

Who cares? Managing obligation and responsibility across the changing landscapes of informal dementia care

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ABSTRACT

This paper explores the different ways in which informal carers for people with dementia negotiate their care-giving role across the changing organisational and spatial landscape of care. In-depth qualitative data are used to argue that the decisions of carers are socially situated and the result of negotiations involving individuals, families and wider cultural expectations. These decisions affect where care occurs. In addressing these issues this paper draws attention to the lack of choice some carers may have in taking on the care-giving role; how and why carers draw upon support; and the different expectations of the care-giver's capabilities across the different sites of care, specifically at home and in nursing homes. It concludes that research and policy attention should focus on how the expectations about the role and abilities of carers are affected by where, and how, care is delivered. In doing so this paper contributes to the emerging health geography literature on care-giving as well as developing the spatial perspective in the established gerontological literature.

KEY WORDS—informal care, dementia, landscapes of care, obligation, responsibility.

Introduction

The way in which carers respond to care needs varies, and is dependent upon, the social, relational and institutional landscape (Sevenhuijsen 1998: 22). This landscape, and its 'complex embodied and organizational spatialities' (Milligan and Wiles 2010: 740), affects, and is influenced by, care-giving relationships, resulting in differences in where and how care is provided.

Dementia is one of the primary causes of disability in old age. In the United Kingdom (UK) in 2010 there were an estimated 766,791 people with dementia (diagnosed and undiagnosed), and this is set to increase to

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1,000,213 by 2021 (Tesco, Alzheimer's Society and Alzheimer's Scotland 2011). UK welfare policy has emphasised the importance of individual and family responsibility assuming that informal carers, *i.e.* spouses, family and friends, will be willing to provide support (Department of Health 1990; Hirst 2001; Milligan 2009; Pickard 2010) as an estimated 63.5 per cent of people with late onset dementia in the UK live in private households (Knapp *et al.* 2007b).

The landscape of care provision is organisationally and spatially fragmented following the introduction in the 1990s of a quasi-market where the statutory sector is encouraged to purchase services from voluntary organisations (Department of Health 1990; Hirst 2001; Lewis 1993; Milligan 2001; Rees Jones *et al.* 2008; Symonds 1998a, 1998b). Therefore those providing informal dementia care may have to navigate a complex landscape of formal support.

This paper examines how informal carers for people with dementia negotiate their caring roles. It looks at the socially situated decisions that carers make regarding their care-giver role, and argues that these are also spatially situated negotiations. The paper examines differing expectations of the care-giver's capabilities across the different sites of care, focusing upon expectations of the care-giver role in the home and in nursing homes. The paper highlights issues to be considered in relation to who takes on the responsibilities of informal care and the varying care-giver role across the changing landscapes of care.

Socially and spatially situating care

Community care policies assume that the community will be willing, and able, to provide appropriate levels of support for people with long-term care needs. It is posited that such policies assume that care decisions are rational ones, not acknowledging the tensions encountered when taken-for-granted routines are disrupted by the provision of long-term care. Informal carers for people with dementia act, and negotiate, their care-giving role, on the basis of the social, cultural, financial and mental resources that they can draw upon (Egdell *et al.* 2010). The term 'rationality mistake' (previously used in the literature on decisions regarding child care) argues that policies that assume rational care decisions are flawed (Barlow and Duncan 2000a, 2000b; Barlow, Duncan and James 2002). Rather care decisions are the result of complex social, moral, emotional and cultural issues.

Individuals provide care not simply out of a sense of duty or obligation but rather through ideas of the proper thing to do in relation to their social context and individual morality, and the way in which care responsibilities

are consolidated over time (Connidis 2001; Finch 1989; Sevenhuijsen 1998). Informal dementia care decisions may reflect the legacy of the past relationship between the carer and the person with dementia (Davies and Gregory 2007; Hellström, Nolan and Lundh 2005). Understanding the marriage biography can help uncover the interaction between the marital relationship and informal dementia care (Hellström, Nolan and Lundh 2005). Care may be framed as a normal part of a loving relationship; and carers may not perceive that they have crossed the boundary from a normal relationship to a caring relationship (Henderson 2001; Rose and Bruce 1995). Spouse carers may frame care provision in terms of reciprocity of the love they receive from their partner (Lewis 1998). Others may not engage with the title of carer because of social, cultural and gendered expectations (Katbamna *et al.* 2004; Mackenzie 2006).

