Chapter 13

“It has had quite a lot of reverberations through the family”: Reconfiguring relationships through parent with dementia care

Elizabeth Peel

Introduction

In this chapter I explore the accounts of adult children caring for a parent with dementia. Dementia is typically understood to be an umbrella term for a large number of conditions, the most common of which are Alzheimer’s disease, vascular dementia and fronto-temporal dementia. These are progressive – ultimately terminal – conditions that affect memory, communication, mood and behaviour. I examine the accounts of interactions with parents with dementia that fracture and reconfigure normative familial relationships. In so doing I suggest that, in the absence of a primary spousal carer, caring for a person living with dementia can necessitate particular issues for adult children that trouble notions of how we understand familial roles, responsibilities and ‘duties’. This issue impacts a significant minority of British adults. There are estimated to be 670,000 informal family carers of people living with a dementia in the UK (Alzheimer’s Society 2013). The total cost of dementia to UK society is estimated to be £26.3 billion, with £11.6 billion being contributed by the work of unpaid carers (Prince et al. 2014). Unpaid care to older or disabled people provided by family member is typically understood to encompass personal care and/or practical household tasks and/or paperwork and administrative duties.

A classic memorial lecture given by Elaine Brody (1985) reflecting on the state of gerontological research in the USA thirty years ago has many current resonances. Brody argued that ‘parent care has become a normative but stressful experience for individuals and families’. And, moreover, she suggested that the experience of caring for a parent was not a brief or short-term concern for adult children, but rather that ‘it is long-term parent care that has become a normative experience – expectable, though usually unexpected’ (p.19/21 original emphasis). What is interesting and resonates today, I would suggest, is the
tension between the notion of a lengthy period of parent care as being normative and unexpected. In many contexts, and in many families, there is a cultural expectation that care work will be undertaken by adult children at some point during the life course, but at an individual level this (often) gradual move into a carer role may not be anticipated or prepared for. Caring for a parent with dementia provides a particularly illuminating focus for considering issues of familial care provision for older adults because care is needed long-term (on average ten years following diagnosis), and degree and reach of dependency increases incrementally and covers cognitive, communicative, social and practical domains.

Returning to Elaine Brody (1985), she used the term ‘family homeostatis’ to signal the destabilizing effect that a parent’s increased dependency has on families – ‘whether it is precarious or well-balanced – [it] must shift accordingly’ (p. 22).

It is also important to acknowledge that ‘parent care’ does not necessarily map onto a particular age or stage in an individual’s life course. There is extensive literature on young carers (for example, Aldridge and Becker 2003), and in the context of caring for a parent with dementia – which is the focus here – while the majority of those informal carers engaged in parent care will be in their 50s onwards, a significant minority of people (estimated to be over 40,000 in the UK alone, Prince et al. 2014) are diagnosed with dementia under the age of 65. Hence, children in their teens and adult children in their 20s and 30s are also positioned as engaging in parent care (Allen et al. 2009; Svanberg et al. 2010; 2011). In this context, Allen, Oyebode and Allen’s (2009) grounded theory study based on data from twelve young people (aged 13-23) caring for a father with younger onset dementia identified five main elements impacting on their well-being, which they labeled ‘damage of dementia’, ‘reconfiguration of relationships’, ‘strain’, ‘caring’ and ‘coping’, and described as constituting an overarching theme of ‘one day at a time’. In terms of the reconfiguration of relationships – a theme I explore later in this chapter – they found that most participants ‘said that they had lost their “real father”’ (p. 466), and that all their participants had a role in the care of their father. These authors suggest that their study ‘highlighted the ways in which stress related to having a father with dementia proliferates and affects almost every area of life, leading to very high levels of distress’ (Allen et al. 2009, p. 477). Therefore, it is important to recognise that parent care in the context of dementia is not solely the preserve of middle-aged adults onwards, although numerically this is the largest group of familial carers in this context.
Caring for a dependent parent is a stressful thing to do (Starrels et al. 1997), and there is extensive psychological and social scientific literature that documents the association between negative mental and physical health and well-being and providing this type of informal care (see Amirkhanyan and Wolf 2006; Etters et al. 2008; Lilly et al. 2012; Shulz and Sherwood 2008). In terms of the early literature focusing on negative mental health experiences in adult children caring for a parent with dementia, Dura et al. (1991) found 34 per cent met the Diagnostic and Statistical Manual (DSM) depression or anxiety criteria compared to eight per cent of the matched controls in their study during the same time period. More recent survey research with 120 US and Australian carers (O’Dwyer et al. 2013) found that 26 per cent had contemplated suicide in the previous year and almost 30 per cent reported they were likely to attempt suicide in the future. Depression predicted the presence of suicidality in this sample, and the authors concluded that their findings suggest ‘an alarming number of people contemplate suicide while caring for a family member with dementia’ (p. 1188). The overarching message from this literature has been summarized as ‘caregiving often results in chronic stress, which compromises caregiver’s physical psychological health. Depression is one of the common negative effects of caregiving. [and] Caring for a person with dementia is particularly challenging, causing more severe negative health effects than other types of caregiving’ (Shulz and Sherwood 2008, p. 26). As I go on to discuss below, this well established finding of high levels of carer stress and strain was echoed in my own research with Rosie Harding. Most questionnaire respondents in our ‘Duties to Care’ project (78.5 per cent, 142) were ‘under strain’ as defined by their responses to the – well used - Caregiver Strain Index (Robinson 1983) that formed part of a more wide ranging questionnaire (Harding and Peel 2013). In the following section I describe the empirical data on which the rest of this chapter is based. However before doing so, it is worth emphasizing that this chapter contributes to a number of arguments associated with a critical health and discursive psychological perspective (Murray 2014; Edwards and Potter 1992; Peel et al. 2005).

