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'Making it better': Self-perceived roles of family caregivers of older people living in care homes: A qualitative study

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Abstract

Background: With growing numbers of frail older people making the move to a care home, family carers are increasingly finding themselves in the position of assisting with this transition and establishing a new caring role within this context. However, the nature of the family caregiving role within the care home setting is poorly understood. Aims and objectives: This paper draws on data from a study, which sought to better understand the experience of nursing home placement from the viewpoint of relatives. The focus here is on the self-perceived contribution of family carers to life within the home.

Methods: A constructivist methodology was used. Data were collected in 37 semi-structured interviews involving 48 people who had assisted a close relative to move into a care home.

Findings: Data analysis revealed three phases to the transition from the relatives' perspective. This paper reports on the findings which relate to the final phase: 'making it better', which documents experiences of establishing a new caregiving role within the care home. Relatives described three main aspects to their role: maintaining continuity, which involves helping the older person to maintain their sense of identity through the continuation of loving family relationships and through helping staff to get to know the resident as an individual; keeping an eye, by monitoring the care received, providing feedback to staff and filling any gaps, and contributing to community through interacting with other residents, relatives and staff, taking part in social events and generally providing a link with the outside world. Relevance to clinical practice: Findings suggest that the potential contribution of relatives to promoting the well-being of both residents and staff is under-developed. Staff in care homes should seek to identify the role that relatives would like to perform and support them to achieve this.

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Keywords: Care homes; Family carers; Relatives; Older people; Roles

1. What this paper adds to the literature

What is already known about this topic?

• Most family caregivers wish to maintain active

involvement in the life and care of their relative

extent of this involvement.

 More generally there is some evidence that involvement with nursing home residents by relatives can have positive effects for both relatives and residents, although there are signs that the involvement of relatives is not always welcomed by staff.

following admission to a nursing home; however, there appears to be little willingness on the part of

caregiving staff to actively negotiate the nature and

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What do we now know as a result of this study?

- Most relatives perceive a clear role for themselves in continuing to support an older person following admission to a nursing home. However, relatives generally have to take the initiative if they wish to continue to play an active role in caregiving.
- Relatives also have the potential to contribute to the wider community within care homes and enhance the well-being of other stakeholders through their interactions with staff, other residents and their relatives.

2. Background

At the beginning of the 21st century, the care of frail older people continues to present one of the most significant challenges for health and welfare systems. While community care remains a key policy objective throughout Europe, a range of models of collective care will nevertheless be needed by increasing numbers of frail older people. As a result, many family caregivers will face the challenges of assisting an older person to move into a care home and of creating a new caring role for themselves within this context. There are currently nearly 13,000 care homes for older people within the UK, providing care for more than 350,000 residents (National Care Standards Commission, 2004). In spite of a number of high profile home closures in recent years, the overall number of residential places for older people actually showed an increase in the year to 2003 (National Care Standards Commission, 2004). Furthermore, as a direct consequence of policies aimed at enabling frail older people to remain in their own homes as long as possible (DoH, 1989, 2003) residents of care homes are becoming increasingly frail and often have highly specialised needs (Siddell et al., 1998; Royal College of Physicians, Royal College of Nursing, British Geriatrics Society, 2000). Higher levels of cognitive impairment on admission to a care home (Godlove Mozley et al., 2000) mean that continuing involvement of family carers is crucial if the needs of an older person are to be adequately assessed and planned for. However, there is currently limited information about ways in which such involvement can best be supported.

From the caregiver's viewpoint, it is now more widely appreciated that the way family caregiving evolves over time is important and that a longitudinal perspective is needed to inform policy developments, service interventions and professional practice (Wilson, 1989; Naleppa, 1996; Nolan et al., 1996). The most sophisticated temporal models of family caregiving recognise that carers' needs will change with the increasing frailty of the cared-for person, in particular once the decision is made to relinquish the major care-giving role and seek some form of residential care. Nolan et al. (1996) have termed

this stage 'reaching the end' and identify a further stage 'a new beginning', in recognition of the fact that the carer is likely to need support to adjust to their new role in the person's life. More recently, Nolan and colleagues (2003) have suggested that these stages represent key transitions that occur in caregiving over time and highlight points at which carers need additional support. A better understanding of these transitions will help practitioners to identify appropriate interventions to support family caregivers at each stage. The aim of this paper is to describe a range of caregiving roles described by relatives who have helped an older person to move into a care home, and continued to support them in that setting. It is hoped that an appreciation of these roles might enable staff within care homes to create more effective partnerships that recognise and value each relative's contribution, as well as supporting relatives to adjust to their new role.

3. Uncertainties about the role of family caregivers following the move to a care home

There is relatively little within the literature concerning the roles that family caregivers might play following an older person's relocation to a care home. This is surprising given the difficulties family carers experience in replacing caregiving, with the sense of role loss at this time having been well documented (Aneshensel et al., 1995; Dellasega and Mastrian, 1995; Nolan et al., 1996; Wright, 1998). A number of studies suggest that role redefinition is a crucial task for carers following placement of a relative in care (Dellasega and Mastrian, 1995; Kellett, 1996; Ryan and Scullion, 2000; Sandberg et al., 2001). Furthermore, carers' sense of ownership of expert knowledge in relation to the older person and their desire to convey this to staff as a basis for care planning is increasingly apparent (Bowers, 1988; Ross et al., 1993; Pillemer et al., 1998; Sandberg et al., 2002). Bowers (1988), for example describes the crucial role of family caregivers in preservative care for the older person living in a care home. This involves sustaining family connectedness; upholding their relative's dignity and hopes, and helping their relative maintain control of the environment. Kellett (1996) highlights four themes that encapsulate the way families seek to maintain a sense of attachment to their relative: engaged involve*ment*—to reduce role loss and create new ways of caring; worth—ensuring that their specialised knowledge of the older person is used as a basis for planning quality care; concern—to negotiate boundaries between themselves and staff in the home; and continuity—remaining involved and continuing to share a fruitful relationship with the older person.

It is increasingly apparent that most family caregivers wish to maintain active involvement in the life and care

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