



CARING RELATIONSHIPS OVER TIME
End of Project Report

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Sandra Hutton and Michael Hirst

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INTRODUCTION

Following a competitive bid, the Social Policy Research Unit (SPRU) was commissioned by the Department of Health to carry out research on *Caring relationships over time: predicting outcomes for carers*. This was one of 13 linked studies which formed part of a research initiative on OUTCOMES OF SOCIAL CARE FOR ADULTS (OSCA). The project commenced in September 1997 with a proposed duration of 22 months. In the event additional funding was obtained for a further six months to explore issues identified in the main stage; the project formally closed in July 2000. The principal investigators were Sandra Hutton (50 per cent full-time), Michael Hirst (50 per cent) and Dot Lawton (20 per cent). Julie Williams assisted with the data analysis.

The aim of the study was to relate outcomes for carers to the timing and duration of care-giving episodes within individuals' life course and for different generations by:

- examining carers' circumstances before and after starting and finishing care
- relating care-giving episodes to the carers' and their families' life course
- identifying what allows carers to continue caring, what determines the end of caring and how far services are a factor
- estimating the changing likelihood of becoming a carer for younger and older cohorts
- charting longer-term trends in care-giving activity and the population of carers.

The research focused on the health, employment, financial and family outcomes for carers in three nationally representative data sets, the *British Household Panel Survey*, the *General Household Survey*, and the *Family and Working Lives Survey*, comparing groups of carers and carers with non-carers.

The relevance of the project stems from the observation that most care for elderly or disabled people is provided by family and friends whose quality of life, living standards, and well-being can be adversely affected. Recognising the costs and opportunity costs of caring is important not least for carers themselves; reducing their impact also underpins the success of community care policy and practice because such costs can influence carers' willingness and ability to continue to provide care. By emphasising change as a key feature of carers' experience, the research aimed to:

- offer a more realistic appraisal of the timing, evolution and duration of care-giving for understanding the overall consequences of community care policy and practice for carers
- indicate how outcome measurement might be related to the timing and duration of caring episodes
- provide better indications than are currently available of how trends in caring activity, and the likelihood of individuals becoming family carers, might evolve
- enable service planners to assess the impact of current demographic and socio-economic trends on the carer population, the continuing scope for family care, and the likely future need for services
- assess the potential benefits of national data sets for routinely monitoring outcomes for carers over time to inform policy and practice.

The purpose of this report is to present the key findings and main conclusions of the research. Part A summarises each of the research reports produced during the course of the project. The full reports have already been submitted to the Department of Health as they were produced. A list of all reports available is given in Appendix C. The full text of more formal publications drawing together these findings and produced for a wider audience of policy makers, service providers and practitioners is reproduced in Part B. Miscellaneous outputs including presentations of the research findings to colleagues and policy advisers are listed in Part C. Further articles in refereed journals targeting professionals, policy analysis and practice in the health and social care field are planned. In addition, dissemination of findings from the OSCA programme as a whole is planned by the Department of Health.

PART A

RESEARCH REPORTS: SUMMARY AND KEY FINDINGS

THE HEALTH OF INFORMAL CARERS:
A longitudinal analysis

SUMMARY AND KEY FINDINGS

This report presents new evidence from the *British Household Panel Survey* on the health of informal carers before, during and after a care-giving episode. The findings confirm that the health of carers and changes in their health are important matters when anticipating the need for informal care, sustaining them in their caring role, or enabling them to limit or relinquish aspects of the care they provide. This research found that:

- a substantial minority of carers present a range of physical and mental health problems even before taking on a caring role
- the health of carers is more likely to deteriorate than improve over time compared with health changes in non-carers
- many of the detrimental changes in carers' health are probably over and above those that would have happened and could be attributed to taking on a caring role
- there is no firm evidence that the health of former carers improves after informal care ceases and the additional health problems of carers are likely to continue beyond the end of care-giving
- caring has greatest impact on carers' emotional health especially on those who could be described as providing 'heavy' care, that is 20 hours or more informal care per week
- spouse carers and mothers looking after a disabled child are more likely to provide 'heavy' care and are most at risk of psychological ill-health
- the first year of informal care and the period immediately after care-giving ends are both marked by increased chances of psychological distress; raised stress levels in carers are also evident in the months before they take on a caring role
- carers' physical health is more likely to deteriorate beyond the first year or so of care-giving possibly anticipating further decline in physical functioning as care-giving continues

- carers are likely to make additional contact with the general practitioner or family doctor services both during and after the care-giving episode.

**EFFECT OF EPISODES OF INFORMAL ON INCOME:
A longitudinal analysis**

SUMMARY AND KEY FINDINGS

The *British Household Panel Study* was used to investigate the effects on income of starting an episode of informal care, of the length of the episode and of finishing informal care.

- *Starting informal care*

The change in income (whether personal or labour market) on starting an episode of informal care was not statistically significant from the change in income that non-carers experienced over the same interval.

- *Impact of longer episodes of care*

Although the differences in labour market incomes after episodes of care of two, three and four years did not differ significantly from those not involved in care over these intervals, there was an observable trend of longer episodes being related to larger gaps in incomes between carers and non-carers. After episodes of care of four to five years and for those with six or more years of care, the differences became significant. For personal and household incomes the differences between carers and non-carers were not significant although graphically there did seem to be a slight widening of the gap with longer episodes of care.

These results held even when the comparisons between carers and non-carers were controlled in regression analyses for background characteristics related to the likelihood of being a carer: age, sex, marital status, full-time or part-time work, education level, and age of youngest child. The differences in personal or household incomes between the groups of carers and non-carers were not statistically significant.

Spending 20 hours or more on informal care might be expected to have a greater impact on

labour market income, the change was not significantly different from that for similar non-carers until the three year episode. The gap between carers and similar non-carers was greater for longer episodes. The difference for personal income, however was not significantly different.

The pattern of the impact on real incomes for those looking after a spouse was interesting with a relatively high and statistically significant effect on labour market incomes on starting informal care but less impact for longer episodes of care.

- *Sources of income*

Monthly benefit income for carers increased significantly relative to that for non-carers for longer periods of care, even when controlled for background characteristics. There were no significant differences for investment income. Reassuringly receipt of ICA increased as expected with longer episode of care, although there was no clear trend over length of care episodes for receipt of means-tested benefits. Receipt of pension income seemed to increase for episodes of care after three and four years.

- *Impact at the end of the six year period covered by the panel study*

Among those who had recorded an episode of informal care during the six years covered by the panel study, those who had recorded intermittent periods of care had the highest income whereas those who had episodes lasting five years had even lower incomes than those who had been recorded as caring at each wave of the study (a period of six years). Differences were significant for monthly and annual labour market income but not for personal or household incomes.

- *Separation of sequence and duration*

Those with the longest episodes of care and currently involved in care are likely to have the lowest annual labour market incomes at the end of the period of six years (£2,818.30 for those caring at every wave of the study) compared with annual labour income of £6,233.88 for those who had finished care three years previously. From an examination of the rankings of incomes in 1996, sequence and duration had the expected impact on income.

For those recorded as caring at every wave of the study, a rather different group from those starting to care during the study (younger, and likely to be caring for children), the duration still had a marked effect on reducing labour market income and moving from full-time to part-time

work. The pattern for personal income suggests that benefit income helped to compensate.

- *Finishing an episode of care*

Contrary to expectations, the labour market income of carers, whether monthly or annual seemed to continue to diverge from non-carers as the time since the end of care increases. The gap between the personal incomes of carers and non-carers since finishing care remained fairly constant, although there was some suggestion that after three or four years the income of carers started once more to approach that of non-carers. Perhaps a longer time than is available in the panel study is required for the incomes of those who have completed a care episode to catch up with those of non-carers.

- *Overall*

The main impact of informal care on income was on monthly labour market income which declined relative to similar non-carers for longer episodes of care. Personal and household income were less affected, and benefit and pension income seemed to compensate. For household income some of the benefit income could be considered to compensate for the additional costs of having a disabled person in the household. To that extent, although the household incomes of carers and non-carers appeared similar, the living standards of the carer household would be lower by the costs of the disability. There was some evidence that the sequence and duration of informal care had the expected effects on incomes but little evidence that incomes caught up after finishing care in the relatively short time period available in the data.

INFORMAL CARE-GIVING IN THE LIFE COURSE

SUMMARY AND KEY FINDINGS

This report summarises new evidence from the *British Household Panel Survey* to provide a quantitative account of carers' circumstances around the start and end of a care-giving episode. The aim is to locate informal care-giving within the lives of different groups of carers and to describe changes associated with transitions into and out of the caring role. As well as emphasising the relationship between the carer and the person they look after, this study explores the extent to which care-giving involves exchanges between the generations and between kin and non-kin.

The analysis concentrates on informal care-giving within households. However, informal care provided between households is not ignored and the links between both spheres of care-giving are also examined.

The findings draw attention to the considerable diversity among carers and their lives. It seems that the demand for informal care can arise at any time in the life course:

- carers span the full adult age range (noting that child care-givers are not identified in the BHPS)
- care recipients, too, span the full age range and thirty years typically separates carers and care recipients who belong to an older or a younger generation
- the personal characteristics and household circumstances of co-resident carers vary widely. These variations are associated in part with carers' ages, their relationship to the person they care for, the stages in life when informal care starts, and the extent to which care-giving involves inter-generational exchange and new household formation
- most informal carers are women but the balance of the sexes is more equal among co-resident carers, especially those who look after parents or parents-in-law
- except for spouse caring, where wives are more likely to be the carer than husbands, informal care-giving between members of the same or of the opposite sex are equally

likely within households

- although carers are predominately in mid-life when they start providing informal care, more than one in four are under 40 years of age and a similar proportion is over pension age
- two-thirds of working age carers are in paid employment though women are more likely than men to work part-time
- seven out of ten carers live with a spouse or partner
- more than one in three carers under pension age have dependent children.

All stages of the life course, therefore, are represented in the population of informal carers, albeit to varying degrees. As a consequence, carers' biographical experiences and their roles in terms of family status, living arrangements, paid work and participation in the community, are likely to be extremely varied. In addition, taking on a caring role itself frequently requires adapting work and family roles to changing circumstances and relationships.

Informal care-giving takes place both within and between households and there is a predictable association between the locus of care and the relationship between the carer and the person they look after:

- more than three-quarters of caring relationships arise between households though the level of involvement in care-giving is greater among co-resident carers than out-of-household carers
- informal care within households is almost always provided by a close family relative
- just over half of those who look after someone outside their own household are related to the cared for person
- spouse caring predominates within households, followed by filial care-giving and the parental care of a sick or disabled child
- the largest group of extra-resident carers look after a parent or parent-in-law, followed by those looking after a friend or neighbour or other relative
- virtually all non-kin care is provided out-of-household, chiefly between friends and neighbours.

Irrespective of the locus of care, informal care-giving frequently involves inter-generational

exchanges:

- around half of all care-giving relationships within households involve inter-generational exchanges, split equally between those carers who look after someone in an older or a younger generation
- inter-generational care-giving between households is at least as widespread as it is within households but is more likely to involve looking after someone in an older generation.

Generally, informal care-giving within households starts and ends with the carer and the care recipient living in the same household:

- More than eight out of ten co-resident caring relationships arise between individuals who already share the same household. As might be expected, carers who look after a spouse or a child invariably live with the person they care for before care-giving starts but prior co-residence is also an important factor, in seven out of ten cases, in determining who cares for a parent or parent-in-law.
- A majority of co-resident caring relationships end with the carer and cared-for person continuing to live together in the same household. However, almost one in four such relationships end with the death of the cared-for person, more so where he or she is a parent/in-law or a husband of the carer.

Within the population of co-resident carers, care-giving relationships are likely to arise at particular stages of life, emphasising the links between the onset of care needs, the carer's circumstances and the context of family relationships and obligations:

- spouse caring predominates at later stages of the family life cycle, following the period of child-rearing. Indeed, spouse carers are typically 20 years older than other co-resident carers and almost half are pensioners
- a sizeable minority of parents are looked after by carers living in non-pensioner couples (with or without dependent children) but single people under pension age account for most of the informal care provided for parents or parents-in-law. Almost half of those caring for a parent in the same household are single or never married; most are under 40 years of age and a substantial minority are under 30 years
- the informal care of children predominates at earlier stages of the family life cycle when siblings of the sick or disabled child are also being raised. Most parents

providing informal care for a child are in their 30s or 40s and living as married.

Further exploration of the data led to the identification of distinct sub-groups of co-resident carers. The findings show that care-giving arises at markedly different stages of life irrespective of the relationship between the carer and the person they look after. One proposed typology indicates that caring for a parent or parent-in-law in particular can arise under quite varied circumstances:

Spouse carers	Informal carers of parents	Informal carers of children
1. non-elderly spouse carers with dependent children	4. single carers under age 35 years	8. parents looking after a dependent child
2. non-elderly spouse carers without dependent children	5. single carers aged 35 years or older	9. parents looking after a non-dependent (adult) child
3. elderly spouse carers	6. carers with dependent children of their own	
	7. carers with a partner but without dependent children	

Moreover, co-resident carers at similar stages of life could be involved in different caring relationships:

- carers in couples with dependent children are as likely to be looking after a spouse or a parent as providing informal care for a sick or disabled child
- carers in couples without children are chiefly involved in spouse caring though a sizeable minority of those under pension age look after a parent or parent-in-law or an adult child.

The start of care-giving within households is associated with changes in the carer's status and circumstances:

- spouse carers, male and female alike, are more likely to reduce their participation in the work force than other co-resident carers
- women are more likely than men to reduce their participation in the work force after taking on a caring role but there is no clear evidence of a switch from full-time to part-time working
- the number of young, single adults in full-time work actually increases around the time they take on the care of a parent, especially among male carers

- there is no evidence that taking on a caring role is associated with marital breakdown. The start of some caring relationships is associated with the formation of new partnerships where a sick or disabled child needs informal care. A few instances of spouse caring also commence in the same year that couples start to live together
- household size increases when care-giving starts reflecting the 'extra-person effect' as some carers or cared-for people move into each others' households. This effect is most clearly observed in the case of those who look after a parent because these caring relationships are more likely to be formed by households combining.

Comparing the ages of carers who start providing informal care within the household with the ages of those who cease suggests that:

- most care-giving episodes last less than five years although there is likely to be wide variation in their duration.

Co-resident carers' circumstances change during the course of a care-giving episode:

- carers devote more time to providing informal care towards the end of a care-giving episode than at the start, especially those caring for an elderly spouse or parent
- spouse carers and those looking after a parent or parent-in-law are less likely to be in paid work towards the end of a care-giving episode than at the outset.

