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'I'm not a carer': The identities of children and young people who have a parent with dementia

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Background

- We know the numbers of dementia diagnoses are increasing
- More families will likely include a person with a dementia diagnosis
- Therefore more young people and children will have a parent with dementia
- Although the impacts of dementia on the construction and deconstruction of the 'self' for the patient have been documented (Caddell & Clare, 2010), there remains a paucity of knowledge on children's perspectives of this

The study

- Narrative interviews, thematic analysis
- Interviews with 22 children and young people aged 6 to 30 who had experience of having a parent with dementia
- Up to three interviews per participant lasting 45 minutes and two hours
- Recruited via social media including Twitter and Facebook in addition to the Alzheimer's Society's newsletter, website and forum 'Talking Point'. Further participants discovered the study website while seeking support online.
- Funded by the Alzheimer's Society, UK

The sample

- **Stages:** Yet to obtain a formal diagnosis; diagnosis < less than a year; years post diagnosis; parent deceased
- **Diagnosis:** Young onset Alzheimer's; Frontal Temporal Dementia Posterior cortical **atrophy**; Dementia with Lewys Bodies; Vascular dementia.
- **Living situation:** At home with their parent; parent in a care home; same town but a different home; Parents remained in the hometown, child had relocated
- **Families:**
 - Affected parent: father (12) and mother (10).
 - The sample incorporates only children (4), sibling pairings (4) and divorced parents (4)

Identity

- The condition may impact family relations and therefore identities of children and young people
- Identification is the process by which we understand ourselves and others (Jenkins, 2008); how others view us; how we see ourselves; comparison to others; similarity and differences. There may be a discrepancy between how we see ourselves and how others see us (Jenkins, 2004)
- Familial and peer relationships important to young people's sense of self
- Little known about identities of children with a parent with dementia

Identifying & managing dementia

- Family members become aware of symptoms.

'We reckon...it was when he bought me a Lego set and he couldn't do them. I think it was when he couldn't do the Lego because I would sit with him and he would pick up the wrong pieces and didn't know what to do and he just kept on sighing, saying 'I just can't do it'. (Austin, 8)

- Searching for explanations

'Dad didn't wanna tell us...I was 23 at the time and my Dad was trying to protect us...he just said you know, 'Mum's been diagnosed with a very bad memory but it's not Alzheimer's' and it was only when my sister was home and she found the drugs ...she Googled them' (Elizabeth, 28).

- *'I was getting older and so I thought 'well maybe this is actually her personality, so she's maybe always been like that and I haven't noticed. Maybe she's always been a bit flappy and I haven't noticed', and actually when I was at University I thought 'oh, maybe she's not as clever as I once thought she was and because I'm now maybe at a different intelligence level' (Lily, 23).*

- A child in the family may dictate dementia management. *'We had a meeting, social services were there and that really upset me, the fact for them to be involved. It was what are they gonna do? She said I've got no concerns which was a big relief'* (Amy, 24).
- Evie's father's aggressive dementia related behaviours prompted his placement in care:
- *'He grabbed my arm and he twisted it...He wasn't letting go and I knew that something had changed...I blamed myself completely, I thought if I'd not said anything about him hurting me, he would have maybe...but he had to go in and I still hate it now'*(Evie, 17).

Family identities

- The roles of mother, father, son, daughter have connotations and expectations.
- There is a double loss – ‘social death’
- *‘I’m gonna lose my Dad twice’ (Harriet, 17).*
- *‘I don't know if he's kind of my Dad anymore. ..My friend's Dad's died of terminal cancer and it was kind of like his body was degrading when my Dad's mentality was degrading...grieving for your parents before they die kind of thing and that was interesting because the shock for them was he's still him, but his body isn't...he's in pain. Whereas mine's kind of the opposite’ (Rachael, 22).*

Changes to roles

- *'You grow up quick...You have to try and grow up. You do lose a bit of your childhood. I feel like I did a little bit. I used to have to send my Dad when he did the weekly shop for the 'girlie things' (Grace, 31).*
- New identities that incurs certain responsibilities, supporting the well parent and role reversal:
- *'After Mum got her diagnosis she wasn't allowed to drive...It was weird because it was a bit of a reversing of roles because literally her getting a diagnosis coincided with me passing my test so it went from her ferrying me around places to me driving her' (Bethany, 21).*

'I'm not a carer'

- However, this did not translate to the adoption of the identification with the carer role:

'I'm not a carer, I'm not directly responsible for my Mum's wellbeing' (Colin, 21).

Stigma and isolation

- *'He **pooed** himself. In Disneyland. How embarrassing can you get?...People tell me, 'I saw your Dad with the dogs in the day', he just wanders. It can be hot outside and he'll be there in a hat and gloves and a ski outfit...Just embarrassing. One day, he took the dog out and the dog ended up on our school field. My year were doing PE, the dog running about, my Dad just stood there...'He's too weird for having people round to the house'*
(Jade, 16).
- *'I was trying so hard to be cool and make friends and see boys...I didn't want to get upset even in front of my best friends'*
(Gabrielle, 23).

Perceptions of self: guilt

- *'I know I feel an awful lot of guilt because when she was, when the symptoms were starting to show, she used to call me four times, there was one day she called me four times in an hour and every single time, she'd say 'I've just put the washing machine on' and I was in the middle of doing an essay, and I was like 'Mum you need to stop calling me, you've already told me this three times today', I got really angry at her' (Ava, 21).*
- *'It sounds awful, but in some ways [death] was a bit of a relief, you don't wanna see them suffer' (Bethany, 21).*

Loss of memory

- *'She knew who my Dad was and not me...I was like fuming with him! Like you're divorced!'* (Madison, 21).
- *'I came out to my parents as gay, in 2010, but my Mum has now started forgetting which is difficult...she keeps asking me if I'm going to get a girlfriend and when I'm gonna marry... So then I remind her...But she used to be really accepting of it...now she's become quite narrowminded. It's no longer in her world, she can't fathom it anymore. She says 'don't you want a family?'...previously she understood that it doesn't mean the end of that idea'* (Colin, 21).

Conclusions

- The focus on the impact of dementia has (correctly) been on the patients affected but it also happens to their families.
- There are currently no specific practice guidelines or tailored services
- Young carers are a minority population and it is a hidden act. Applied to dementia, the young people in our study confirm the difficulty adopting this identity.
- Dementia services and children and young people's services should provide greater support. Furthermore, a construction of dementia that acknowledges that it is not merely about one type of patient (ie. older variants) is required.