



This is a repository copy of *'Making the best of things': relatives' experiences of decisions about care-home entry.*

White Rose Research Online URL for this paper:
<http://eprints.whiterose.ac.uk/1520/>

Article:

Davies, S. and Nolan, M. (2003) 'Making the best of things': relatives' experiences of decisions about care-home entry. *Ageing and Society*, 23 (4). pp. 429-450. ISSN 0144-686X

<https://doi.org/10.1017/S0144686X03001259>

Reuse

Unless indicated otherwise, fulltext items are protected by copyright with all rights reserved. The copyright exception in section 29 of the Copyright, Designs and Patents Act 1988 allows the making of a single copy solely for the purpose of non-commercial research or private study within the limits of fair dealing. The publisher or other rights-holder may allow further reproduction and re-use of this version - refer to the White Rose Research Online record for this item. Where records identify the publisher as the copyright holder, users can verify any specific terms of use on the publisher's website.

Takedown

If you consider content in White Rose Research Online to be in breach of UK law, please notify us by emailing eprints@whiterose.ac.uk including the URL of the record and the reason for the withdrawal request.



eprints@whiterose.ac.uk
<https://eprints.whiterose.ac.uk/>

‘Making the best of things’: relatives’ experiences of decisions about care-home entry

SUE DAVIES* and MIKE NOLAN*

ABSTRACT

Despite the growing awareness of the significance of helping a relative to relocate to a care home as a key phase in the care-giving career, relatively few British studies have explored this experience in depth. Informed by a constructivist perspective, this study sought a better understanding of nursing home placements from the viewpoint of relatives. Data were collected in 37 semi-structured interviews involving 48 people who had assisted a close relative to move into a nursing home. Analysis revealed three perceived phases to the transition: ‘making the best of it’, ‘making the move’ and ‘making it better’. The relatives’ experiences through these phases had five perceived elements, all of which were continua, from absent to very strong, reflecting the extent to which they were felt. They were: operating ‘under pressure’ or not; ‘in the know’ or ‘working in the dark’; ‘working together’ or ‘working alone’; ‘in control of events’ or not, and ‘supported’ or ‘unsupported’ both practically and emotionally. This paper reports findings about the first phase of the transition, ‘making the best of it’, and documents the experiences of decision-making about nursing home placements. It is argued that health and social care practitioners have enormous potential to influence whether or not helping a relative to move into a nursing home is perceived as a positive choice.

KEY WORDS – nursing homes, admission to care homes, family carers, care transitions.

Studies of care-home entry have focused on the experience of residents and staff, and few studies have explored relatives’ experiences of helping a family member to move into a care home and how they then establish a new role (notable exceptions include Kellet 1999; Ryan and Scullion 2000; Wright 2000). This represents an important gap in our understanding, as temporal models of care-giving indicate that when carers assist an older person to move into a care home, they enter a new but still involved phase, and require support to achieve a smooth transition (Aneshensel *et al.* 1995;

* School of Nursing and Midwifery, University of Sheffield, UK.

Nolan, Grant and Keady 1996). There is however little research evidence to suggest the type of support that is most effective during this often difficult period. The main intention of the study reported in this paper was to develop a deeper understanding of the experiences of relatives and family care-givers of older people who move into a nursing home, to enable health and social care practitioners to provide more appropriate assistance.

Literature search and review

The Medline, Cumulative Index of Nursing and Allied Health Literature (CINAHL), Psychlit, ASSIA and AgeInfo electronic databases were searched for relevant literature published during 1988–1999.¹ Search terms included: relatives, family carers, family care-givers, admission, nursing, nursing practice, nursing homes, residential homes, elderly, aged, older people, long-term care and continuing care. This process identified more than 2,000 references, full bibliographic details of which were entered into an Endnote library (Version 3.0, Niles Software 1988). Relevant references were selected using two criteria: they described the experiences of older people and/or family care-givers at the time of, and following, the move to a care home; and they described structures and processes likely to impact upon the experiences of older people who were moving and their family care-givers. This process identified 220 items, all of which were considered. The literature review examined the selected items and identified key themes.

Entry to a care home is a difficult period for most carers and care recipients, but is poorly understood. Moreover, most studies have examined the views of older people (*e.g.* Reed and Payton 1995; Reinardy 1995; Morgan *et al.* 1997; Wilson 1997), while the experiences of family care-givers have been relatively under-explored. Only about 20 per cent of the selected publications specifically concerned the experiences of family care-givers. It is clear, however, that competing tensions make decision-making about long-term care options extremely difficult for many family care-givers.

Tensions in decision-making about long-term care options

Several factors simultaneously prompt and militate against a decision to place a relative in a care home. The existence of multiple stressors, such as incontinence and wandering behaviour, combined with reduced caregiver resources and greater feelings of burden, have all been associated with placement (Pruchno *et al.* 1990; McFall and Miller 1992; Naleppa 1996; Chenier 1997), while other studies suggest that living apart from the

relative, and the need to balance care-giving with paid employment, are better predictors of care-home placement than functional ability (Tsuji *et al.* 1995). Carers who gain few satisfactions from care-giving are also more likely to seek care-home placement (Pruchno *et al.* 1990). Other important influences are outside the care-giving relationship, and include a lack of flexibility in community support services (Wright 1998), and the pressure to discharge older people from hospital rapidly (Clemens 1995; Wright 1998).

