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The roles of friends and neighbours in providing support for older people

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ABSTRACT

Most published research on informal care for older people focuses on the support provided by relatives. The role of non-kin carers can, however, also be significant in supporting older people in their own homes. In this paper, we report the findings from an exploratory study of the support provided by friends and neighbours who are the main carers of frail older people. It draws on interviews with an opportunistic sample of friends, neighbours and older people, which explored their views about the support arrangements, the reasons why help was provided and any difficulties experienced. Several friends and neighbours provided intensive and frequent help, and some played a key role in co-ordinating other services. One of the main forms of direct support related to older people's quality of life, at a broader level than the practical help provided by statutory services. The flexibility of such support, and the friends' and neighbours' concern for older people as individuals, were particularly important to the people they helped. Nevertheless, such help was not provided without costs to the carers. The study highlights the need for policy-makers and practitioners not to take help from friends and neighbours for granted and, in line with the White Paper *Modernising Social Services*, to provide the support services they need.

KEY WORDS – carers, non-kin, older people.

Introduction

The steadily rising numbers of older people in the UK have been widely documented (OECD 1994; ONS 1996). The numbers of people aged 80 and over, for example, are projected to rise from 2.1 million in 1990 to 3.6 million by 2040 (OECD 1994). In addition, the proportion of households consisting of a person over retirement age and living alone is expected to increase in England from 14.6 per cent in 1996 to 16.4 per cent in 2016 (Department of the Environment 1995). Those

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older people who do not live alone are likely to be living with an elderly spouse.

Given that health and social care needs increase with age, the demographic changes will lead to larger numbers of older people requiring support. Despite some earlier predictions, this is no longer seen as presaging a major crisis, either in terms of care provision or finance (House of Commons Health Committee 1996; Joseph Rowntree Foundation 1996; Royal Commission on Long-Term Care 1999). Nevertheless, the support has to come from somewhere. Social services departments and community health services have been experiencing financial constraints for a number of years, and the pressures are unlikely to decrease. In response to these constraints, social services are directing their resources towards increased amounts of support for smaller numbers of older people with the greatest needs – which means that people with less urgent needs are receiving little or no help (Department of Health 1997, 1998; Richardson and Pearson 1995).

The majority of support for older people is provided by their families (McGlone *et al*. 1996). Nevertheless, the availability of support from relatives is changing as more younger women take up paid employment, families become more geographically dispersed, and higher divorce rates lead to more older people living on their own (Doty 1984; ESRC 1997). Analysis of the 1986 British Attitudes Survey showed that a fifth of older people did not live with or near to a close family member (Jarvis 1993). Reduced fertility and larger proportions of women choosing to remain childless means that, in future, older people will have fewer children from whom to obtain support (Clarke 1995; Grundy 1995). However, it is difficult, on the basis of existing information, to make firm assumptions about the future availability of informal care from family members (Royal Commission on Long-Term Care 1999) and questions need to be raised about the willingness and capacity of younger people to provide care (Millennium Debate of the Age 1999). Many older people, for their part, believe that children should not be obliged to care for their parents when they are old, and express a preference for professional rather than informal help (Finch 1995).

The availability of support from friends and neighbours

For a significant minority of older people receiving care, support is provided by friends and neighbours. Analysis of the 1996 British Household Panel Survey (carried out for this study) indicates that

11 per cent of carers care for non-relatives. The 1995 General Household Survey suggested a figure of 20 per cent, albeit using a broader summary definition. Other surveys of carers report that between two and 11 per cent of carers are not relatives (Bagshaw and Unell 1997; CAN 1992, 1996; Wyn Thomas 1990). Bamford *et al.* (1998) found that friends and neighbours counted for eight per cent of the main supporters of a random sample of 650 frail older people. For many people with dispersed families or no close relatives at all, friends play a central role as a helping resource, particularly in the provision of support and companionship (ESRC 1998). Friendship can be crucially important to a person's sense of wellbeing in later life, in sustaining morale and self-identity and as a source of psycho-social support (Phillipson 1997; Wenger 1994). However, friends are often of a similar age and may not be able to assist with practical tasks; for people over the age of 85, the availability of age peers will in any case be limited (Johnson and Troll 1994).

Neighbourly help, for its part, has been affected by changing economic and social factors. Different housing and employment patterns, social networks that are not limited by geographical proximity, and the widespread availability of private transport, have all altered the foundations on which closely-knit, mutually supportive neighbourhoods were built in the past (Bulmer 1986). Despite this, help from neighbours remains an important source of support, alongside reliance on local or more distant networks of family and friends (Wenger 1994).

The type of support provided

The support available from friends and neighbours generally appears to be different in quantity and kind from that provided by family carers. Some studies have found that friends and neighbours limit their support to the provision of company, and to practical tasks such as help with shopping or transport, and that they rarely provide intimate or physical care (Bamford *et al.* 1998; Green 1998; Hills 1991; Sinclair 1990; Twigg and Atkin 1994; Wenger 1984). Qureshi and Walker (1989) report that friends and neighbours most frequently provided a back-up to relatives by helping with tasks such as heavy shopping, heavy housework, preparing and cooking hot meals, and gardening; they were not a real substitute for family care or formal services. The basis on which help is provided is inevitably different in the case of friends and neighbours from that in which help is provided by family carers; whereas the motivation for family caring is often based on

obligation and duty, albeit within the context of particular relationships (Finch and Mason 1993), this does not apply to the same extent with non-relatives (Atkin 1992; Salvage 1995). Compared with formal services, the help provided by friends and neighbours is, however, often considered better quality and preferable, at least for some older people (Abrams 1980; Cantor 1979; Gottlieb 1985). Moreover, support in the form of encouragement, personal attention and conversation can help endorse an older person's sense of identity and worth (Twigg and Atkin 1994). There is no clear evidence, however, as to whether the role of friends or neighbours falls within a specialisation model, in which tasks are carried out by the people who are best placed to do them, or a substitution model, according to which friends and neighbours are only involved if family members are not available (Jarvis 1993). It would appear that people turn to those who live close by and whom they see regularly (at least once a week), whether these are friends, neighbours or relatives; proximity and intimacy are thus more important factors than the relationship as such (Jarvis 1993).