Reciprocity may guide the limits of normative kin obligation and adult-children may feel less inclined to support parents who neglected past parental duties (Aboderin 2004). Having a high-quality intergenerational relationship may make it easier for adult-children to support their parents (Merz *et al.* 2009). However, relationships may be ambivalent: adult-children who feel close to a parent may also experience negative sentiments (Luescher and Pillemer 1998; Pillemer *et al.* 2007; Willson, Shuey and Elder Jr 2003). Filial norms may also change over the lifecourse, weakening after mid-life, and may be linked to situational factors (Gans and Silverstein 2006). Furthermore, framing by the carer of informal dementia care may affect their experience of either care-giver strain or fulfilment, and use of support services (Lawrence *et al.* 2008).

There is growing interest in the health geography literature in the spatially situated nature of care, seeing it as shaped by the sites and spaces where care occurs as well as interpersonal relationships (Milligan and Wiles 2010). In framing the home as the preferred site of long-term care, community care policies have framed the home as a therapeutic landscape (a physical and social environment that is conducive to healing (Gesler 1996: 96)). However, the therapeutic potential of the home is not always realised due to the realities of 24-hour care provision. The extent to which the home is a defensible space changes over the lifecourse (Peace 1993). Illness forces individuals to reconsider their relationship with the home as health and social care providers may have to enter this space to give support. Negotiations are then made between the home as a private space and home as an institutional space (Milligan 2009; Yantzi and Rosenberg 2008). Individuals may feel the need to take control and mark their ownership of the home space in new ways (Dyck *et al.* 2005).

This paper examines how the site where care occurs shapes the expectations of the care-giver's role and abilities. Care in the home may be

taken-for-granted and there may be unwillingness on the part of professionals to enter these private spaces, disrupting long-standing relationships (Arksey and Glendinning 2007; Twigg and Atkin 1994) and equally older people may cease to visit friends who have been diagnosed with dementia because of fear (Corner and Bond 2004). Gerontological and health geography literature show that once care shifts to institutional settings there is a power-shift as informal carers and the person they are caring for lose control. Carers renegotiate their care-giver identity as they lead 'private lives in public places' (Willcocks, Peace and Kellaheer 1987) in a context where their emotional needs may be overlooked because of institutional structures (Milligan 2005; Ryan and Scullion 2000). Informal care does not end when a person enters institutional care, but takes on new meanings (Whitaker 2009). Carers may be uncertain about their role and how to interact with staff (Aneshensel *et al.* 1995). Carers may not be asked about how, or if, they wish to remain involved in care provision (Davies and Nolan 2004), and their experiences may depend upon relationships with staff and their care delivery approach (Brown Wilson, Davies and Nolan 2009). While the institutional environment may limit the carer's involvement, carers may continue to provide support in subtle ways that do not impinge on nursing home staff, such as sharing meals and washing hair (Ryan and Scullion 2000; Whitaker 2009).

Methods

Thirteen carers for people with dementia who were in different care-giving situations participated in the study. The study was carried out in a city in the north-east of England and recruitment, data collection and data analysis were ongoing between May 2007 and November 2008. Ethical approval was provided by a NHS Research Ethics committee.

Sampling and recruitment

Aneshensel *et al.*'s (1995: 23) care-giver career provided the framework for purposive sampling to ensure that recruitment captured diversity in care-giver experiences. As Table 1 shows, the sample spanned those who were preparing for and acquiring the role of an informal carer (stage 1); those who were actively enacting care-related tasks and responsibilities (stage 2); and those who were disengaging from caring following the death of the person with dementia (stage 3) (Aneshensel *et al.* 1995: 22–3). As well as drawing participants from across the care-giver career, recruitment was focused in three socio-economically contrasting areas of the city in order to