In opposition to these various 'drivers' of institutional placement are the almost universal feelings of hostility and negativity which admission to care engenders among both older people and their carers (Jani-le-Bris 1993). Care homes are commonly viewed as alienating places where older people go to die (Nay 1995). Furthermore, there is a perception that individual rights are likely to be subsumed by institutional routines and regulations (Levine 1995). Given the recent shift of long-term care into the private sector, nursing home owners are often seen as profiting from an 'aged care industry', and are not perceived to have the best interests of residents at heart (Anson 1995). Compounding such negative general perceptions, older people themselves are likely to be resistant to the idea of moving into a care home (Kelly *et al.* 1998), and while entry to care can be a 'positive choice' for some older people (Allen *et al.* 1992; Nolan *et al.* 1996), this appears to be exceptional and admission is more often associated with the end of 'independent life' (Lewyeka 1998). Consequently, there can be considerable psychological and emotional resistance to the idea of entering care (Roberts *et al.* 1991).

Not surprisingly, therefore, the prospect of admission to care is rarely discussed openly. The almost universal negative image of care homes produces reluctance among family members to initiate the decision-making process, which is frequently left until the last minute. As a result, older people often feel that crucial decisions are initiated and made by others (Johnson *et al.* 1994; Nay 1995), notably authority figures such as doctors (Morgan and Zimmerman 1990; Naleppa 1996). While each care-giving situation is unique, and care-home placement is likely to be accompanied by a complex interplay of factors (Groger 1994), personal conflict is a frequent feature (Aneshensel *et al.* 1995). For this reason, information and support are essential.

Family care-givers' need for information and support

Whatever the circumstances that surround an admission to a care home, family care-givers are increasingly expected to play a significant role, both in the initial decision to seek care, and subsequently in selecting an appropriate

home (Dellasega and Mastrian 1995; Nolan *et al.* 1996; McAuley *et al.* 1997; Ryan and Scullion 2000). The time available for placement decisions is however often limited (Dellasega and Nolan 1997; McAuley *et al.* 1997; Wright 1998), and the assessment of the carer's needs is poorly developed (Social Services Inspectorate 1996; Audit Commission 1997). Consequently, appropriate information and support may not be provided, and attention is concentrated on completing the bureaucratic processes rather than on a holistic assessment of need (Cotter *et al.* 1998). Moreover, although it is widely advocated that alternatives to nursing home placement are thoroughly explored by considering the advantages and disadvantages of institutional care, this rarely occurs (Centre for Policy on Ageing 1996; Lewyeka 1998; Wright 1998). The complex and ambivalent emotions that carers experience during the placement are frequently not addressed (Lewis and Meredith 1989; Roberts *et al.* 1991; Nolan *et al.* 1996).

It also appears that, once the decision to place has been made, the concerns of older people and their carers receive relatively little attention, and there is limited communication with the prospective home (Sulman *et al.* 1996; Reed and Morgan 1998). This represents a lost opportunity, as several studies have stressed the need for nursing home staff to be made more aware of relatives' needs at the time of admission and subsequently (McDerment *et al.* 1997; Pillemer *et al.* 1998). Relatives experience loss and grief during this period, and these emotions often continue throughout the time that the older person remains in the nursing home (Johnson 1990; Dellasega and Mastrian 1995; Tilse 1997; Kellet 1999; Ryan and Scullion 2000).

Despite the current advocacy of user involvement and choice, it is apparent that older people themselves frequently do not figure prominently in the decision-making process, and often do not have the opportunity to visit the home before moving in (Allen *et al.* 1992; Hunter *et al.* 1993; Myers and MacDonald 1996; Audit Commission 1997; Brown 1998; Cotter *et al.* 1998; Reed and Morgan 1998). Yet the selection of an appropriate home is crucial. Reed *et al.* (1998) highlighted the importance of 'place' when seeking admission to a care home. Ideally, the location of the home should allow new residents to share memories of their community with other residents, while maintaining links with family and friends.

Given the deficiencies of care placements and the gaps in understanding that have been identified from the literature review, the following objectives were formulated for the study reported in this paper:

1. To explore, describe and interpret the experiences of family care-givers when helping a relative to move into a nursing home and continuing to support them afterwards.

2. To explore, describe and interpret current practice in relation to supporting and involving family care-givers, particularly around the time of admission.
3. To compare the perspectives of family care-givers, residents of care-homes and staff.
4. To generate understanding and insights to inform, assist and empower people who experience admission to a nursing home.
5. To generate publications and debate to inform and improve the practice of health professionals, particularly nurses working in hospitals and nursing homes.

Methodology

The twin aims of the study were to provide new insights into the experience of care-home placement and to generate knowledge to inform practice. In selecting a broad methodological approach, Rodwell's (1998) advocacy for a constructivist model was persuasive. It contends that a context-specific ontology and an emic perspective generates an explicitly pluralistic and dialectic epistemology, and that this provides a form of 'rigorous knowing' that is a helpful guide to practice. Two periods of data collection were undertaken. The first involved semi-structured interviews with carers who had placed a close relative in a care home. They focused on the time leading up to the admission, the experience of relocation and the participant's subsequent involvement in the care home. The second phase comprised detailed case studies in three nursing homes, which contextualised and illuminated the placement experiences. This paper focuses on the initial phase of the study, and its explorations of the relatives' experiences of decisions about care-home entry. Full details of the study and findings from both phases of the research are reported elsewhere (Davies 2001).

The interviews with relatives

The semi-structured interview schedule reflected the key themes that emerged from the literature review. The principal topics were the events leading up to admission, the factors that influenced the decision-making, and the experiences of the move and subsequently. To implement the constructivist perspective, the following research design features were incorporated:

- An extended negotiation of the agreement to participate in the study, with at least two contacts.

TABLE I. *Number of participants by recruitment path*

Strategy	Participants (n)
Contact with nursing home managers	20
Advertisement in local newspaper	6
Contacts made on visits to nursing homes	3
Advertisement in <i>Carers' Newsletter</i>	3
<i>Sheffield Transitional Care Forum*</i>	3
Local branch of <i>Relatives' Association</i>	2
Total	37

Note: *An association of practitioners and service users in Sheffield who are interested in improving care around the time of admission to a nursing or residential home.