First, and most obviously, the literature on informal carers generally, and in the dementia context specifically, has largely focused on the experiences of heterosexual spousal carers (Braun et al. 2009; Calasanti 2006; Hellstrom et al. 2007; Hong & Coogle 2014). While this particular group of informal carers is, of course, significant and many insights from this group are transferrable into other relational contexts, this focus has arguably led to a marginalization of the perspectives of adults who provide parent care. In my dementia
projects, of the total sample of 185 original questionnaire participants\(^2\) 33 per cent (62) were caring for a parent (see also Harding and Peel 2013; Peel and Harding 2014; Peel 2014). The study was explicitly framed as adopting an inclusive definition of ‘carer’. The participant information sheet stated:

The study aims to be inclusive of all people who care for someone with a diagnosis of dementia. The person that you care for could be a relative or friend that either lives with you or lives in a residential setting. You may provide day-to-day care or you may not (or no longer) be responsible for daily care. Caring for a person with dementia includes emotional care, or emotional and practical care.

This construction of ‘carer’ may have contributed to a third of participants caring for a parent. I contend that foregrounding the experiences of this sub-set of carers may offer a critical lens on family dynamics and the processes and practices of caring more broadly. Thus the framing of the study as explicitly inclusive, and the desire to draw attention to the understandings from an under-researched sub-group of family carers fits with a critical psychological perspective (see also Riggs and Peel 2016).

Second, (some) forms of critical psychology and discursive psychology enjoin us to take language seriously, and view discourses – as marshalled by people - as actively constructing particular representations of the social world and, in this instance, caring relationships. Thus, bearing these concerns and foci in mind, in the analysis that follows I take a broadly discursive psychological approach to these carers’ talk (Edwards and Potter 1992), being mindful of the types of actions (that is, justifying, complaining) participants are accomplishing as well as the topical focus of their accounts of caring. However, I apply a critical realist rather than a thoroughgoing social constructionist perspective to carers’ accounts for feminist/political reasons. Social constructionism may risk potentially presenting participants’ accounts in a somewhat detached, even slightly ironic fashion. This sits uncomfortably alongside my own position as an ex-carer of a parent with dementia who is personally and politically supportive of carer’s experiences and perspectives (Peel and Harding 2015), therefore a critical realist epistemological stance recognises the grounding of participants’ accounts in their lived reality. Having said this, I am mindful of the actions accounts are achieving in their local context that is, for instance, presenting oneself positively by attributing responsibility to external factors, or through comparison. To offer one concrete example from later in the chapter, while Laura’s account of her brother’s
contribution to their father’s care - “unfortunately my brother just said ‘I don’t care, let- you do it, you do it’” – is a reflection of her reality, it simultaneously functions to construct her via contrast as a responsible, caring daughter. So the positioning, by participants’, of siblings as behaving in problematic, infantilising or disruptive ways also serves as a form of positive self-representation.