Bamford *et al*. (1998) found that where friends and neighbours provide support they were less likely than family carers to report any social or opportunity costs arising from caregiving, their social activities and holiday arrangements were less likely to be restricted and they were more likely to feel appreciated (55 per cent, compared with 27 per cent of spouses and daughters and 40 per cent of other relatives). However, they were as likely as spouses and other relatives to say they felt angry about the caregiving situation (39 per cent).

Policy issues

Although the Carers (Recognition and Services) Act 1995 stopped short of requiring local authorities to provide services to support carers, its focus on assessing carers' needs did at least emphasise the importance of such support. The Royal Commission on Long-Term Care (1999) noted, nonetheless, that carers were often left to bear the full burden and responsibility of caring themselves. It is in this context that the White Paper, *Modernising Social Services*, stated that one of the benefits of current plans for services is that 'carers who look after family members, neighbours or friends will be given greater support by social services and other agencies' (Department of Health 1999: s.2.24). This has been given additional weight in the National Carers Strategy, which is designed to enable carers to 'make more choices for themselves and to have more control over their lives – for their own health and

wellbeing' (Department of Health 1999: 53). The subsequent Carers and Disabled Children Bill represents one means of arranging such support, through proposing that carers should have the right to an assessment even where the people they help are not receiving services (Department of Health 2000). The increasing emphasis on providing support for carers should help to reverse the practice in some areas, of seeing the availability of informal care as a reason for *not* providing formal services (Twigg and Atkin 1992). Given the demographic changes outlined above, however, together with continued pressures on local authority resources, it is possible that authorities may be tempted to rely on support from friends and neighbours rather than providing services themselves.

The extent to which the support of non-family members can be seen as a resource depends very much on the availability of friends and neighbours in the first place, their willingness to carry out particular tasks, and the factors which might motivate them to do so. Atkin (1992) warned that because they will generally feel less of an obligation to care than do family carers, their involvement should not be taken for granted. Similarly, the high proportion of friends and neighbours who reported feeling angry about the caregiving situation caused Bamford *et al*. (1998) to suggest that a greater reliance on them could lead to their alienation. Not least, the incorporation of friendship or neighbourliness into formal social care packages carries the dangers of bureaucratisation and the loss of a more spontaneous approach to helping (Bulmer 1986). Abrams (1978) noted that the informal values of reciprocity and proximity in neighbourhood support are very different from concerns with formal provision, coverage, accountability and external social control that exist within formal social care. What remains unclear is which policies might provide 'incentives' for people to be carers (Millennium Debate of the Age 1999). Some who want only a small amount of support in caring, may also want reassurance of help being available when required (Millennium Debate of the Age 1999).

The research study

Although national surveys and smaller-scale studies have recognised that non-family members provide support to significant numbers of older people, most published research to date has focused on care provided by family members, as well as on related gender issues. However, the extensive work on support networks carried out by

Wenger and her colleagues (1984, 1994) and the study by Bamford *et al*. (1998) on informal care, pay considerable attention to support from non-family members within the broader context of informal support available to older people. The study that is reported here sought to add to existing knowledge, by exploring in more detail the specific nature and impact of the support provided by friends and neighbours as primary carers of older people. It was designed as an exploratory study with the objectives of:

- examining in depth the experiences and views of a number of friends and neighbours who provide support to older people, as well as of older people receiving such support;
- identifying key issues for possible inclusion in a larger study;
- considering methodological issues is gaining access to people providing or receiving support;
- highlighting policy implications.

The research explored in detail the nature of the support provided by friends and neighbours: the basis on which the support began and how it developed, any limits placed by friends and neighbours on the type or quantity of support, the factors which motivated them to provide such support, any strains experienced, and relationships with statutory services. The study was planned in collaboration with a research team at the University of Dortmund, Germany, in order to provide a comparative perspective, and was funded by the Anglo-German Foundation. This paper focuses on the research carried out in the UK.

Because the study sought to identify and explore issues involved in caring for friends and neighbours, our focus is on the views and experiences of those providing and receiving care. The study was not designed to generate statistical information which could be generalised to the population as a whole.

The sample

Three geographical areas were selected for the study: two cities and a mixed though predominantly rural area, all in the North of England, and selected on the grounds that the research team already had contacts with older people's and carers' organisations in those areas. Inevitably, for such a relatively 'invisible' phenomenon as the support of friends and neighbours, we were reliant on intermediary organisations and individuals to identify potential participants for the study. The recruitment of friends, neighbours and older people was carried out via carers' organisations, social services departments, 'Better Government for Older People' projects, branches of Age

Concern, the Alzheimer's Disease Society, and local volunteer and care provider agencies. Notes or leaflets about the research were included in the newsletters of five carers' organisations, a social services department and a voluntary organisation. Presentations were made at the meetings of two voluntary organisations.

The criteria for inclusion in the research were that:

- an older person was receiving regular support from a non-relative;
- the non-relative was the main carer;
- without this support, it was likely that more services would be needed from health or social services.

These criteria were designed to identify people receiving or providing an intensive level of support. It transpired in the course of interviews that a small number of those included did not meet these criteria; however, their experiences help to indicate the range of support that is provided.

Potential participants in the research either (i) approached the researchers directly, following an item in a newsletter or leaflet, (ii) approached an intermediary organisation (*e.g.* a carers' centre), or (iii) were approached by the intermediary organisation. Where people expressed an interest in taking part, further discussion initially took place by phone. A face-to-face interview was then arranged where appropriate, usually in the person's own home (but occasionally at their place of work or another meeting place).

