

The experience of looking after a parent with dementia: Past and present relationships

Dr Devon Perfect & Dr Gerry Riley

devon.perfect@nhs.net

Objectives:



To provide an overview of my
doctoral research



To talk about how this may
relate to practice moving
forwards



To explore how this relates to
the vision of the PPN



Why relationships in dementia?

- Family relationships have been shown to be central to the care, wellbeing and quality of life for people with dementia and for the wellbeing of the family carer.
- A developing area of work in dementia research focusses on the idea of relationship continuity and discontinuity.
- This concept of continuity has mostly been explored within the marital relationship, where discontinuity has been linked to adverse effects in carers emotional responses to the caring role.



Aims of the study:

- Explore the impact of dementia on the relationships between sons/daughters and their parents who have dementia.
- To explore the concept of ‘relationship continuity’ and how this relates to the son/daughter and parent relationship with a parent who has dementia.

Method

- Qualitative Interviews – 2 x 45-90 minute interviews conducted over Skype during the year 2020
- Sample: 6 participants, all carers of parents with dementia a minimum of 2 hours directly per week. Diagnosis necessary. 4 daughters, 1 granddaughter (who viewed her nan as her mother figure) and 1 son.
- Recruitment: 3rd sector recruitment through charities/ local carers groups was planned, due to pandemic mostly utilised Join Dementia Research (JDR).
- Analysis method: Qualitative using Template Analysis

Results:

- Well... That was unexpected!
- A brand new template was formed as a result of the analysis. Main themes that emerged as a more helpful conceptualisation: Challenges in offering care to a parent with dementia & what helps/hinders in offering care to a parent with dementia.
- What about continuity/discontinuity?



Final Template

Challenges to offering care for a parent with dementia:

- Taking on an increased level of responsibility for parental health and wellbeing – enabling parental independence
- Providing good quality, loving care for parent with dementia – providing this in line with the parents wishes and juggling their own competing responsibility
- Upsetting elements of the situation – Loss and changes

What helps or hinders the adult-child when dealing with challenges :

- Sense of commitment as a son/daughter
- Past and present quality of the relationship
- Individual characteristics of parent e.g. stubborn
- Sharing moments of warmth and connection
- Help from others either family or professionals
- Acceptance of new roles

What lessons can we take forward into practice?

Bearing in mind the importance of the pre-dementia relationship and the challenges that this can bring up for adult children.

The moments of love/connection are of utmost importance, what can we do to ensure that these can still happen?

Relationships with professionals can have a direct impact on the parent-child relationship.

Acceptance of new roles and responsibilities – can we offer support during this process? This may include support from the grieving process.

It does not appear as cut and dry in parent-child relationships as spousal relationships, complexity exists that we need to be mindful of in our work.

Limitations:

- Small sample size (n=6)
- Mostly daughters – less of the voice of sons
- All looking after mothers with dementia rather than fathers
- Subjective nature of qualitative research

How does this fit in with the PPN vision?

- Commitment to “Put people first”: This work centred around the voice of the adult-children in the sample and was led entirely by their experience and may help us to improve the overall quality of care and treatment across settings.
- It also fits with helping our communities to thrive, as we can use this information to enable us to prevent avoidable stress for carers and their parents with dementia, who are a seldom heard voice.
- Commitment to making all health and care psychological, as this work could be used to inform memory clinic setting in debriefing families and enable better direction to support for the adult child. May assist in forming better pathways to help this group and in turn, improve the quality of care provided to the parent with dementia without sacrificing the mental health of the adult child.
- Interesting to hear the voice of a carer from a different ethnic background, who was caring for her grandmother who she viewed as her mother – thinking about different cultures and how this may impact on care.

Thank you – Any
Questions?