- Posting the interview schedule in advance to allow the participant to prepare.
- Iteratively 'checking' understandings throughout the interview.
- The interviewer sharing her own views and experiences.
- Creating a hermeneutic cycle in which the issues and themes that emerged from the early interviews were raised with subsequent participants.
- Sending a summary of the interview to each participant for comments.
- At the end of the study, sending a summary of findings to each participant for comments.

The main inclusion criterion for participants was that, having previously been informed about the focus of the study, an individual felt that they had something of relevance to share. The first phase of the study accordingly involved subjects who identified themselves as, first, a close relative of a nursing home resident (or of a relative who had been a resident and had recently died), and, second, were personally involved in the admission process. It was a convenience sample and participants were recruited using several strategies (Table 1). The most productive recruitment strategy proved to be letters to nurse managers of the sampled nursing homes which invited them to distribute information packs about the study to relatives.

This strategy was used for a sample of nursing homes in Sheffield, which were selected from the local registration and inspection unit list of those registered for elderly medical and elderly mentally ill (EMI) residents. The homes varied in number of beds and location. The first letter described the aims of the study, and was followed by a phone call to provide further information. Information packs were then posted to the nurse manager. These included information about the study, a reply slip and a reply-paid envelope. An advertisement in the local daily newspaper prompted six

TABLE 2. *Relationship of main participant to older person living in a care home*

Relationship to older person	Number
Daughter	18
Husband	7
Son	5
Wife	4
Niece	2
Nephew	1
Total	37

relatives to make contact and all were interviewed. Other participants were recruited by opportunistic contacts and through networking with service-user groups. Most interviews took place in the participant's home, their duration was from 45 to 115 minutes, and all were tape-recorded and transcribed. A summary of each interview was written soon after each contact.

A total of 37 interviews were undertaken and they involved 48 relatives. Table 2 shows the relationships of the main participants to the relative who was or had been a nursing home resident. For 16 of the participants (11 spouses, four adult children and one niece), the older person had been co-resident prior to their nursing home admission. The time since admission ranged from three weeks to eight years, although most occurred within the previous two years. For the few participants who reported that the admission had taken place several years ago, the events remained vivid and were easily recalled.

Analysis of the interviews

An inductive approach to analysis sought to develop theoretical propositions that accurately reflected the participant's feelings, thoughts and actions (Maykut and Morehouse 1994). Detailed analysis was undertaken after each batch of interviews, which is again consistent with the constructivist method (Lincoln and Guba 1985).² It comprised four steps:

- Unitising: locating units of meaning within the text.
- Categorising: sorting the units into categories of ideas.
- Filling in patterns: searching for convergent and divergent opinion, and seeking explanation for the discrepancies.
- Member checks: feeding back the categorisation to participants.

'Leads' from the literature review came into play as concepts and meanings from the interviews were recognised from previous research. A framework of categories under headings and sub-headings was developed,

No pressure	↔	Under pressure
<i>Being encouraged to take time to make decisions, to be yourself, to say what you want to happen</i>		<i>Feeling the need to make decisions quickly, to conform, to conceal your own needs</i>
Being in the know	↔	Working in the dark
<i>Having access to all relevant information to play a full and active role in the life and care of the older person</i>		<i>Lacking the relevant information to continue to play a full and active role in the life and care of the older person</i>
Working together	↔	Working apart
<i>Being able to work with health and social care staff to ensure best care for the older person</i>		<i>Barriers to working together with health and social care staff or with family members</i>
Being in control	↔	Losing control
<i>Being able to maintain ownership of decisions about your future and the future of your relative</i>		<i>Feeling that decisions have been taken out of your hands; that you can no longer influence events</i>
Feeling supported	↔	Feeling unsupported
<i>Feeling that others are aware of the consequences of the move for you and for your relative; they are willing to listen to you; and a feeling that others are there for you</i>		<i>Feeling that your own experiences and/or those of your relative are of little consequence to others</i>

Figure 1. Relatives' experiences during phases of the admission to a care home.

reworked and modified by the data from each subsequent interview. The expressions attached to each code were repeatedly reviewed in the generation of category titles and descriptive sentences. Inclusion criteria for a category were written as propositional statements (Lincoln and Guba 1985), and used to formulate theoretical ideas to explain the relatives' experiences (exemplified in Figure 1). As the process of category definition proceeded, the integrity of each participant's data was monitored by entering the revealed categories onto a matrix and by examining the

linkages between themes. Similar cases were identified using the identified categories and by comparing the participants' experiences. This process facilitated the development of 'meta-themes'.

Findings

All participants described in some detail the events leading up to the decision to seek a nursing home placement, and the search for a suitable home. These activities frequently prompted the reaction or theme, 'making the best of things', showing that even in the more positive admissions some difficulties were encountered. In the worst cases, 'making the most of a bad job' applied. Three main patterns of decision-making could be discerned, and they were associated with whether the events were or were not planned:

- *Making the decision*: instances of a relatively proactive and planned approach to deciding that placement was needed.
- *Reaching the decision*: where a decision was not made on a planned or a rational basis but, rather, reached following indecision.
- *Realising the inevitable*: when decisions were precipitated by a crisis and the decision to admit was neither made nor reached, but rather accepted.

The first pattern, of gradual decision-making, was associated with the most positive experiences of the move, but was described by only three participants. Even when entry to a nursing home was part of a long-term strategy by the older person and their family, the actual admission usually took place at a time of crisis, often following hospitalisation. As a result, the selected home was chosen in a rush (and often subsequently found to be unsuitable). Among the entire sample, admission following hospitalisation was experienced by 29 of the 36 families (two interviews involved members of the same family).