TABLE 1. *Description of the research participants*

Participant	Stage in the care-giver career	Study area	Age group	Cares/ed for	Marital status	Current living arrangements of the carer and the person with dementia
Mrs F	1	Other	50 s	Husband	Married	Co-resident
Mrs J	1	C	70 s	Sister	Widowed	Lives alone – sister lives in own home
Mrs T	1	C	50 s	Mother	Married	Lives with husband – mother lives in own home
Miss D	2	C	40 s	Mother	Partner	Lives alone – mother lives in own home
Mr A	2	A	80 s	Wife	Married	Co-resident
Mr P	2	Other	70 s	Wife	Married	Lives alone – wife in nursing care
Mr U	2	C	50 s	Mother	Married	Lives with wife – mother lives in own home
Mrs Q	2	A	50 s	Father	Married	Lives with husband – father lives in own home
Female	2	A	70 s	Husband	Married	Co-resident
Female	3	C	90 s	Husband	Widowed	N/A
Mr E	3	B	80 s	Wife	Widowed	N/A
Mr O	3	B	70 s	Wife	Widowed	N/A
Female	3	C	70 s	Husband	Widowed	N/A

Note: For details of stages and study areas, *see* text.

reflect the different social, cultural and community infrastructure that shaped the carer's daily experiences. Area A was a more deprived area, Area B had pockets of deprivation and affluence, and Area C had high levels of affluence.

Due to issues of self-identification and stigma (Henderson 2001; Rose and Bruce 1995), informal carers may be difficult to recruit. Fifty-eight voluntary sector organisations, support groups, churches and community groups operating in the study areas, and at a city-wide level, acted as gatekeepers for recruitment. Willing organisations distributed posters and participant information sheets amongst their members. The objectives of the research were presented in person at six carer support groups and three luncheon groups. Advertisements were placed in two newsletters and recruitment also occurred through snowballing with participants suggesting involvement in the research to other care-givers they knew living in the study areas. Summary profiles of the participants are provided in Table 1. While efforts were made to ensure that the sample was evenly distributed across the three different study areas, care-givers needed to be emotionally ready in order to

want to discuss their experiences and participate in the research, and issues of self-identification (Henderson 2001; Rose and Bruce 1995) could have still played a role despite efforts made to mitigate against this.

Data collection

Semi-structured interviews of 45–90 minutes were conducted by the author with all participants. The interviews were audio-recorded with the participants' consent. The majority of the interviews took place in the participant's own home although three were held in other locations at the request of the participant. Although an interview schedule was used to ensure issues relevant to the aims of the research were addressed, the questioning was flexible and participants were encouraged to guide the discussion. Themes from previous interviews guided questioning in following interviews (Charmaz 2006).

All the participants who were currently caring for someone either at home or in institutional care were asked to complete a diary for two to three weeks, in addition to the interviews. Five agreed. Diary guides were provided to assist completion. These diaries gave a voice to everyday experiences and highlighted points of friction in daily life (Jacelon and Imperio 2005; Johnson and Bytheway 2001).

Data analysis

The transcribed interview and diary data underwent rigorous thematic analysis following the three-stage coding process described by Strauss and Corbin (1990, 1998) in their Grounded Theory guidelines (it should be noted that Grounded Theory was not used to guide the whole methodological approach, only the three-stage coding process). Open coding was used to categorise and discover the key properties/themes of the data. This was a detailed process but was essential preparation to taking the themes to a more abstract level. The data were reassembled through axial coding with connections between themes identified. Selective coding united all the data sources by identifying primary themes and sub-themes that were key to the participant's story. The qualitative analysis software NVivo 7 was used as a tool in the coding process.

Negotiating care-giving roles

This section considers the different ways in which informal carers for people with dementia negotiate their care-giving role across the changing landscapes

of care, drawing on the research participants' narratives. 'D' is used to indicate if a diary is the source with all other extracts coming from the interviews.

Who cares and why?

The issue of why an informal carer supports the person with dementia is not always questioned. Through the narratives of all the spouse carers it was apparent that the issue was not really considered and it could be argued that care provision in marriage is expected and not questioned (Henderson 2001; Rose and Bruce 1995). Three key issues emerged as influencing who provides care and why these individuals did so: relationships, geography and employment.