A total of 29 interviews were carried out (following two pilot interviews), of which 20 were with friends and neighbours providing the support. Of the nine interviews with older people, six were with people whose friends or neighbours had already been interviewed; one of the others was not currently receiving regular informal help. All but one of the interviews were tape-recorded and, subsequently, partially transcribed. Two of the people who were interviewed provided substantial written notes about the circumstances of the people they helped and the nature of the help they had given. A list of the older people and their helpers is given in Table 1. In this paper, helpers are identified with two letters, the first being H; older people are referred to with single letters.

The helpers

Although 20 interviews were undertaken with friends and neighbours, they involved 25 helpers (as, in some cases, more than one person in the household provided support). Of the 25, 20 were women and five were men. Their ages ranged from 39 to 89: 10 were below retirement age

TABLE 1. *The older people and their helpers*[1]

The older person (age[2])	The helpers (age)	Relationship to older person/s
Mrs A (86)	Mr and Mrs HA (72, 70)	Neighbours
Miss B (86)	Mr and Mrs HB (68, 71)	Friends
Mr C (66)	Mr HC (50)	Friend
Mrs D (92) and Mrs E (86)	Mrs HD (50)	Neighbour
Mrs F (78)	Mrs HF (39)	Neighbour
Mrs G (88)	Miss HG (68)	Paid helper / friend
Mr H (80)	Mrs HI (89) and Mr and Mrs HH (70, 67)	Former landlady Son-in-law and daughter of Mrs HI
Miss J (86) and Mrs K (76)	Mrs HJ (56)	Neighbour
Miss L (92)	Miss HL (78)	Friend
Mrs M (89) and Mrs N	Mrs HM (61)	Friend
Mrs O (92)	Miss HO (65)	Neighbour
Mrs P (88)	Mr and Mrs HP (71, 69)	Neighbours
Mrs Q (86)	Mrs HQ (54)	Former neighbour
Mrs R (84)	Mrs HR (48)	Friend
Miss S (89)	Miss HS (43)	Paid helper / friend
Mrs T (90)	Mrs HT (69)	Neighbour
Mr U (78)	Miss HU (40)	Friend
Various	Ms HV (40s)	Neighbour
Various	Mrs HW (75)	Neighbour
Mrs Z (77) and others	Ms HZ (54)	Neighbour
Mrs X (82)	Mr HX (70)	Neighbour
Mr Y (77)	Various	Neighbours and friends
Mr I (91)	Little informal help	

[1] This list only includes details of some of the older people who received support.
[2] Details of ages were not always provided.

and, of these, four were in part-time paid employment. None were in full-time employment. Eight lived alone and one had school-age children at home. Eleven were involved in organised voluntary work.

The people receiving help

Fourteen of the 20 interviews focused on support for one older person. The remaining helpers helped two or more people: some spoke about up to six older people that they assisted, and information was provided about a total of 34 older people who received help (27 women and seven men). In addition to the older people about whom they spoke in some detail, some friends and neighbours provided a lesser degree of support to several other people.

Of the people receiving help, one was aged 66, the others were aged between 76 and 92. Seven of the people receiving help had died recently but all but two of the helpers were still providing help to older people. Only three of the people receiving help did not live alone: two had moved in with their helpers and one lived with her sister. The

availability of family members varied considerably: some had no living relatives, in some cases children lived a long distance away, but some older people had children or other relatives living nearby (although the amount of contact with them varied considerably).

Findings

Beginnings of the helping relationship

The helping arrangements had typically developed from small beginnings. Initial help variously involved transport to shops or to hospital, shopping, lighting a fire in the morning, making meals when the older person's partner was in hospital, practical repairs, providing company, sharing cooked food, and help with gardening. In the case of both neighbours and friends, it was often the helper who offered help (or simply carried out a job which needed to be done). In Mrs HD's words, 'it just happened'. On other occasions the older person initially asked for help with what was usually a small task. Although the helping relationship generally emerged spontaneously and willingly, in one instance it resulted from an older person needing help and no other people in a church group having the time to assist. One couple, Mr and Mrs HH, felt they had no choice but to allow Mrs HH's mother's lodger of 40 years' standing, Mr H, to come with her when she moved in with them. In two instances, the friendship grew out of a paid helping relationship, with the helper then going in at additional times (unpaid) and providing a wide range of support. Only in four cases did the help begin after a crisis: the death of a husband, hospitalisation, or a bad fall.

The help provided

The type of help that people eventually gave varied considerably. Mr HC visited his friend Mr C three or four times a week, including one day when they went shopping. Most of his visits were for social reasons: company, a chat, and occasional help with cooking. He estimated, though, that this might involve between 16 and 20 hours a week. He also defined his role as a 'carer': although it did not affect his current position as a 'job-seeker', he felt that the term 'carer' was preferable to being 'unemployed'. Ms HV, on the other hand, provided support to a number of neighbours: this involved visiting older people who lived on their own, accompanying them when they went out and obtaining information for them. Mrs X described how most of the help from her neighbours took the form of practical help in the house and

garden. The help was often minor and occasional, such as opening bottles or jars, though its importance to the recipient could be significant. Mrs X pointed out that 'it's help when I need it … things that happen on the spot … I know it may not sound much, but it means a lot'. Several helpers referred to the importance of providing company to older people who were lonely or depressed. In some instances, this accompanied other practical help, but sometimes it was the main focus of the contact.

The help could also be more regular and frequent, involving several contacts a day. For one person (Mrs A), who had senile dementia, the support from her next-door neighbours (Mr and Mrs HA) involved Mr HA going in at 7 a.m. to make sure she was well and taking Mrs A her tablets. Later he went round when the home help was there (from 8.15 a.m.) and subsequently gave Mrs HA any messages about, for example, things to buy for Mrs A. Mrs HA did any necessary shopping during the day and collected books from the library as required. She cooked a meal for Mrs A in the afternoon and took it in to her between 4 and 5 p.m. She made sure Mrs A had something to drink beside her. She or Mr HA went in again later to make sure the electric fire and other appliances were turned off.