Whatever the nature of admission, the relatives described an overwhelming desire to ensure that the older person received the best possible care. During the initial phase of the transition, they had two main concerns: they wanted to make the right decision about the need for long-term care, and they wanted to choose the best available care home. The data suggested that the extent to which they were able to achieve these aims was determined largely by the interaction of five continuous dimensions (Figure 1). The respondents' experiences of the decision-making process are considered below with reference to each of the five dimensions in turn.

Under pressure or not

When making decisions about long-term care options, relatives often needed to reconcile several competing factors and interests, including the views of the older person, the views of other family members, the opinions of service providers, and their own needs as the primary carer. Despite these ‘pressures’, several participants resisted placement for as long as possible. In some cases they had promised the older person that they would never have to move into a nursing home. Others felt a responsibility to continue to care for the older person, and described a sense of duty, of wanting ‘to do the right thing’, and of struggling to support the older person at home for as long as possible:

We have had a lot of arguments [with other family members]. You tend to think that it is your responsibility. You’re battling with your conscience. You should be doing it; you shouldn’t be passing your responsibilities onto somebody else. (Betty, daughter-in-law)

This pressure to continue to care was compounded by the negative views of nursing homes, as portrayed by the media and in some cases personal experience. In other cases, the decision to place was prompted by the realisation that their relative needed a level of care and expertise that they were unable to provide, and that consequently helping the older person to move into a nursing home was seen as the ‘right thing to do’:

The only way we sort of came to terms with it was that she was in a lot of pain. And both me and my sister said that we’re not nurses, and we could do a lot more harm than good. And we said, as we saw her getting weaker, ‘We can’t do this, we need specialised care’, and she knew. (June, daughter)

Such considerations were generally experienced as competing pressures, so that for most participants there was no ideal solution and, whatever decision was reached, it was necessarily a compromise. The views of service providers were particularly influential: many appeared to tip the balance in favour of care-home admission. In this sense, the decision was commonly ‘expert driven’, with the views of medical practitioners being especially persuasive. Indeed, in a number of cases, the opinion of family doctors or hospital consultants that nursing home care was the only viable option seemed to have persuaded the family that this was the right course of action.

Once the decision to pursue nursing home care had been made or accepted, many participants experienced further competing pressures while searching for an appropriate home. Most relatives felt a heavy burden to make the right choice, particularly when the older person had little ability to make the decision. For some families, the logical choice was

the home that had previously been used for respite care, as the older person was familiar with this environment. In other cases a 'default mechanism' operated, when an emergency placement alleviated a care crisis and became permanent. This precluded the possibility of exploring alternative placements.

Even when a choice was possible, the process of visiting homes was time consuming and expensive but, given the frailty of the older person, it was a duty that many of the participants had to undertake. For all who did, it was the first time that they had been called upon to make such an important decision on behalf of their relative. The process was less traumatic if they received appropriate support and information from service providers.

Working together or alone

The extent to which participants felt that they were able to make decisions about long-term care options in collaboration and negotiation with others had a marked influence on the experience. The majority were caring for an older person who was too cognitively impaired to take an active part in the decision. This increased both their sense of responsibility for the relative and the burden of guilt, particularly when other family members did not play a major role. Indeed some participants continued to question several years after the move whether they had made the right decision.

The opportunity to work together with community services, which might have enabled the older person to continue to live at home, was an important factor in some participants' decisions. Many were unaware of the kind of support that might have been available, and few could recall a community package being offered. For others, the unavailability or unacceptability of community care meant that admission to a care home was the only realistic option. Reg, who had struggled for two years to support his wife at home as she became increasingly disabled with Alzheimer's disease, when asked if he had received any help from the social services, gave the following reply:

No, no, they offered. But I didn't know what they could do, and I said 'What can you do?' She said, 'Well, we can get her dressed in the morning', because that's where I was having a problem. I says, 'Fair enough, but what time are you going to come and get her up?' She says, 'Well what time do you want me?' I says, 'I don't know, she gets up any time; pick a time from two o'clock in the morning onwards'. I says, 'I know you can't come'.

A small number of co-resident participants suggested that community care would not have been an appropriate option as they would have resented the presence of carers in the house 'round the clock'. When the relative

needed 24-hour care, admission to a care home became the only realistic option. It was rare for family members to be involved in case-conference discussions about the future care for their relative. Even when this did happen, it did not always signify a partnership approach to care, as Stella recalled:

I found it was a battle that I lost at the time because I didn't want her to go to a home and everybody did, social workers, doctors: everybody thought she needed 24-hour care and I couldn't cope. So it was like [they were saying] 'you can't cope, you can't manage, you can't manage a job and your mother', and they were probably right. (Stella, daughter)

Being in control or losing control

For some participants, the limited opportunities to work collaboratively with service providers produced a sense of losing control over the situation. In particular, the dominant voice of health care professionals, particularly medical practitioners, caused relatives to feel that decisions about long-term care options were 'out of my hands', as one daughter recalled:

Anyway he went into hospital for some reason and while he was in hospital they decided that they would assess him. That was the first assessment he had ever had. They came up to the flat, where he was living, the social worker, there was a house-full. They completed an assessment of his needs. They decided at the end that they couldn't do it. The woman (my mother) had been doing it on her own for years, but they couldn't do it with all of their resources, so he would have to go into a home. We had no choice, we didn't know anything about anything. This social worker said where he would go, and we had nothing to do with it. (Mary, daughter)

Many relatives also found that the choice of home was outside their control. In some cases financial barriers prevented the selection of what appeared to be the most appropriate home, for there were substantial shortfalls between the amount available from social services and the fees. Some found that their relative did not meet the nursing home's criteria for admission, as when they were too impaired visually or cognitively. One carer remembered coming up against an unanticipated barrier, which prompted the sense of the decision being outside her control:

So I had to go on this long trek of finding somewhere, and I found that very traumatic, because [at] a lot of places they suggested, the matron in charge went into the place where she was to assess her [her mother], and what they evidently did, they sat back and watched, and I thought that isn't very good ... I don't think she knew. But she obviously showed herself in a bad light and they refused to have her. (May, daughter)

Working in the dark or being in the know

The sense of losing control during this phase of the move was compounded for many participants by the limited information that they received. Not being aware of the alternatives to a nursing home meant that most relatives were dependent on health and social care professionals to provide information and guidance, but such assistance was frequently lacking. A small minority had prior knowledge of 'the system' or had the resources to seek out information themselves. 'Being in the know' put them in a much stronger position to negotiate an appropriate package of care.