The end of co-resident care-giving is marked by further changes in the carer's circumstances:

- women carers under pension age are more likely than their male counterparts to take up or return to paid employment after care-giving ceases
- the workforce participation of male spouse carers continues to decline after care-giving ceases
- the end of care-giving is likely to be marked by important changes in the carer's role, status and living arrangements especially for those in caring relationships which end in the death of the cared-for person. The consequences are most clearly observed among former spouse carers and, to a lesser extent, among those carers who are bereaved of a mother or father.

Informal care between households is more widespread than within households:

- for every co-resident caring relationship there are more than three caring relationships between households
- the provision of informal care for parents or parents-in-law is common to both spheres but fewer than one in eight such relationships occur within the household of the son or daughter (in-law) who provides the care.

Moreover, co-resident and extra-resident care-giving are largely separate spheres of activity:

- before, during or after a spell of co-resident care, around one in six carers also engage in looking after someone living in another household. At any one time, however, no more than one in twenty carers look after someone both inside *and* outside their own household
- there is no evidence of a net change in the extent of extra-resident care-giving when informal care within the household starts or stops
- very few co-resident caring relationships appear to have started as out-of-household care-giving.

Compared with co-resident care-giving, informal care between households generally arises under less varied conditions. *Irrespective* of their relationship to the person they look after, most extra-resident carers:

- start to provide informal care between their mid-30s and before reaching pension age
- live with a spouse or partner
- do not have dependent children or elderly relatives living at home.

Out-of-household care-giving has rather mixed effects on carers' economic activity suggesting that factors other than taking on a caring role are as important, or more so, in determining changes in employment patterns.

Just over half of all extra-resident carers are related to the person they care for (usually a parent or parent-in-law) and the distinction between kin and non-kin care-giving points to different sorts of caring activity and behaviour:

- kin carers are mostly under 50 years of age when they start providing informal care whereas most non-kin carers are aged over 50 years
- kin carers generally devote more hours per week to informal care than do non-kin

carers

- non-kin care-giving arises under a broader range of circumstances and is much less age or stage specific than informal care for a relative. Extra-resident carers who look after a parent or parent-in-law, for example, are mostly in their 40s to mid-50s and live with a spouse or partner. By comparison, extra residential carers who look after a friend or neighbour are distributed across the entire adult age span and all stages of the family life cycle.

Although caring for a parent or parent-in-law forms a substantial part of both co-resident and extra-resident care-giving, the locus of care is associated with other differences in the nature and timing of such care:

- caring for a parent or parent-in-law living in the same household as the care-giver frequently starts at an earlier stage than informal care provided by sons and daughters (in-law) who live in a different household
- compared with extra-resident carers, those looking after a parent or parent-in-law within the same household are younger, more likely to be single or never married and more likely to be sons rather daughters of the cared-for person. They are also more heavily involved in informal care than extra-resident carers

Conclusions

Policies and services which assume that carers form a distinct, homogeneous sub-group of the population are likely to be inappropriate and ineffective in meeting their needs for information, advice and practical support.

Knowledge of informal carers' circumstances and how these change, including their position within the life course, will inform an understanding of the family context, the carer's need for support and the way in which that support might best be delivered.

RECENT TRENDS IN INFORMAL CARE

SUMMARY AND KEY FINDINGS

This report presents new evidence from the *British Household Panel Survey* on trends in informal care between 1991 and 1996. As well as charting the prevalence of informal care it investigates transitions in to and out of the carer population, focusing on changes in the annual rate of new carers and the amount of time spent caring each week. Although the total proportion of people involved in care-giving remains constant during the study period, the findings indicate that the chances of becoming a carer are declining. For those who take on a caring role, however, the chances of providing informal care over successive years and devoting more time to caring activities are increasing. Over time, more carers are likely to be heavily involved for longer spells of care-giving.

- the prevalence of carers has remained steady year on year though the proportion of co-resident carers and those providing 20 hours or more informal care per week is somewhat higher towards the end of the study period
- in any one year, and over the study period as a whole, *net* changes in the carer population have been negligible. Little net change hides a lot of change at the individual level and the number of individuals changing their carer status each year often exceeds those who continue in a caring role
- there has been a decline in both the proportion of individuals who take on a caring role and those who stop providing informal care each year, suggesting that periodic care-giving has diminished over time
- the proportion of those who provide informal care over successive years has increased suggesting that care-giving spells have lengthened on average over time
- the increasing tendency for carers to continue in a care-giving role applies especially to those providing 20 hours or more informal care per week and, over time, carers are likely to increase the amount of time they spend giving care.

**THE RISK OF INFORMAL CARE:
An incidence study**

SUMMARY AND KEY FINDINGS: DISCUSSION

The chief aim of this report is to provide national estimates of the annual rate at which individuals take on a caring role. Incidence rates have been estimated, for the first time, from the *British Household Panel Survey* (BHPS) and are presented here in tables and charts with an indication of their precision as population values. At the national level, these rates should inform the setting of public policy including the allocation and targeting of resources to support informal carers and assess their needs. They can also be applied to local populations, to help service planners and managers estimate more accurately the number of new carers in their areas and to describe their characteristics - provided of course that the often considerable differences between national and local population profiles are taken into account.

A secondary aim is to describe and interpret variations in the incidence of informal care according to selected social, economic and demographic characteristics of the population. Relative risks are estimated to compare the extent to which sub-groups in the population take on a caring role. Models of relative risk have also been estimated to identify those factors that differentiate the annual intake of new carers.

The purpose of this discussion is to relate the key findings to previous studies, comparing strengths and weakness, and speculating on differences. A more thoroughgoing and systematic review of the literature is required, covering in particular the numerous secondary analyses of the *General Household Survey* (GHS); what follows is a preliminary attempt to place the findings of this report into a wider context.

Age and sex

Studies of the prevalence of informal care have repeatedly shown that women are more

likely than men to be care-givers. The GHS shows that this is the case chiefly because women are more likely to be caring for someone in another household; there is no difference between the proportions of men and women caring for someone in the same household (Rowlands, 1998, p. 12). Identical conclusions are drawn from this study of incidence rates.

The 1995 GHS also shows that the proportions of men and women caring for 20 hours or more per week are very similar (four and three per cent respectively; *ibid.*). In contrast, the findings reported here indicate that women are half as likely again as men to become heavy carers. Different explanations could account for the apparent discrepancy. It may be that men's spells of heavy care-giving last longer on average, or lighter episodes are shorter, than those provided by women so boosting the prevalence of men devoting 20 hours a week or more to caring. However, carers are likely to increase the hours they devote to caring over time (Hirst, 1999b). Men may be more likely than women to do so but even if this is not the case, men would be more likely than women to cross the 20 hours a week threshold if more of them start providing informal care at lower levels of involvement. This latter interpretation would be consistent with the findings reported here but further investigation is required to test these hypotheses.

The GHS points to the distinctive age profile of informal carers. In 1995, the proportion of carers increased from six per cent among those aged under 30 years, to 20 per cent of those aged 45 to 64, and then fell to 13 per cent of those aged 65 years or more (Rowlands, 1998, p. 13). Short-term caring episodes are likely to be under-represented in cross-sectional surveys like the GHS and the incidence rates estimated here indicate that slightly more carers are aged between 30 and 44 years or over pension age when taking on a caring a role. The former age group coincides with the onset of much inter-generational care, especially of children but also of parents, while the latter often covers the start of spouse care-giving (Hirst, 1999a). Nonetheless, the age-specific incidence rates describe a 'bell-shaped' age profile when all new carers are combined, strikingly illustrated by the smoothed estimates plotted in Appendix 3 of the original report (Hirst, 1999c). Such an age distribution is also typical of those who start providing 20 hours informal care or more per week but not so for those taking on the care of someone in the same household. The chances of individuals becoming co-resident carers increase more or less linearly with age.

Variations in the incidence of informal care are clearly associated with carers' ages and the association remains statistically significant irrespective of the other factors considered here. The explanation seems fairly straightforward. Care-giving often takes place between people of similar age: spouse caring is the clearest example and predominates over other caring relationships within households. Inter-generational care-giving, on the other hand, is provided by individuals who are typically around 30 years younger or older than the person they care for. If the onset of care needs occurs at particular stages of the life course, there will be a strong link between the incidence of informal care, and both the care recipient's and the carer's ages. Whether or not an individual is faced by such needs will, of course, depend on his or her family relationships and social networks, and who actually provides informal care may be determined by norms and negotiation of family obligations. Qureshi and Walker (1989) show, for example, that the care of elderly people follows hierarchies of expectations that relate to the closeness of kin ties, which run as follows: spouse, relative living in the same household, daughter, daughter-in-law, son, other relatives or neighbours. We have also observed that patterns of care-giving are shaped by demographic differences, social class and other background factors. However, the *timing* of informal care episodes is driven more by the incidence of age-related events - congenital malformations, accidents, health risks at work, and ageing - than by the potential carer's circumstances. As a consequence, the start of most care-giving relationships occurs at predictable stages in the life course and produces the distinctive age profiles described above.

Annual incidences of informal care for each year of life can also be summed to estimate the cumulative or lifetime probability of an individual taking on a caring role. These cumulative rates indicate that almost everyone will identify themselves as a carer at some time over a full adult life span. In many instances, such care-giving might be best described as neighbouring or friendship rather than personal care or tasks associated with tending activities requiring attendance or supervision. Nonetheless, it is estimated that men and women alike have a fifty-fifty chance of having cared for someone in the same household by the time they have reached their early 60s. Women are as likely as not to have begun a care-giving episode of 20 hours a week or more before reaching pension age while men have a 40 per cent chance of doing so before their 65th birthday. Translating estimates of risk derived from population-based studies to individuals may not be justifiable but these lifetime indications of risk draw attention to the volume of human resources devoted to informal care

over time. They also underpin the importance of current debates about how best to help informal carers maintain their health, continue their life beyond a caring role, and remain in or return to paid work (Department of Health, 1999).

Ethnicity

It is difficult to draw comparisons between the white population and minority ethnic groups from this analysis of the incidence of informal care. The sample data on ethnic minorities are insufficient for making satisfactory inferences as shown by the width of the resulting confidence intervals. It was necessary to combine all minority ethnic groups into one category although we recognise that the risk of informal care is unlikely to be uniform among ethnic minorities. Inequalities in health and material resources as well as demographic differences between the Indian, Pakistani, Bangladeshi and Black Caribbean communities, for example, will affect the supply of and demand for informal care (Nazroo, 1997; OPCS, 1996).

From the limited analysis that was possible, there is no firm evidence that the incidence of co-resident or heavy care-giving differs significantly between the white population and all other ethnic groups. Minority ethnic groups, however, are much less likely to become extra-resident carers: this affects the incidence of all informal care combined because care-giving between households predominates over care-giving in the same household. As a consequence, the overall probability of becoming an informal carer is significantly lower in the ethnic minorities than in the white population.

The literature on informal care indicates that socio-demographic differences between ethnic groups, rather than variations in the propensity to provide informal care, account for differences in the incidence of extra-resident care-giving (Atkin and Rollings, 1996). Part of the explanation for the relative absence of between-household care-giving in minority ethnic groups lies in the living arrangements of Asian families. Evidence from the fourth national survey of ethnic minorities, conducted in 1994, shows that a very high proportion of Asian elders, around two-thirds, live with one or more of their adult children (Berthoud and Beisha, 1997, p. 45). Whereas the great majority of white parents who were being helped by their children lived in a different household, around half of the parents in ethnic minorities receiving informal care lived with an adult son or daughter (*ibid.*, p. 55).

Such living arrangements would reduce the extent of extra-resident care-giving in Asian communities but do not necessarily lead to a higher incidence of within-household care-giving. Ethnic minorities have a much younger age profile than the white population and most minority ethnic adults living in Britain are not of an age when they would require informal care. Moreover, few Caribbeans and south Asians actually have elderly parents living in Britain because many are migrants whose parents have remained in their country of origin. Not surprisingly, therefore, individuals from minority ethnic groups are less likely than those from the white population to be caring for parents or parents-in-law.¹ This difference is clearly indicated in the charts plotting the cumulative incidence of informal care over the life course. These show lower risks for minority ethnic groups in the 40 to 55 year age groups, precisely when many would otherwise start looking after elderly parents. Clearly, where Asian sons and daughters provide informal care for their parents, they are more likely than other ethnic groups to do so within the same household. If the proportion of Asian households with two adult generations persists, therefore, the incidence of co-resident care-giving within minority ethnic groups as a whole is likely to increase - at least in the short-term.

The analysis points to a further difference between ethnic minorities and the white population, namely the increased risk of minority ethnic men becoming co-resident carers. Though not statistically significant, this too may reflect demographic differences between the two populations. There is a preponderance of men in minority ethnic groups as a whole and more especially in the Asian communities compared with the white population (Owen, 1996, p. 111). On the face of it, therefore, minority ethnic men are more likely to be available to take on a caring role than their white counterparts. However, cultural differences may play a more important role in how family obligations and expectations of informal care actually operate. In Asian communities, for example, the youngest son is normally expected to be responsible for parents and there is generally greater reliance on sons and daughters-in-law, as opposed to daughters, for social support (Ahmad, 1996, p. 57). Indeed, male obligations and responsibilities, and their power in the household, may

1. If the focus shifts to those with elderly parents actually living in Britain, south Asians are as likely as their white counterparts to be looking after a parent (Berthoud and Beisha, 1997, p. 55).

lead married men to report their wives' care-giving as their own. Hard evidence on this is lacking though difficulties in transferring the concept of informal care across language and ethnic boundaries, as well as gender, may also be a factor. We also recognise that some carers may not recognise themselves as such because, as far as they are concerned, they are simply fulfilling family obligations.

Further research to elucidate cultural differences in the perceptions of, and responses to, survey questions on informal care will underpin the success of a new question on caring proposed for the 2001 census (Department of Health, 1999). If such a question is included, it will help meet an urgent need for information about carers in minority ethnic groups at the local level.

Marital status

The association between marital status and informal care is particularly complex because its impact varies for men and women, depending on their age and employment status, and who they care for. Being married or living as married increases the likelihood of taking on a caring role including providing 20 hours or more informal care per week. The extent to which people marry into potential caring relationships is most clearly observed among women though sex differences are less pronounced among co-resident carers reflecting the extent of spouse care-giving. In contrast, widowhood reduces the risk of becoming a carer and this is more or less equally the case for both men and women. Thus living with a partner and losing a partner through death respectively introduce individuals to, and remove them from, potential caring relationships. As well as spouse care, those individuals who are married or living as married may provide informal care for a son, daughter, parent or parent-in-law, amongst others. Although many widows and widowers may have provided informal care in the past, most likely before their partner died, the loss of a partner often occurs late in the life course when the chances of taking on these other caring relationships role are much reduced.

