

Caring for older people in the 21st century: ‘Notes from a small island’

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Abstract

Drawing on carer narratives from research undertaken in New Zealand, this paper considers the interrelationship between place and the care-giving experience. In doing so, it considers: first, how informal carers of older people experience the transition in the place of care from the home to care homes; second, how they negotiate new identities for themselves as carers in these new care settings; and third, carers’ views on how we might develop more inclusive models of care in care home settings. While much current work on care-giving in the home highlights the blurring of the boundaries between formal and informal care-giving, this paper suggests that the blurring of the boundaries of care may also be manifest in an increased penetration of informal care-giving within the semi-public space of the residential care home.

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Introduction

The subject of ‘who cares’ for frail older people and where has been the focus of growing interest in both political and academic communities in recent decades. In part, this stems from the ageing of society—particularly the growth in the ‘old old’—at a pace where life expectancy is exceeding healthy life expectancy (Office of National Statistics (ONS), 2004), in part from an increased political and ideological shift away from care delivered within institutional settings towards programmes aimed at ‘ageing in place’ (Belgrave and Brown, 1997). Such shifts place an increasing emphasis on the home as the key site of care-giving with informal (or familial) carers forming the ‘frontline’ of primary care. These developments have occurred in tandem with

growing concern about the ability of the traditional welfare state to deal with many welfare problems and a breakdown in consensus in many neo-liberal economies that these problems can be dealt with through the encouragement of private markets. As a consequence we have seen increased emphasis on a mixed economy of care, one facet of which has been the promotion of individual and familial responsibilities over statutory rights to care (Cheyne et al., 1997). Such changes have contributed to an increase in the complexity of the care-giving relationship and claims that we are seeing an increased blurring of the boundaries between formal and informal care (e.g. Twigg, 2000).

In New Zealand, the increased importance attached to the development of community-based care has been reflected in a number of recent policy and guidance documents (Ministry of Health (MoH), 2001, 2002). For frail older people, these policies focus on the enhancement of support systems that will facilitate their ability

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to ‘age in place’, with a concomitant reduction on institutional care. In comparison to other advanced capitalist states, however, *public* provision of community care supports remains relatively under-developed and can be difficult to access (National Health Committee, 1998; Pool, 2000; McPherson, 2003). Indeed, McPherson (2003) has argued that the inadequate state resourcing and provision of support services for frail older people in New Zealand is such that the extent to which care-giving falls on families (particularly female family members) is likely to impact adversely on their own quality of life. This echoes the findings of research undertaken in other comparable states that has highlighted the adverse effects of caring on the physical and mental health of informal carers¹ (see, e.g. Denihan et al., 1998; Schneider et al., 1999; Burns, 2000). Low levels of community-based care supports in New Zealand are, thus, likely to lead to a greater frequency of carer burnout than might be the case in other comparable countries, with care home placement as the only real viable alternative.

How informal care-giving is experienced in New Zealand is generally under-researched, though a few researchers have undertaken some important work in this area (see, e.g. Baker, 1992; Abbott and Koopman-Boyden, 1994; Belgrave and Brown, 1997). The outcome of this work was reflected on in the National Health Committee’s (1998) report: *How Should We Care for Carers?* which set out an agenda for discussion about how the needs of informal carers in the community can best be met. This report mirrors a general trend amongst political communities to focus on support for informal care-giving within the home and community. For example, while the report clearly notes that, “carers’ responsibilities don’t end when they [care recipients] go into a rest home” (p. 11), its concern is with care given within the domestic home and does not extend to care home settings.

As Kellet (1999) notes, informal carers’ experiences of care home placement have rarely been the focus of research. While a few studies have considered family perceptions of nursing home care (i.e. Bowers, 1988; Ryan and Scullion, 2000; Herzberg et al., 2001) most studies tend to focus upon the *resident*, and thus fail to acknowledge the needs of informal carers at what can be an extremely vulnerable time of their lives. Still less attention has focused on the longer-term experience of informal carers whose spouse or close family member resides in a care home setting. One study by Belgrave and Brown (1997), however, has indicated that there

may be a surprisingly high level of informal contribution to the care of older people in these settings. Indeed, they estimated that the extent of such informal care-giving could be equivalent to as much as 14% of a Stage II rest home² weekly fee (p. 38). This finding is of considerable significance, and highlights the need for a better understanding of how informal carers experience and cope with caring for their elderly relatives within residential care homes, and how they can be best supported to continue to provide care. These are important issues, not only can informal carers undertake significant levels of care-giving in residential care homes, but also indications are that continued family involvement after the admission of a relative to residential care may influence the quality of care received (Rowles and High, 1996).

While the work cited above offers some significant insights into the relationship between family carers and care homes, they are aspatial in their analysis. As such they largely ignore how place may act to shape the care-giving experience and vice versa. Within health geography, informal care-giving has been the focus of a small but growing field of interest (see, e.g. Williams, 1996, 2001, 2002; Milligan, 2000, 2003; Brown, 2003, 2004; Wiles, 2003a, b). Focusing on the political drive to promote caring in place, this work has sought to examine not only how place and community act to shape the experience of care, but also how the interrelationship between carers (both paid and unpaid) and care-recipients impacts on those environments within which care takes place. Milligan’s (2000) work on carers of older people, e.g., drew attention to how the restructuring of health and welfare at both the macro- and micro-level has affected not only the spatial equity and access to formal care, but also to an increased blurring of the boundaries between those places in which formal and informal care-giving takes place. For some older care-recipients, she argued, ageing in place is more synonymous with an institutionalisation of their homespace. Also concerned with care in the home, Williams (2002) sought to elucidate how caring households deal with the homecare process, and in doing so attempted to draw out some of the ways in which the homespace might be manipulated to promote a more therapeutic landscape (Gesler, 1992). Brown’s (2003) work has taken a different perspective as it seeks to draw out the spatial

¹An informal care is defined as a relative or friend who provides unpaid support to someone who is ill or disabled with personal tasks such as dressing, bathing, toileting shopping and household tasks, or who offers other sorts of practical or emotional support (Milligan, 2000).

²Care home settings in New Zealand encompass: Stage II rest homes, Stage III specialist units (e.g. for those with poor mental health or learning disabled), continuing care hospitals and high dependency psycho-geriatric hospitals. Rest homes and hospitals are the two main types of non-private dwellings used by those over the age of 65. Facilities are generally privately owned. Prospective residents seeking state subsidies are means tested. Unless explicitly stated, the term ‘care home’ in this paper refers to both rest home and hospital care in New Zealand.

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