When selecting a nursing home, the experience of 'working in the dark' was common. As noted earlier, most participants were responsible for finding a home, but they did not know where to start. The majority were provided with only a list of homes, but no guidance about ways of comparing them. Two participants did not even have the usual list of registered homes and had to rely on the telephone directory. In the absence of support and advice from health and social care services, the distinction between the various types of home (elderly frail or elderly mentally ill, residential or nursing) was puzzling. Where a choice of home was possible there was often little option but to 'trail around' for one that appeared acceptable, but most relatives did not know what marked a 'quality home'. Doreen, for example, described how difficult it was to judge the suitability of a particular home in the absence of indicators of quality:

The list he gave me, I didn't know which to start at. We looked at about eleven [homes]. What I don't agree with in these places ... it's the lack of any grading system on the homes. You didn't know what sort of place you were putting your relative in who you love. You don't know whose care you're putting them into – that's appalling! I mean you can go in and everything looks fine ... of course it does! They're not going to do what they normally do. So where is the yardstick to measure these places by? (Doreen, daughter)

When assessing homes, relatives tried to balance various factors such as travel distance, cost and the availability of activities. Other repeatedly mentioned aspects included: absence of odour, good décor and comfortable furnishings, and the intangible 'feel' of the home. Most participants also paid careful attention to the other residents, looking for clues as to whether their relative would be happy. All the participants wanted to be able to visit their relative regularly, so proximity to their own home was important, but in several cases this consideration was counter-balanced by a wish that their relative continued to live close to their friends and neighbours so that they could visit.

Relatives were desperate for ‘insider knowledge’ to help make the decision, but most found that social workers (in particular) were reluctant to recommend individual homes. Personal recommendation, especially from a health or social care professional was highly valued, and often determined the selection. More frequently, however, relatives had to rely on less formal contacts. When able to glean information about a particular home from friends, relatives and colleagues, the sense of ‘being in the know’ was an important influence on the decision. Most relatives found it difficult to know what questions to ask on visiting a home. While they usually inquired about the available activities, few asked about staffing levels. Very few were aware that they could access the local registration unit’s inspection reports, and none asked to see them. Invitations for the older person to spend a day at the nursing home prior to making a decision were rare but welcomed when made.

Making the financial arrangements for the move was another task with which many relatives felt they were ‘working in the dark’, and was a major concern for more than half of the participants. The complex system for funding long-term care was described as ‘a nightmare’ and ‘a minefield’. One man complained that the assessment form he had to fill in had 37 pages. Most participants did not know which benefits they were entitled to, nor how the nursing home fee would be calculated. For some this caused extreme anxiety over a long period:

Reading this form it’s still £117, it started off at £200 and something. I signed it, but I still don’t know whether this £117 is going to be made up with her pension and the other bit. If I get a bill for £117 a week I’ll just die ... It’s still not clear. (Edwin, husband)

Feeling supported or unsupported

In the minority of cases when relatives had received sensitive support from service providers, were well informed, and had been encouraged to ‘take their time’ to make the decision, the help was much appreciated and significantly improved the experience of placement. John’s description of the support he received from his social worker makes this apparent:

He knew exactly what I was on about. ... He knew what was going on in here (points to head). He knew what was going on in here (points to heart). He was totally sympathetic. He listened to what we wanted to do. He knew that at that time – initially we were looking at this 24 hour care business – he knew it was not what I wanted, he knew why we were looking at it, he was still prepared

to go through it all and came up with the numbers and we could have had it, the 24-hour care, and he was not the slightest bit phased when I rang him and told him that we'd decided to go for the residential care. He's been down to see my dad. A really, really nice bloke. (John, son)

More usually, however, the participants felt that they lacked support when having to decide what care to arrange and accept, particularly those without close relatives:

I really, *really* would have *loved* (respondent's emphases) somebody to talk to at that time and there was nobody in my situation to talk to. There were nursing staff on the ward but I really didn't want to talk to them about it then. I wanted someone in my situation, and at that time there wasn't anybody, not just for me. (Stella, daughter)

Such experiences contrasted sharply with those of the few participants who were either confident in their ability to make difficult decisions, or received close support from social services personnel. Feeling supported by highly trained people who knew what they were doing contributed to a sense of 'working together', and enabled relatives to retain a feeling of 'being in control'. Unfortunately, this was the exception rather than the rule.

Discussion

It is increasingly appreciated that family care-giving evolves over time and that it is important to apply a longitudinal perspective in policy development, service interventions and professional practice (Wilson 1989; Naleppa 1996; Nolan, Grant and Keady 1996). The most sophisticated temporal models of family care-giving recognise that the final stages in the care-giving career are often associated with a realisation that the carer's physical and mental health are suffering and that alternative care arrangements are necessary. These models also acknowledge that most carers continue to play an active if modified role after their relative enters a residential or nursing home. The decision about alternative long-term care arrangements should be an important focus for supportive interventions. A better understanding of the pressures and difficulties that the decision causes to family care-givers will help practitioners develop appropriate interventions.