The quantity and intensity of help could be very high. Mrs HF did all the cooking, washing and shopping for her neighbour of five doors down, Mrs F, who had senile dementia. Although social services did provide home care, this had proved problematic and Mrs HF had decided to undertake these tasks herself. She put Mrs F's clothes out for her in the morning, collected her pension, paid the bills, and took her to the doctor and chiropodist. Mrs F came to Mrs HF's house many times each day to ask, for example, where she (Mrs F) would be going that day or what Mrs HF would be making for her (Mrs F's) next meal. On weekdays Mrs F went to a day centre from 10 a.m. to 3 p.m., which enabled Mrs HF to work in her husband's business (where she had previously worked full-time until she started caring for Mrs F). Mrs HF, who also had two school-age and two older children at home, stated that 'I'm basically running two households'.

Mrs HQ was also in part-time employment. In the mornings she phoned her former neighbour, Mrs Q (who lived further down the same road), and later went to see her. She carried out any practical work (such as vacuuming) and sat and chatted with her for around an hour. Sometimes she paid for a taxi for Mrs Q to come to her house for a few hours. On other days she took her to the city centre shops. Because Mrs Q had become increasingly forgetful, in addition to having mobility problems, Mrs HQ collected her pension, did some

shopping, washed her clothes, helped her to have a bath in her (Mrs HQ's) house, gave her the tablets to be taken each day, and contacted the GP and social services as required. In the evenings she visited again, but Mrs Q sometimes phoned her during the night when she had a panic attack. Utility bills were sent direct to Mrs HQ.

The tasks the helpers carried out were sometimes unpleasant or difficult. Mrs HD had provided intensive help for two neighbours (in adjoining houses), both of whom occasionally soiled their bedclothes at night; Mrs HD then washed them in the morning. Other helpers had had similar experiences. Mrs HF used to put incontinence pads on Mrs F, although the home carer later started doing this. When an older person's condition deteriorated, the helpers often had to provide more support. Mrs E, for instance, needed hospitalisation one night; the locum GP who visited her was unable to find a hospital bed and asked Mrs HD if she could stay with her: she slept there that night. In the morning she gave her a bedbath, sorted out her clothing and changed her bed. Miss HO, for her part, found that her neighbour, Mrs O, had fallen on the floor and injured her leg and fluid was leaking from the leg. The doctor visited in the evening but, again, was unable to find a hospital bed and the district nursing service said they could not provide a nightsitter at such short notice. Miss HO phoned a private nursing agency and hired a nurse for the night at her own expense; she stayed until the nurse arrived at 10.30 p.m. The following day she was involved in lengthy discussions with the GP, district nurse, Macmillan nurse, home help and relatives. A bed was found in a rehabilitation hospital from where, with Miss HO's and a relative's support, she was transferred to a nursing home where she later died.

The special nature of the help

Some older people stressed the importance of support being available when needed. Mrs P, for instance, said she felt safer knowing that Mr and Mrs HP were next door. A helper, Miss HU, felt that Mr U would have found it much more difficult to come out of the depression following his illness if she had not been there to support him. In addition, she provided flexible help, at times and on days that suited him, unlike the formal services which he had received in the past. Mrs HD pointed out that social services are not available at 6 a.m. or 11 p.m., when help might be needed. Mrs HJ thought that many older people preferred help from someone they knew and who 'just pops in'; this was perceived very differently from having to have help from an agency. Mrs HM stated that:

I think it helps the older person if you are a friend and it develops from that, because then it helps their self-esteem – you're not there because you've been sent … It's because you want to be involved with them as a person, rather than you want to be involved with *any* person … I suppose they just feel very low to think that somebody needs to be sent to them, that they haven't anybody of their own.

Motivation

Several helpers noted that they helped others because it was in their nature to do so: in Mrs HD's words 'my nature is to give, I suppose'. Similarly, Miss HG said that, even if she had known what difficulties would occur, she would still have helped Mrs G 'because I know me' and because 'I feel sorry for her'. Mrs HF drew a parallel between Mrs F and herself: neither of them had had any love or affection in their childhood. Speaking of herself, she added that she was 'not a person that likes to offend people or upset people', whereas Mrs F was 'just a lonely old lady that's got nobody … and you can't turn your back on people like that'. Mrs HT said, more generally, that she helped others 'because I love people' and added, in common with several others, that doing so was a way of putting her religious beliefs into practice. Mrs HM felt it was only proper that, since she had good health and access to private transport, she should use these to assist others. For Mrs HJ, helping was integrally linked to her own childhood in a village where helping was 'second nature, you do it. You did, where I came from anyway. I grew up with it'. In her town, now, there were 'pockets of caring' where 'people do help one another, there is a network. We watch out for the older people'. This was very different from Mrs HF's inner city experience and contacts with social services: other neighbours had tried to dissuade her from helping Mrs F, while social services staff had told her that most of the complaints they received were from neighbours complaining about older people pestering them. Another inner-city resident, Ms HZ, who helped a number of neighbours, emphasised that it was not a sense of duty that caused her to help older people: 'I do it because I want to and because I like to do it … You get satisfaction from helping people out'.

Reciprocity

In some cases, the older person had assisted the helper in the past. Both Mrs D and Mrs P had baby-sat for their neighbours, Mrs Q had been very fond of Mrs HQ's children since they were born (and they, for their part, treated her like a grandmother), and Mrs R had helped care

for a group of children (including Mrs HR's). Mr and Mrs HB's friend Miss B had helped them out when Mr HB had had a stroke, and Mrs O had been a close friend of Miss HO's mother. Nevertheless, previous assistance was never mentioned as a specific reason for providing help now or as a reason for a sense of obligation – though it clearly formed part of the relationship within which the current helping took place. The motivation to help generally appeared to derive more from a sense of humanity rather than from obligation (in contrast to many kin relationships).