Divorce or separation is also associated with reduced chances of becoming a carer but the effect is not as striking as being widowed because divorce or separation occurs more widely across the life course. Moreover, the effect of divorce or separation on reducing the likelihood of providing informal care is most evident among men. They are less likely than

their former spouses to maintain responsibility for the care of their children and like men in general are less likely to look after elderly parents. In contrast, divorced or separated women are as likely as their married counterparts to take on a caring role and provide 20 hours or more informal care per week.

If marriage increases the scope for providing informal care, not getting married can limit or prevent potential caring relationships. Thus single or never married people are least likely to become extra-resident carers or to provide heavy care. Within households however, single or never married people are more likely than those who are widowed, and as likely as those who are divorced or separated, to take on a caring role. In this case, being single or never married is a proxy for adult sons or daughters who have never left home or who have been able to return home more readily than their married siblings to look after disabled or elderly parents.

Sex differences in the provision of informal care are often mediated by marital status. We have already observed that women are more likely than men to become carers. The findings also focus attention on the rate at which married and divorced or separated women take on a caring role and become heavy care-givers. Thus: marriage or cohabitation further increases the likelihood of women becoming informal carers while not being married or not living as married further reduces the likelihood of men taking on a caring role.

Some of these associations between informal care and marital status are evident from the GHS, in particular the extent to which individuals marry into potential responsibilities or are 'available' to provide informal care and how this varies by age, sex and the relationship to the cared-for person (Parker and Lawton, 1994; Rowlands, 1998). Direct comparisons are difficult because of these complex interactions. What is new here is that we have been able to investigate individuals' marital status *before* they become carers. It is therefore possible to demonstrate more precisely how marital status affects the rate at which individuals take on a caring role in association with other factors. The findings indicate that marital status is more important in differentiating women carers rather than their male counterparts for whom age and employment status assume greater importance in determining the rate at which they take on a caring role. They also indicate that differences in marital status have more impact on the rate of care-giving within households than between households.

In addition, the findings provide no evidence that taking on a caring role alters the individuals' chances of marrying or maintaining an existing relationship. Marriage or cohabitation pre-dates most caring relationships: marital breakdown can reduce the chances of taking on a caring role especially for men, and being widowed is often associated with the end of a care episode. In short, marital formation and dissolution are more likely to determine the incidence of informal care rather than the reverse. Comparisons of marital status before and after the start of care-giving show further that taking on a caring role does not lead to marital breakdown or prevent the formation of new relationships, at least during the first year of care-giving (Hirst, 1999a).

Employment status

There is a wealth of evidence on the costs of informal care in terms of employment opportunities foregone, reduced participation in the labour force, and diminished promotion prospects (Atkin, 1992; Parker, 1990). This study concentrates on the economic activity of individuals prior to taking on a caring role and focuses attention on the extent to which paid employment might be combined with care-giving or influence the decision to provide informal care. As might be expected, the effect of employment on the risk of informal care varies between men and women.

We distinguished between those who were in full-time or part-time work and those not in any kind of paid employment. For women, the risk of becoming a carer increases systematically across these three categories. Those women who are not in the labour force are more likely to provide informal care than those in part-time work who, in turn, are more likely to do so than those in full-time work. This is the case for both co-resident and extra-resident care provided by women. Not surprisingly, the increasing risk of becoming a carer, relative to those who work full-time, is most significant for heavy caring suggesting that the level of women's initial involvement in care-giving is determined by their participation in, or attachment to, the work force: the fewer hours women work, the more care they can provide (Hutton, 1999).

A different picture emerges for men. Those men who are not in paid work are most at risk of taking on a caring role, including heavy care, but most of them are over pension age. By comparison, those who are below pension age are much less likely to provide informal care

regardless of whether they are engaged in part-time or full-time work. In fact very few men work part-time and those that do are not at a significantly greater risk of providing 20 hours or more informal care per week. Women under pension age are much more likely than their male counterparts to be heavily involved in the care of sick or disabled children, elderly parents or parents-in-law. By comparison, the level of involvement of working age men in terms of the amount of time devoted to caring is considerably less than that of women.

In short, working full-time, part-time or not at all helps define the 'availability' of women to provide informal care. Women are often expected to provide informal care when required by a family member and the extent to which they do so is likely to vary according to employment patterns. For men of working age, maintaining their attachment to paid employment takes priority over informal care-giving. They are less likely than women to become carers and the likelihood of taking on a caring role does not increase significantly where they are working part-time. Although single men are more likely than single women to look after a parent in the same household, this is because the former have not left the parental home: in fact most of them worked full-time before taking on a caring role and not a few start paid work *after* becoming a carer (Hirst, 1999a). In contrast, men who are not engaged in paid employment are mostly over pension age and those who are married or living as married are especially at risk of providing informal care for a spouse.

Social class

In her analysis of the 1985 GHS on informal care, Green (1988, p. 11) found very little variation in the proportion of carers between the manual and non-manual socio-economic groups, suggesting that informal care-giving is not related to social class. However, Arber and Ginn (1992) felt that this was because she focused on all carers combined rather than separating extra-resident and co-resident care-giving which are associated with social class in opposite ways.

Although informal carers as a whole are drawn equally from all classes, they argued that informal care is more likely to be provided in working class households reflecting poorer health and higher morbidity levels compared with middle class families. In contrast, middle class households are more likely to provide extra-resident care, to elderly parents, clients of voluntary organisations and friends and neighbours, because the possession of material,

financial and cultural resources enable them to provide care 'at a distance'. Further analysis of the 1985 GHS provided confirmatory evidence. Arber and Ginn (1992) found that individuals in manual occupations are more likely to care for someone in the same household whereas non-manual occupational groups are more likely to provide informal care for someone living in a different household. They also found a stronger class gradient for men than women in co-resident care-giving suggesting that whether men provide informal care is contingent on class whereas for women it largely depends on the health of family members. Social class patterns for extra-resident care varied with age and showed either no linear trend or a *decreasing* proportion of carers across the social scale from the Professional to the Unskilled occupational groups.

This study produced comparable findings. These confirmed that the manual social classes are more likely than their non-manual counterparts to take on the care of someone in the same household. This tendency was strongest among those who start to provide 20 hours or more informal care per week. Moreover the probability of becoming a co-resident or a heavy carer increases systematically with each successive increment from Social Class I (Professional) to Social Class V (Unskilled).

The findings also point to sex differences in the social class gradient. Variations in the incidence of co-resident and heavy care-giving across the social scale are more sharply defined for men than for women. The explanation is that non-manual men are even less likely than non-manual women to take on these caring roles compared with their counterparts in the manual classes. As a consequence, the social gradient is much flatter for women. However sex differences in the social class gradients of care-giving are less pronounced when marital and employment status are taken into account, reflecting the predominance of spouse care among those who look after someone in the same household.

There is no social class gradient in the overall risk of taking on a caring role when all the factors considered here are taken into account but this masks the different way in which class is associated with co-resident and extra-resident caring respectively. As noted above, those in the manual classes are significantly more likely than non-manual classes to provide co-resident care. The opposite is the case for care-giving between households but the social class gradient is not statistically significant. However, class differentials in the risk of

providing extra-resident care increase with age and accordingly the class gradient is more pronounced in the older age groups. Thus, older individuals in the non-manual classes are significantly more likely than their counterparts in the manual classes to provide informal care for someone in a different household.

These findings are broadly consistent with those of Arber and Ginn (1992; 1993) and support their conclusion that providing informal care for someone living in another household is more widespread in middle age and the later stages of the life course with the higher to middle class more likely to be extra-resident carers than the working class. In contrast, manual classes are more likely than non-manual classes to look after someone in the same household and provide 20 hours or more informal care per week. Moreover, working in non-manual occupations reduces further the likelihood of men providing co-resident or heavy care whereas class differences have significantly less effect on the rate at which women take on such caring roles. The findings reported here therefore confirm that questions about who provides and who needs informal care are mediated in part by social class and demonstrate that the greater burden of care-giving is often borne by those with the least resources.

A concluding note

This report has focused on variations in the probability or risk of becoming an informal carer. We have shown, for example, that more than one in ten individuals in various subgroups of the population are likely to take on a caring role each year. A separate question is how that level of risk compares with the probability of other events that individuals' experience.

Calman (1996) has proposed a six-point scale ranging from 'negligible' to 'high' to describe a range of health risks (see box). On this scale, the risk of becoming an informal carer, including the likelihood of caring for someone in the same household and providing informal care for 20 hours or more per week, would be rated 'high'. According to Calman's examples, this is

Term used	Risk range
High	$\geq 1:100$
Moderate	1 to 10:1000
Low	1 to 10:10 000
Very low	1 to 10: 100 000
Minimal	1 to 10: 1 000 000
Negligible	$\leq 1: 1 000 000$

equivalent to the risk of transmission to susceptible household contacts of measles and chickenpox or the transmission of HIV from mother to child (in Europe). While drawing

attention to the extent and importance of informal care, such comparisons may not be wholly appropriate though adverse health effects and additional health service costs are associated with taking on a caring role (Hirst, 1998). An alternative approach, however, would be to compare the incidence of informal care with the probabilities of events that fall within the normal range of people's life experiences, such as moving house, passing a driving test, starting work, becoming a grandparent, bereavement, taking a holiday abroad, receiving a windfall, and so on.

Data from the BHPS could be used to estimate many of these probabilities and develop a scale of 'social risks'. Respondents are also asked to identify up to four important events that have happened to them or their family in the previous year. Caring responsibilities (excluding normal child care), and who is cared for, are coded from the verbatim responses making it possible to assess the perceived significance of care-giving relative to other life events or to actually taking on a caring role. Further research is required to evaluate the risk of informal care along these lines.

**THE EMPLOYMENT OF THOSE UNDERTAKING INFORMAL CARE:
A longitudinal analysis**

SUMMARY AND KEY FINDINGS

This report presents the results of analyses of the first six waves of the British Household Panel Study to determine the employment outcomes for individuals who are providing informal care for someone else. The majority of the work relates to people looking after someone in their own household, but includes some analysis of extra-household care.

- *Employment status changes on starting informal care*

In general employment status does not change on starting an episode of informal care: 83 per cent remained in the same status as before care started. Fifty three per cent remained in paid work. Those in full-time work were less likely to alter their status than those in part-time work. Among part-time workers (who are mostly women) 70 per cent stayed in part time work, ten per cent left paid work.

- *Effects on employment of the duration of informal care*

There is less change in status between year two and year three than earlier. Routines perhaps become more settled.

As the duration of the provision of informal care increases the reduction in the likelihood of being in paid work compared with non-carers becomes statistically significant. After the third year of informal care those offering 20 or more hours of care were significantly less likely to be in paid work.

The effect of the time since care had finished and the simple duration of care seemed to be subsumed in the significant increasing effects of periods of heavy care. As the length of time

spent in heavy care increased the likelihood of being in paid work at the end of the panel survey (a six year interval) decreased.

- *Other aspects of paid work*

Informal care seemed to have little effect on the number of hours worked over a period of informal care, probably as a result of the relative inflexibility of the labour market.

Estimates of the total hours per day spent on informal care, paid work, and travel to work showed that a quarter of carers spent 12 hours or more per day on these activities compared with seven per cent of non-carers. Because men work full-time, 54 per cent of men compared with 39 per cent of women spent ten or more hours per day on paid work, travel and care.

Part-time workers with co-resident care responsibilities were less likely to be in permanent jobs and jobs with annual increments than non-carers. The private sector was less likely to employ those with caring responsibilities.

- *Influence of who is cared for*

Looking after a partner reduces the likelihood of being in paid work compared with other caring relationships over the duration of an episode of informal care.

Extra-household care has a significant effect on reducing the likelihood of being in paid work after the start and over the duration of an episode of informal care but heavy care does not seem to have the same effect as for co-resident carers.

- *After finishing an episode of informal care*

If carers were in paid work before finishing an episode of co-resident informal care, they were much more likely to be in paid work after the episode of care had finished, but having been involved in heavy care meant that the likelihood of being in paid work was significantly reduced, and the effect endured and even increased slightly, the further from the end of the episode. For women, working part-time while providing informal care increased their chances of being in work after the end of the provision relative to those not working, and working full-time increased it even more.

Even after finishing informal care for someone outside the household, the likelihood of paid work is reduced for carers compared with non-carers.

**HEALTH AND SOCIAL CARE SERVICES USED BY
PEOPLE PROVIDING INFORMAL CARE**

SUMMARY AND KEY FINDINGS

This paper, using information from the British Household Panel Study, studies the use of the following health and social care services: health visitor or district nurse, home help, meals on wheels, social worker, chiropodist, alternative medicine, psychotherapist, speech therapist, physiotherapist, or any other service.

- The use of health and social care services by carers and non-carers was similar and changed little between 1991 and 1996. The most commonly used services by those providing care were chiropody, and the services of a health visitor or district nurse
- At the household level, households which provide informal care are more likely to use health services than those not providing care because the services provided to the recipient of informal care are included.
- As expected recipients of care are more likely to use services than informal carers but the differences in low level use (any services or one service) are not as great as might have been expected. In households where three or more services were used, the services were more likely to be used by the recipients. The services of a health visitor or district nurse, a social worker, a chiropodist, and a physiotherapist were much more likely to be used by the recipient of care than the carer.
- Household use of services increased as the length of time the household provided informal care increased from one year to the intermediate category 2, 3, or 4 years but declined for those involved in longer term care of five years or more. The use of three or more services increased more uniformly over time. Use of some services were more likely to increase over time than others and this may be because the type of care

is related to the length of an episode.

- Whether the household was involved in heavy care did not add significantly to the likelihood of using services.
- The influence of the presence of recipients of care with limited abilities to undertake daily activities on service use proved inconclusive providing further evidence of the difficulty in relating the use of services to the need for them.

EVALUATION OF CURRENTLY AVAILABLE NATIONAL SURVEY DATA FOR MONITORING OUTCOMES OF SOCIAL CARE

SUMMARY AND KEY FINDINGS

There is a wealth of quantitative information on informal care available in three, large-scale nationally representative surveys of the general population:

- *General Household Survey (GHS)*
- *British Household Panel Survey (BHPS)*
- *Family and Working Lives Survey (FWLS)*.