The findings of this study show that some moves into a care home are precipitated by a sudden crisis that demands immediate action, while others follow a gradual deterioration during which suitable care

alternatives can be carefully considered. Relatives' experiences of the placement decisions are influenced by many factors, not least the actions and responses of health and social care practitioners. Depending upon their responses, relatives were enabled to reach a decision, rather than being forced to accept placement as a *fait accompli* (Nolan *et al.* 1996). For most relatives, the need to balance various irreconcilable tensions, including the wishes of other family members, the views of professionals, and their own ability to continue to care, resulted in pressure to decide quickly. Moreover, their ability to 'do their best' for the older person was often constrained by factors outside their personal control. The lack of suitable alternatives to nursing or residential home care was a particularly important influence on the decisions.

It is apparent from both the findings of this study and previous studies that decisions about care-home placement are complex and involve many stakeholders, multiple decisions, distinct phases, several modes of interaction between the actors, and variable outcomes that are provisional and may change over time (Grogger 1994; Bell 1996; Keefe and Fancey 2000). Clearly, there is room for considerable improvement in current practice: indeed, a consensus is emerging about the areas that most require attention. The evidence presented here confirms earlier findings about the factors that promote successful placements (Nolan *et al.* 1996). It was suggested that four attributes of a transition are predictive of whether it is regarded as a positive choice: anticipation (the extent to which prior thought and discussion had been given to placement); participation (the extent to which older people and carers had participated fully in the decision-making process); information (the quality of information and advice given to older people and their carers); and exploration (of alternatives to care, of a range of care-homes, and of emotional responses to the prospect of placement). This framework was based primarily on the experiences of older people rather than family carers.

For relatives, the most positive experiences of the decision to move a frail relative into a care home occurred when the move had been anticipated and they had had time to discuss the alternatives with their relatives. In this study, however, few older people or their relatives anticipated the admission to a care home. This suggests that a useful role for community-based practitioners and hospital staff would be to encourage the exploration of long-term care options at an early stage. This does conflict, however, with the current community-care ethos that an 'institution' is the least desirable option (Peace 1998). It is therefore argued that the important role of institutions in long-term care should be more readily recognised and reconsidered (Jack 1998; Stanley and Reed 1999).

Turning to the relatives' participation in the decision, in more than half the cases it was the carer who had made the final decision about placement (usually because of the cognitive frailty of their relative). Consequently there were few opportunities for carers to work with the older person to achieve the best outcome. Many carers were therefore left to make the decision alone, with little chance to discuss the emotional impact on themselves. Several indicated that the research interview was the first opportunity that they had had to discuss their feelings. In the few cases when relatives did receive continued support from a person who appreciated their needs, it was perceived as enormously helpful. The absence of sustained support was compounded by a lack of information. Relatives expressed a particular need for information and advice about alternatives to long-term care, financial issues, appropriate levels of care, and activities in a home. They also craved meaningful information about what constitutes a 'quality home'. Those who did receive adequate support and information experienced a far more positive transition.

Relatives frequently sought information, but few were able to turn to relatives who had experienced a similar transition and made a successful adjustment. Very few references were made to service-user groups, although all those who accessed them found them helpful. Professional care staff were reported as making little effort to encourage such contacts. Very few relatives perceived opportunities to discuss their feelings and explore alternatives to admission with health and social care staff. In summary, few of the requirements of a positive nursing home choice were evident in the interviewees' accounts. The factors that influence a carer's experience of a placement which supplement those included in the previously mentioned framework (Nolan *et al.* 1996) are all aspects of carers' perceptions: that they felt under pressure, were 'working in the dark' (had inadequate information), felt out of control, and were working in opposition to health and social care staff.

Recommendations for practice

The research reported here suggests that new service models to ease the transition between care environments are required. Their development may be timely, for nurse-led intermediate and transitional care units have the potential to undertake comprehensive assessments of older people's needs, to promote appropriate choices about long-term care options, and to encourage adequate preparation. Alternatively, intermediate care packages at home are sufficiently flexible to be acceptable to older people and their families and might reduce the sense of 'crisis'. What is abundantly clear from this research is that an acute hospital ward is an inappropriate

setting for making decisions about long-term care arrangements. More generally, the findings of this research suggest that at each phase of the transition practitioners should aim to:

- Work in partnership with older people and their family care-givers.
- Be aware of the pressures which family care-givers experience and minimise them wherever possible.
- Ensure that older people and their family care-givers are well informed.
- Enable older people and family care-givers to maintain control over events and decision-making.
- Ensure that older people and family care-givers are supported, in both practical and emotional terms.

Health and social care workers who regularly support older people and their families should help prospective residents and their families identify the points to consider when choosing a nursing or residential care home. Written 'checklists' should be available through local organisations representing older people and on the Internet. Managers of care homes should also consider making such guidance available to prospective residents and their families. Few of the relatives in this study were aware of the Registration and Inspection Unit of the local health authority and its inspection reports.³ Such reports contain valuable information, and well written, accessible summaries should be readily available to prospective residents and their families. Home managers should consider making copies of the most recent report available to prospective residents and their families. Telematic systems have been shown to provide considerable help to relatives who make these decisions, and should be developed (Hanson *et al.* 1999).

Many older people needing long-term care are unable to visit a prospective home before they move in, and many decisions are made with insufficient information. This places even more responsibility on relatives. Even though most admissions are for a trial period, in reality many barriers prevent between-home transfers, not least the wish to avoid another upheaval. It is therefore highly desirable that older people and family care-givers should spend time at the home before making a final decision. At the very least, the prospective resident should spend a day at the home. Family care-givers should also have the opportunity to spend an extended period of time at the home. Creative approaches to funding the cost of accommodation, meals and transport should be explored by local authorities, home managers and voluntary organisations.