The adult-child carers did discuss why they provided care. Mrs F, who was supporting her husband, had previously cared for her mother. As an adult-child carer she had felt a sense of reciprocity.

... children do it more for parents because one you think well they're getting on in years, and then the other thing is ee well they've done all of that when I was younger. (Mrs F)

Thus Mrs F experienced a feeling of role reversal when she had supported her mother, whereas caring for her husband was an expected part of their relationship.

... with me Mam it was role reversal ... [with] me husband it's, well it's like part of you. (Mrs F)

Different expressions of closeness between spouses, and parents and adult-children, affect the response to care-giving tasks and feelings of role reversal. Mrs F found it easier to help her husband with intimate tasks, than she had with her mother, because of the previous physical relationship.

... when I used to give me Mam a bath ... I used to try and keep her dignity ... I don't feel as though when it come to [husband] having a bath that I have to have that dignity to him in the same respect because of our physical relationship ... you're used to seeing each other with no clothes on. (Mrs F)

The support required by the person with dementia may be difficult for the carer to deliver. Having to help with bathing may not reflect the levels of intimacy that had previously characterised the relationship. This may be of particular relevance in the adult-child and parent relationship, but as Parker (1993) found, intimate care provision may not be necessarily easier in marriage. While the spouse carers in this study did not raise concerns about intimate care provision, it could indicate that intimate care may be provided in marriage without question due to social expectations or because of the previous relationship irrespective of social expectations. Intimate care

provision may only be considered when comparison can be drawn to other care-giving situations.

While Mrs F's narrative draws attention to role reversal and reciprocity, those of the other adult child carers' highlight that care-givers provide care by default. Siblings may not negotiate the support of parents because of assumptions that their parents would not need support. Individual siblings may take on the care-giver role because of geography, gender assumptions or because no-one else took responsibility (Willyard *et al.* 2008).

Mr U described how geography played a role in why he had become his mother's primary care-giver. While his brother lived outside the city, Mr U lives within walking distance of his mother's home. Therefore Mr U provides the majority of support to his mother. Mr U wishes his brother provided more support but he feels that there is little that he can do to change the situation.

[Brother] basically never comes . . . I'm very hurt but anyway there's nothing I can do about it because I'm local I have to be the point of contact. (Mr U)

Employment demands had also to be balanced. Thus it was often those who were not in (paid) employment, for example Mrs T and Mrs Q, and those who did not have established careers, for example Miss D, that were expected to provide care. As a result it is those with the least (financial) resources who may take on the demands of care, while also drawing attention to the lower social value placed on care provision in relation to paid employment (Folbre 2001; Jarvis 2007; McDowell 2004).

Miss D had only just re-entered the labour market following a long period of illness whereas her siblings had established careers. Therefore, it was seen as easier for her to drop out of work:

I was . . . just getting back into the hang of working again, so, it wasn't a lot for me to drop back out of work. (Miss D)

Similarly, Mrs T undertook voluntary work, whereas her sister had full-time paid employment. It was perceived that voluntary work could 'more easily be scheduled around the demands of caring' (Mrs T, D), although through her interview and diary narratives it became apparent that this was not as easy as first thought as Mrs T had difficulty reducing her voluntary work commitments.

Mrs T was the only adult-child carer who had discussed sharing care with a sibling, highlighting limits to adult-children's sense of obligation and responsibility:

if I look after her now, when she needs to go into a care home she can go to one where my sister is . . . and then at least you know my sister and I will have shared the care between us. (Mrs T)

It is planned that Mrs T's mother will eventually move into nursing care near Mrs T's sister's home. By making these plans it can be argued that Mrs T's and her sister's expectations of the care-giver role in the nursing home environment are much less than the care-giver role in the home. This assumption is considered further later.

Negotiating the boundaries of the caring role

The participants negotiated the boundaries of their care-giving role in the home in different ways. While some considered the limits of the support that they were prepared to provide, others negotiated whom they could expect to receive assistance from. This was shaped by the relationship the carer had with the person with dementia. While all the adult-child and sibling carers discussed boundaries in terms of how to limit the care provided, spouse carers discussed the boundaries of their caring role in relation to where, and when, they would, or would not, expect support. In addition, some did not know how to obtain support.