Benefits for the helpers

The sense that they were helping someone was satisfying for many of the helpers. Mr HC noted that 'I feel quite good that I'm helping someone … you just feel that you're doing something reasonably worthwhile', while Miss HS said 'I can actually see that I am really making a difference to the day-to-day life of another human being. I am doing something hands-on immediately that is improving, hopefully, that person's state of being'. For Mrs HJ, helping Mrs K was not particularly satisfying in itself, but she felt it was 'my bit of input into the community'. Of Miss J, though, Mrs HJ said: 'I think I was privileged in the end, to know her better than most … We had fun … I did get an awful lot out of it'. She said she learned a lot from Miss J, particularly about 'fortitude in disaster'. Several helpers spoke of the friendship they derived from the person they helped. Mrs HM said that Mrs M was 'someone I grew to love … I did love her, she was a lovely person … You become very close to people'. Mrs HP described Mrs P as her friend, and Mr HP added that 'we love her and look after her'.

In speaking of their willingness to help an older person, several helpers mentioned the importance of the older person's personality. The people they helped were variously described as 'very likeable' (Mrs A), having 'a sense of humour' (Miss S), 'a nice old lady – she appreciates everything you do for her' (Mrs F), or 'a delightful little lady' (Mrs P). Mrs HA said that Mrs A was 'not a cranky old woman – if she were, I wouldn't go near', while Mrs HM noted that she had gradually withdrawn from one person whom she had been helping after that person sought to manipulate her by over-stating the extent of an illness.

Payment

Payment for the help provided was a delicate issue, which some had negotiated to the satisfaction of both sides. In some instances, however,

the fact of payment or non-payment seemed to determine the limits of the help that was asked for. Three of the helping relationships involved formal payment. In two of these, as already mentioned, the help began as paid assistance, though the helpers then added extra hours on additional days on an informal basis. In Miss HU's case, her friend Mr U, whom she was already helping, managed to obtain Attendance Allowance and persuaded her to apply for Invalid Care Allowance in her own right. She had previously refused payment but felt it would help lift his self-esteem if she claimed the allowance: he wanted her to be paid for the help she gave.

Other helpers had similarly refused payment from the older person; in some cases, this would have affected their own benefit entitlement. Mrs X wished that her neighbours would accept payment; because they did not, she was reluctant to ask them to help as much as she would have liked, even though she was sure they would have been happy to do so. Instead, she paid outside workmen to do jobs for her. For some people, payment helped to firm up the helping relationship. When a GP and local priest arranged for Mr and Mrs HA to take charge of Mrs A's finances (which allowed them to retain some of her benefits, including Attendance Allowance), this made the help they gave her more acceptable to them. In other cases, older people received Attendance Allowance but did not offer to pay for the support they received. Miss HG felt she did not know how to broach the issue with Mrs G, even though Mrs G's social worker had suggested Mrs G should give her some of the allowance. Mrs HF did not want to be seen as 'money-grabbing', though the money might legitimately have been used to pay for the help she was providing and would have been useful. Mrs M, on the other hand, used her Attendance Allowance to pay for care services from a voluntary organisation: the services were excellent and they relieved Mrs HM from having to help with practical tasks.

Impact and strains for helpers

Most of the helpers were pleased with the way the helping relationship had developed and the type of help they had agreed – or were being expected – to provide. This help did, however, often have an impact on the helpers' own lives. Some had made changes to their weekly routines in order to provide sufficient contact for the people they were helping. Although many maintained their social activities and, for instance, went on holiday as before, several were conscious of the significance of their help and tried to ensure they visited at the usual times, or phoned regularly if they did go away. Mr and Mrs HQ sometimes did not go

away at weekends if Mrs Q was unwell, just in case she needed assistance. Mrs HF noted that:

> I can't go away or do anything. I've got to consider [Mrs F] first … I've got to consider [her] all the time if I want to do anything. I can't just get in my car and go anywhere.

However, neither Mr and Mrs HQ nor Mrs HF felt that such considerations were a real problem: they were prepared to make such adjustments to their own lives in order to help the older person. Nevertheless, Mrs HF did feel under strain as a result of Mrs F calling at her home several times a day:

> It is quite torture, actually, the constant backwards and forwards with her … The actual practical jobs, the cooking a meal, the shopping and pension, does not bother me at all. The only thing that gets to me sometimes is [her] constant backwards and forwards to my house.

Other helpers also expressed reservations about the arrangements. For Mrs HR, visiting weekly was sometimes a strain (especially as she cared for her mother, who also needed help). However, she did not like to ask anyone else to help Mrs R, in case the latter felt that Mrs HR no longer cared about her. Both Mr and Mrs HA and Mr and Mrs HB felt their help was being taken for granted. For Mr and Mrs HB, the helping "had gradually accumulated, from the tiniest of beginnings" to the point where the weekly shopping had become an unwelcome commitment: 'in the end, it becomes quite arduous … I think she just reels the list off and she seems to have no comprehension that the library is a mile walk'. In their case, an initial willingness to help, based on friendship, appeared to have developed into a sense of duty as the demands had increased.

Some other helpers noted that the older people they assisted wanted them to spend more time with them than they felt able to give. Most then made clear how much time they had available, though Mrs HF in particular was only able to reduce Mrs F's demands on her by arranging for her to attend a day centre. As it was, she had lost earnings through caring for Mrs F when her husband died and now through only being able to work part time. Mrs HQ, for her part, found Mrs Q's constantly repeated questions to be a strain, though she tried not to show this. Both Mrs HF and Mrs HQ said they would both like to move house – Mrs HF to a better house, Mrs HQ nearer to her daughter. Neither, however, felt they could move while Mrs F and Mrs Q needed their help.

For Mr and Mrs HH, the strain of having both Mrs HH's mother, Mrs HI, and her former lodger, Mr H, in the house was particularly

great. They had additional practical work, had cut down their social activities and were unable to go away on their own for more than four days. Even during short breaks, Mrs HH felt guilty at leaving her mother behind:

> I don't feel as I can go out without feeling guilty, even if it's just, say, down to the garage. 'Cos I sort of think, no, I'd better not go and leave them.

She also felt she was sometimes 'piggy in the middle' between her husband becoming irate (in relation to Mr H) and her own wish to protect her mother and Mr H: 'I feel sometimes as though I'm being squashed up and I feel as though I could scream'. Mr HH described the current situation as a form of blackmail on Mrs HI's part: they could not say anything to Mr H or do anything for him unless she agreed.