Notwithstanding the current policy of community care, placing a relative in a nursing home is likely to become an increasingly common

experience and should be viewed as a usual stage of a caring career (Aneshensel *et al.* 1995; Nolan, Grant and Keady 1996; Jack 1998). A recent literature review on experiences of residential placement recognised the value of locating the placement in a temporal framework (Lee *et al.* 2002). The authors concluded that for older people, 'adjustment to residential care is more than just a discrete event. It begins well before placement actually occurs and continues beyond'. Our findings confirm that the same is true for family carers.

NOTES

- 1 *Medline* (1966-) networked CD Rom, Ovid Online. *CINAHL* (1982-) *Cumulative Index of Nursing and Allied Health Literature*, networked CD ROM, Ovid Online. *PsycLit/PsycInfo* (1887-) networked CD ROM, APA Online. *ASSIA* (1987-) networked CD ROM, Cambridge Scientific Abstracts. *AgeInfo* (1970-) CD ROM, Centre for Policy on Ageing, London.
- 2 The QSR*NUDIST 1997 programme was used for unitising and categorising the data.
- 3 Now replaced by the 71 area offices of the National Care Standards Commission.

References

- Allen, I., Hogg, D. and Peace, S. 1992. *Elderly People: Choice, Participation and Satisfaction*. Policy Studies Institute, London.
- Aneshensel, C. S., Pearly, L. I., Mullan, J. T., Zarit, S. U. and Whitlach, C. J. 1995. *Profiles in Caregiving: The Unexpected Career*. Academic, San Diego, California.
- Anson, M. 1995. Nursing homes are for nursing people. *Elderly Care*, **7**, 3, 37.
- Audit Commission 1997. *The Coming of Age: Improving Care Services for Older People*, Audit Commission, London.
- Bell, J. 1996. Decision making in nursing home placement. *Journal of Women and Aging*, **8**, 1, 45-60.
- Brown, S. 1998. 'I don't want to go into a home': entering residential or nursing home care, care management and decision-making. Paper given at the British Society of Gerontology Annual Conference, Sheffield, September 1998.
- Centre for Policy on Ageing 1996. *A Better Home Life: A Code of Good Practice for Residential and Nursing Home Care*. Centre for Policy on Ageing, London.
- Chenier, M. C. 1997. Review and analysis of caregiver burden and nursing home placement. *Geriatric Nursing*, **18**, 3, 121-6.
- Clemens, E. L. 1995. Multiple perceptions of discharge planning in one urban hospital. *Health and Social Work*, **20**, 4, 254-61.
- Cotter, A., Meyer, J. and Roberts, S. 1998. Humanity or bureaucracy: the transition from hospital to long-term residential care. *NT Research*, **3**, 4, 247-56.
- Davies, S. 2001. Relatives' experiences of nursing home entry: a constructivist inquiry. Unpublished PhD thesis, University of Sheffield, Sheffield, Yorkshire.
- Dellasega, C. and Mastrian, K. 1995. The process and consequences of institutionalising an elder. *Western Journal of Nursing Research*, **17**, 2, 123-40.

- Dellasega, C. and Nolan, M. R. 1997. Admission to care: facilitating role transition amongst family carers. *Journal of Clinical Nursing*, **6**, 6, 443–51.
- Groger, L. 1994. Decision as process: a conceptual model of black elders' nursing home placement. *Journal of Aging Studies*, **8**, 1, 77–94.
- Hanson, E., Tetley, J. and Clarke, A. 1999. A multimedia intervention to support family caregivers. *The Gerontologist*, **39**, 6, 736–41.
- Hunter, S., Brace, S. and Buckley, G. 1993. The inter-disciplinary assessment of older people at entry into long-term institutional care: lessons for the new community care arrangements. *Research, Policy and Planning*, **11**, 1/2, 2–9.
- Jack, R. 1998. Institutions in community care. In Jack, R. (ed.), *Residential versus Community Care: The Role of Institutions in Welfare Provision*. Macmillan, Basingstoke, Hampshire, 10–40.
- Jani-le Bris, H. 1993. *Family Care of Dependent Older People in the European Community*. EU Publishers, Luxembourg.
- Johnson, M. A. 1990. Nursing home placement: the daughter's perspective. *Journal of Gerontological Nursing*, **16**, 11, 6–11.
- Johnson, R. A., Schwiebert, V. B. and Rosenmann, P. A. 1994. Factors influencing nursing home placement decisions: the older adult's perspective. *Clinical Nursing Research*, **3**, 3, 269–81.
- Keefe, J. and Fancey, P. 2000. The care continues: responsibility for elderly relatives before and after admission to a long-term care facility. *Family Relations*, **49**, 3, 235–44.
- Kellett, U. M. 1999. Transition in care: family carers' experience of nursing home placement. *Journal of Advanced Nursing*, **29**, 6, 1474–81.
- Kelly, L. E., Knox, V. J. and Gekoski, W. L. 1998. Women's views of institutional versus community-based long-term care. *Research on Ageing*, **20**, 2, 218–45.
- Lee, D. T. F., Woo, J. and MacKenzie, A. 2002. A review of older peoples' experience with residential care placement. *Journal of Advanced Nursing*, **37**, 1, 19–27.
- Levine, D. 1995. Your aging parents: choosing a nursing home. *American Health: Fitness of Body and Mind*, **14**, 5, 82–5.
- Lewis, J. and Meredith, B. 1989. Contested territory in informal care. In Jeffreys, M. (ed.), *Growing Old in the Twentieth Century*. Routledge, London, 186–200.
- Lewyeka, M. 1998. *Finding and Paying for Residential and Nursing Home Care*. Age Concern England, London.
- Lincoln, Y. S. and Guba, E. G. 1985. *Naturalistic Inquiry*. Sage, Beverley Hills, California.
- Maykut, P. and Morehouse, R. 1994. *Beginning Qualitative Research: A Philosophic and Practical Guide*. Falmer, London.
- McAuley, W. J., Travis, S. S. and Safewright, M. P. 1997. Personal accounts of the nursing home search and selection process. *Qualitative Health Research*, **7**, 2, 236–54.
- McDerment, L., Ackroyd, J., Tealer, R. and Sutton, J. 1997. *As Others See Us: A Study of Relationships in Homes for Older People*. Relatives' Association, London.
- McFall, S. and Miller, B. H. 1992. Caregiver burden and nursing home admission of frail elderly persons. *Journal of Gerontology*, **47**, 2, S73–9.
- Morgan, D., Reed, J. and Palmer, A. 1997. Moving from hospital into a care home: the nurses role in supporting older people. *Journal of Clinical Nursing*, **6**, 6, 463–71.
- Morgan, M. and Zimmerman, M. 1990. Easing the transition to nursing homes: identifying the needs of spousal caregivers at the time of institutionalisation. *Clinical Gerontologist*, **9**, 1–7.
- Myers, F. and MacDonald, C. 1996. 'I was given options not choices.' Involving elder users and carers in assessment and care planning. In Bland, R. (ed.), *Developing Services for Older People and Their Families*. Jessica Kingsley, London, 97–111.
- Naleppa, M. J. 1996. Families and the institutionalised elderly: a review. *Journal of Gerontological Social Work*, **27**, 1/2, 87–111.