Third, my aim in this chapter is to tease out some of the different ways that concepts of duty, worry, care and vigilance are talked about in these interview and focus group data with informal carers currently providing, or previously providing, parent care. The dialectic tensions of dependence versus interdependence (Brody 1985) can be felt particularly acutely in the dementia care context wherein the person with dementia may exhibit behaviours that challenge those around them, and become increasingly ‘child-like’ (see also Riggs and Peel 2016). The risks of infantilizing people with dementia, communication difficulties and cognitive impairments are real and problematic, and the notion of role-reversal has been argued to be ‘a superficial concept at best’ (Österholm and Samuelsson 2015, p. 23). Role-reversal may well, on one level, be a superficial concept, but as I go on to highlight in this chapter, the role demands associated with caring for a parent with dementia are such that normative familial relationships are fractured and reconfigured, in ways which can leave families negotiating conflicntual situations.

Duties to Care and Dementia Talking - Method

As mentioned earlier, this chapter is based on qualitative data collected through the interlinked ‘Duties to Care: A socio-legal exploration of caring for people with dementia’ and ‘Dementia Talking: Care, conversation and communication’ projects. As Table 1 indicates semi-structured interviews and focus groups conducted with eleven adults caring for either a mother (n=9) or a father (n=2) with dementia. The mean age of participants was 58 (range 47-65). All participants were white and heterosexual aside from one bisexual interviewee (Sue). Interviews (averaging 1 hour 37 minutes) were conducted in participants’ homes between November 2011 and January 2012. Most interviews were conducted in the Midlands, three were conducted in the North of England and two in the South. Fifteen participants attended four focus groups held in two large cities and two towns in central and southern England between September and December 2011. In total 8 hours 40 minutes of focus data were collected, with each group lasting around two hours.

Table 1: Interview and focus group participant demographic information
<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Age</th>
<th>Class</th>
<th>Person care for/ age</th>
<th>Dementia type</th>
<th>Residence of PWD</th>
<th>Caring status</th>
</tr>
</thead>
<tbody>
<tr>
<td>Victoria (I)</td>
<td>63</td>
<td>Middle class</td>
<td>Mother, 88</td>
<td>Alzheimer’s</td>
<td>Own home</td>
<td>Current</td>
</tr>
<tr>
<td>Carlos and Anne (I)</td>
<td>58</td>
<td>Working class</td>
<td>Father, 87</td>
<td>Alzheimer’s</td>
<td>Own home</td>
<td>Ex-carer</td>
</tr>
<tr>
<td>Jan (I)</td>
<td>58</td>
<td>Working class</td>
<td>Mother, 87</td>
<td>Vascular dementia</td>
<td>Residential home</td>
<td>Current</td>
</tr>
<tr>
<td>Sue (I)</td>
<td>59</td>
<td>Working class</td>
<td>Mother, 87</td>
<td>Vascular dementia</td>
<td>Residential home (self-funding)</td>
<td>Current</td>
</tr>
<tr>
<td>Derek (I)</td>
<td>65</td>
<td>Working class</td>
<td>Mother, 86</td>
<td>Vascular dementia</td>
<td>Own home</td>
<td>Ex-carer</td>
</tr>
<tr>
<td>Maureen (I)</td>
<td>60</td>
<td>Middle class</td>
<td>Mother, 95</td>
<td>Alzheimer’s</td>
<td>Nursing home (self-funding)</td>
<td>Ex-carer</td>
</tr>
<tr>
<td>Chloe (FG1)</td>
<td>58</td>
<td>Middle class</td>
<td>Mother, 84</td>
<td>Vascular dementia</td>
<td>Nursing home</td>
<td>Ex-carer</td>
</tr>
<tr>
<td>Laura (FG1)</td>
<td>55</td>
<td>Working class</td>
<td>Father, 88</td>
<td>Vascular dementia</td>
<td>Nursing home</td>
<td>Current</td>
</tr>
<tr>
<td>Peter (FG1)</td>
<td>58</td>
<td>Working class</td>
<td>Mother, 92</td>
<td>Mixed: Alzheimer’s and Vascular</td>
<td>Own home</td>
<td>Current</td>
</tr>
<tr>
<td>James (FG2)</td>
<td>47</td>
<td>Middle class</td>
<td>Mother, 77</td>
<td>Vascular dementia</td>
<td>Own home</td>
<td>Ex-carer</td>
</tr>
<tr>
<td>Alan (FG4)</td>
<td>59</td>
<td>Working class</td>
<td>Mother, 89</td>
<td>Alzheimer’s</td>
<td>Own home</td>
<td>Current</td>
</tr>
</tbody>
</table>
The focus group questions placed more emphasis on the legal and practical aspects of caring, while the interviews were more focused on communication. There was, however, overlap in the questions asked in the interviews and the focus groups. Participants were asked in both studies about their experience of caring for someone with dementia, and what, if any, support they received from others. Focus group participants were asked about both negative and positive views about dementia care services, whilst interviewees were asked about ‘low’ and ‘high’ points in their experience of caring.