Mrs T, an adult-child carer, reflected on previous experiences of care-giving in her own life when deciding what was an appropriate level of support to provide to her mother. For 20 years Mrs T's mother and father looked after Mrs T's grandmother. Mrs T felt that her mother 'was just running herself into the ground' (Mrs T). Reflecting on the proper thing to do in relation to her social and biographical context (Connidis 2001; Finch 1989; Sevenhuijsen 1998), Mrs T outlined that she had established a limit to the support she was prepared to provide. She felt that it was not appropriate for her mother to live with her, marking the limits to obligation in the physical landscape.

Putting limits on the amount of care they would provide was a process full of ambiguities and contradictions for all the adult-child and sibling carers. Both Mr U and Mrs J stressed that they did not think of themselves as carers. By embracing this term they felt others would perceive them as having responsibility for the person with dementia, and it can be argued that they themselves would feel the need to provide more support than they were providing currently. However, both provided high levels of support (visiting regularly, shopping, and liaising with statutory care providers).

The spouse carers negotiated the boundaries of the caring role in different ways by identifying when, where and from whom they expected support. They placed limits upon the support they drew upon based on ideas of responsibility and obligation towards the person they were supporting. This challenges assumptions that carers draw upon their support networks (Phillips *et al.* 2000). Three spouse carers stated that they had children living nearby but that they did not draw on their support. Mr E believed his sons

should prioritise the care for their own families, as they could not take care of two families simultaneously. Twigg and Atkin (1994) also found that older carers might not turn to their adult-children for support as they think that they have their own lives to lead. For Mr E supporting his wife was perceived as the normal part of a loving relationship.

[Sons] had their own families to look after . . . you cannot look after two families, and I didn't mind looking after my wife, I loved my wife. (Mr E)

However, while Mr A felt that it was his responsibility to deal with the practical and emotional care-giving problems he encountered, this led to a sense of resentment because his 'daughter doesn't really understand the situation, because she sees [her mother] for a couple of hours and then she's gone' (Mr A).

In other instances support was expected, but was not forthcoming. When Mr E's wife was diagnosed with dementia the hospital staff assured him that he would receive support. However, he stated that for the first years of his care-giver career he did not receive any formal support at home. He felt that health and social care professionals were more qualified to take care of his wife and that he needed to be supported as a medically unqualified spouse:

a nurse, who's got to look after, a patient with Alzheimer's or any of those things, have got to be qualified . . . A spouse, they don't have to be qualified. (Mr E)

Some carers were unable to make informed choices about the ways in which they provided care/negotiated their care-giving role because they did not know that they could ask for formal support and/or that formal support was available (Brodaty *et al.* 2005; Denton *et al.* 2008). Mrs Q described how she had not asked for support at the beginning of her care-giver career because she did not realise that she could.

. . . eventually we got all the help once he was ill, really poorly . . . we didn't know before that we could [ask for help], and I think that's a problem with a lot of carers, they just stay at home and they just think they've got to cope on their own. (Mrs Q)

This was an issue that was raised in the majority of the carer's narratives: they shouldered the demands of care alone at home because they did not realise that they were entitled to support. This could be because of social and cultural assumptions about gender. In addition, the dementia care-giving situation is often very new and because of the silence and stigma that surrounds dementia, carers may not be aware of the course of the disease. Others may recognise that they need support but require signposting (Neufeld and Kushner 2009). The implications of this is that some carers may be providing levels of support at home that they are not comfortable with because they do not know that they can ask for support, or that support is available.

The changing landscapes of care

The changing landscapes of care were experienced in two ways: changes from the situation before the start of care-giving and changes as care-giving progresses.

