I walk into the house on my own...Oh God, and realise the loneliness of this work” (wife)

“I find that the worst days are the days that I cant get out” (husband)

“I don't do lots of things that I used to do. I don't say I miss them. I miss the ability to do them more than I actually miss them” (daughter)
Living with risk

“Your fear for years is that you would go in some morning and find her dead but you know that she would not have wanted to move out of her home” (daughter)

“She had candles lit all around the house and near the curtains in the hall. God knows what would have happened if I hadn’t walked in!” (son)

“I got the smell of burning. She had wrapped bananas in a tea towel and put them into the oven” (husband)
Needs of caregivers

Information on:

- Dementia, causes and progression
- Managing behaviour and aggression
- Counselling and coping strategies
- Financial advice

“One of the biggest thing is the lack of information....sometimes you feel that they are putting you round in circles” (wife)

“It is important to know what you are dealing with. There are decision to be made and if you don't have the right information, you can’t make the decisions” (son)

“Some kind of counselling would be good” (daughter)
Needs of caregivers

Support:
- Family and friends
- Health and social care professionals
- Respite services

“My partner is very good...he is not emotionally involves and he is a good source of support” (wife)

“My brother never helped even though he only lived 5 minutes away” (daughter)

“The social worker wanted mum to go to a home but she chased her” (daughter)

“They kept cutting the home help hours and I couldn’t manage” (son)
Views on respite

- Not a consideration
- A life line
- Unsuitable or expensive
- Stigma attached particularly in rural areas

“She never settled in that whole fortnight...it was just awful”
(daughter)

“I certainly appreciate it, it gives me a chance to clear my head, sit down and maybe read the paper”
(wife)

“I just want a holiday...I don’t want to go anywhere or do anything...I just want a holiday in my own home”
(daughter)
Typology of family caregiver

- The Dutiful Caregiver
- The Detached Caregiver
- The Distant Caregiver
- The Realistic Caregiver
- The Resilient Caregiver
- The Defeated caregiver

Remember:
(1) Caregivers are not a homogenous group of people
(2) The relationship that existed before the caregiving situation arose will have an impact.
The Dutiful Caregiver

“She looked after me for 36 years and now it’s my turn to look after her” (husband)

“You only get one set of parents and the one chance of doing something for them” (son)

“I don't see it as a burden. I only do what I think you should do. As well as that, I know what she wants and I have a fair idea of her outlook on things” (daughter)

“My conscience would not let me admit him to a nursing home, not even for respite” (wife)
The Detached Caregiver

“We felt guilty about the state of the house she lived in but there is only so much you can do” (son)

“I feel that maybe I could do more but you have to live your own life” (daughter)

“My mother should not have to pay for home help. The NHS should provide for her because she is ill” (daughter)
The Distant Caregiver

“We visited every Sunday and he was always dressed but during the week people said that he wouldn’t have shaved for three or four days. You hear these things afterwards” (daughter).

“When he was in hospital, it became obvious that people out there had been looking after him and worrying about him but didn’t want to say anything” (son)

“I was told by the social worker that it is the families that look after the parents. I was told that I should be at home looking after my mother when I had been in England for 33 years” (son)
The Realistic Caregiver

“I knew there was no point in bringing him to where I live for two reasons. First of all, there is nobody in our house during the day and secondly, it wouldn’t have worked out because there would have been disagreements from the first moment” (son)

“She really couldn’t have come here because we have the stairs. We could have put a bedroom downstairs but we felt that once you bring someone into your home, it is a very hard thing” (daughter)

“I do the best that I can and that’s all that I can do” (husband)
The Resilient Caregiver

“ You are very much on your own and you just get on with it and life goes on” (daughter)

“I get through it, I am very resilient. There is not a lot of support from anyone. What I find the hardest is trying to get into his mind and do what he would have wanted. This is an awful thing as we wouldn’t have thought the same” (wife)

“I’m surviving...getting on alright. You sort of adapt into a different routine. The children are away at University” (daughter)
The Defeated Caregiver

“The doctor said that it had to come to an end. It was getting to me but I wasn't giving in to them. He said that it was going to kill me and John would end up in a home anyway” (wife)

“You feel so guilty that you were inadequate as a daughter or as a child of a parent who has to gone into a nursing home....the guilt is so terrible and it doesn't get any easier as time goes by” (daughter)

“I knew that I had to part with him and probably never see him back home. It is still hard...I feel it every time I go down and leave him” (wife)
The Caring Continuum

→ Increasing needs of the person with dementia →

→ Reduction in the carer's ability to cope →

→ Increasing health and social care interventions →

Home care ___________________ Nursing home care
Caregivers characteristics that influence decisions about entry to care

‘Sense of existential self’...... caregivers willingness to make placement–related decisions is influenced by their ability to derive meaning from their lives and a ‘sense of self’ apart from the caregiving situation (Hagan, 2001).

**Role captivity** (Aneshensel et al, 1993)

**Role engulfment** (Skaff and Pearlin, 1992)

Winslow (1998) referred to health and social care professionals ‘giving permission’ for the move to a care home.
The Role of Health and Social Care Practitioners

- Provision of information and support

- Services must adopt a more enabling and facilitative role working with carers as partners in a way which is sensitive to caregivers’ existing expertise and stage of caring history.

- Recognition of the expertise of family caregivers

- **NB** Services should not support caregivers beyond the point at which their own health suffers
The purpose of poking and prying!

The introduction of legislation to safeguard the rights of carers e.g. Carers’ (Equal Opportunities) Act (DOH, 2004)

The centrality of family carers to the success of community care recognised in key policy documents and reports.

Health and social care documentation included an assessment of carers needs

Family caregiving now a part of the curriculum for health and social care practitioners.

Further research on family caregiving with a focus on specific client groups.
On-going research and development

- An exploration of the needs of older family caregivers of older people with learning disabilities at home.

- The experiences of sons caring for a parent with dementia.

- Assessing telecare for carers of older people.

- Enabling older people to stay at home and age in place: the roles, responsibilities and services provided by home helps/domiciliary care workers

- Mental health disorders among residents of care homes: Incidence, prevalence and societal comparisons.