Others referred to the sense of responsibility they had for their friend or neighbour. This was not always seen as a burden. Mrs HF and Mrs HQ, for instance, voiced no objections to having the power of attorney for their neighbours' affairs. Others were named as executors of wills or were specified as the 'person to contact' on medical notes or in case of emergency. Some, though, found the responsibility unwelcome. Mrs HB voiced the dilemma of deciding when to call a doctor if her friend did not wish the contact to be made. Miss HG referred to her earlier frustration and anxiety that Mrs G's family had not shared her concerns and no services had been involved. At that stage, she said, 'I felt as if it was all on my shoulders and I was a bit worried in case anything happened'. She was relieved when a social worker started to co-ordinate services. For Mrs HM, the sense of responsibility for her friend Mrs M made the relationship more difficult: she knew, for instance, that Mrs M would be unhappy when Mrs HM was away, but she herself was concerned for Mrs M because she was lonely and physically very frail.

Setting limits

Several of the carers sought to place limits on the support they provided, both to safeguard their own time and, in some cases, to encourage the older person's independence. Some spent time caring for members of their own families, others were involved in voluntary work, some were in paid employment. Mrs HB limited her help to shopping once a week and refused to take in cooked meals, saying that 'I feel that, when you start that, there's no limit'. Mr HC, for his part, said he could not regularly cook meals for Mr C as Mr C would then expect

him to stay and share the meals with him. Miss HG would be prepared to help Mrs G with meals but felt this would be inappropriate: 'I don't want to take everything from her, because otherwise she's just going to become a cabbage'. Miss HO refused to contact Mrs O's brother on her behalf, saying Mrs O could do this perfectly well herself. She also made a point of not giving Mrs O any advice about how to deal with difficult requests from her brother. Similarly, Miss HS encouraged Miss S to contact the GP's surgery herself, though she would help by dialling the number for her.

Although a helper might need to set limits, this could sometimes be a very difficult decision, with serious consequences. Mrs HD, for instance, needed to go out to work to support her children after her husband died: this was at a time when Mrs D's care needs were increasing and she had come to rely on Mrs HD to help her. Mrs HD had been looking after her throughout the day but Mrs D now needed 24-hour nursing care – more than Mrs HD felt she could give her. At this point, Mrs HD asked her if she would go into a nursing home:

> I feel that it [my support] should have been terminated earlier. But that was probably my choice because I felt a bit guilty stopping the help. And it was my choice and my words, to say, '[Mrs D], I can no longer help you'. And sometimes that's difficult, isn't it, when you've loved and cared and supported somebody for such a long period of time.

A number of the helpers thought that, if the older person's condition deteriorated, they would probably have to provide more help, though they felt it would cause them difficulties. Others voiced reservations about increasing the help they gave. Mrs HR's work commitments would prevent this, while Miss HS had already decided against becoming a live-in carer because it would be too disruptive of her own lifestyle. Also, both were aware that if their own families needed more help, they would have to reduce the amount of help they were giving. For others, their state of health would limit what they could do.

Contact with family members

About two-thirds of the people receiving help had never had any children, or their children had died. Of the remainder, five (about half) had sons or daughter living close by. Mr C, for example, had a son and daughter in the same town. They visited at weekends and helped with correspondence and other private matters. According to Mr HC, Mr C did not want them to do any more. He preferred to ask Mr HC for help when he needed it, rather than waiting until his family visited.

Both Mrs HJ and Mrs HD were very critical of sons who lived a very

short walk away from their mothers but who visited only rarely. Miss J's daughter-in-law occasionally washed sheets for her but contact ceased when she and Miss J's son split up. Mrs D's son lived 20 yards from his mother but had apparently visited just five times in the 20 years that Mrs HD had been helping his mother. On one occasion, Mrs HD took Mrs D into her own house when Mrs D had diarrhoea; the following morning she phoned the daughter-in-law, who stated she could not do anything because she had to go to work. Another time, Mrs D had a fall in the night; Mrs HD wanted to phone her son but Mrs D did not want this, saying that he had been on nights and would be in bed. Mrs HD stated: 'so it was OK for me, who still had to go to work at six o'clock in the morning, but it wasn't OK for her son and her daughter-in-law'. Mrs E's son also lived less than a mile away but provided little support. Mrs HD described how he once brought Mrs E, his 84-year-old mother, back from a two-week stay in hospital and left her at the front gate without seeing her inside. She had diarrhoea the following night and died two weeks later. Mrs HD said that 'I can't believe that that could happen today, but it does'.

Some of the older people had other relatives who lived nearby. Mrs G went to stay with her sister every other weekend, Mr U had regular phone contact with his sister, and Miss S's nephew, who lived in the Midlands, kept in weekly phone contact and visited several times a year. However, other nieces and nephews visited only once or twice a year, despite living less than three miles away.

Although some of the contacts between helpers and the older person's family were helpful and unproblematic, others could be difficult. As noted earlier, Miss HG felt that Mrs G's brother and sister had failed to take any notice when she told them of her concerns about Mrs G – which left Miss HG with the responsibility for providing support. Mrs HQ had felt awkward helping Mrs Q while the latter still had close family nearby – but she said she could not leave her without help. Managing the boundary between the roles of family and friends or neighbours could be problematic. Mrs HJ felt that helping Miss J to complete a form for Attendance Allowance might be to 'step in front of the family', though she queried whether the family would help with this. Miss HG arranged for Mrs G's son to be present when Mrs G was seen by a psychiatrist because Miss HG did not want to be criticised subsequently for any decision that might be made. When Mrs HD told Mrs E's daughter-in-law that a phone extension was needed, she was accused of interfering. Shortly before Mrs E died, Mrs HD offered to take her into her own home, but only if she got approval from Mrs E's son. She stated that:

there's a very fine line from being a good, helpful neighbour to an interfering, unhelpful neighbour. And that fine line can be destroyed very easily if the family don't agree with what you're doing and they term it as interfering rather than terming it as being supportive.

