findings

The effect on carers of a frail older person's admission to a care home

Over half a million older people currently live in long-term residential or nursing home care in the UK. A qualitative study by Fay Wright of the Age Concern Institute of Gerontology King's College London examines the consequences for adult children and spouses following an older person's admission to a care home. It focuses specifically on how and why a care home was chosen, any financial consequences for family members and their involvement in care-giving activities in a residential setting. The research found that:

- Most family caregivers found the process of choosing a suitable care home intimidating and would have welcomed more advice and support. Social workers generally declined to advise about individual care homes and choices had to be made from an area list. Many family caregivers only looked at the care home in which the placement was made.
- Many family caregivers had previously assumed that the costs of long-term care would be met by the NHS. A surprising number reported that they had only really understood that there would be means-testing after the cared-for person's admission to a care home.
- Spouse caregivers experience inequitable treatment because spouse liability to contribute towards a partner's care is interpreted in different ways both by individual local authorities and by individual social workers within one authority.
- Rules about the capital limits to savings being used to pay care costs are often misunderstood by local authority employees and family caregivers. The savings of several people in care homes had continued to be used to meet care costs even though savings had been reduced well below the limits.
- Although the relationship between the cared-for person and a child was often improved following admission to the home, this was not the case for the relationship between spouses.
- Most family caregivers handled the cared-for person's finances and kept an eye on the quality of care. Very few were involved or encouraged to be involved in practical caregiving in the home setting.

Policy context

The balance of long-term continuing care for older people has changed radically in recent years. Whereas the majority used to be looked after in either NHS hospitals or public sector care homes and the minority in the independent sector, the position is now reversed. In 1995, 74 per cent of long-term institutional care places were in the independent sector.

The system of paying for long-term care in independent sector care homes is far from straightforward. Since April 1993 local authorities have handled the financial and needs assessments of those wanting State funding. Residents are entitled to Income Support at the same level as those remaining in the community. They have to use their own income, including any social security benefits and capital, to meet fees. Capital over £16,000 is regarded as wholly available to meet care costs and between £10,000 and £16,000 as producing a notional income. With certain exceptions, such as a partner or a spouse living there, a property is counted as part of a resident's capital.

Although children are not regarded as having a financial liability for a parent, spouses are in a different situation. Under Section 42 of the National Assistance Act 1948, a man is liable to maintain his wife and a woman her husband. If one married partner is admitted to a residential or nursing home a local authority can ask the spouse remaining in the community to contribute towards care costs.

Bereavement or living alone makes an admission to institutional long-term care more likely but by no means all of those entering care homes are widowed or single. The 1991 Census indicated that approximately one in ten people in long-term institutional care are married.

Choosing a care home

Two out of three people who had previously been supported by a family caregiver in the community entered a care home following discharge from hospital. Several inter-related factors usually led to family caregivers deciding that a care home was appropriate: a caregiver's own health problems, lack of sleep, inability to cope with incontinence and physical inability to lift. At the point that care in the community broke down, those being cared for by a spouse tended to be more dependent than those supported by a son or daughter. Conversely when a spouse was the caregiver, statutory support coming into the home was less likely. But a person supported by a spouse was more likely to have day care on at least one day of the week. Wives were particularly likely to have rejected an offer of help from the statutory services with a husband's personal care. When interviewed after the cared-for person's admission to a care home, few caregivers thought that more support from the statutory services would have helped them to remain at home.

Many family caregivers felt intimidated by being given a complete list of all care homes in the area and being told to choose somewhere suitable. The social workers involved usually insisted that they could not give advice about individual care homes. Many family caregivers felt under pressure from hospital staff to choose a care home swiftly. Very few potential residents visited a care home before admission. Half the spouse caregivers and one in three children, only managed to visit the one care home that the cared-for person entered. Two important factors influencing caregivers' choice of care home were location and atmosphere.

Financial consequences for spouses

Approximately one in three of the spouses interviewed were either currently paying towards a partner's care from savings or had done so in the past. Although there is a statutory liability to contribute towards a partner's care, a spouse's declaration of income is voluntary. However, a spouse's liability was interpreted in different ways both by individual local authorities and by individual social workers within one authority. Several respondents reported being discouraged from declaring savings by a social worker carrying out a local authority assessment. Other spouses had had a different experience and had been encouraged to make a full declaration of income and savings.

A local authority must ignore the value of a property if a spouse is living there. The situation is less straightforward, however, if the spouse remaining in the community decides to sell the matrimonial home and buy somewhere smaller. Although national guidance makes it clear that a resident's share in the matrimonial home should be ignored in these circumstances, the research found that this was not necessarily an interpretation shared by local authorities. One of the wives interviewed, who had moved from a house to a smaller property because of shortage of money, had been forced to hand half the capital difference to her local authority. Other spouses interviewed felt unable to move to smaller properties because of the understanding that a local authority would be able to claim any financial difference.

Misunderstanding capital limits to savings

Capital limits appeared to be misunderstood both by family caregivers and by local authority employees. Several respondents handling finances for a resident had continued to pay towards care costs even though savings were already well below the specified limits.

