



## Disparate routes through support: Negotiating the sites, stages and support of informal dementia care

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### ABSTRACT

Worldwide people with dementia are usually cared for at home by informal carers who may themselves have poor health and/or live in social situations which intensify their needs. The scale of these needs continues to be underappreciated and they are exacerbated by the limited social, cultural and emotional resources that carers can draw upon. This paper looks at the disparities in support, and the complex negotiations made by carers, as they reconcile the everyday realities of informal care in the home. Appreciation of these issues is essential in understanding carers' coping strategies in an ageing population.

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### 1. Introduction

In the United Kingdom (UK) people with dementia are often cared for at home by informal carers. Since the 1950s, under policies of community care, the home has been the locus of long-term care (Lewis, 1999). This shift of emphasis away from institutional care is shaped by assumptions that the community (notably women) will provide appropriate care (Finch and Groves, 1980; Lewis, 1994; Oakley, 1994; Milligan, 2000, 2001, 2006; Williams, 2002). Since the 1990s a quasi-market has been established with the State commissioning agencies to provide health and social care services (Symonds 1998; Rees Jones et al., 2008). As welfare provision shifts from the public to the private realm, older and disabled people occupy a liminal position in the care market as both consumers and subjects of assessment by commissioners (Powell and Biggs, 2000; Phillipson and Powell, 2004). Similar measures in Europe and North America also frame the home as the site of long-term care (see Kane and Saltman, 1997; Pacolet et al., 2000; Williams, 2002; Dyck et al., 2005). This marks an ideological shift from dutiless rights, to conditional welfare and individual self-reliance. The family is 'idealised' and becomes a site for active citizenship through informal care (Powell, 2000; Gilbert and Powell, 2005; Macmillan and

Townsend, 2006). In emphasising family responsibility for welfare provision, community care policy seeks to lower demands on the State (Lewis, 1994; Oakley, 1994; Symonds, 1998; Milligan, 2000, 2001; Parker and Clarke, 2002).

Despite the increased profile of informal care and calls to recognise (inter)dependency in society, the language of the market cannot make sense of resources that fall outside the limits of the recorded realm of monetary exchange (Himmelweit, 1995; Kittay, 2001; Jarvis, 2007; McDowell, 2004, p. 146). Consequently informal care is undervalued and its complexity is partially hidden. Romantic assumptions about the home do not acknowledge the tensions encountered when care disrupts previously taken-for-granted routines (see Dyck, 1995; Milligan, 2000; Williams 2002; Wiles, 2003; Crooks and Chouinard, 2006; Yantzi and Rosenberg, 2008). It therefore can be argued that home-based care occupies a shifting position at the intersection of the State, the family and the market (Daly and Lewis, 2000, p. 296).

### 2. Aims

There are approximately 700,000 people with dementia in the UK and 24.3 million people worldwide. By 2025 it is expected that this will rise to 1 million due to the effects of an ageing population and earlier and improved diagnosis. Worldwide 4.6 million new cases are diagnosed per annum. The scale of the potential demand on health and social care services continues to be underappreciated (McNamee et al., 2001; Bond et al., 2005; Ferri et al., 2005,

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p. 2112; Knapp et al., 2007, p. ix). Dementia is a term that describes a number of clinical conditions including Alzheimer's disease and multi-infarct dementia. The behavioural and psychological symptoms of dementia place the most stress on carers. Symptoms include aggression, repetitious questioning, wandering and anxiety (Knapp et al., 2007, p. 3). The stigma of dementia often leads to the social isolation of the individual and their carer.

This paper examines the complex negotiations made by carers as they manage the unrelenting demands of informal care in the home. This is addressed by examining the different ways in which carers mobilise and draw upon their support networks. Carers have to reconcile individual and macro-level assumptions about their capabilities and the meanings of 'good' care. The success or failure in these negotiations depends on the social, cultural, financial and emotional potentials that carers have available. They also affect the impact of home-based long-term care on carer identity. It is argued that as a result of the changing landscape of care provision individual carers negotiate caregiving across multiple sites and in situations over which they often have little control. These aims are achieved through the use of carer vignettes, which, although not representative, highlight common stories that raise pressing issues in relation to the rising public and private concern of dementia care.