- Nay, R. 1995. Nursing home residents' perceptions of relocation. *Journal of Clinical Nursing*, **4**, 5, 319–25.
- Niles Software Inc. 2000. *Endnote Version 3.0, 1988–1998*. Niles Software Inc., Berkeley, California.
- Nolan, M. R., Grant, G. and Keady, J. 1996. *Understanding Family Care: A Multidimensional Model of Caring and Coping*. Open University Press, Buckingham.
- Nolan, M. R., Walker, G., Nolan, J., Williams, S., Poland, F., Curran, M. and Kent, B. C. 1996. Entry to care: positive choice or *fait accompli*? Developing a more proactive nursing response to the needs of older people and their carers. *Journal of Advanced Nursing*, **24**, 2, 265–74.
- Peace, S. M. 1998. Caring in place. In Brechin, A., Walmesley, J. and Peace, S. (eds), *Care Matters: Concepts, Practice and Researching Health and Social Care*. Sage, London, 107–25.
- Pillemer, K., Hegeman, C., Albright, B. and Henderson, C. 1998. Building bridges between families and nursing home staff: the 'Partners in Caregiving' programme. *The Gerontologist*, **38**, 4, 499–503.
- Pruchno, R. A., Michaels, E. and Potashnik, S. L. 1990. Predictors of institutionalisation among Alzheimer disease victims with caregiving spouses. *Journal of Gerontology Social Sciences*, **45**, 6, S259–66.
- Qualitative Solutions and Research 1997. *QSR NUD*IST*, Qualitative Solutions and Research Pty Ltd, Bundoora, Victoria, Australia.
- Reed, J. and Morgan, D. 1998. From hospital to care home. Paper given at British Society of Gerontology Annual Conference, Sheffield, September.
- Reed, J., Payton, V. R. and Bond, S. 1998. The importance of place for older people moving into care homes. *Social Science and Medicine*, **46**, 7, 859–67.
- Reed, J. and Payton, V. 1995. *Working to Create Continuity: Older People Managing the Move to the Care Home Setting*. Centre for Health Services Research, University of Northumbria, Newcastle-upon-Tyne.
- Reinardy, J. R. 1995. Relocation to a new environment: decisional control and the move to a nursing home. *Health and Social Work*, **20**, 1, 31–8.
- Roberts, S., Steele, J. and Morse, N. 1991. *Finding Out About Residential Care: Results of a Survey of Users*. Working Paper 3, Policy Studies Institute, London.
- Rodwell, M. 1998. *Social Work Constructivist Research*. Garland, New York.
- Ryan, A. and Scullion, H. F. 2000. Nursing home placement: an exploration of the experiences of family carers. *Journal of Advanced Nursing*, **32**, 5, 1187–95.
- Social Services Inspectorate 1996. *Moving On*. Social Services Inspectorate, London.
- Stanley, D. and Reed, J. 1999. *Opening Up Care: Achieving Principled Practice in Health and Social Care Institutions*. Arnold, London.
- Sulman, J., Rosenthal, C. J., Marshall, V. W. and Daciuk, J. 1996. Elderly patients in the acute care hospital: factors associated with long-stay and its impact on patients and families. *Journal of Gerontological Social Work*, **25**, 3/4, 33–52.
- Tilse, C. 1997. 'She wouldn't dump me': the purpose and meaning of visiting a spouse in residential care. *Journal of Family Studies*, **3**, 2, 1986–2008.
- Tsuji, I., Whalen, S. and Finucane, T. E. 1995. Predictors of nursing home placement in community-based long-term care. *Journal of the American Geriatric Society*, **43**, 7, 761–6.
- Wilson, H. S. 1989. Family caregiving for a relative with Alzheimer's dementia: coping with negative choices. *Nursing Research*, **38**, 2, 94–8.
- Wilson, S. A. 1997. The transition to nursing home life: a comparison of planned and unplanned admissions. *Journal of Advanced Nursing*, **26**, 5, 864–71.
- Wright, F. 1998. *Continuing to Care: The Effect on Spouses and Children of an Older Person's Admission to a Care Home*. York Publishing Services Ltd, York.

Wright, F. 2000. The role of family care-givers for an older person resident in a care home. *British Journal of Social Work*, **30**, 649–61.

Accepted 17 February 2003

Address for correspondence:

Sue Davies, Department of Community, Ageing, Rehabilitation,
Education and Research, School of Nursing and Midwifery,
University of Sheffield, 301 Glossop Road, Sheffield S10 2HL, UK.

e-mail: s.davies@sheffield.ac.uk