Social services

About a third of the older people in the study received home care. In some cases, this was at the instigation of the friend or neighbour, who felt unable to carry out all the work alone. However, some older people refused or had cancelled home care. Mrs K had told a hospital social worker that she had friends who helped her out: Mrs HJ did not like to tell social services that this was untrue, and felt that it can be hard for non-family members to raise issues such as this with agencies. Miss J apparently cancelled services because she did not like spending money on them, and Mrs T preferred to give some money to another neighbour rather than to social services. The means test, and consequent need to pay, similarly caused Mrs D to refuse services. Mrs O, on the other hand, had cancelled the offer of an 'evening' meal that would be delivered at 3.30 p.m. She would have liked someone to stay with her during the night but did not meet social services' criteria. Mr U apparently did not want a home carer because he knew from past experience that he would not be able to organise his life in the way he wanted: for instance, if he wanted to go out one day and have the help on another day.

Many older people and their helpers were very pleased with the support they received from home care staff. Some, though, criticised social services for the policy of frequently moving staff around. This lack of continuity could be disruptive for older people, who often preferred help from someone they had got to know and who knew their needs. In some cases, staff were transferred to other work at short notice. Home carers were also not allowed to assist with some practical tasks such as putting up curtains, cleaning windows or turning mattresses – tasks which the older people themselves saw as important. Mrs HF had experienced considerable problems with Mrs F's home carer: she had had one heated argument with the carer, which had left Mrs F in tears and about which Mrs HF then lodged a formal complaint. She also stated that the home carer tended to become agitated, which left Mrs HF feeling upset and confused.

A few older people attended day centres: again, in some cases this was arranged by their helpers as a way of obtaining relief. Others had had short-term breaks in residential or nursing homes (often to give the

helper a break, but also to introduce the older person to a residential setting in case long-term care was needed in the future). Some social services staff had offered to provide more assistance for the helpers if they needed it, for instance with additional home care. However, Mrs HD said that 'social services were quite happy to let it happen and let you do it, because it didn't cost them anything', while Mrs HQ felt that social services were 'shirking a lot of their responsibility'. A further complaint was that social services did not appear to tell older people as a matter of course about their eligibility for benefits such as Attendance Allowance.

Support from other neighbours and friends

Some older people received help from other neighbours or friends, although the extent of help or visiting was usually less than from the person who had been interviewed. Mrs X, for example, received help from a range of friends. She was able to spread her requests among various friends in addition to a 'good neighbour' from Age Concern who helped with shopping: 'people do it very willingly when you ask, but I can imagine that they'd get very tired of it if you asked too often'.

In a number of instances, reference was made to a lack of interest or support from other neighbours. Despite having lived in a small village almost all her life, Mrs A now only had contact with Mr and Mrs HA and, very occasionally, one other neighbour. Mrs F had received help from another neighbour when her husband had been in hospital; he, though, had been very unpleasant towards this neighbour, who then ceased all contact. Miss J had been very well known in the town. However, she had no contact with others after she became more frail: Mrs HJ commented that 'when you retire, you quietly disappear into your little cottage'. She described how another neighbour had started going to see a neighbour with cancer but had found this too frightening and had stopped going.

Support for the main helper

Family members who lived with the helpers all appeared to be supportive, both in accepting adjustments to the helpers' and their own routines and sometimes through helping the older person themselves. Mrs HR's daughter helped with household work at home, which greatly helped Mrs HR.

Other friends and neighbours sometimes assisted when the main helper was unable to do so: for instance, by preparing a meal or keeping an eye out for any signs of concern. Some helpers could draw on support from church contacts. Mr and Mrs HA had an arrangement with the home care service that, when they went away, a home carer would visit Mrs A three times a day; Mrs HD arranged for Mrs D to go into short-term residential care when she was on holiday. Nevertheless, going away could be difficult for both the helper and the older person. Mrs HM was concerned about going away even though other friends of Mrs M's would visit: 'I think she became like a Mum … Perhaps it was silly, but I was the one she wanted to go in'.

Alternatives to informal support

According to their helpers, some of the older people would have managed somehow if they had not been there. Once practical services were provided by a voluntary organisation, for instance, Mrs HM's role became that of a companion, albeit an important one. However, Mr U might have found it more difficult to keep going without Miss HU's support: she said he would probably 'give up'. Mr and Mrs HP did not know how Mrs P would manage if they did not help her; Mrs X was at a similar loss if her own neighbour was not available. For Miss S, a range of help would have been necessary, involving for example cleaning, someone to supervise her medication and more support from friends from her church. This would both cost more and involve a number of different people. The support she received from Miss HS appeared to be a substitute for this complex range of formal and informal care.

It is impossible to specify the preventive nature of the help provided. Nevertheless, Mrs HJ thought her support had given Miss J another four years of life. Miss J had been in hospital with pneumonia during the four winters before Mrs HJ started helping her. When Mrs HJ began to do her shopping Miss J did not need to go out when the weather was bad. Without that support, Miss J would probably not have been able to stay in her own home, even with a fuller care package. Similarly, on one occasion, Miss HO had found Mrs O very ill and had helped arrange an emergency admission to hospital. Without this, the outcome for Mrs O might have been very serious.

A number of other helpers thought that the alternative to their input would be admission to a residential or nursing home. Mrs HQ had arranged short breaks for Mrs Q in a nursing home but, given Mrs Q's dislike of it, she saw a permanent admission very much as a 'last resort'.

Mrs HF thought that, without her own help, Mrs F would have been in a home a year ago. This was something that Mrs F herself feared intensely: she had been put in a children's home as a child, and did not wish to be put in another home to die. She sometimes said to Mrs HF, 'you're not going to put me in an old folks' home, are you'? Mrs HF said, 'I choke actually and I think to myself what am I going to do?' Of the older people who had died shortly before the interviews took place, two had been admitted to nursing homes.