As well as providing a firm basis for constructing cross-sectional profiles of carers, caring activities and care recipients, these surveys provide data which can be analysed longitudinally. The GHS provides information on informal care at three points in time (1985, 1990/91, 1995/96) while the BHPS follows the same individuals each year since its start in 1991. By comparison, the FWLS was undertaken at one point in time, 1994/95, but asked retrospectively about caring responsibilities over the life course. There is also one-off cross-sectional information, for example in the Family Resources Survey, but this paper will concentrate on the three data sets above which provide information over time.

Prior to the work undertaken at the Social Policy Research Unit, these data sets had not been analysed longitudinally apart from an exploration of differences in the carer population and care-giving activities between the 1985 and 1990/91 GHS (Parker and Lawton, 1993; 1995) and a review of the potential of the FWLS for investigating informal care (Barnes *et al.*, 1997).² It was recognised that the availability of repeated survey measures, panel data, and retrospective information from these data sets provide an unrivalled opportunity for investigating care-giving careers and for comparing the experience of care-giving across different cohorts over time. Coincidentally, there was growing recognition of an urgent need

2. Since the start of this project, two reports on informal care incorporating longitudinal analyses of the GHS and BHPS respectively have been published (Rowlands, 1998; London Economics, 1998).

for a temporal perspective on informal care-giving (Nolan *et al.*, 1996). Longitudinal analysis of these data sets, it was argued, could be used to inform strategic planning, the timing of service inputs, and the targeting of resources at the local level. In particular, they provide valuable information for monitoring trends and outcomes of informal care.

This paper evaluates the strengths and weaknesses of the three data sets for investigating the effects or consequences for carers themselves of providing informal care. It also considers their application to the regular monitoring of outcomes and trends in caring relationships over time at the national level. The aim is to provide a clear picture of what can be routinely monitored as further survey sweeps could continue to provide information on informal care in future years. In the next section, we consider how a temporal perspective on informal care-giving might contribute to policy formation, service planning and social care practice and then go on to review each data set in turn.

Current policy and practice increasingly focuses attention on the consequences, effects or outcomes of community care including the impact on carers but there is considerable diversity in what should be measured and how (Nocon and Qureshi, 1996, pp.20-1). The various arenas in which policy decisions are shaped and implemented make such diversity inevitable. At the individual level, assessments by social care professionals can be reviewed to determine whether the user's needs for social care, health and housing services and the carer's needs for advice, information and practical support have been met. A better understanding of how care-giving changes over time can inform the timing and design of interventions intended to support carers at each stage in the evolution of their caring responsibilities and activities and the transitions or turning points between them. Repeated assessments at regular intervals can establish more precisely the consequences of service provision for different client groups, relating outcomes to service inputs and client characteristics and their implications for carers. At the population level, comparisons between client groups including those who do not receive services are often the focus of policy. Service planners, for example, might want to monitor the availability of respite services for people with long-term care needs and the extent to which these enable their carers to take a break. Comparisons between carers and non-carers are also required to evaluate outcomes including the scope for improving carers' pension entitlements and enabling carers to combine paid work with care-giving or return to work when their caring

responsibilities cease (Department of Health, 1999).

Clearly, different kinds of information collected in a variety of ways according to the scope and purpose of an evaluation are required to investigate outcomes for carers. We also recognise that decisions about evaluation strategies and methodologies are not value free and take place in a social and political context, reflecting the concerns of various stakeholders. However, common to all approaches that aim to measure outcomes is an emphasis on change as vital to evaluating the appropriateness of policies and the effectiveness of practice. The idea of an outcome implies change 'since an impact or effect upon someone must involve either a change in state, or the prevention of a deleterious change' (Nocon and Qureshi, 1996, p.11). Outcome measurement, therefore, is about detecting changes over time and identifying the factors underlying change.

As well as outcomes for carers, policy making and service provision must also respond to the changing demands faced by each new cohort of carers. Here the focus shifts to the wider context that shapes informal care-giving: changes in the size and composition of the population of elderly or disabled people requiring assistance with everyday activities, and changes in individuals' capabilities for, and expectations of, providing such care in the home. Trends in divorce and cohabitation, the decline in the proportion of single women, the emergence of new family forms including lone parent families and step families, and women's labour market participation are thought to influence the supply of informal care while the aging of the population, changes in the onset of long-term care needs, and policies on admission to institutional care can affect the demand for care in the community (Parker, 1998). Social, economic and demographic changes are also thought to have altered attitudes towards, and expectations of, taking on a caring role and their impact is likely to vary across different age cohorts. State provision can never replace the contribution of the family in delivering care. Monitoring recent changes and anticipating future trends in the supply of informal care are therefore key elements in evaluating the impact of policies and services which aim to support carers' willingness and capacity to continue caring (Department of Health, 1999).

In our research on outcomes of social care, we have focussed on changes in the needs or circumstances of carers. The question can be expressed as: 'was the observed change in

those who became carers significantly different than in non-carers and could that change have been caused by taking on a caring role?'. We have used information at the national level, drawing comparisons between groups of carers and between carers and non-carers to measure and explain the effects of care-giving on their health, economic activity, income and family circumstances. We have also investigated trends in informal care over time and described carers' circumstances around the start, during, at the end of, and after care-giving episodes. In the next section, we review briefly the three sources of data and then go on to summarise how they can be used for monitoring trends and outcomes for carers.

When using the three data sets reviewed above, the investigator is faced initially with two choices: which outcomes to monitor and for whom. Not all those who identify themselves as carers in such surveys are the focus of policy concern and the carer population can be segmented in different ways. The Carers (Recognition and Services) Act 1995, for example, concentrates on those who provide 'a substantial amount of care on a regular basis'.³ Support for carers of disabled children may be a special responsibility of family services providers while health services may concentrate on those caring for someone with a specific condition such as dementia, stroke or physical impairment. By comparison, carer support groups may target individuals in long-term caring relationships.

Each of the surveys allow carers to be classified in different ways but the following distinctions cover the most important dimensions:

- locus of care, chiefly within or between households but also covering informal care provided for someone living in a residential care or nursing home
- relationship between the carer and care recipient
- level of involvement according to the number of hours devoted to informal care each week
- duration of care-giving episodes although in the case of the BHPS duration has to be inferred (as described in Appendix 1).

3. Local authorities are expected to form their own judgements about what amounts to regular and substantial care. The practice guidance talks about the 'heavily involved carer' and 20 hours or more informal care per week appears to be a rule of thumb.

- level of responsibility in terms of sole, main or joint carer
- type of caring activities, including personal care, physical assistance, and attendance or supervision.

We have concentrated on the distinction between co-resident and extra-resident carers, that is between those providing informal care for someone in the same household and those looking after someone living elsewhere. Within these two spheres of care-giving, we have distinguished different types of caring relationships, whether kin or non-kin, and care-giving within or between the generations. Duration of care-giving is a key dimension for evaluating outcomes and we have charted changes in carers' circumstances during care-giving episodes and post-care periods of varying length. We have also distinguished carers according to their level of involvement describing those providing 20 hours or more informal care per week as 'heavy' care-givers. In addition to these aspects of their care-giving role, carers can also be classified according to their social, economic and demographic characteristics using commonly-accepted survey classifications (age, sex, ethnicity, marital status, economic activity, social class, and so on).

We have used information from the three data sets to look at how health, employment, financial and family outcomes for carers change over time and are related to the context, timing and duration of care-giving episodes. More specifically, we have shown that the survey data can be used to monitor:

- carers' circumstances around the start and end of care-giving, including their household characteristics, family relationships, residential mobility associated with informal care, and caring relationships that end in death or admission to institutional care
- the timing of informal care episodes in relation to the carers' and their families' life course according to the relationship between the carer and the care recipient and comparisons between co-resident and extra-resident caring relationships
- changes in individuals' physical, emotional and mental health before, during and after providing informal care and the impact of heavy care-giving
- changes in employment status, hours worked and types of work on starting episodes of informal care; the numbers combining informal care and paid work; if there are further changes as care continues; and if there is a return to paid work or other changes after

the episode of informal care is completed

- the effects on levels and sources of income for the individual and the household involved in informal care and if these effects are reversed after finishing informal care
- if providing informal care leads to increased poverty levels
- changes in the receipt of primary health, community health and social care services by the carer and the care-recipient during a care-giving episode at both the individual and household level
- trends in the prevalence of informal care over time and in the amount and type of care provided, comparing younger and older age cohorts
- estimates of the annual incidence of informal care and the cumulative or net risk of taking on a caring role during adult life
- trends in the number of individuals starting, ceasing and continuing to provide informal care each year, including estimates of the annual rate of new carers, transitions into and out of the carer population, carer turnover, and changes in carers' level of involvement over time
- variations in the annual incidence or rate of new carers according to their age, sex, ethnicity, marital status, employment status and social class.

Our investigations have also revealed gaps in the information available at the national level for monitoring outcomes and trends. These include:

- short-term intensive care-giving episodes, including hospital discharge
- within household transfers which can be directly attributed to the giving and receipt of informal care
- receipt of practical support and other policy measures intended to prevent or alleviate the adverse effects of care-giving or accommodate the care-giving role, for example, flexible employment conditions, respite or shared care services, and the timing of such inputs relative to the process of the caring episode
- whether and how the care-giving role shapes personal decision-making including residential mobility, family formation, and participation in the labour market
- life-time impact of informal care-giving including carers' earnings, pensions and investments
- carers' unmet needs for advice, information and practical support and their perceptions of the care-giving role

- receipt of informal care provided by someone living in another household
- details of those deciding not to provide informal care, of any alternative arrangements they make and the reasons why
- the provision of informal care by children and young people under the age of 16 years.
- informal care-giving within minority ethnic populations
- the number of carers in areas covered by local social services authorities, health authorities, and labour markets.

Some of these issues might be best addressed at the local level, however a question in the 2001 census will provide useful information on the latter three topics. The aim of this question is to record whether or not individuals provide unpaid personal help for a friend or relative with a long-term illness, health problem or disability and the time spent each week providing such care (ONS, 1999). It will be possible to link the responses to this question with other census information including economic activity and limiting long-term illness. In this way it should be possible to build up a comprehensive picture of variations in informal care at the household level across small geographical areas.

SUMMARY AND CONCLUSION

This paper has set out the information on informal care which is currently available for secondary analysis in national surveys. It has shown that these surveys are a rich source of such information and that a wide range of analysis of the different outcomes of undertaking informal care can be performed without having to gather new data. So there is a wealth of quantitative data available at the national level for monitoring outcomes and trends of informal care.

An important aspect of evaluating the outcomes of informal care is the need to know what has gone before. The availability of a national panel study has improved the possibilities for analysis over time of the factors which influence the outcome and we have shown how examination of these influences can contribute to the development of policies for informal care, service planning and social care practice.

There are some gaps in the information available, as we have demonstrated, and for the future it would be beneficial to consider the addition of certain questions to the surveys

which are the basis of these government sponsored data sets.

The main message from this evaluation of currently available national information, however, is that there is considerable scope for future monitoring of trends and outcomes of informal care particularly as additional waves of data become available.

INFORMAL CARE IN ETHNIC MINORITIES

SUMMARY AND KEY FINDINGS

This report presents new evidence on minority ethnic carers in Britain distinguishing between the four main minority ethnic groups: Black Caribbean, Indian, Pakistani, and Bangladeshi. The findings are based on secondary analysis of the *Family and Working Lives Survey* of adults aged 16 to 69 years which was conducted in 1994/95. As well as investigating variations in the prevalence of informal care and patterns of care-giving across ethnic groups, including the White population, lifetime estimates of informal care and its impact on carers' employment patterns are also examined.

Chapter 1 describes the background to this report and the aims of the research. It goes on to outline the survey design and questionnaires developed for the FWLS, focusing on the representativeness of the sample, the classification of ethnicity, and how informal carers are identified. Comparisons with other national surveys indicate that the FWLS questions on informal care are quite restrictive and the discussion acknowledges that the prevalence rates presented in later chapters should be regarded as conservative or minimum estimates.

Chapter 2 describes the demographic profiles, family and household structures and economic circumstances of the main ethnic groups identified in the FWLS. It also summarises respondents' language preferences and provides a brief outline of their own and their parents' migration and settlement histories. The aim is to understand the context within which care-giving takes place by examining the social, demographic, economic and other factors that are often associated with variations in informal care. A further aim is to anticipate how demographic and other trends might affect informal care across the ethnic groups in the short to medium term.

The findings draw attention to the considerable diversity of circumstances within each ethnic group as well as several striking differences between them. These include the

youthful age profile of minority ethnic groups compared with the White respondents, the large, multi-generational Asian households compared with the lone parent and single person Black Caribbean households, the severe financial hardship typical of many Pakistani and Bangladeshi households, and the substantial proportion of minority ethnic respondents whose parents have not moved to live in the UK. The analysis also touches on the difficulties likely to be faced by a sizeable minority of Asian respondents whose first or preferred language is not English.

The discussion tries to anticipate how these differing circumstances might affect variations in the volume, pattern and timing of informal care across ethnic groups. It is argued that variations in informal care have more to do with socio-economic disadvantage, migrant status, demographic change and their impact on marriage patterns, family composition and living arrangements. A classification of ethnic groups may encompass many of these factors and, as a consequence, ethnicity may be associated with or predict variations in informal care but cultural factors as such are unlikely to play a major role. Moreover the circumstances and needs of minority ethnic groups are likely to change rapidly as living standards rise, educational levels improve and progressive ageing shifts their demographic structure towards one that is more typical of the population as a whole. In the meantime there will be an increasing number of minority ethnic elders and people in later working life. This is likely to lead to an absolute increase in the number of caring relationships involving elderly people and elderly spouses carers.

Chapter 3 presents findings on the numbers and types of carer identified in each ethnic group and describes their relationship to the person they look after. As well as describing current patterns of care-giving, all previous caring episodes are identified and linked with individuals' ages when caring began to help locate informal care in the life course. One adult in twenty under age 70 is engaged in care-giving and a substantial minority, around 40 per cent, were providing 35 hours or more care per week. Asian respondents are twice as likely to be informal carers as Black Caribbean or White respondents; Pakistani and Bangladeshi carers are generally the most heavily involved.