They wrongly assumed that as local authority employees had initially recorded a resident's financial details there would be automatic notification when savings had reached the specified limits. As far as spouses were concerned Income Support rules appeared to be misunderstood. If a couple both live in the community the savings limit is the same as for a single person. But if one spouse lives permanently in long-term care the couple should be treated as two single people as far as savings are concerned. Some of the spouses interviewed reported being told that they had to continue paying from joint savings until these were reduced to the limit specified for a single person.

Topping up local authority payments

Several family caregivers reported that their relative was in a care home with a fee higher than the local authority was prepared to pay. The sources for these topping up payments varied. Sometimes charities paid and sometimes sons or daughters themselves. An agreement to pay extra could cause relatives great financial hardship if financial circumstances change. There were enormous pressures to find the necessary money if failing to do so would result in a resident being moved to a cheaper care home.

Extra costs in the care home

Fees do not cover all the costs in a care home and extra costs are incurred. Different items will be covered in different independent sector homes. Virtually all the residents concerned had to pay extra for hairdressing. Although incontinence supplies were included in the fees for most people, several caregivers reported paying extra for them. Chiropody was another item that might not be included in the fees. Underwear and night clothes had to be replaced frequently because of the wear and tear entailed in the vigorous care home washing procedures. Just under half the caregivers thought that the personal expenses allowance was adequate for additional expenses but half reported that it was not and had to meet some costs from their own pockets.

Other costs

Two out of three family caregivers reported travel costs to the care home. Some wives had particularly high costs. They often visited daily but as none were car drivers and public transport routes were rarely convenient, they often had to go by taxi. Some found it difficult to pay for this.

Losing an inheritance

Because a resident's savings are taken into account in meeting care costs, approximately half the sample of children had effectively been disinherited by a parent entering a care home. Although half in this situation were phlegmatic, the other half were angry. On the whole those who were angry tended to be parents and grandparents themselves who wanted to pass on an inheritance to the next generation.

Contact between family caregiver and resident

Spouses and children tended to have different visiting patterns. Most spouses visited as often as five times a week or more and few visited as little as once a week. Daughters and sons tended to visit less often, half visiting at least weekly, and half, more frequently. Other differences were evident. Few spouses had taken their partner out of the care home since the admission. The high dependency level of many spouses in care was one important factor. A second was access to a car; none of the wife caregivers had learned to drive. In contrast all the children either drove, or had access to, a car and most took a parent out occasionally for a meal or simply a drive.

Most contact between the caregiver and the cared-for person took place in the care home. Privacy was often difficult to achieve because bedrooms were not suitable venues. Meeting in a public place, such as a residents' lounge, could offer welcome distractions to some caregivers particularly if the resident concerned had little to communicate. Other caregivers, however, became distressed at such public meetings.

Although most family caregivers had been offered, and accepted, tea and biscuits during their visits, few reported being invited to regularly take a meal in the care home. Some family caregivers had been invited to participate in a meal on a special occasion such as Christmas or a wedding anniversary. Although some expressed a wish not to eat at the care home, others, particularly spouses, would have welcomed an opportunity.

Relationships after admission

There were differences in the way children and spouses described their subsequent relationship with the cared-for person. Very few daughters and sons described the relationship with the parent as worsening after admission; most relationships either remained the same or improved. In contrast none of the spouse caregivers thought there had been any improvement in the relationship with the cared-for person. Although a few thought their relationship had remained good despite a husband or wife's admission, most did not. They described a relationship that had either been, and remained, poor or one that had deteriorated since admission.

A family caregiver's role in the care home

Good practice guidance has relatively little advice to staff on how they should behave towards relatives or on what an appropriate role for those relatives in a care home might be. Few respondents reported continuing to help the cared-for person with personal care. Several spouses reported wanting to continue assisting the cared-for person in a practical way but being discouraged by staff from doing so at an early stage. Daughters and sons were more likely to be relieved that their involvement in personal care had ended.

A prime concern for family caregivers was to ensure that the cared-for person's needs were being met and their main role was in monitoring the quality of care and handling the cared-for person's finances. Few were regularly involved in other practical support such as shopping or doing laundry. Although most caregivers expressed satisfaction with the care home as a whole, no less than half found fault with some aspect of care. Shortage of staff was felt to be responsible for many shortcomings such as inadequate stimulation and poor standards of cleanliness.

About the study

This small qualitative study was carried out from the Age Concern Institute of Gerontology, King's College London. A sample of 61 family caregivers was selected though the managers of 35 independent sector nursing and residential care homes. It included 27 spouses (11 husbands and 16 wives) and 34 adult children (24 daughters and 10 sons). The residents concerned had been admitted since 1 April 1993, when the new system of local authority funding was introduced and had been assessed as needing care by a local authority. Interviews were mainly qualitative but financial information was collected using a structured questionnaire.

How to get further information

Further information on the project can be obtained from Dr Fay Wright, Age Concern Institute of Gerontology, King's College London, Cornwall House, Waterloo Road, London SE1 8WA, Tel: 0171 872 3035.

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