**Fracturing and Reconfiguring Normative Familial Relationships**

In the analysis that follows I explore core concepts connected to duty, worry, guilt and vigilance, and the ways in which caring for a parent with dementia can fracture and reconfigure normative familial relationships with references to two main themes. The first is *sibling conflict and collaboration*, the second is *parentification and infantalisation*.

‘Parentification’ is a term used to describe how carers’ ‘felt that they were cast in a more parental role’ (Allen et al. 2009, p. 467) and, as we see below, this concept can be usefully applied to these data. With regard to overt reference to ‘duty’ it was the men in this sample who made reference to filial relationships creating the conditions for them taking on caring responsibility for their parent (McDonnell and Ryan 2013). As identified in the literature on male caregivers in dementia (McDonnell and Ryan 2013) the men who were carers in this research talked about their experiences in a way that was less ‘emotional’ than the women caring for parents. A ‘factual’ account of a sense of duty and familial role was presented by Derek, for example:

> I think when I actually became my mum’s fulltime carer, it would have been very, very difficult to move her. [...] I don’t expect a medal or anything but the reason I did it was because she’s my mum, and it was my duty. I’m her son. And it was my duty to care for her. You know, she cared for me when I was a child, so I- you know, I felt, I’ve got to do this, because she’s my mum [...] in a nutshell, I-I took it on because it was my mum. (Derek)

Here Derek explicitly accounts for the caring work he undertook with his Mum in terms of duty and in terms of reciprocity of roles – “she cared for me when I was a child”. This emphasis on familial caregiving expectations is reminiscent of the ‘custodial’ task-focused and deficit based style of caring identified in Ward-Griffin et al.’s (2007) Canadian study of mother-daughter dementia caregiving relationships: an approach in which they identified
‘duty’ as the defining characteristic. In contrast to findings from a study of predominantly female Australian Italian dementia caregivers (Benedetti, Cohen and Taylor 2013) Carlos – an Italian male carer in this study – drew on the familial values associated with Southern European societies: “I didn’t want to look after my dad but I promised, on me mum’s deathbed I promised that I’d look after him, er and I won’t go back on my promise. So I took on that responsibility, but not knowing what I- what was- what was ahead of me” (Carlos).

So, for Carlos, a promise and commitment to his mother underpinned the caring role he undertook for his father. Other participants who were acting as full-time carer for their parent, such as Alan, positioned themselves as being “on a knife-edge myself,” but the demands of caring were also discussed by those participants whose parent was now residing in a care home.

The ongoing demands of caring in a non-resident capacity were most often framed in terms of worry, vigilance and guilt. Jan – whose mother had moved into residential care – explicitly recounted how: “the worry never goes away, you wake up with it, you wake up with this sinking feeling (laughs) in the pit of your stomach, oh, you know, what’s going to happen today, is she going to be all right”. The extreme case formulation (Pomerantz 1986) ‘never’ and the ever-present constancy of the worry, conveyed as unconscious as well as conscious worked to highlighted the embeddedness and the degree to which this sense of worry permeates Jan’s relationship with her mother now she is not providing day-to-day care. Chloe, reflecting on her relationship with the nursing home care provision during the last months of her mother’s life, also emphasized some of the challenges and concerns connected to care being provided in this context.

One of the most important things for me was knowing, especially when Mum was in bed, that she wasn’t left for hours. […] the thought of her, not having anybody go in that room for three hours was horrendous, and that always used to worry me and-and I often used to think at different times during the day, I wonder if Mum’s seen anybody today. […] And, of course, once she was in bed, they did have to go every two hours to turn her. But it was that- it was that horrible feeling of thinking that- have they forgotten she’s in her room, that was really really important to me.