Participant narratives of how their relationship with the home was transformed are described below. Mr U expressed feelings of being trapped in his home and neighbourhood: he was no longer able to take trips away. He also felt that the statutory sector only wanted to ensure that they could secure outcomes and ‘tick their own little boxes’ (Mr U), and that they were not really interested in the wider realities of care provision by informal carers in the community. Housing issues and the spatial organisation of carers’ lives can heighten feelings of claustrophobia if carers cannot ‘physically get away’ (Twigg and Atkin 1994: 45). This change in the relationship with homes after the start of care-giving was also echoed in the narratives of the majority of the participants with Mr A commenting that:

I sometimes wish that we could go out at night . . . we used to eat out a lot at one time . . . but we don’t do that now. Life’s a bit dull. (Mr A)

Experiences of feeling trapped also occurred in the care-giver’s home even if they were not the sites where care was being delivered. Thus the care-givers lost the therapeutic potential of independent living. Two of the adult-child carers who were not co-resident with the person they were caring for described how the therapeutic potential of their homes as somewhere to rest was limited.

Establishing a routine of having a day off in her own home became important for Miss D as her health had deteriorated when she had solely been providing care for her mother. Privately hired carers facilitated this day off. However, the following diary extract illustrates that when Miss D was taking time off in her own home she was still doing a range of tasks for her mother:

Day off . . . Took phone call . . . 20 minutes – from Mum’s stand in carer . . . Spend evening dealing with backlog of [mother’s] paperwork, started laundry, spend lot of time on phone; boyfriend + friends . . . All-in-all spent 3 hrs on behalf of Mum. (Miss D, D)

Similarly, Mrs Q described how she continually worried about her father when in her own home.

You never stop thinking is he ok, is he alright? . . . it’s always on your mind, so it’s not just the physical it’s the mental side. (Mrs Q)

The emotional investment of care-giving is hard to measure (Lloyd 2000; Rose and Bruce 1995) and the therapeutic potential of the home can be compromised by the carer’s emotional investment.

Informal dementia care provision is also spatially manifested in the changing configurations of the domestic landscape. All the older male spouse participants spoke of the role reversal that took place when they started caring for their wives. Shifts in the care dyad were often marked by changes in responsibility for household tasks and a reordering of the domestic landscape. Their wives had previously taken on the majority of the household tasks and the transition for these men, into the previously concealed world of home-based care work, was difficult to adapt to (Russell 2007).

she used to do all the shopping and cooking, I never used to do anything . . . only now do I realise how good she was when I've got to do it. (Mr A)

This difference between the reactions of male spouse carers and Mrs F's experiences (cited previously) to role reversal is perhaps indicative of the gendered nature of care. Mrs F did not see spouse care-giving as role reversal, whereas the husband carers did. It could be argued that female carers may have previously been responsible for the care of children and family and therefore the dementia care situation may not present much of a shift in the domestic landscape. Male spouse carers, in taking on household tasks previously performed by their wives, may find the configurations of the domestic landscape very much changed. Female carers may be expected to cope alone as informal dementia care is framed as a continuation from previous care-giving experiences. Male carers may not be expected to cope and therefore be offered support (Bywaters and Harris 1998). The domestic landscapes experienced by male and female care-givers may be very different.

The landscapes of care may also change over the care-giver career with the expectations of the care-giver role varying between different sites. While care in the home may be taken-for-granted and carers may be expected to provide care without the support of health and social care professionals, family or friends; those caring for a person in a nursing home have to negotiate their role in these new landscapes. The participants who had cared for someone in nursing care did not want to relinquish their care-giving role but found it difficult to provide intensive levels of support. Mr P found more subtle ways in which to provide support (*see also* Ryan and Scullion 2000; Whitaker 2009) with his whole day structured around a visit to feed his wife a meal, something that gave him great satisfaction:

. . . it's really a joy to feed her even though it's very, very slow . . . But I get some satisfaction out of feeding her that one meal. (Mr P)

This routine limited his social activities as his sense of responsibility had not diminished following his wife's move to nursing care.

I've got loads of options . . . but I think I would be feeling I wonder what's happening back here. (Mr P)

In nursing home environments carers' actions are monitored and it was more difficult for Mr E and Mr O to continue to provide support in ways they wanted to. They were told by nursing home staff to reduce the number of visits they made, ostensibly for the good of their own health.