Minority ethnic carers, especially Asian carers, are much younger on average than White carers largely reflecting demographic differences between the ethnic groups. Minority ethnic

carers are also more likely to be current care-givers while White respondents are much more likely to have provided care in the past. These differences are further reflected in the carers' relationship to the person they look after. Most informal care-giving involves inter-generational exchanges especially looking after parents or parents-in-law. Providing informal care for an older person accounts for most of the former or completed caring episodes in each ethnic group. Parents or parents-in-law also figure in the majority of current caring relationships especially those reported by Indian and White carers. Around a third of current carers look after their spouses or children, more so among Pakistani and Bangladeshi carers

Although completed episodes of care lasted around five years on average, most were less than half this length. Current episodes are generally two or more years longer than completed spells reflecting a shift from looking after parents or parents-in-law to caring for a spouse or a sick or disabled child.

Chapter 4 re-presents the prevalence estimates of informal care, this time based on sample data weighted to correct for household size and multi-household addresses. The confidence intervals that are likely to encompass the rates that would have been obtained if the total population had been surveyed are also given. These rates can be applied to local populations to estimate the number of carers aged 16 to 69 years in the ethnic groups described. The findings draw attention to the contrast between the higher rates of informal care among Asian respondents on the one hand and the lower rates estimated for Black Caribbean and White respondents on the other: Asians are more than twice as likely to be informal carers. Service providers, therefore, can expect to recognise and support proportionately more care-givers under the age of 70 in the Asian population than in the other ethnic groups.

It is recognised that the upper age limit for inclusion in the survey, 69 years, means seriously under-estimating the true prevalence of informal care in the White adult population *as a whole*, especially spousal care which predominates in an older age group. By comparison, the youthfulness of the ethnic minorities means that the prevalence estimates of care-giving for those under 70 years of age are probably close to the overall adult prevalence rates for the minority ethnic groups considered here. However such congruence will not last much longer: progressive ageing in the ethnic minorities will have dramatic effects on care-giving in the coming decade. The expectation is that there will be an absolute if not a relative increase in the number of minority ethnic carers as the number of elders needing informal care rises. Minority ethnic carers themselves will be increasingly drawn from an older age group as spouse care in old age becomes more widespread.

Not surprisingly, the proportion of individuals who have provided informal care at some point in their lives, that is lifetime prevalence, is lower in the ethnic minorities because they have faced fewer opportunities on the whole to provide informal care than the White respondents. As well as their youthfulness, a sizeable proportion of minority ethnic respondents have never been joined in the UK by their parents or other elderly relatives. After taking into account their different demographic structures, however, the lifetime estimates of informal care for Indian respondents actually exceed those for White respondents, while the estimates for Pakistani and Bangladeshi respondents match those for the latter group. Although these estimates are conditioned by the upper age limit for inclusion in the sample, 69 years, they point to the likelihood that informal care could eventually be more widespread in the Asian than in the White population as their age structures converge. In contrast, lifetime estimates of informal care for Black Caribbean respondents are much lower than those of other ethnic groups reflecting their different family and household living arrangements, in particular the higher rates of lone parenthood, cohabitation and small household size.

Irrespective of ethnic group differences in the provision of informal care, the lifetime estimates indicate that *over time* substantially more carers will be identified than in a single snapshot or cross-sectional survey. The prevalence rates of current care-giving are substantially below the lifetime estimates and the differences reflect the rapid turnover of informal carers as individuals stop providing care and others take on a caring role or vary

their level of involvement.

Chapter 5 assesses the evidence for adverse effects on paid employment of providing informal care. Unfortunately, the number of minority ethnic carers is too small for detailed statistical analysis. In particular, there is no firm evidence to suggest that the employment effects of informal care vary significantly across the ethnic groups included here. Overall a substantial minority of carers were not working when caring began and taking early retirement to provide informal care was relatively uncommon. However, a majority of those in paid work said that their employment was adversely affected by providing informal care, chiefly through having to stop work altogether or reducing the number of hours worked. In other words, adverse effects are more likely to be reported than no effects at all by those who were actually in paid employment. The evidence indicates that providing informal care adversely affects the employment of between 40 and 50 per cent of all carers, often their terms and conditions of work. Giving up paid work on account of providing informal care affected one in four carers who were actually in employment when care-giving began, that is around one in six carers overall.

The vast majority of carers remained in the same activity after starting care, whether in or out of a job or some alternative to paid work, as they were before providing care. Continuity of employment status rather than change of circumstances is the predominant outcome around both the start and end of caring episodes. What carers were doing before informal care began largely determines what they continued to do during the caring episode and beyond. Even so, the relationship between informal care and paid work is complicated by a few carers moving in and out of jobs during the caring episode itself. Clearly, providing informal care does not necessarily prevent carers remaining in or returning to paid work. Moreover, some carers were able to work longer or more flexible hours after care-giving ceased. However the findings show that giving up paid work to provide informal care affects not only a sizeable minority of carers: carers are much more likely to leave jobs when providing informal care than they are to return to paid employment when care-giving ends. The marked imbalance between the numbers leaving and returning to paid work draws attention to the reduced employment prospects following a spell of informal care and, by association, poorer pension rights.

PENSION ARRANGEMENTS AND INFORMAL CARE

SUMMARY AND KEY FINDINGS

This paper explores the impact of people providing informal care on their contributions to pension schemes during their working lives, on circumstances in their pre-retirement years, and on their incomes in retirement. It uses two data sets: the General Household Survey (GHS) which in 1995 included a series of questions on the provision of informal care, and the Family and Working Lives Survey (FWLS) also undertaken in 1995. The GHS is a cross sectional data set which provides information on those currently providing informal care. The FWLS provides retrospective information on those who have been carers in the past.

Pension contributions during the working life

The analysis of the GHS separates the circumstances of those who look after someone in the same household and those who provide care outside the household. Men and women are equally likely to care for someone in the same household whereas those who care for someone outside the household are more likely to be women. Those looking after someone in their own household are also more likely to be heavily involved with care responsibilities.

From the analysis of the GHS, in general 30 per cent of those of working age contribute to an occupational pension scheme, but the proportion is lower (20 per cent) for those currently caring for someone within their own household. This group are also half as likely to contribute to a personal pension scheme than others, 11 per cent compared with 20 per cent. Contributions to pension schemes depend to a large extent on employment status. When comparisons are made for those in full-time work, the likelihood of contributing to an occupational pension scheme does not differ between those caring for someone in the same household and non-carers (58 per cent) although those caring for someone outside the household are slightly more likely to contribute (63 per cent). Approximately a quarter of those caring for someone outside the household and non-carers are members of a personal pension scheme compared with a fifth of those caring for someone in the same household.

For those in part-time work, similar proportions of those looking after someone in the same household and non-carers (around a fifth) and slightly more of those caring for someone outside the household contribute to an occupational pension. A minority contribute to personal pensions: only five per cent of those caring for someone in the same household.

Incomes in the pre-retirement years

Those caring for someone in the same household are considerably more likely to describe themselves as permanently unable to work or inactive than others but are not more likely to say they are retired. Thus the hypothesis that carers take early retirement does not seem to be upheld.

Income from earnings is the major source of income pre-retirement whether or not people are providing informal care, but benefit income contributes 10 per cent more for carers than non-carers. Those looking after someone in their own household have lower individual incomes than others and are more likely to be in the lowest 20 per cent of the pre-retirement income distribution than others. In contrast, those caring for someone outside the household are more likely to be in the top 20 per cent income band. Consistent with this result, women caring for someone outside the household have lower levels of benefit income. Providing informal care may be rather more of a voluntary activity for them than for those looking after someone in the same household.

The low personal incomes of women in the pre-retirement group are exacerbated by providing informal care. Nearly half of women looking after someone in the same household are in the lowest income band compared with 12 per cent of men providing this type of care, and compared with 35 per cent of other women.

Pre-retirement carers are not more likely than others to receive income from occupational or personal pensions but they are considerably more likely to receive income from National Insurance Sick Pay and Invalidity Benefit and Income Support. Benefit income rather than pension income supports the provision of informal care during the pre-retirement years.

Incomes over state retirement age

In retirement, incomes for those currently caring for someone in the same household are lower than non carers, and, in particular, than those looking after someone outside the household. However, benefit income, which includes state retirement pension is also lower for carers than others. Both of these findings may be a result of ongoing caring responsibilities, starting before and continuing into retirement, which prevented contributing to pension schemes during the working life.

Carers, surprisingly, are more likely to receive income from occupational pensions than others although those who care for someone in the same household receive a lower amount from 'other income' which includes income from private pensions and investments than either non carers or those looking after someone outside the household.

Benefit income, which includes the state retirement pension, is the major source of income for those looking after someone in the same household, however, they are less likely to receive income from this source than others.

Over half of women looking after someone in the same household are in the lowest 20 per cent band of the pensioners income distribution, compared with a third of women caring for someone outside the household, and 29 per cent of non-carers. A very small minority of men, less than 2 per cent, irrespective of any care provision are in this position.

Impact of past informal care provision on incomes

The FWLS contains information on whether individuals have ever provided informal care in the past as well as whether they are currently providing care.

Among those of working age, people who have been carers in the past are slightly more likely to have ever belonged to an occupational pension scheme than either current carers or non carers, and the same is true of membership of private pension schemes. Men who have ever provided informal care are 20 per cent more likely than similar women to have ever belonged to an occupational pension scheme and are twice as likely to belong to a personal pension scheme.

Some information is available about how pension contributions change over the progress of an episode of informal care. Half of those starting informal care were not in a pension scheme throughout. Otherwise people were most likely to withdraw from the scheme at the start of a care episode, and few left during. A relatively large proportion left after care had finished but this may just be because it was time for retirement. Fourteen per cent joined the pension scheme after finishing informal care and among this group 56 per cent had joined a scheme within five years. For younger people half had joined within three years, but overall return to 'normality' after the end of a care episode was not immediate.

Further investigation of a possible relationship between informal care and early retirement was undertaken with the FWLS. There are more detailed questions on retirement status in the FWLS compared with the GHS. Respondents in the FWLS are asked to say whether, even if their official employment status is not retired, they consider themselves to be retired. Among those who do not give their employment status as retired, current carers are slightly more likely than others to describe themselves as semi-retired or retired. They may still be formally employed but on sick pay or invalidity benefit as suggested in the GHS.

In the pre-retirement group, membership of occupational or private pension schemes is lower for those who have ever provided informal care than others, although overall membership is greater in the pre-retirement than the retired group, a cohort effect.

The analysis of the FWLS confirms the finding in the GHS that people are not accessing pension but benefit income to support informal care.

For those over state retirement age, people who have ever provided informal care have lower incomes from occupational pensions than those who have not. This is true of benefit income, which at this age mostly consists of the state retirement pension. This is a similar finding on the incomes of current carers over retirement age observed in the GHS.

Overall, among the issues this paper has set out to explore, it is clear that providing informal care reduces the likelihood of contributing to pension schemes, whether state or private, during the working life. The result is that incomes in retirement from state and private pensions are lower both for current carers and for those who have provided informal care

earlier in their lives. Women over retirement age caring for someone in the same are particularly likely to be in the lowest income band compared with other pensioners. Providing informal care during the pre-retirement years, a time of high likelihood of providing care, seems to be mainly funded by benefits rather than occupational or personal pensions contrary to the initial hypothesis of the paper.

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PART B

PUBLICATIONS

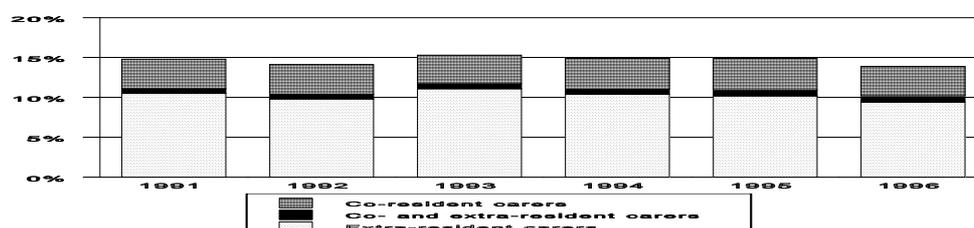
INFORMAL CARERS - A MOVING TARGET?

(Published in *Cash & Care* 23 (1999) - newsletter of the Social Policy Research Unit)

The population of informal carers is changing constantly. New evidence from the *British Household Panel Survey* shows that care-givers in any one year are not necessarily carers in the next. More than a third take on or cease care-giving every year and 'heavy' carers, those caring 20 hours or more a week, are even more transient.

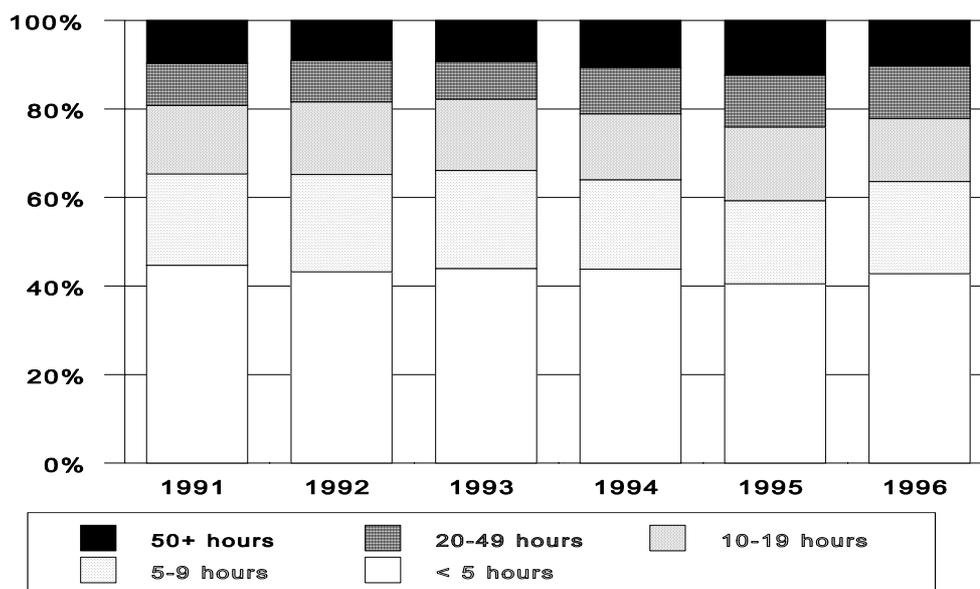
Population trends

Around one in seven adults describe themselves as informal carers and this proportion has varied little since the early 1990s. Three out of ten carers look after someone in the same household (Figure 1). In a typical locality of 250,000 adults there are an estimated 35,700 to 37,300 carers overall, of whom 10,500 to 11,400 live with the person they care for.[1]



Between 198 and 220 households per 1000 are involved in care-giving at any one time; the prevalence of co-resident care is estimated at 55 to 68 per 1000 households.