(Chloe)

We can see in Chloe’s account a similar emphasis on the anxiety created through not ‘knowing’ whether and when her Mum was having contact with care staff when she was bed
bound. Chloe had worked with staff in the nursing home to operationalise a chart in which staff documented when they went into her mother’s room to (Edwards 2014). Previous research has emphasised the difficulties experienced by long-distance caregivers, for example, over half of the participants in Koerin and Harrigan’s (2002) study reported at least one negative impact on employment and having given up leisure activities, hobbies and holidays. Relationships with partners can be strained and friendships can be lost due to the commitments of providing care and the associated lack of time (Edwards 2014; Suitor and Pillemer 1993). Chloe, here, conveys the “horrendous” “worry” and “horrible feeling” created through caring at a distance and being reliant on care workers to ensure regular contact with her mother. Sue also conveyed this sense of anxiety regarding her mother: “she’s gone into a nursing home now but my sister and I both still have to be quite vigilant, I’d say”. Thus, keeping a careful watch for potential danger or difficulty, when parents were in a residential care setting, was in part about monitoring the provision and quality of care in these settings as well as the deterioration of the parent with dementia. Edwards (2014, p. 176) used the phrase ‘orchestrator in the background’ to reflect the demanding commitment that monitoring and arranging care and services is for distance caregivers.

Further examples of the fracturing of normative familial relationships were conveyed through the challenges of remote caregiving and the lack of control, or certainty regarding the parent with dementia’s health: “It’s a horrible thing to have to put your mother in a home; you have to get over that one. And then the slow decline and then the phone might ring any minute, your mother’s had another blah, blah” (Sue). Or as Maureen emphasised: “the constant worry of who was going to be on the phone next; was it going to be the police again to say she’d been found wandering, ah, was it the neighbours to say that she’d been aggressive and unpleasant and erm, didn’t know where she was; erm, was it going to be the carers to say she’d had a fall, or what was the next crisis going to be.” The concept of ‘compassion fatigue’ has been well documented with respect to professional healthcare providers, but has only been explored in a limited sense with familial caregivers (Day et al. 2014). Day, Anderson and Davis’s (2014) interview research with adult daughters caring for a parent with dementia concluded that this group are at risk of the combination of helplessness, hopelessness, inability to be empathic, and sense of isolation that results from prolonged exposure to perceived suffering. Chloe, for example, emphasized another difficulty with distance care giving “if you don’t go, you then feel terrible for not going”, and
Victoria articulated the ‘chore-like’ character of caring for her mother who was living in her own home:

It feels like sort of like a chore, you know you’ve got to keep communicating with this person because if you don’t it’s going to get even worse so that- because the faster she deteriorates the bigger the problem for my sister and I looking after her.
You know, even if we’re paying other people to do it, it’s still actually, in one way or another, is more of a problem because it’s us who’s having to take decisions, it’s us who’s having to be the intermediary, even if we do less and other people do more.
So- so keeping her healthier for longer, there’s like a- there’s something in it for me, but it is a chore. There- no, I would say there’s no pleasure in it whatsoever, no, no.
(Victoria)

Therefore the lack of ‘pleasure’ in caring for a parent with dementia, the worry, guilt and vigilance were all evident in the fracturing of normative familial relationships between adult child and parent for the adult daughters. Duty and responsibility were also foregrounded, most explicitly in the adult sons’ accounts. The reconfiguring of relationships – particularly regarding being mis-perceived – was present in adult sons but not daughters’ accounts.
Derek, for example, provided a lengthy account his “mum wanting me to- to go to bed with her” which precipitated her being admitted to hospital:

It’s terrible to think that your- your own mother doesn’t know you. [...] she came up to my bedroom, and erm, it- it was quite obvious from the things that she was saying to me that she thought I was her husband, because she was saying things like “you don’t want to get in- you don’t want to be in bed with me, do you? Why? What have I done? Why won’t you get in? Why won’t you come to bed with me?” So I said “look, Mum, I’m not Dad. I’m Derek. I’m your son”. “How can you be my son? I’m not- I haven’t got a son.” Well, she- she became very, very aggressive. We came back downstairs, and uh, then she started banging and slamming all the doors, and knocking on the walls [...] I didn’t know how to cope with it, Liz, so I thought “what am I going to do?” So in the end, I phoned […] and a very, very nice doctor came out […] [he said] “it’s not fair on you. You can’t possibly cope with your mother in this condition.” So he got my mum admitted. (Derek)