Implications for statutory services

Respondents expressed differing opinions about the optimum role for statutory services. One felt very strongly that younger family members lacked the experience of caring that had been common in previous generations. Another decried the decrease in neighbourliness. Both felt that, for these reasons, social services might need to play a greater role in the future. On the other hand, another person suggested that social services have only a scanty knowledge of the true extent of need – which would preclude them from being able to address that need effectively.

Although some social services support for older people was described as excellent, there were also a number of criticisms. Some agencies appeared to rely on friends and neighbours to help out, without any statutory support being provided. Other agencies were said to have withdrawn services if older people appeared to be managing on their own – even though they might still be experiencing difficulty. Frequent changes in home care staff were disruptive and confusing for older people, and meant that their needs might not be adequately met.

The inflexibility arising from meeting the needs of a large number of service users would, for its part, strengthen the argument for direct payments for older people to enable them to obtain the types of services they prefer – as announced in *Modernising Social Services* (Department of Health 1998). It is unclear how easy it would be to use such payments to pay friends or neighbours for their support. Evidence from this study indicates that such payments would be welcomed by some helpers and might provide an incentive to continue to provide assistance. Given that direct payments offer a means for people to obtain the services they need, such provision would offer an opportunity to secure services in those instances where payment would be appropriate. Monitoring the payments would provide a means of checking with older people and their helpers how payments are being used. However, it is also the case that many helpers saw payments as either unnecessary or contrary to

the spirit of friendship or neighbourliness. The usefulness of such payments would need to be determined in each individual case.

For many older people, the support provided by friends and neighbours was with minor tasks, with which statutory agencies generally offer little or no help. One older person said there was a real need for help with such tasks, and also with small amounts of help before a crisis occurred. The lack of such help could cause considerable stress, as she herself knew, yet it was only when she had had a stroke that help was provided. Such experiences underpin the need for preventative strategies (Fiedler 1999), which could themselves be linked to direct payments schemes in the future.

Some respondents voiced concern about the lack of awareness by statutory services of the circumstances of older people with whom they had been in contact. Examples were given of people being discharged from hospital without formal support, yet there seemed to be little questioning of the availability or nature of help from friends or neighbours, nor any subsequent follow-up to determine whether needs were being met. Where older people declined services because they would be required to give details of their financial circumstances or pay towards those services, their needs, again, generally remained unmonitored.

More broadly, there is no evidence from this study to suggest that friends and neighbours could provide substantially more support for older people than is the case already. Most friends and neighbours who might be able or willing to help out will be aware of the needs of the older people they know; if, moreover, statutory services can provide help, there is potentially little reason why friends and neighbours should take on a greater helping role themselves. For statutory services, the emphasis should be on ensuring that existing support arrangements are sustained for the benefit of the older people and their helpers, thereby preventing the need for additional statutory input and, in some cases, enabling older people to remain in their own homes when residential care options might otherwise have to be considered. Such support reflects the emphasis in *Modernising Social Services* on the need to promote independence (Department of Health 1998).

Social services are not the only agency in contact with older people and their carers. It is essential, for example, that primary health care staff are alert to the potential needs of those older people who receive support from friends and neighbours, and to their helpers' needs. Their assistance in applying for financial benefits or in seeking support from social services may be crucial if the support provided by non-family members is not to be pushed beyond acceptable limits.

Conclusions

This study has helped to extend out understanding of informal care. While much previous research focuses on issues of kin and gender, this study has allowed a preliminary, but in-depth, examination of the nature of non-kin care, its benefits for older people and their supporters, the strains that some of them experience, and their concerns about the future.

One of the key issues to emerge relates to the fuzzy boundary between neighbourliness and friendship on the hand, and 'care' on the other. The resentment that some express about arrangements indicates that they feel they have been pulled across a normative boundary. In some of these instances, financial payment provides some compensation for the extra work involved. Other helpers would appreciate additional services from other agencies – but older people are not always willing to accept these. Some helpers seek to limit the older people's requests for support. However, this can be difficult where older people are unable to change their own behaviour or if the helpers think that limits might be seen as a form of rejection.

Nevertheless, resentment is not experienced by all helpers and many are happy to provide considerable amounts of support, often at some cost to themselves; for example, delaying moving house because of the effect this might have on the older person, and giving up paid work in order to provide more care. In such cases, neighbourliness seems to become a 'quasi-kin' relationship.

This study adds to our current understanding of informal care through indicating that the motivation for friends and neighbours does not depend on direct reciprocity, duty or obligation. As in the case of family caring, the negotiation of support can develop over time in the course of interaction between individuals (Finch and Mason 1993). Commitments may have a material basis, with payment being made in cash or in kind, but they can also develop on moral grounds. While the moral foundation for extrafamilial support differs from that of family relationships, this study supports Finch and Mason's argument that the processes of negotiating support apply to non-kin as well as kin. For some helpers, their structural position within the community (for instance as church members) appears to have shaped their involvement, though this reflects just one strand of their identities as moral beings.

A distinction also needs to be made between the initial offer or agreement to help and the continuing input. Small initial steps involve little commitment. Greater commitment, though, can develop with time and often is not explicitly negotiated (Becker 1960). Initially help

is largely provided to people helpers like and with whom they are already on friendly terms. Where the demands subsequently increase and become 'unreasonable', they may find it difficult to withdraw because they feel they have built up a sense of duty or commitment. The motivation to help thus tends to shift, while continuing to be based on a sense of humanity or good citizenship. Nevertheless, demands that are perceived as excessive might well jeopardise the helping relationship.

Importantly, the comments made by the helpers in this study highlight the benefits that are derived from contacts with older people: the pleasure that is obtained from getting to know older people and the two-way nature of the relationships in terms of friendship. It is, indeed, the interpersonal nature of the relationship that distinguishes it from the support that is typically available from caring agencies. In addition, support from friends and neighbours may well be perceived as preferable to input from statutory agencies, with all the connotations of dependence and failure that the latter may involve. While such support cannot be artificially created, the value placed on it by older people requires that it should be nurtured and supported in its own right.

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