Two out of three carers devote fewer than 10 hours per week to their caring activities. However, one fifth of all care-givers, 6800 to 7600 adults in a typical locality, spend 20 hours or more caring per week, representing 40 to 53 households per 1000. The proportion of 'heavy' carers has increased since 1993, coinciding with the implementation of community care reforms to promote domiciliary care services and prevent inappropriate admissions to institutional care (Figure 2). Although this proportion fell back in 1996, it remains above pre-1993 levels.



Population dynamics

Cross-sectional trends mask considerable change in the carer population as individuals stop providing informal care and others take on a caring role, or vary their level of involvement. More than a third start or cease care-giving each year and over half are replaced by another cohort of carers every five years. Turnover is higher among co-resident carers and more so among 'heavy' carers:

- Two out of three co-resident carers were not looking after someone in their household five years ago.
- Three-quarters of those providing 20 hours or more informal care per week were not 'heavy' carers five years earlier.

Table 1 shows how the population of carers changes each year in a typical locality.

	Starting	Continuing	Ceasing
All carers	13,300 to 14,500	23,100 to 24,600	13,600 to 14,800
Co-resident carers	3,400 to 4,000	7,100 to 8,000	3,100 to 3,700
'Heavy' carers	3,000 to 3,600	3,700 to 4,300	2,600 to 3,300

The greater the turnover, the more individuals will be involved in care-giving over time: five year prevalence estimates are almost twice the annual rates (Table 2).

	One year	Five years
All carers	206 (198 to 214)	354 (344 to 363)
Co-resident carers	60 (55 to 65)	110 (103 to 116)
'Heavy' carers	43 (39 to 47)	87 (81 to 93)

Key issues for local authorities

The turnover of carers has financial and administrative implications for social services authorities. Underestimates of turnover would result in the needs of many carers, and the people they care for, not coming to the authorities' attention and a risk that service inputs

and processes are slow, inflexible and therefore inappropriate. Overestimates of turnover could lead to wasteful care management resources and higher unit costs.

Under the 1995 Carers Act, local authorities must carry out an assessment of a carer's needs if the carer provides a substantial amount of care on a regular basis and a request is made to the local authority. The kind of assistance that might be available depends on the resources available, the role of health and social care practitioners, and local priorities. The appropriateness of needs assessment and any practical support for the carer also depend on their timing in relation to the cared-for person's changing needs, the impact of family and household change on the caring relationship, and how the carer's responsibilities evolve.

Local services should be responsive to carers' varying needs for support and take account of changes in the population of carers. Performance standards might usefully include indicators of the time between referrals, needs assessment and service provision, and the timeliness of these processes. Carer's needs and circumstances beyond the care-giving episode also suggest areas where audit might be focussed.

[1] The 95 per cent confidence intervals for prevalence rates and population estimates are shown. Period prevalence rates are low estimates because care-giving episodes that start and end between waves are not recorded.

INFORMAL CARE OVER TIME

(Published in *Benefits: Social Security Research, Policy and Practice*, **28** (2000) 9-12)

The government's strategy, *Caring about Carers*, aims to introduce new measures to support those who look after sick, disabled or elderly relatives and friends, and to help them sustain their other roles, including paid employment (Department of Health, 1999). Monitoring and

evaluating policy and service support requires an understanding of how care-giving changes over time and the consequences for carers and the people they care for.

Previous research provides valuable evidence on the circumstances and needs of carers in particular localities, or those looking after someone with a particular condition or in contact with services. In the absence of longitudinal data, however, it is difficult to draw firm conclusions about the timing and impact of informal care. Our approach draws on national data sets derived from panel interviews, repeated surveys and retrospective life histories to investigate recent trends in care-giving and outcomes for carers identified in population surveys.

Longitudinal perspectives on informal care

Longitudinal approaches focus attention on the considerable changes that carers typically experience and point to the cumulative impact of care-giving. A longitudinal perspective can also inform policy making, service planning and professional practice:

- monitoring changes in the size and composition of the carer population, the impact of family and household changes, and wider social, demographic and economic trends can help anticipate the supply of informal care and the changing likelihood of taking on a caring role for younger and older generations.
- identifying stages in the evolution of caring responsibilities and activities indicates how services and practical support, including benefits, can be tailored to meet carers' changing needs and coping strategies during care-giving episodes and at key transitions or turning points.
- marking the onset and timing of care-giving episodes in relation to individuals' life course and stages of the life cycle draws attention to their other roles, including paid employment, their material and social resources and the support from partners and other family members.
- charting carers' use of time and aspirations provides a framework for the design and delivery of interventions, including respite care and social security provision, intended to alleviate or compensate for the demands of care-giving and the opportunity costs of providing informal care.
- examining carers' circumstances before and after starting care and during a caring episode

can pinpoint the health, employment, financial and other outcomes of taking on a caring role and help evaluate the range, quality, effectiveness and acceptability of services and welfare entitlements intended to support informal carers.

- tracking carers' health, financial and employment circumstances during and after care-giving ends points to the longer-term consequences of providing informal care and a need for service support and social security provision, including pension entitlements, in the post-care period.

Priorities for policy, planning and practice coalesce around supporting individuals through change and transition, enabling positive outcomes and preventing or alleviating adverse consequences. The development of appropriate benefit regimes also depends on understanding change in the lives of those providing informal care. Change and transition point to areas where performance assessment and audit could be usefully focused.

This paper describes the changing population of carers, where informal care occurs in the life course, and assesses employment and financial outcomes for carers drawing on longitudinal evidence from the *British Household Panel Survey*. The BHPS interviews the same representative sample of around 10,000 adults each year. We have used the first six waves from 1991 to 1996 to identify carers around the start, during and at the end of care-giving episodes.

The changing population of informal carers

The literature on informal care rightly focuses attention on the continuing demands facing long-term carers and their support needs. Indeed, recent trends indicate that more individuals are likely to be heavily involved in providing longer episodes of care.

Whether younger generations will provide such levels of personal and physical care in the future is less certain; this remains an important policy issue because state provision could never replace the contribution of family and friends to delivering care. However, despite increased female participation in paid work, trends in divorce and cohabitation, and new family forms including lone parent and step families, the proportion of carers in the population has remained steady - at least during the 1990s.

Yet overall trends mask considerable changes at the individual level: longitudinal information shows that the composition of the carer population is constantly changing. More than 40 per cent of heavily involved carers (those providing 20 hours or more informal care per week) change every year as individuals stop providing care and others take on a caring role or vary their level of involvement. The number of adults heavily involved in care-giving doubles over five years: in any one year around 43 per 1000 provide a spell of heavy care while over a five year interval the prevalence estimate rises to 87 per 1000.

Figure 1 shows how the probability of becoming a heavy carer accumulates with age. During a typical life span, six out of ten individuals are likely to assume heavy caring responsibilities at some point in their lives. There is a fifty-fifty chance of women becoming heavy carers at least once before reaching age 59; men must live 15 years longer on average to have an even chance of providing heavy care (▲).

The turnover of carers has important financial and administrative implications for supporting carers at an organisational level or over a geographical area. These include questions about the identification of informal carers, the resources available to assess their needs and those of the person they care for, the responsiveness of health and social care professionals, the demand for benefits and welfare rights advice, and the timeliness of service inputs and processes.

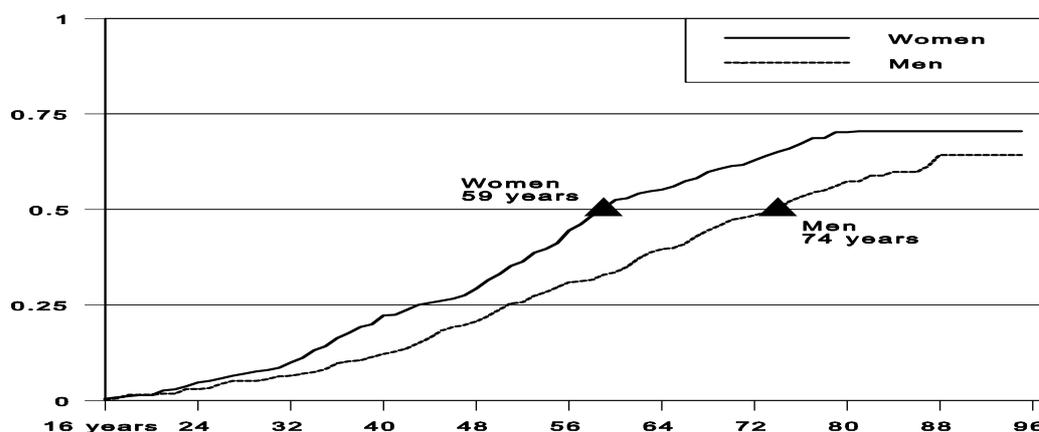


Table 1 shows that health and social care professionals in a typical locality might be expected to address the information and support needs of around 3000 new, heavily involved carers every year, that is 12 per working day on average. These estimates also challenge family doctors,

employers and others to address key concerns of the national strategy to maintain carers' health and enable them to remain in or return to paid work when their care-giving responsibilities cease.

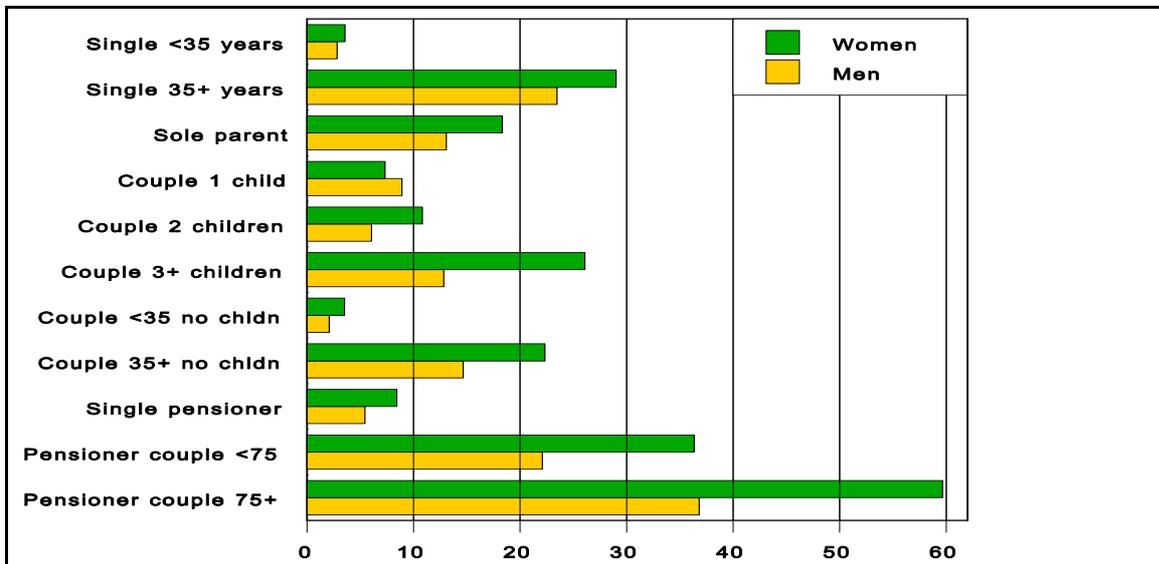
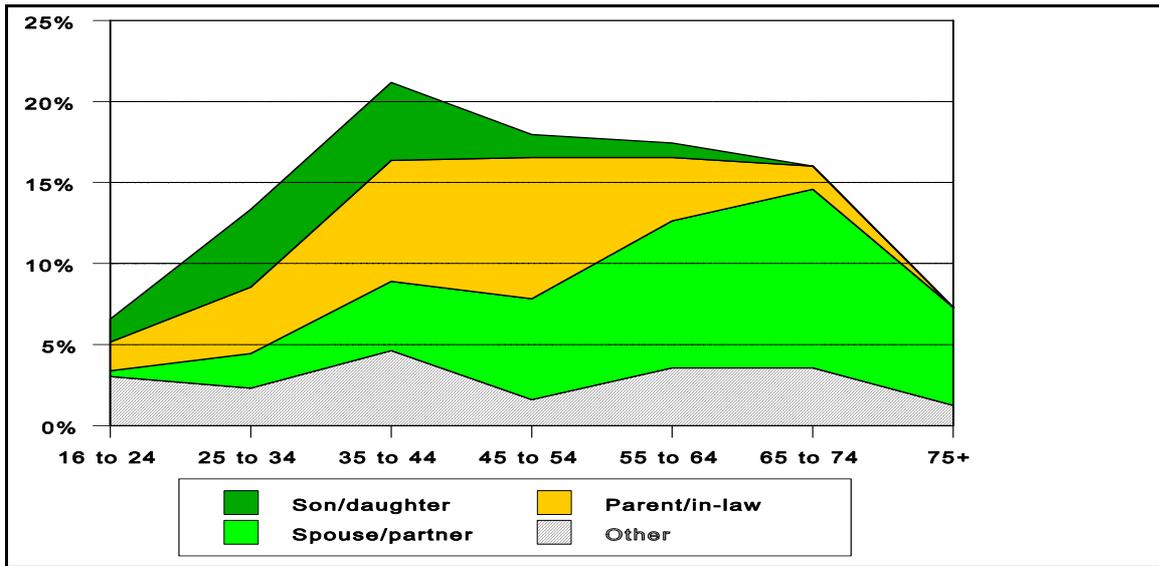
20 hours or more care per week	Local authority	Benefits Agency local office	General practice partnership	Medium-sized employer
Starting	3 300	1 200	60	9
Continuing	4 000	1 450	70	6
Ceasing	2 950	1 050	55	7
No. of adults (16 years or over)	250 000	90 000	4 500	1 000 (below pension age)