Behaviour that is challenging to others - known as behavioural and psychological symptoms of dementia (BPSD) - is a common experience in caring for a person with dementia, and
often precipitates a move into a hospital or residential setting and the initiation of anti-psychotic medication (Harding and Peel 2013). In Derek’s case their relationship being (temporarily) reconfigured as wife and husband, rather than mother and son was vividly recounted, and Derek’s challenge to his mother’s perception of reality precipitated not only ‘very aggressive’ behaviour but her removal from her home. The gulf between who, and how, the person was and their current behaviour was especially marked in the accounts of sons caring for their mothers. Derek also, for example, reported the disconnect between his mum swearing at him and his understanding of her previous self: ‘my mother wouldn’t say boo to a goose she was a very gentle lady’. James discussed the reconfiguring of his relationship with his mother in different terms:

Strange to say, even though she wouldn’t recognise me as her son, deep down there was something there, because I was the one person she would be at most ease with, is probably the best way I can put it. But it got to stage whereby, for example, my Mum would see my car in the front drive and say “oh my boyfriend is here, my boyfriend is here”. […] The first time this happened I thought ‘now what do I do now?’ [Laughs]. So I decided to change my clothes, my top and trousers, and suddenly I was her boyfriend. And this went on for quite a few months and it was not only just once a day, every time she saw my car – it might be four, five, six times a day. […] That was the most, you could say, the strangest story I could, I could quote. Erm, but I took it as, erm, a compliment, because I was assuming she was going back to times when she- when my father- late father was, ah, courting my Mum. (James)

James, here, recounts engaging in role-play with his mother in order to maintain her reality that he was ‘my boyfriend’ rather than her son. While use of deception, on both sides, has been described with respect to mothers and daughters (Ward-Griffin et al. 2006) it is interesting in James’ case that by actively engaging in his mothers’ reality – and rationalizing the situation as ‘a compliment’ – this circumvents any BPSD-related aggression. James’ positioning of these relationship reconfiguring events as the ‘strangest story’ in his experience of caring for his late mother sit very differently to Derek’s experience of not ‘know[ing] how to cope’.

There were other ways in which caring for a parent with dementia fracture and reconfigured normative family relationships: sibling conflict and collaboration; and parentification and
infantilisation. I now go onto to discuss these before drawing some conclusions about the nature of parent care in this context, and what might be understood about ‘care’ more broadly from these data.

**Sibling Conflict and Collaboration**

Previous research has emphasised that ‘stresses experienced during the development of parental dementia seemed to increase conflicts in the family’ (Barca et al. 2014). An Australian survey, for instance, identified family conflict in the context of younger onset dementia by a large minority of carers (41 per cent) (Luscombe, Brodaty and Freeth 1998), and in these data it was only Maureen – who had been estranged from her brother for many years prior to her mother developing dementia – who reported that having ‘everything [...] on my shoulders’ would have been alleviated by ‘having a sibling to share it with’. For most participants’ relationships with siblings were recounted as a significant source of additional stress. In Laura and Derek’s case of brothers: “unfortunately my brother just said ‘I don’t care, let- you do it, you do it’” (Laura) and; “I did feel angry about it, because I didn’t get any help from him” (Derek), or because of role conflict, or other differences created by the demands of caring for a parent who does not have capacity. Conflict about money – and discomfort about having uncertainty or distrust in their siblings’ approach to spending money under power of attorney regulation – was discussed in a number of the female carers’ accounts. Chloe, whilst emphasizing that her sister “didn’t do anything remiss” did not “know if she ever paid Mum back for those few bits she bought that day”, and Sue discussed a range of issues that she and her sister had “come to blows about”, including money:

> What I’d like is a calm interchange because Bev’s got her own views about how to deal with my mum. [...] And we have come to blows about I don’t think we should do that. [...] I think maybe we were just so stressed [in the hospital] and we just had a big bust up. [...] And the money was a big thing, keeping an eye on the money. Bev would just go into her account and I’d say ‘what’s the money going on?’ ‘Why are you saying I’m pinching mum’s money?’ ‘Well no, I’m not, we need to keep a check on it, we’ve got power- [...] And I thought we’re going to need this money. [...] it’s going to run out and we need as much as we can to pay this bill because once it’s runs out we’re in shit street. So we’ve fallen out about- not about the money but, you know, we needed to sort all that out and the actual day to day caring. [...] she’s got the cash card but I keep my eye on the bank account. [...] I think it has affected
our relationship, definitely, my sister and I. We’re okay but it’s not what it was, there are still a lot of things unsaid. (Sue)

