findings

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Parents living with children in old age

Living with children remains an important form of supported accommodation for older people. Yet we know little about how and why this decision is made and whether parents and children find sharing a household satisfactory. An in-depth study of 24 such households by the Policy Studies Institute found:

- The parents in this study were mostly very old and frail widows with poor health and limited mobility who had moved to live in a daughter's household.
- The move to live with family was usually precipitated by illness and the family had little time to consider the implications.
- These daughters and sons were motivated by a strong sense of duty to care for the parent, and although most wanted to carry on, nearly all found the shared household arrangement stressful. None knew how long family care would continue: a few children saw it as a stage before institutional care, others for as long as they could manage, while most expected it to be until the parent died.
- Most families had not discussed the option of going into a home with the parent. Most children had a poor opinion of institutional care, while many older parents found the idea quite abhorrent.
- Family carers had difficulty finding out what help was available. Most received some but seldom enough help from public services, but were reluctant to ask for more since they knew that community services were hard pressed. The greatest unmet need was to have regular breaks from caring.
- The elderly parents expressed great gratitude toward their family, hoped to remain with them, but felt anxious about being a burden. Being able to pay their way in the household was often the only contribution they felt they could make.
- The daughters and sons in this study fitted the demographic profile of family carers, since most were home-owners, had an adequate income, and their children had grown up. Most importantly, the married children generally had a supportive partner.



Introduction

Community care policies are based upon the assumption of family care both between and within households. Although fewer older people moved to live with family during the 1980s, than moved into institutional care, living with others remains a significant supported accommodation option for frail older people. For example, one in ten octogenarian and older women in private households live with children. The trend away from care within the family, however, suggests that community care policies will have to try harder to make this a viable option for older people and their families.

The typical elderly parent in this study was a very old and frail widowed mother with poor health, limited mobility and some degree of confusion. These older people (usually prompted by their families) had decided that they could no longer manage to live alone. They had been assisted in their own home by family and by community services but most now needed more intensive help:

She had a fall and came here because she wasn't very well. Then the doctor diagnosed her as having the start of Alzheimer's and said she couldn't go back to the flat on her own. (Daughter)

The adult children in this study fitted the demographic profile of family carers, since most were middle-aged married daughters whose children were grown up. Also, these were mostly owner-occupier households with an adequate income and hence some capacity to take another person into their home.

Moving in with children

These daughters and sons all felt a strong sense of obligation, so that 'doing their duty' gave a sense of satisfaction:

It was one of those things that I just felt had to be done. (Daughter)

Although many had an affectionate relationship with their parent, opting for family care did not depend upon a close relationship (though this made for a happier household). Most felt guilty about the idea of "putting mum in a home":

I would have felt very guilty if I hadn't made an effort and had just walked away from the situation. I mean I still feel guilty now that she has finally gone into a home. People say to me, well, you know, you shouldn't feel guilty, you've done your best. (Daughter)

Another characteristic of these households was that most married children regarded their partner as very supportive. These daughters, for example, believed that having an elderly parent come to live with them was only manageable with their husbands' support: *My* husband, who is fantastically supportive, said that she must come and live with us. If I am honest, I think that I was hoping he might say, well, I don't think we can cope with this. (Daughter)

These older people felt apologetic about staying in their child's household since they had "always said that I would never live with my children". But they had come to the point of being unable to carry on alone and felt that it was natural to turn to family, preferably to a daughter, rather than to strangers:

When you have got someone of your own who you know is looking after you, your mind is at rest, you don't have to worry. She is my baby daughter and she is very good to me. (Mother)

Most older parents and children had made the decision to move in a crisis without fully investigating the options. Older people had little opportunity to recover from an illness or accident before being rushed into a decision, and family members had little time to make plans:

We just thought this is what we have to do. It was a sudden decision and after that everything just piled up on top of us. (Daughter)

Older people themselves were often not fully involved in considering the options or in making the decision since going into a home was virtually a taboo topic with these families. While some daughters and sons had considered the possibility, most parents insisted that "it has never been mentioned":

I have got my family, so there was no question of that. (Mother)

These families had a low opinion of institutional care and most saw it as a last resort or as a failure of responsibility on their part. Older people themselves were strongly opposed to and even fearful of the idea of moving into a home:

I've heard so many rumours. I know several people who have been there. One woman was covered in bruises. I couldn't. No. My daughter brought me straight here from the hospital and I have been here since. (Mother)

Making room

Home-ownership gave these households some room for manoeuvre. Most had modified the house to the needs of an elderly person with restricted mobility by swapping rooms to avoid stairs, installing ramps and rails, or putting in an extra bathroom. Most would have liked more privacy for the parent and for the family, usually only possible with extensive and expensive house adaptations and additions: The main thing that most concerned me was that we should have our own space. That is the biggest source of conflict. And to do your own thing when you want. (Daughter)

Most of these parents required considerable care and saw themselves as a dependant in their child's home. Although older parents had little say in the running of these households, they arguably still had more control over their daily routine than people in residential homes, and certainly more sense of identity as a person in their own right with their own life story:

I feel I am living in a real home. Perhaps not my own, but I don't feel out of place. I don't think of it as my home, but it is a very nice home. (Mother)

Making a contribution

These older people stressed that they were "paying their way". They contributed pension money to the household budget, paid a share of the bills, and had a little extra money to buy treats:

I' m not helpless or penniless. I am living on my pension that I paid for from the age of 14. Everybody gets their pension, don't they? If they are short of money and I have it in my purse, I do help them, oh yes. (Mother)

The older women who were able to, tried to help with household chores, which their family recognised, and they were pleased when given something that they could manage:

I try to help. I don't like to be a nuisance and do things wrong and make it even worse for her. I do try. I must do something. You've got to feel that you are helping in some way so you do the best you can. (Mother)

Benefits and services

Most families were getting home care or other assistance from Social Services but the amount of help was variable and unpredictable, and seldom felt to be enough. Most people were very grateful for what they got and were appreciative of the staff who came into their homes:

She is wonderful and like a friend of the family. (Daughter about carer)

These family carers complained, however, that "nobody tells you" about what is available:

At no stage have Social Services said that your mother needs this and we are going to provide it. It has been a case of discovering what might be available and then asking. I think that I'm fairly clued up and fairly articulate. When I needed things, I found the right person to ask. But I am sure that there are plenty of people who don't. (Daughter) They also had to be persistent in order to obtain benefits and services. These women felt apologetic about asking for help, however, since they had been told that Social Services funds were scarce and must go to those in most need.

This study asked family carers what would help them most to care for their parent successfully, and as in other studies, regular and responsive respite care was a key request. The family carers in this survey had a range of respite needs, including live-in temporary care, day minding at home, and day centre attendance. Respite care admissions could be distressing, however, and had to be handled carefully:

I did have her in a respite place for a week. When I went to collect her she was crying, she wouldn't let go my hand. So I thought never again. I'm never going to do that to you again. (Son)

The Social Security carer's money was seen by family carers as some recognition of their efforts, but it was also important to older people who saw it as a payment on their behalf towards family care.

Long-term care

Most families found caring for a parent a manageable but very demanding household arrangement. One group saw family care as a stage between independent living and institutional care; a second group thought there would be a stage such as incontinence or severe dementia beyond which they could not continue; while a third group expected to look after their elderly parent for "the rest of her days". This range of views is illustrated in the following quotes:

It is emotional rather than physical stress. I feel emotionally worn out, absolutely worn out. No, there are no good things about the arrangement, none at all, none at all. (Daughter)

If she ever gets to the stage when she is completely senile, then there is no way I could cope, and she'll go into a home. But while she knows I'm here, and she thanks me every night when she goes to bed for what I am doing for her, I couldn't possibly send her away. (Daughter)

She is contented. I've got her for as long as I can manage her and hopefully that will see her to the end of her days, and then after that I will feel happy with myself. If you do what you can, you have no regrets after. (Daughter)

Older parents were extremely grateful for the security of family care rather than being put in a home. All wanted to remain with their family despite anxieties about being a burden:

My daughter said, "Don't be silly mum, we love having you," but I still feel that I am a nuisance. (Mother) A real mother-daughter relationship. I couldn't wish for better. I feel part and parcel of it here. I'm accepted. Whatever arrangements they make, I'm always included. I don't have to worry and that is a very great thing when your mind is at rest. You go to bed and you don't have to worry what will happen at night, or whether you will get up in the morning. (Mother)

Conclusions

The researchers conclude that:

- Parents and their adult children need more information about the advantages and disadvantages of a shared household, and about the available assistance, if they are to make an informed choice. Ideally this option should be considered before a crisis precipitates the decision about a supported living arrangement. Considerable information is available about care in a residential or nursing home but very little about care in a family home.
- Cash and services are important, not only to family carers but also to the older person being cared for. Many of these older people felt apologetic about living in their child's home and benefits and services lightened older people's sense of being a burden.
- Family care is a workplace as well as a household issue. Half the women family carers in this study had managed to retain their employment mainly because they could afford to supplement public services with extra paid private help; they had part-time work with flexible hours; and they had employers who were understanding in an emergency. A family-friendly workplace is crucial to family carers. Most wanted to keep their jobs, others were worried about regaining employment after a period of family care, and most needed the extra money since household costs had risen since the elderly parent came to live with them.
- A good family care policy should include a greater range of adequate services. Family carers need more support so that exhaustion does not damage the relationship with their parent. As one daughter said, "We are the embodiment of care in the community."

About the study

Interviews were conducted in late 1996 and early 1997 separately with the older parent, and daughter or son and their partners, in 24 households where the parent had moved usually within the previous year to live with family. These households were recruited mainly through health and welfare organisations.

Further information

The full report, Family matters: Parents living with children in old age by Judith Healy and Stella Yarrow, is published by The Policy Press in association with *Community Care* magazine and the Joseph Rowntree Foundation.

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