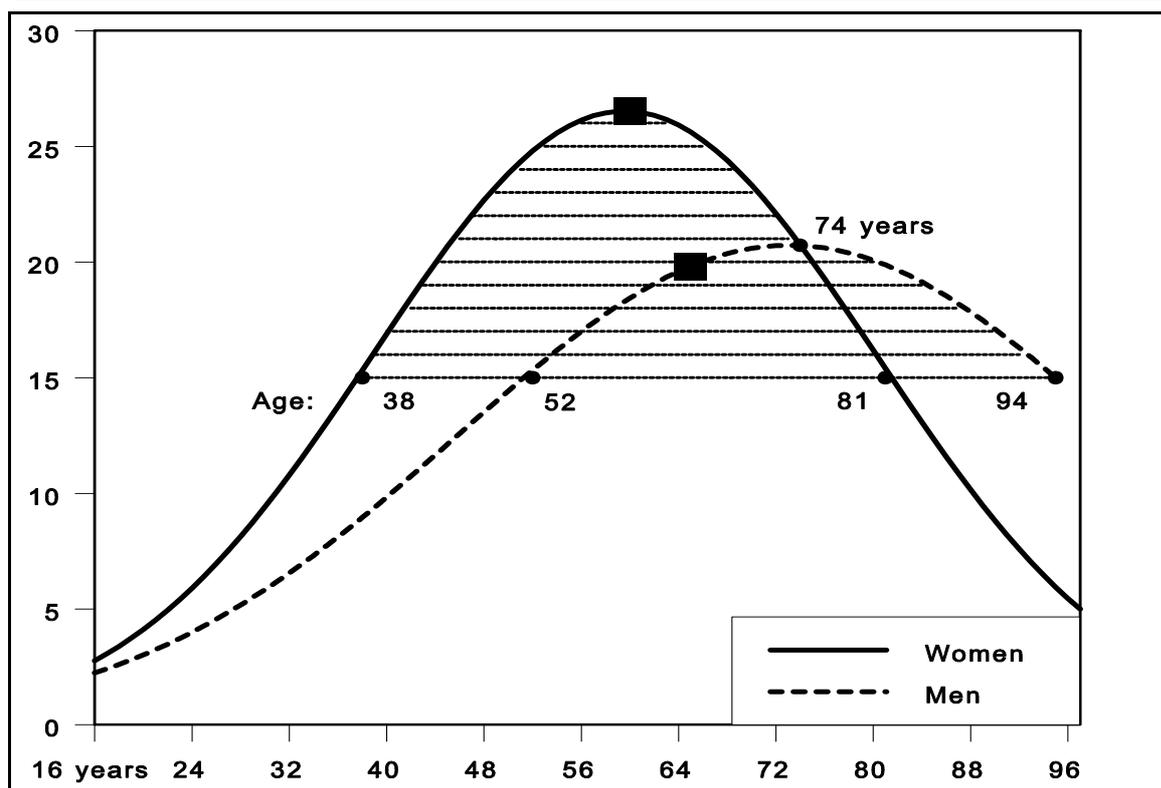
Informal care in the life course

Carers' circumstances are diverse because care-giving can arise at any point in the life course and interacts with household dynamics and family structures. Not surprisingly, caring for sick or disabled children commences mainly during the child-rearing years, before parents reach their mid-40s (Figure 2). The need to look after disabled or elderly parents occurs across a wider age span but starts mainly when carers are in their mid-30s to mid-50s. The likelihood of spouse care increases with age and predominates from the mid-50s onwards.

Care-giving therefore takes place alongside other family roles and its onset is related to stages of the life cycle. Figure 3 shows that the likelihood of becoming heavily involved in providing informal care is raised for larger families and lone parent families, older single people and couples above and just below pension age. Each year, for example, fewer than 5 per 1000 single people aged under 35 years start providing 20 hours or more care per week compared with 60 women per 1000 living in a pensioner couple where the head is aged 75 or over.

Overall, the likelihood of becoming a heavy care-giver peaks in late middle and early old age though above average rates (15 per 1000) span 40 years of adult life (Figure 4). The transition to heavy care-giving occurs later for men and those over 75 years are more likely than women to take on a caring role because more of them still have spouses who need care.





Age and sex differences also mediate the association between care-giving and employment. Paid work and informal care are virtually separate spheres of activity for men; those providing heavy care are mostly over pension age or otherwise out of the workforce. By comparison, women under pension age are better able to combine both roles: the fewer hours in paid employment the more care they provide.

Social class differences partly drive the demand for informal care and have important consequences for access to service support. The least advantaged face higher risks of poor health while households able to draw on material, financial and cultural resources are better placed to purchase and negotiate personal and social care services. As a consequence, manual occupational groups are more likely than non-manual classes to become informal carers and the odds increase systematically across the social gradient, more so for men. Non-manual men are much less likely than non-manual women to provide heavy care compared with their counterparts in the manual classes. Moreover, those who undertake informal care are more likely to be in households below the poverty line than those who do not.

Informal care, employment and income

It is widely known that those providing informal care are less likely than others to be in paid

work. Difficulty in combining paid work and informal care can immediately lower earnings, and can have long term effects through loss of pension rights. Conversely, paid work provides carers with income to help with the costs of care, and maintains social networks. (This work is reviewed in The Royal Commission on Long Term Care, 1999.)

Longitudinal analysis shows that, among those of working age, individuals who take on a caring role are less likely, than others, to be in paid work before informal care starts. People generally do not change their employment status on starting informal care: 83 per cent remain in the same status, whether paid work or not, as before care-giving started. Over half are in paid work before starting informal care and remain in paid work. Those in full-time work are less likely to change than those in part-time work.

As the episode of informal care lengthens or intensifies, those providing informal care increasingly withdraw from paid work compared with non-carers. After a third year of informal care, those offering 20 or more hours of care are significantly less likely to remain in paid work. Some carers spend long hours each day on informal care, paid work and travel to work. A quarter of people looking after someone in their own home spend 12 hours or more per day on these activities compared with seven per cent of non-carers. Because men are more likely to work full-time, 54 per cent of men compared with 39 per cent of women spend ten or more hours per day on paid work, travel and care.

If carers were in paid work before care-giving finished, they are much more likely to be in paid work after the end of the episode of care than otherwise. Providing more than 20 hours of care per week, however, means that people are much less likely to be in paid work after finishing informal care, and the effect endures and even increases slightly over the relatively short period covered by the data. The chances of being in paid work after finishing informal care are greater for women who work part-time and even greater for those in full-time work compared with those not in paid work while providing informal care.

Informal carers in paid work often experience poorer employment conditions than other employed people. Carers are also less likely to be employed in the private sector which generally pays higher wages. Part-time workers with co-resident care responsibilities are less likely to be

in permanent jobs or jobs with annual increments than others. As well as lower wage levels, such jobs are also less likely to provide satisfactory pensions.

Informal care has greatest impact on monthly labour market incomes which decline relative to similar non-carers for longer episodes of care, partly because of the kind of jobs carers have and their reduced working hours. In particular, after episodes of care lasting four to five years, and for those providing six or more years of care, the difference in income levels between carers and similar non-carers widens.

Personal and household income are less affected than labour market income because benefit and pension incomes contribute. Receipt of ICA increases with longer episodes of care but there is no clear trend over time for receipt of means-tested benefits to increase. This may relate to the greater likelihood of carers not to be in paid work when care starts and to be drawn from lower income groups. Some benefit provides compensation for the additional costs of a disabled person in the household, so although the household incomes of carers and non-carers appear similar, the living standards of the carer household would be reduced by the costs of the disability.

Receipt of pension income, both state and private, seems to increase for individuals providing care over three or four years. This relates to the age when the likelihood of providing informal care reaches its peak and to the possibility of choosing to provide care if pension income can substitute for employment income. Taking early retirement, however, in order to provide informal care could affect the level of pension received.

Longer and more recent periods of informal care have greatest impact on carers' incomes and there is little evidence that, in the relatively short time period available in the data, incomes catch up after finishing care. Benefit income for the care recipient and the carer can stop immediately the episode of care-giving ends.

Conclusion

Policy measures that respond to the diversity of caring roles will be most effective in supporting carers through changing circumstances. Moreover, policies to tackle poverty and social exclusion should encompass the particular disadvantages faced by those taking on a care-giving role.

Turnover among those providing informal care and their changing circumstances also have important implications for the responsiveness of the benefit system and support services. Longitudinal data enable us to focus on the changing population and lives of those providing informal care and research which aims to understand such changes would benefit a large section of the population over time.

A majority of people will provide informal care at some point in their lives. The onset of care-giving peaks in late middle and early old age as at this time of life there may be a need to provide care for parents, for disabled children, or for partners. This is the time when financial provision for old age is consolidated. As episodes of informal care lengthen, carers withdraw from paid work (particularly for episodes longer than two years) and they take some time to return to work after care-giving ends. Labour market income declines correspondingly although personal and household income are supported by benefit and pension incomes. However, benefit income is also intended to compensate for the costs of disability, and it does not fully compensate for loss of labour market income or pension contributions.

Those in manual social classes and pensioner couples on low incomes, often at poverty levels, are disproportionately likely to take on a caring role. A trend towards longer spells of more intensive care-giving means that those under pension age (mainly women) will find it increasingly difficult to regain the ground lost while providing care in terms of labour market participation and income.

Two issues are particularly important for developing benefits to support carers. The first is the time it takes for income to recover after the end of a caring episode; the second is the reduced access to good pension provision for those combining part-time work and informal care and for those who lose contact with the labour market during a spell of care-giving.

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INFORMAL CARERS COUNT

(Abridged version published with Hilary Arksey in *Nursing Standard*, **14**, 42 (2000) 33-34)

Nurses working in primary and community health care are potentially key actors in identifying informal carers, meeting their health needs and ensuring carers know of their rights to an assessment under the Carers Act (Box 1). This role is set to expand. The government's strategy *Caring about Carers* emphasises the importance of providing information to carers, supporting carers to care, and maintaining carers' health and well-being (DoH, 1999). It intends that carers become part of the health care agenda and, to this end, primary care teams and social services staff are expected to have systems in place for identifying carers by April this year (DoH, 1998).

Box 1 Informal carers

The term carer applies to those individuals who look after a relative or friend who needs personal help, practical assistance or watching over because of age, physical impairment, learning disability, or illness, including mental illness.

Although the term is generally applicable, there are wide variations in carers' responsibilities and activities. The experiences of carers of people with mental health problems differ from those looking after people with a physical impairment; caring for a disabled child is different again (Twigg and Atkin, 1994). Effective support requires an understanding of each carer's particular needs and circumstances and those of the person they look after, including their cultural and religious resources and language preferences (Katbamna *et al.*, 1998).

Young carers under the age of 18 present additional challenges for policy makers and service providers (Becker *et al.*, 1998).

Alongside these developments are recently issued quality standards for supporting carers at the local level including primary care (DoH, 2000). These include helping carers maintain their own health and social well-being through training, health promotion and other opportunities for personal development. In addition, the Carers and Disabled Children Bill will give carers new rights to assessment and service support independently of the person they look after.

Survey estimates indicate that a typical general practice or health clinic serving 4,500 adults, would expect to find about 650 carers of whom around 130 would be providing 20 hours or more informal care a week. This threshold is commonly adopted to identify those providing a substantial amount of care on a regular basis for the purposes of the 1995 Carers Act. Trends during the 1990s indicate that more carers are likely to be heavily involved in providing longer episodes of care.

At least 20 hours of care a week	Local Authority	Primary Care Group/Trust	GP practice	GP list
Starting	3000 to 3600	900 to 1070	54 to 64	18 to 21
Continuing	3700 to 4300	1110 to 1290	67 to 77	22 to 26
Ceasing	2600 to 3300	800 to 970	48 to 58	16 to 19
Number of adults (16 years or over)	250 000	75 000	4 500	1 500

However, the population of informal carers is changing constantly. Care-givers in any one year are not necessarily carers in the next, greatly complicating their recognition by service providers. More than 40 per cent of heavily involved carers (those providing at least 20 hours of care a week) change every year as individuals stop providing care and others take on a caring role or vary their level of involvement. Table 1 shows that health and social care professionals in a typical locality might expect to address the information and support needs of around 3000 new, heavily involved carers every year, that is 12 per working day on average. Carer turnover represents a major challenge to primary care teams aiming to identify informal carers and provide timely support appropriate to their changing needs.

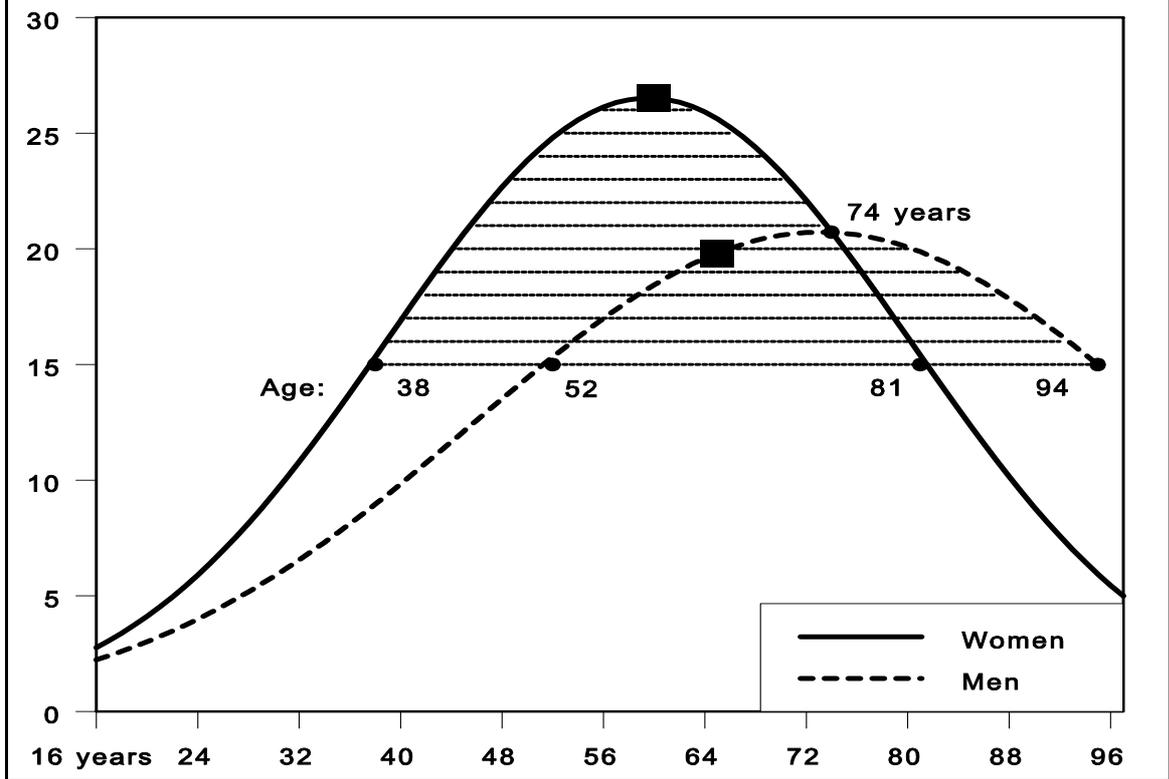
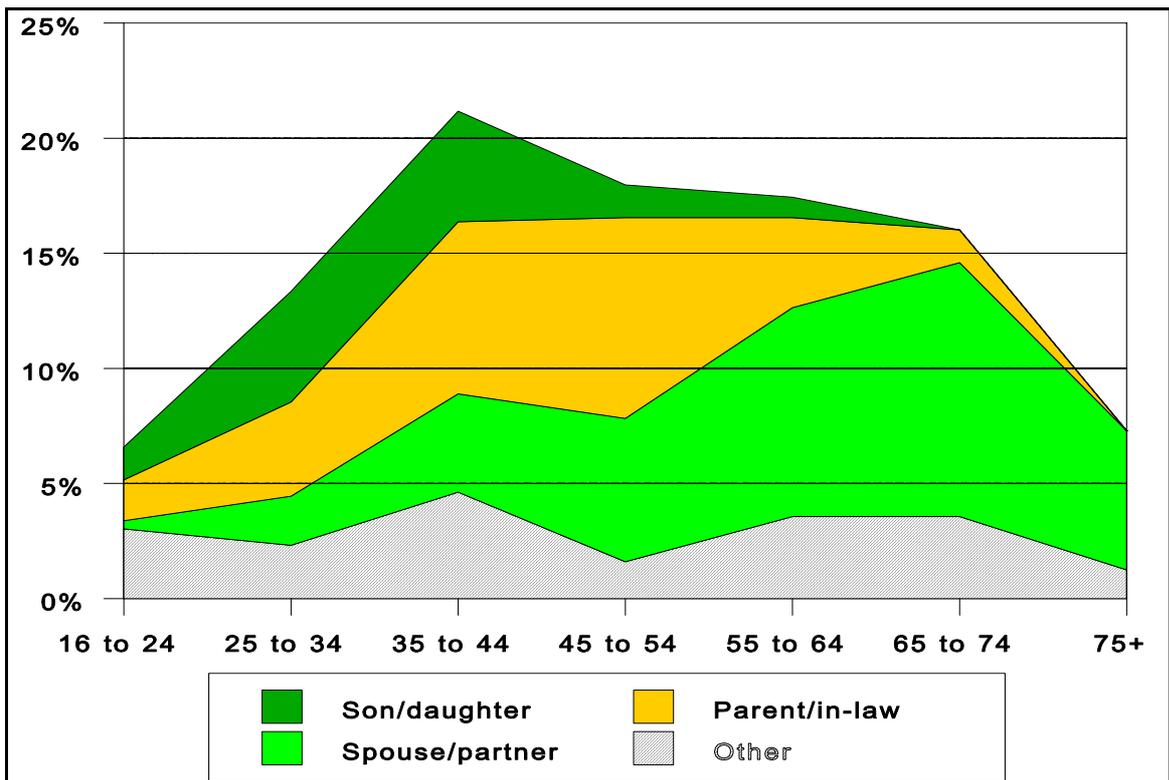
Cumulative risk in percent	Women's age	Men's age	All
20	39	47	43
30	48	55	50
40	54	64	57
50	59	74	66
60	68	84	75