We can see in this account that differences in approach to engaging with their mother, stressful situations (such as hospital admission) and the ongoing provision of practical and emotional support now that their mother is in a residential home all impact on the relationship Sue discusses having with her sister. However, the worry about ending up in ‘shit street’ if their mother’s finances did not enable them to continue to pay for her care is a particularly stressful aspect of dementia care in England and Wales, which relies on joint powers of attorney adopting a similar approach to financial management that can be difficult to negotiate and achieve. Whilst Sue claimed that her relationship with her sister was ‘okay’, Jan’s relationship with her sister had ‘totally broken down’ during the course of caring for their mother and her being moved by Social Services into a residential home:

The worst thing was trying to communicate to my siblings how bad mum was. I- I was very close with my sister and our relationship’s totally broken down over it because she was just in denial. [...] I really thought she would understand. And when mum was diagnosed and we came to register the Power of Attorney she totally backed out of it all, she just said “No, I don’t remember signing anything” and- and wouldn’t do anything, wouldn’t- just wouldn’t get involved. And the only phone calls I ever got from her were sort of, sort of criticisms of what we were doing, you know “Oh mum’s like that cos you do too much for her” and “Mum’s always been content to sit back, if you cook her meals course she won’t bother” and things like that, you know, really unhelpful stuff. [...] she would even come and have rows in front of mum, you know, it was, that was awful. I would say if anything that was the worst, that was the worst aspect of it, you know? [...]After Mother went into a care home] I had her [sister] crying on the phone and saying how awful I was- and I was grieving myself, I didn’t want to do that either, you know, and we ended up having a real humdinger and me saying “Look, this isn’t about you, this is about mum, we’re keeping mum safe and don’t you think it’s hurting me as well?” you know “I’ve been in there every single day for nearly eighteen months, you know, don’t you think it’s hurting me?” [...] it’s gutted me cos we were always so close [...] I was just gutted that she weren’t there when I needed her, you know. (Jan)
The interpersonal conflict and the perceived lack of support for Jan, who was their mother’s main carer, are very present in her account of this sibling conflict as ‘the worst thing’ she had experienced with regarding to caring for her mother. Although conflict and difficulty between siblings was most evident in participants’ accounts there was, in line with some previous research (for example, Allen et al. 2009), some evidence from Victoria of siblings supporting each other. Victoria compared the experience of sharing caring responsibilities with her older sister in a comparatively favorable light to caring for a partner with dementia as ‘we’re equals’:

We keep each other sane, yes. (laughter) I actually sort of like feel- erm I go to Alzheimer’s Society er carer’s coffee mornings and I actually, I don’t know how people who are like married to somebody cope because there isn’t like somebody else that you can say- cos like my sister and I are in the same sort of place, you know, like we’re equals so you can be honest with each other [...] when we’re both in town we sort of like share it out week-by-week because we’re now at the stage where my mother has a daily check. [...] And it depends like on who’s there, who happens to be there on the day, who finds out what needs doing and then we sort of like liaise between us (Victoria)

Victoria’s account contrasted quite sharply with those of other participants in that equality, honesty and ongoing liaison are emphasised, whereas in much of the other data regarding interaction with siblings an implicit lack of honesty and an absence of a collaborative approach to parent care was evident. The final theme which connects to fracturing and reconfiguring normative family relationships is parentification and infantalisation which I now go on to discuss. With regard to the latter it is also important to note that infantalising talk to the parent with dementia was also articulated as a source of sibling discontent. For example, as Alan suggested: “my sister speaks to her like she was a child and I don’t think that’s a good thing”.

Parentification and Infantalisation
There were numerous examples in these data of participants’ being cast in a parental role and utilizing many of the strategies and approaches which their parents may have used with them as children (for instance, using ‘time out’ as a strategy to manage their frustration with their parent’s behaviour – ‘furious enough that I’ve just walked away’ Victoria). All the participants talked in ways which suggested that they were mindful of simplistic “role-reversal” notions regarding the progression of dementia; yet, as Victoria suggested as
symptoms of dementia worsen and parental dependency increases over time “the adult relationship has gone and all you’re left with is the fact that you’re mother and child and therefore you are irrevocably tied together”. Victoria and Sue, especially, reflected on the changed relationship with their mother. Victoria’s account below highlights how deception and concealment reconfigure the relationship in ways outside of normative patterns ‘at this stage of life’, which positions a woman in her 50s as a ‘teenager’.

