Experiences of home care services for people with dementia requiring intimate care

Home Care Research Forum - 17th May 2017

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Outline

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Background

- Dementia: Everyday tasks become difficult leading to increased dependency on others for support in daily activities that may include support with using the toilet and managing incontinence (intimate care).

- People with dementia are three times more likely to have urinary incontinence, and four times more likely to have faecal incontinence than those without dementia living in the community (Grant et al., 2013).

- For many people living at home with dementia, this type of intimate care is provided by a cohabiting family member.

- Managing incontinence is a significant factor in the decision to move a person with dementia to a care home (Young, 2015).
Aims

To explore the lived experiences of managing incontinence (including using the toilet) and intimate care for people with dementia and their main family carer over time.

1. How do carers and people with dementia experience managing incontinence and intimate care at home?

2. Do they perceive their relationship to be affected by managing incontinence and intimate care provided? If so, how?

Consider the implications for health and social care professionals supporting people with dementia and their family carers.
Sample

Cohort of people with dementia and incontinence or problems using the toilet, living at home and their main informal carers (Drennan et al, 2008).

Recruited through admiral nurses, GP surgeries, carer support groups.

Inclusion

• People with dementia living at home with their main family carer.
• Family members living with and caring for a person with dementia
• Capacity to consent to participate in the research
• People with dementia needing support with incontinence or with using the toilet
Methods

• 3 semi-structured interviews with each participant over a year

• Topic guide

• Field notes

• Demographic and health information

• NHS Ethics Committee and other approvals
Data collection – over time

Characterising participants

Interview 1  Interview 2  Interview 3
0 6 12

Months

current relationship

Past and current relationship  current relationship

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People with dementia characteristics

**Gender:** 9 women, 4 men

**Age:** 75-98 years old

**Dementia:** Majority diagnosis of Alzheimer’s disease and in the late stages of dementia

**Incontinence problem:** Majority double incontinence
All 13 people with dementia wore incontinence pads

**Mobility:** 3 people with dementia were unable to stand

**Behaviours:** whole range, particularly agitation, apathy
Family carers’ characteristics

Relationship type
- Spouse (4 wives & 3 husbands), adult child (4 daughters & 1 son), and sibling (1 brother)

Spouse carers
- Age range: 67 – 88 years
- All had two or more children

Adult child carers
- Age range: 48 – 72 years
- None were married or had children
- One worked full-time, two took a career break

Sibling carer
- Carer and person with dementia were both single and without children

Home Care Workers
- The majority had daily paid care, 3 had no paid care
Findings

Experiences of family carers

1. Family carers’ attitudes towards their situation

2. Involvement of health and social care services

3. Impact on the relationship
1. Family carers’ attitudes towards their care situation

a) Caring for a relative with dementia and incontinence/intimate care needs
   • Feeling fortunate: things could be worse
   • Feeling frustrated: life should be different
   • Making the best of things

b) Managing excreta and providing support with intimate care / using the toilet
   • Negative emotional responses
   • Perceptions of necessity
   • Emotional need to provide intimate care
   • Difficulties with using the toilet and behaviours that challenge...
2. Involvement of Health and Social Care Services

a) The impact of ineffective healthcare services

b) Gaining and maintaining control of social care

• Perceptions of well-meaning ‘others’ interventions

• Intrusion of home

• Direct payments

• Weighing up options of care home move
2a. The impact of ineffective healthcare services

“If you wanted to design a system to be difficult, disjointed, uh frustrating and often didn’t work, this is the one you’d design. It’s an ah, it’s a dogs dinner quite honestly. It’s dreadful. Absolutely dreadful” (Daughter, P05-T1).

“. . . the system wasn’t accommodating enough. Nice to have the pads but, you know if they’re the wrong pads, not entirely suitable, then that kind of defeats the object” (Husband, P07-T2).
2b. Gaining and maintaining control of social care

Perceptions of well-meaning ‘others’ interventions

“. . . because they have all the reasons why somebody needs to be here to take him to the toilet at seven and to do what I was doing. I’ve done it for years and I was quite content and happy to go back again, but I’m afraid the family stepped in. ‘No, no....’” (Wife, P01-T3).

Intrusion of home

“I’m more like a prisoner in (my) home now” (Wife, P09-T2)

“Now they have to go into the bedroom” (Wife, P09-T3).
2b. Gaining and maintaining control of social care

Direct payments

“Um, so she’s [person with dementia] more cooperative you see because she quite likes the people that are around her now. Whereas before she didn’t. Uh, and nor did I. So, having changed it all, uh it’s made a huge difference” (P05-T2).

“So that’s [the care package] much better so when we spend time together I’m not having to do, either make up what somebody else hasn’t done or do the jobs myself, you know, we can have a chat, we can have a cup of tea, we can.... I can concentrate on the other things, the other bits of it [being a carer]” (P05-T2).
2b. Gaining and maintaining control of social care

Weighing up the options of a care home placement

“I am in the process of arranging for a home for her. Not because I want to get rid of her... cos I refuse to hang on when it’s not to her benefit. Uh, and I think that she would be better off in a, where, somewhere where she would be stimulated” (Husband, P10-T1).

“No, cos we tried it out and it didn’t work out. I wasn’t happy about it, you know. In so far as.... Look this way (living at home).... this way she has one-to-one caring. She’s not going to get that anywhere” (Husband, P10-T3).
3. Impact on the family relationship

a) Intimate care and managing incontinence does not directly affect the relationship
b) Intimate care and managing incontinence makes the relationship stronger
c) Indirect effects of intimate care and managing incontinence on the relationship

Energy expended in dealing with support services to gain integrated, person-centred care and products caused time spent together to be limited or the family carer to be short tempered.
Conclusions

Some family carers appeared to have a ‘need’ to care for the person with dementia and incontinence.

For some the thought of intimate care or managing incontinence was worse than actually doing the task.

Problems with using the toilet and challenging behaviours had an impact on the family dyad relationship for some.

The family relationship is strengthened due to the need of intimate care and managing incontinence for some.
Practice Implications

Silent subject - encourage health and social care practitioners to speak openly about intimate care and incontinence with people with dementia and their family carers.

Professionals lacking knowledge and confidence in continence should learn about local and national resources.

Mindful of not undermining the care provided by the main family carer - offering a service or signposting has to be acceptable.

Carers support groups and services may offer continuity of support – professionals to signpost and encourage / support these groups.

Direct payments work well for some.
References


Grant, et al. (2013). First diagnosis and management of incontinence in older people with and without dementia in primary care: A cohort study using the health improvement network primary care Database. PLoS Medicine, 10(8), 1-8.


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