The greater the turnover, the more individuals will be involved in care-giving over time. Indeed, the vast majority of people will provide informal care during their lifetime and Table 2 shows how the probability or risk of becoming a heavy carer accumulates. During a 75-year lifespan, six out of ten individuals are likely to assume heavy caring responsibilities at some point in their lives. There is a fifty-fifty chance of women becoming heavy carers at least once before reaching age 59; men must live 15 years longer on average to have an even chance of providing heavy care.

Carers' circumstances are extremely diverse because care-giving can arise at any point in the life course and interacts with household dynamics and family structures. However most care-giving is based on close personal relationships, often between generations, and these largely define the volume, pattern and timing of caring episodes. Most heavily involved carers are looking after a spouse or partner (39 per cent) followed by parents or parents-in-law (27 per cent) and children (14 per cent).

As might be expected, caring for sick or disabled children commences mainly during the child-rearing years, before parents reach their mid-40s (Figure 1). The need to look after disabled or elderly parents occurs across a wider age span but starts mainly when carers are in their mid-30s to mid-50s. The likelihood of spouse care increases with age and predominates from the mid-50s onwards.

The overall likelihood of becoming a heavy care-giver peaks in late middle and early old age although above average rates for taking on a caring role, over 15 per 1000 adults, span 40 years of adult life (Figure 2). The transition to heavy care-giving occurs later for men and those over 75 years are more likely than women to take on a caring role because more of them still have spouses who need care.



Caring episodes vary enormously in length from a few months to 30 years or more. Most last no more than five years although caring responsibilities in later life draw attention to the particular needs of long-term carers. Carers over 50, mostly women, may be looking after still dependent children, adult disabled children, or parents before the need arises to provide informal care for a spouse. Some carers will need support beyond the caring episode to resume their lives, especially when caring ends in the death of the cared-for person.

We know surprisingly little about how individuals come to define themselves as carers or what prompts them to seek help and access services. The reasons are complex and include severity of the care recipient's symptoms and changes in their condition, the impact on the carer's quality of life and relationships, other events in the carer's life, their health beliefs and expectations of health advice and care. Older carers in particular often have health problems of their own and a considerable body of research draws attention to the onset and maintenance of stress-related illnesses, physical injuries while caring, fatigue and other carer-related symptoms. Whatever the circumstances, the most important contact for many carers is with their GP, the district or community nurse, or another member of the primary care team (Henwood, 1998).

Identification of carers is the first step towards helping them and nurses can usefully take the initiative. Family carers often regard care-giving as part of their normal, everyday responsibilities and are likely to remain invisible unless encouraged to talk about their situation. Brainstorming with colleagues working in both the practice and the community can identify patients already known to have caring responsibilities or who are looked after by a relative or friend at home. A further approach is to ask about caring responsibilities when registering new patients or during routine consultations. Annual health checks of people over 75 years and special clinics provide opportunities for identifying particularly vulnerable groups of carers. Some practices distribute leaflets or letters with a tear-off slip for carers to return or ask patients to complete a short questionnaire which includes a question about caring responsibilities. Others have printed an invitation on prescriptions asking carers to identify themselves. The time is ripe for a trial of all these methods but once identified as a carer the patient's record can be tagged for follow-up and future reference.

Nurses are well-placed to take a lead supporting carers and home visits provide good opportunities for understanding the carer's circumstances. Supporting carers might include:

Health promotion

- enabling carers to maintain their own health and well-being.
- encouraging stress management and time off from care-giving.
- working in partnership with carers to maintain/improve the health of the care recipient.

Practical support

- offering training in lifting, mobility, basic nursing tasks and appropriate technical skills.
- following up after hospital discharge and re-evaluating care arrangements.

Emotional support

- counselling and listening to carers, helping them to acknowledge and deal with their feelings about care-giving.
- enabling carers to adjust when care-giving ends especially following admission to long-term care or bereavement.

Information and advice

- providing information, advice and advocacy, help with claiming welfare benefits, and signposting sources of information.
- ensure carers know of their rights to an assessment of their own needs under the Carers Act and the forthcoming Carers and Disabled Children Act.
- advising carers on what to do in case of an emergency and ensuring they know how to access NHS Direct.
- providing information, with permission, about the illness or impairment of the person cared for, and about their treatment and medication, including possible side-effects and changes in treatment.

Referral to other agencies

- enabling carers to access other health, housing and social care services, including carer support groups, services providing short breaks or long-term care, and local voluntary organisations.

On the face of it, supporting carers could have major resource and workload implications for primary care. However there is no evidence to warrant concerns about extra work or the fostering of unrealistic expectations. Many carers are already in contact with their GP and most simply want recognition of their role and the reassurance that there is someone to turn to who

understands their situation. Indeed, supporting carers through general practice could save time and money. Experience suggests that carers do not make unnecessary demands and anecdotal evidence points to fewer inappropriate enquiries, shorter consultation times and reduced prescription costs (Warner, 1999).

The adoption of carer development projects in general practices and health clinics is evolving rapidly and various approaches have been taken to identify and support carers (Carers National Association, 1998). Many projects involve partnership working between GP practices, health clinics and a local carers resource centre or similar organisation. Sometimes, these offer a fairly basic service such as providing information to staff, maintaining carers notice boards and encouraging referrals to local carers organisations. Some GPs have welcomed more active involvement.

Brent Carers Centre, jointly financed since 1993, has pioneered several primary care development projects. In one practice, the Centre funded a receptionist to identify carers when inviting patients to their over 75 health check. All carers were sent an information pack from the Centre and many received further help directly from one of its support workers or were referred to another agency. In another project, a carers linkworker received referrals from the GP, practice nurse or carers themselves. Carers were followed up by telephone and most attended a carers surgery held on practice premises by the linkworker to offer practical help, information and emotional support. In a third project, the linkworker worked closely with the primary care team to develop an overall strategy for identifying, supporting and involving carers. As well as following-up referrals and developing a carers group, the linkworker helps support, train and keep practice staff up-to-date with developments in carers' issues and concerns (Linyard, 1999; Warner, 1999). Health and social services authorities are increasingly sympathetic towards funding such posts.

<p>Box 2 Bolton Carers Health Partnership: four steps to carer-friendly practice</p> <p><i>Level One Acknowledging</i> The practice agrees to display information for carers in public waiting areas, in poster and leaflet form [43 per cent].</p> <p><i>Level Two Identifying</i> Level one involvement plus the practice agrees to identify carers, creating a carers</p>

register or tagging the patient's records [33 per cent].

Level Three Supporting

Levels one and two involvement plus the practice agrees to practically support a specific group of carers, for example those aged over 75 [14 per cent].

Level Four Including

Levels one to three involvement plus the practice team commits itself to a strategic look at how they can inform and support carers across the board. This will involve changes to existing systems, for example carer priority appointments, a carers surgery, or inviting carers to an annual health check [10 per cent].

A simple tool for monitoring the involvement of general practices has developed from a Carers Health Partnership funded by joint finance in Bolton. Four levels of increasing commitment to carer support are recognised and practices are monitored over time to capture new initiatives or record other changes (Box 2). The figures in brackets show the proportion of practices at each level in December 1999 following the first round of contacts with two-thirds of Bolton's GP practices by a carers linkworker.

Box 3 The Carers Compass - carers want:

- account
their own
1. To be fully informed
 2. To be recognised and have their own health and well-being taken into
 3. Quality services for the person cared for and for carers to have a life of
 4. Opportunities for a break from caring
 5. Emotional support
 6. Training and support to care
 7. Financial security
 8. Having a voice in service development and delivery

The Carers Compass, developed from the experience of 19 carers projects around the country, provides a comprehensive checklist for primary care teams to use in both audit and performance management (King's Fund 1998; Banks and Cheeseman 1999; Unell 1999). The compass points towards eight key outcomes that carers want (Box 3) and sets out the policies and practices which primary care staff need to develop to meet those outcomes.

Conclusion

State provision could never replace the contribution of family and friends to delivering care and since the early 1990s their particular needs have attracted greater priority. Informal carers count on moral, social and economic grounds and they are now increasingly recognised as essential

members of the health care team. Almost all carers would benefit from some help and support to enable them to continue providing care and sustain their other roles. Supporting informal carers is now high on the government's agenda for improving the nation's health and reducing health inequalities. Practice and community nurses are at the forefront of these changes. Having some identifiable strategy for working with carers matters more than what that strategy is.

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For further information:

www.carers.gov.uk

PART C

MISCELLANEOUS OUTPUT

PRESENTATIONS, SEMINARS AND RELATED OUTPUT

Sandra Hutton discussed the project with the Secretariat of the Royal Commission on Long-Term Care for the Elderly on 25 February 1998.

Michael Hirst gave a presentation on the project to the OSCA Workshop on 4 March 1998.

Michael Hirst gave a presentation on 'Outcome measurement' to a joint meeting of all research groups within the Social Policy Research Unit on 29 September 1998.

Sandra Hutton attended a meeting convened by the National Carers' Strategy Project on 6 October 1998 to review the research base.

Sandra Hutton, Michael Hirst, Dot Lawton and Julie Williams met with members of the National Carers' Strategy Project on 17 November 1998 and presented findings on informal care and paid employment and early findings were sent to them.

Sandra Hutton and Michael Hirst gave a seminar on 'Outcomes of informal care' at the ESRC Research Centre on Micro-Social Change at the University of Essex on 30 November 1998.

'Are informal carers a moving target?' by Michael Hirst was published in *Social Care Outcomes*, the newsletter of the OSCA programme, April 1999.

Michael Hirst gave a presentation to the Department of Health Review team on the occasion of its site visit to the Social Policy Research Unit, 5 May 1999.

Michael Hirst gave a presentation on 'The changing population of carers' to a joint meeting of all research groups within the Social Policy Research Unit on 23 November 1999.

Sandra Hutton gave a presentation on the project to the OSCA Workshop on 24 November 1999.

Reports prepared for the National Carers' Strategy Project

Note on the relationship between employment status and the time spent in informal care
(DH 1575 10.98) Sandra Hutton

Note on episodes of informal care in the life course and the effects on employment: Information from the Family and Working Lives Survey (FWLS)
(DH 1609 12.98) Sandra Hutton and Julie Williams

Poverty over time for those recorded as informal carers in the British Household Panel Study
(DH 1610 12.98) Sandra Hutton

The characteristics of economically inactive carers
(DH 1611 12.98) Dot Lawton

LIST OF WORKING PAPERS RELATED TO THE OSCA PROJECT

DH 1555 4.98 MH	Family carers - a moving target?
DH 1563 9.98 MH	The health of informal carers: A longitudinal analysis
DH 1575 10.98 SH	Note on the relationship between employment status and the

	time spent in informal care
DH 1599 12.98 SH	Effect of episodes of informal care on income: A longitudinal study
DH 1609 12.98 SH/JW	Note on episodes of informal care in the life course and the effects on employment: Information from the Family and Working Lives Survey (FWLS)
DH 1610 12.98 SH	Poverty over time for those recorded as informal carers in the British Household Panel Study
DH 1611 12.98 DL	Characteristics of economically inactive carers
DH 1633 3.99 MH	Informal care in the life course
DH 1670 6.99 MH	Recent trends in informal care
DH 1680 8.99 MH	The risk of informal care: An incidence study
DH 1684 8.99 SH	The employment of those undertaking informal care: A longitudinal analysis
DH 1688 9.99 SH	Health and social care services used by people providing informal care
DH 1697 10.99 MH/SH/DL	Evaluation of currently available national survey data for monitoring outcomes of informal care
DH 1731 5.00 MH	Informal care in ethnic minorities
DH 1745 7.00 SH/JW	Pension arrangements and informal care