VI: I’ve learnt to lie, I lie to her. [...] I’ve learnt to deceive her. You know, like my sister erm, when she was at the stage of- sometimes she’d like appear on my sister’s doorstep for the fifth time, erm and sometimes it would be to ask the same question again, and my sister was like oh, going completely crazy, it’s like she would not answer the door even though she was in the house.

EP: Right.

VI: Cos she said “If I’m not there she’ll just go off and wander back home, and it won’t be the end of the world and she’ll cope and she’ll get on. No, no, it doesn’t matter, if it really is urgent she’ll come back again another hour later.” You know, so- you know, that’s a lie isn’t it?

EP: Yeah, yeah, yeah. And I mean how does it feel being- like doing- like you and your sister doing that with your mum?

VI: A bit of a surprise (laughs) no, a bit of a surprise. And- and odd because it’s the sort of thing you do when you’re a teenager (laughs) you know, yeah, and I’d say it’s the same sort of feeling, you feel you’re being a bit of a naughty teenager. You’re hiding things from them that at this stage of life you weren’t expecting to, you know, you would be open with them. [...] it’s just that like the truth is going to be more hassle than I can cope with, I’m not going there today, you know.

That Victoria was ‘surprise[d]’ by her own behaviour and the way she interacts with her mother is reminiscent of James’ ‘strange’ role-playing and Derek’s verbalized distress at his mother wanting him ‘to go to bed with her’. These aspects of care within this particular context are more complex and challenging than the provision of emotional, practical and personal care might suggest. The negotiation of care for caregiver and care recipient is shaped by the cognitive and BPSD aspects of dementia as well as historical and contemporaneous familial relationships and roles. ‘Elderspeak’ or infantalising communication has been highlighted within dementia research (see, Österholm and Samuelsson 2015) and, in these data, problematic communication from siblings was
highlighted as in the case of Alan (above) and as Sue commented “my brother’s not very good with her, he takes the mickey out of her a bit, makes jokes. [...] and she looks at him and she doesn’t understand”. But what was also interesting was the ways in which the provision of ‘hands on caring’ could be produced as infantalising by the parent with dementia:

The hands on caring [...] She was awful, I didn’t do anything right. “Don’t treat me like a baby” and, you know, it’s very difficult to get it right, isn’t it? She was doing things which- “I can walk, I’m not an invalid”. [...] the path from independence to dependence [...] For us as a family, perhaps not for the professionals because she’ll take it from them, but for the family it’s been really difficult. (Sue)

Sue, here, formulates her mother’s journey from independence to dependence as one that has been, and continues to be, ‘really difficult’ for the family particularly.

**Concluding Remarks**

As I noted at the start of this chapter, the academic literature about informal carers in general, and dementia carers in particular, has predominantly explored the experiences of heterosexual spousal carers. This emphasis has meant that the perspectives of adults children who provide care – broadly conceived – to a parent with dementia have received less attention and are eclipsed by the partner-carer experience. I have focused here on daughters and sons interview and focus group talk about caring and highlighted some of the ways in which normative familial roles, responsibilities and ‘duties’ are fractured and reconfigured in the context of dementia care. There are many difficulties that form part of informal dementia carers’ experiences – including behavioural and psychological symptoms (Harding and Peel 2013), incontinence (Drennan et al. 2011), financial management (Langan and Means 1996), and difficult decisions towards the end of life (Wilkinson 2015). Whilst there is much to be done to explore the perspectives of people with dementia themselves, especially women who are disproportionately affected both directly and as formal and informal carers (Erol, Brooker and Peel 2015), this analysis has offered a perspective on family dynamics and the processes and practices of caring more broadly.

**References**


http://www.alz.co.uk/women-and-dementia


Peel, E. & Harding, R. (2014). “It’s a huge maze, the system, it’s a terrible maze”: Dementia carers’ constructions of navigating health and social care services. Dementia: The International Journal of Social Research and Practice, 13(5) 642–666.


1 I gratefully acknowledge the support of the British Academy (Small Grant no. SG1000017 and Mid-Career Fellowship no. MC110142) for funding the projects giving rise to this research, and Chris Beasley and Rosie Harding for helpful editorial input.

2 Ethical approval was granted from University ethics committees. The recruitment strategy for this study involved third sector organisations (for example, Dementia UK) advertising the study, and is described in detail elsewhere (see, Harding and Peel 2013; Peel and Harding 2014). All but five of the focus group and interview participants were recruited from the original ‘Caring for People with Dementia’ questionnaire – there was no overlap between interviewees and focus group participants.

3 This is sometimes referred to as elderspeak.