And they all got on to us . . . So I thought it over, and I agreed with them . . . I took one day off a week . . . so I could do the shopping and everything . . . (Mr E)

twice day going down to visit her, and the manager and some of the staff actually turned round and told me . . . you're going to end out in an early grave the way you are going. (Mr O)

Carers have an uncertain role when the person they support moves into nursing care (Milligan 2005) and they have to reconcile the different expectations of their capabilities and re-negotiate their carer role. While Mr E felt that health and social services had too great an expectation of his capabilities in the home and his ability to cope was taken-for-granted, in the nursing home setting the expectation of his capabilities, obligations and responsibilities were much lower.

Obligation and responsibility across the changing landscapes of care

The carer narratives highlight the tensions encountered when informal carers for people with dementia negotiate their care-giving role. Care-giving responsibilities and obligations are framed in different ways. Practices reflect social and cultural norms, as well as individual and family biography. While all the care-givers in this study were providing care, they had different expectations about the support they should receive. Equally the support that they received varied, shaped by where care was provided. This final section considers the way in which care-giving obligations and responsibilities are distributed across care-giving networks and how these negotiations are spatially manifested.

Community care policies assume that households will care and, as such, the care-giver identity may be thrust upon people. Spouses may be expected to cope simply because they are married to the person with long-term care needs (Oliver 1983; Parker 1993). Care decisions are situated in a web of social relations and individuals make difficult decisions about how they will balance competing demands. There may be little negotiation of care-giving tasks for parents amongst siblings and as a result individuals may provide by default because of geography, gender or because no one else took responsibility (Willyard *et al.* 2008). Not all sources of support are drawn

upon. Older spouse carers may not expect their adult children to support them as they had their own families to look after (Aboderin 2004; Twigg and Atkin 1994). Some carers may limit the formal support they draw upon in order to maintain control of the care-giving situation (Lawrence *et al.* 2008). It cannot be assumed that carers will draw upon their networks for help in times of need (Phillips *et al.* 2000). Carers balance care-giving labour using the social, cultural and moral resources available (Egdell *et al.* 2010).

Participants in this study did not necessarily expect that they should cope alone and saw themselves as medically unqualified informal carers who needed support from health professionals. Carers did not take care at home for granted and had limited expectations of their own capabilities. However, carers may be unaware that they can ask for formal support (Twigg and Atkin 1994). Equally carers may not draw on family support but this can lead to a sense of resentment if they feel that, as a result of these decisions, their needs are not understood. Carers may become tied to the home and neighbourhood, and the day-to-day realities of care provision may remain hidden.

Some participants set and maintained clear boundaries in order to define the limits of care-giver obligation. Boundaries were marked in the physical landscape through decisions that the person with dementia would not be co-resident with the carer, and that they would enter a nursing home when they could not longer live alone in their own home. Decisions reflected the legacy of previous relationships and care-giving experiences (Aboderin 2004) and may counter gendered assumptions that daughters/sisters are willing to provide high levels of support.

Care responsibilities are unevenly distributed with support network members performing different tasks for individuals. For some, intimate tasks and the emotional labour of care work are taken-for-granted and framed as a normal part of family and especially marital life (Henderson 2001; Rose and Bruce 1995). However, other carers may have to provide personal care for people with whom they have never had an intimate relationship: an adult son or daughter may have to help bathe their mother. Managing the emotions associated with providing intimate care may be hard to manage for both the carer and the person being cared for (Isaksen 2002; Twigg and Atkin 1994). Some may feel that intimate care is easier to provide in marriage as it is an extension of the existing relationship.

Care is not just interpersonal relationship-based but also is shaped by the sites and spaces where care occurs (Milligan 2009; Milligan and Wiles 2010). Whilst some individuals may find that their powers to exclude people from the home are overridden by care needs (Milligan 2009), others may find that there is an unwillingness to enter these private spaces (Arksey and Glendinning 2007; Twigg and Atkin 1994). The therapeutic potential of the home and other potential sites of respite may be compromised because

of the emotional nature of care provision. The changing relationship between the carer and the person they are caring for may also be manifested in the configuration of the domestic landscape with male spouse carers taking on more domestic chores than previously, for example.