### 3. Geographic interest in the changing care landscape

In response to the restructuring of welfare provision there is a growing academic interest in the changing geography of care provision and in the situated experiences of being cared for and caring for someone in the community. This literature recognises that places/spaces, such as the home, are social, cultural and emotional products whose meanings are in flux. Places are the outcome of a set of social relations and a complex web of multiple meanings that vary over time and space (see Williams, 2002). Therefore, it is argued that the sites of care are fluid and interdependent. In a study of older women suffering from rheumatoid arthritis, Moss (1997, pp. 24–25) uses the concept of home environment to conceptualise relational notions of space. The concept integrates the various sites where particular material and social practices take place; the relations that maintain a home; and the situated experience of these relations. As such, the home environment (and other sites of care) is not confined to a fixed set of boundaries but is spatially and temporally constituted and reproduced through socio-economic relations. The experiences of health and illness are situated in society and space (Crooks and Chouinard, 2006). For example, daily life is rooted in intersecting relations of age, gender and class (Moss, 1997). This paper contributes to this literature by exploring the conflicts encountered when the home is the site of dementia care.

Care in the community has complex spatial and temporal dimensions with meanings constantly (re)negotiated. The experience of illness and healthcare provision influences, and is influenced, by place (Wiles, 2003). Of particular relevance here is the literature on the home as a site of care. Illness forces affected individuals and their informal carers to reconsider the private home-space, public spaces and interactions with the support network (see Dyck, 1995; Milligan, 2000, 2001; Wiles, 2003; Crooks and Chouinard, 2006; Yantzi and Rosenberg, 2008). The changing relationships with the home are especially palpable as long-term care disrupts taken-for-granted activities, everyday routines and meanings (Allan, 1989; Yantzi and Rosenberg, 2008). For example, it has been shown in studies of women suffering from multiple sclerosis (Dyck, 1995) and rheumatic/arthritis illness (Crooks and Chouinard, 2006) that interactions with the home-space, in particular, change as individuals respond to their

changing bodily capabilities. These findings are mirrored in studies of carers for older people (see Wiles, 2003). Links can also be made to the literature on the management of 'wandering' in people with dementia. Healthcare professionals frame wandering as dangerous. However, carers may have a greater tolerance of risk as they try to maintain the autonomy of the person with dementia using the resources available to them. As a result the people with dementia will experience differing spatial freedoms (Clarke, 2000; Robinson et al., 2007). This paper demonstrates how carers reconsider their home-space and engagement with public space, and may experience a shrinking of their social (and spatial) worlds with an increased confinement to the home.

Part of the re-negotiation of home-space outlined by Dyck (1995) and others surrounds the blurring of the boundary between public and private space. As care becomes focused in the community, healthcare provision is increasingly home-based. Milligan (2000) shows that the introduction of formal care services in the home forces informal carers to negotiate their relationship with the home as a private space and the home as an institutional space. This theme of the blurring of the public/private boundary has been observed by Twigg (1999) who examines the spatial elements of bathing provision in the home by care workers. Privacy in the home is graded (Allan, 1989). Normally, visitors would be admitted to public rooms such as the living room. Access to the bedroom would be restricted. When care workers enter the home the privacy gradient is disrupted as they enter the once-protected spaces of the bedroom and the private bathroom. This transgression of the public/private boundary requires negotiation from the care recipient and the care worker. Twigg (1999, pp. 384 and 393) found that care workers would wait until they were invited into private spaces or leave the bathroom during bathing to maintain their client's sense of privacy. Domiciliary care workers trigger and help renegotiate the public/private binary of the home. This disrupts policy assumptions of the 'home as a private haven' (Crow, 1989).

The therapeutic landscapes literature defines place as a fluid social and cultural category whose meaning varies between individuals (Williams, 2002). Feminist critiques assert that the home can be exclusionary, suppressive, contradictory and depoliticising (see Valentine, 1993; Leonard, 2001; Williams, 2002; Blunt and Dowling, 2006). Varley (2008), however, warns that one has to be careful in making these criticisms as the home is central in maintaining individual and collective identity. What is implicit, although not fully developed, is that this changing landscape of care is not only located in space and time but also socially stratified and is general within households. Care falls unevenly onto households. The assumption that caring is intrinsically feminised has led to its devaluation and the capabilities of male carers can be underestimated (see Himmelweit, 1995; Bywaters and Harris, 1998; Folbre, 2001; Kirsi et al., 2004; England, 2005; Russell, 2007). There are also assumptions about how married couples will experience care within the dyad. Oliver (1983, p. 73) argues that "*the ability to cope is bestowed with the wedding ring*". However, as Parker (1993) argues, intimate care does not become less difficult if the carer and the person they are caring for are married. Similarly children may not be motivated in any straightforward sense to care for a parent out of feelings of duty, obligation and reciprocity. For example, gender and past and present care obligations can shape negative as well as positive attitudes and motivations (see Silverstein et al., 1995; Aboderin, 2005).

Community care is also founded on the premise that carers will be supported by their social networks. The composition of an individual's support network is understood as predictive of health and social care outcomes (Wenger, 1992; Fast et al., 2004). Wenger (1992, 1995, 1997) developed a typology of five different support

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