

THE EXPERIENCE OF SONS CARING FOR A PARENT WITH DEMENTIA

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Background

- ▶ Limited research on sons in a caregiving role
- ▶ Caregiving is gendered (Campbell & Carroll, 2007)
- ▶ Women provide more care than men
- ▶ Caregiving and its effects experienced differently by men (Pretorius *et al*, 2008)
- ▶ Male caregivers: suffer less emotional, physical and psychological distress.
- ▶ Men approach caregiving as a task to be completed

Aim of study

To explore the experiences of sons caring for a parent with dementia.

- ▶ What factors predispose sons to take on a caregiving role?
- ▶ How do sons manage their caregiving role?
- ▶ How do sons feel about their caregiving role?
- ▶ How does caregiving role impact on other aspects of a son's life?

Design and Method

- ▶ Qualitative study
- ▶ Exploration to gain a deeper understanding of the experience
- ▶ Study site –predominantly rural part of Ireland
- ▶ Sample accessed through The Alzheimer's Association and The Carers Association
- ▶ Cover letter and information pack

Participants

- ▶ Purposeful sample of sons caring for a parent with dementia (n=13)
- ▶ Primary carer
- ▶ Co-habiting in parent's home
- ▶ Not Co-habiting but organising and supervising care
- ▶ Willing to participate in the study
- ▶ Consent and ethical approval

Data Collection and Analysis

- ▶ Data collected between March and July 2010
- ▶ Semi-structured interviews
- ▶ Interview schedule
- ▶ Open –ended questions
- ▶ Audio-taped and transcribed
- ▶ Duration- approx. 1 hour
- ▶ Analysed using Colaizzi's (1978) seven-stage process

ESTABLISHING RIGOUR

▶ Rigour ensured by following the 'trustworthiness' Criteria (Lincoln and Guba (1985))

1. Creditability
2. Dependability
3. Confirmability
4. Transferability

▶ Peer Review

FINDINGS

- ▶ 29 information packs, 13 participants
- ▶ Mean age 48, Caucasian
- ▶ 12 caring for mother, 1 for father
- ▶ Duration of role 2-5 years
- ▶ All participants had siblings
- ▶ 10 worked outside home,
- ▶ 1 retired
- ▶ 2 had to give up work to facilitate role
- ▶ Parents age ranged from 79-95yrs
- ▶ 1 widower, 11 widows, 1 married couple

THEMES

- ▶ Parental Bond
- ▶ A Binding Role
- ▶ Co-ordinating Care And Support
- ▶ A 'getting on with it 'approach

PARENTAL BOND

Motivated by a strong sense of devotion, loyalty and respect for their parent *“voluntary done out of love “ “doing the best.”*

“Mother was always there for us...we were her life and she did everything for us and now we a going to do everything we can for her....It’s payback time” (interview 8)

Satisfaction with role:

“To be able to do this for her gives me a sense of living up to her wishes” (interview 3)

Maintaining the person at home:.... *“doing right” by the parent*

“As long as I can, I will look after her...I would not like to put her into care...I don’t think about that” (interview 2)

A BINDING ROLE

A time of readjustment and evaluation of their role

“Always on your mind...at the back of your mind, thinking about getting back and is everything ok?” (interview 1)

“You are on a curfew...it’s like doing a life sentence” (interview 4)

Vigilance and awareness

“If the phone rings at night, the first thing on my mind is ..Is mam ok?” (interview 12)

A BINDING ROLE

Acknowledgement of restrictions imposed

“You hear people planning a week ahead....that’s not me...I am limited where I can go...the problem is trying to get someone to look after my mother” (interview 2)

Role engrossing and consuming

“I care for her one hundred per cent of the time.. no time for anything else..had to give it all up” (interview 4)

Personal relationships and perceptions of others

“Your social life had to stop.....even relationships. Telling a person you are caring for your mother. They look at you as if to say “that’s not a job for a man!” (interview 4)

CO-ORDINATING CARE AND SUPPORT

Level of care had enabling and disabling effects on sons

“Why is it always one has to seek help from those who should be there for you, why should I have to ask them to come do what they should be doing themselves. I would like more support from family...ringing them to come to do what they should be doing...it takes the good out of it” (interview 12)

Taking from one area of life

“There is fallout looking after him...my family feel the stress as well as me...you are giving to one and taking from the other” (Interview 5)

CO-ORDINATING CARE AND SUPPORT

Respite care

“allows a sense of relief and freedom from the caring role so you can relax. If services not there, I could not cope” (interview 3)

Difficulty in getting information

“told one thing by one person and another thing by someone else and some were unhelpful or just awkward” (interview 1)

Specialist services

“The doctor called to talk with me. He asked me how I was how I was coping and if I was managing . It was nice to be asked. It’s important, it may not make much of a difference to them but it makes a difference to me. (Interview 10)

GETTING ON WITH IT

Rational and realistic manner

“Not taking on the future dealing with the here and now” (interview 6)

Being my mother and all, I was embarrassed for her. She is my mother...a private person. I was conscious of her and how she would feel ..being her son. That's the unfortunate side of the disease. You just have to do it and when you have something to do you just do it and you don't really think twice about doing it” (interview 8)

Determination and inner strength

“Inner strength and courage get me through it ..willpower and determination.. ...I am determined not to let it get in on me. There are times it does get you down but I will keep going as long as I can” (interview 10)

Limitations

- ▶ Small sample size
- ▶ Purposeful sample
- ▶ Narrow geographical base
- ▶ Lack of diversity in terms of ethnicity

CONCLUSIONS

- ▶ Acknowledgement is needed of the role of sons as caregivers.
- ▶ Many aspects of caregiving role are gender neutral.
- ▶ Perceptions of health and social care professionals
- ▶ ‘One size fits all’ approach to caregiver support fails to meet the need of such a diverse group.

“The more research into the phenomenon of male caregivers the more normalised the dogma of the male caregiver will become”. (Siriopoulos et al, 1999)

Publications

Mc Donnell, E & Ryan, A (2011) Male caregiving in dementia: a review and commentary . *Dementia* 12 (2), 238-250.

Mc Donnell, E & Ryan, A (2013) The experience of sons caring for a parent with dementia. *Dementia* . DOI: 10/1177/147301213485374.