The landscapes of care change over the care-giver career. Carers establish their identity through their interactions with different spaces. Informal caregiving takes on new meanings during home to nursing care transitions as carers renegotiate their role (Aneshensel *et al.* 1995; Milligan 2005, 2009; Whitaker 2009). Carers may not be asked about how, or if, they wish to remain involved in the care of the person once they have moved into nursing care (Davies and Nolan 2004). Although the nursing home environment may limit the intensive involvement of the informal carer, it can continue in more subtle ways (Ryan and Scullion 2000; Whitaker 2009). While the often stifling and unrelenting nature of care within the home can remain hidden, it is only when carers become part of the nursing care system that their input is monitored. This raises questions as to why the statutory sector views the care-giver's capabilities in the home to be much greater than those of care-givers for someone in nursing care. Informal carers may be encouraged to take time off from nursing home visits. Support may not be offered in the home but this could be in part because reasons for nursing home entry may include the deterioration in care-giver's health and the need for more assistance (Buhr, Kuchibhatla and Clipp 2006). More research is needed to ascertain if nursing home staff have fewer expectations of the informal care-giver because of this. This paper only considered the expectations of the care-giver at home and in nursing homes and further research is needed to establish whether variations in the expectations of the care-giver role are found in other sites of care such as supported living facilities and day centres.

Limitations

This study has various limitations. The study findings cannot be generalised because of the specificities of informal dementia care, and the small localised recruitment for this sole researcher study (Bertrand, Fredman and Saczynski 2006; Clipp and George 1993). However, the paper highlights that care-giver experiences go beyond objective factors. The findings are specific to the UK/English policy context although comparisons can be drawn with other countries that focus on home care, although the extent of state-funded support services varies (Daatland 2001; Kane and Saltman 1997; Knapp *et al.* 2007a; Pacolet *et al.* 2000). Although the small sample is not representative, the data provide nuanced insights into the care-giver experience.

Conclusions

This paper explored the different ways in which informal carers for people with dementia negotiate their care-giving role across the changing organisational and spatial landscape of care. It has demonstrated that care-giver decisions are socially situated and are the result of negotiations involving individuals, families, and wider social and cultural expectations which affect where care occurs. This paper draws attention to the lack of choice some carers may have in taking on the care-giving role; how and why carers draw upon support; and the different expectations of the care-giver's capabilities across the different sites of care. In doing so this paper contributes to the emerging health geography literature on care-giving as well as developing the spatial/geographical perspective in the established gerontological literature on informal (dementia) care, drawing attention to the need to acknowledge and examine the influence of space in the care-giver experience.

While all the participants in this study were providing care, some placed limits on the support they were willing to provide and/or expected support from others. However, the support from statutory providers may vary because of different expectations of the care-givers' capabilities across the individual sites of care. Carers may be expected to shoulder greater demands in the home than in nursing care. The realities of care provision in the home may remain hidden but informal care provision beyond the home may be difficult. Carers have to balance differing expectations of their capabilities, shaped by where they are providing care.

In conclusion, carers negotiate their role drawing on complex social, cultural, moral, emotional and spatial rationalities. Research and policy attention should focus upon how where care occurs affects the expectations about the care-giver role and abilities.

Acknowledgements

This paper draws on data collected for a PhD study entitled 'The Changing Landscape of Informal Dementia Care: Mapping the Sites, Stages and Support'; hosted by the School of Geography, Politics and Sociology and the Institute of Health and Society at Newcastle University. Dr Helen Jarvis, Professor John Bond, Dr Katie Brittain and Professor Ian McKeith supervised the study. Thanks go to the participants and gatekeeper organisations, who must remain anonymous, for all the time that they gave taking part in the study. The author is grateful for the comments made by the two anonymous reviewers, and Professor Ronald McQuaid, on earlier drafts of this paper. An earlier version of this paper was presented at the British Society of Gerontology 2010 conference. The Economic and Social Research

Council and the Medical Research Council (PTA-037-2006-00003) jointly funded the PhD study.

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Accepted 21 March 2012; first published online 30 April 2012

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