
Health Inequalities and Informal Care: End of Project Report

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The views expressed are those of the author and are not necessarily shared by any individual, government department or agency.

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Summary

This report describes research that set out to measure, monitor and evaluate health inequalities associated with the provision of unpaid care. It outlines the scope and design of the project and presents the key findings.

The adverse health effects of caring are primarily psychological and often manifest themselves as symptoms of anxiety, depression and social dysfunction. Caring-related inequalities in psychological well-being are quantifiable and significant; they are most pronounced at key turning points in the caring trajectory and in the more demanding care situations. Caregiving is associated with an increased risk of both onset and recurrent distress, and legacies of poor health persist beyond the end of caregiving.

An increased risk of mental and psychological distress attributable to caring activities affects a substantial minority of carers who provide long hours of care over extended spells. Carers who provide at least 20 hours care per week are often at greatest risk of poor health and adverse health changes because of their caring responsibilities. Overall, women face greater risk of psychological distress because of their caring responsibilities than men in comparable care situations. Caring for a spouse or partner is particularly associated with additional health problems beyond those that might be attributable to other determinants of health. Caring-related inequalities in psychological distress did not diminish during the 1990s indicating that the evidence for addressing carers' health needs is as compelling as it ever was.

Taken together, the findings begin to validate caregiving as an underlying social determinant in the creation of health inequalities, and help to identify the circumstances in which caregiving might be an important variable in epidemiological analysis. A final section considers implications for policy and practice towards carers and concludes by suggesting that caregiving should be recognised by policy makers, service planners and practitioners as a public health issue and become part of the health inequalities agenda.

List of abbreviations

BHPS	British Household Panel Survey
DH	Department of Health
GHQ	General Health Questionnaire (Goldberg and Williams, 1991)
GP	General (Medical) Practitioner
HMSO	Her Majesty's Stationery Office
NHS	National Health Service
ONS	Office for National Statistics
SF36	Short-Form 36 Health Survey Questionnaire (Jenkinson <i>et al.</i> , 1996)
SPRU	Social Policy Research Unit

1 Introduction

Following a competitive bid, the Social Policy Research Unit (SPRU) was commissioned by the Department of Health (DH) to carry out research on Health Inequalities and Informal Care. This was one of nine projects funded under phase two of a research initiative on inequalities in health. The project commenced in October 2001.

This report provides an overview of the project, summarises the key findings, and discusses the implications and recommendations arising from the research. The purpose of this chapter is to outline the context of the study, drawing attention to some of the issues that informed the research and its relevance for policy and practice.

1.1 The value of unpaid care

The contribution of unpaid carers is hugely important and support for their caring responsibilities is high on the government's health and social care agenda:

- Most disabled and elderly people live in private households and the support they receive in the community is almost wholly provided by family, friends or neighbours (Grundy *et al.*, 1999; Thompson and Hirst, 1994).
- There are an estimated 6.8 million adults providing unpaid care for disabled and elderly people in Britain according to the 2000 General Household Survey, including over 1.7 million who provide 20 hours or more care per week (Mayer and Green, 2002).
- Around three out of four adults look after a disabled or elderly relative inside their own household at one time or another and over half are likely to provide at least 20 hours care per week at some point in their adult lives (Disney *et al.*, 1997; Hirst, 2002).
- The cost of replacing unpaid care by formal service provision is variously estimated to lie between £34 billion and £57 billion per year (Carers UK, 2002; Nuttall *et al.*, 1994).
- Since the 1980s, successive governments have increasingly recognised that community health and social care services would struggle to cope without the contribution of unpaid carers. Service developments, social security provision and professional responses to support carers are regarded as a necessary and cost-effective strategy for sustaining care in the community (DH, 1990).

1.2 Policy towards carers

Current policy thinking aims to support carers in their caring role and enable them to continue caring for as long as they wish to do so (DH, 1999a). The government's national strategy for carers sets out a package of measures to meet carers' needs for information, support, and help in maintaining their own health. These include:

- Health and social care professionals working together to support carers in their caring responsibilities.
- Ring-fenced grants for local authorities to develop the range and quality of services for giving carers a break from caring.
- Opportunities for training, personal development, and reducing social isolation, including measures enabling carers to retain or take up paid employment.
- New legislation, the 2000 Carers and Disabled Children Act, to give carers a right to assessment of their own needs and service support independently of the person they look after (DH, 2001a).

Improving support for carers also forms part of the government's wider agenda for modernising health and social services, and implementing the NHS plan (DH, 1997, 1998, 2000a). The national service frameworks for older people and mental health recognise the importance of meeting carers' needs and supporting them in their caring role (DH, 1999b, 2001b). The experiences of carers have also informed the development of the proposed National Service Framework for Long Term Conditions (Harris, 2003). In addition, providing emotional support and promoting carers' own health are incorporated in quality standards for developing and monitoring local carer support services (DH, 2000b).

Driving current policy interest in supporting the caring responsibilities of individuals and families is the need to plan for an increasing number of elderly people who will require health and social care (Pickard *et al.*, 2000). The bulk of that care is provided by spouses, partners and adult children (Maher and Green, 2002).

1.3 Health effects of caring

In recent years, the literature on unpaid care has increasingly drawn attention to the rewards and satisfactions of looking after family, partners or friends who need help and support because they are disabled, ill or frail (Nolan *et al.*, 1996, p. 82). It is important to highlight the positive aspects of caregiving, not only to gain a balanced understanding of caring relationships but also to appreciate the types and sources of satisfaction that can sustain carers in their caring role.

However, there is a wealth of studies which show that providing unpaid care for disabled and older people is associated with increased rates of psychological

distress, including symptoms of anxiety and depression (Schulz *et al.*, 1990, 1995). There are also carers' own reports of caregiving adversely affecting their emotional well-being and social functioning, as well as evidence of psychiatric illness and compromised immune response in those who feel burdened by their caring responsibilities (Kiecolt-Glaser *et al.*, 1991; Mayer and Green, 2002; Singleton *et al.*, 2002). Studies comparing the physical health of carers and non-carers are less conclusive although some carers face particular risks of injury associated with their caring activities, and emotional distress associated with caregiving may increase susceptibility to physical illness (Brown and Mulley, 1997; Dyck *et al.*, 1999). Care-giving may also be an independent risk factor for mortality (Schulz and Beach, 1999).

A multitude of stressors are associated with caregiving (Nolan *et al.*, 1996; Schulz *et al.*, 1995). These may be physical (e.g. sleep disturbance, fatigue, back injury), emotional (e.g. absence of rewards in providing care, quality or history of relationship with the cared-for person, guilt), social (e.g. motivations to care, marital or family conflict, isolation, lack of support), or economic (e.g. loss of income from giving up paid work, costs of caregiving). Aspects associated with the illness or impairment of the cared-for person may also be stressful for the carer (e.g. challenging behaviour, incontinence, cognitive impairment, uncertainty about prognosis).

Despite the body of research evidence that unpaid care is associated with adverse health effects, critical appraisals of the literature have highlighted methodological weaknesses in studies that attempt to quantify the health impacts of caregiving. These limitations include small, unrepresentative or non-probability samples, absence of comparison groups, inappropriate research designs, uncontrolled confounding effects, and inadequate health measures (Baumgarten, 1989; Burton *et al.*, 2003; Schulz *et al.*, 1990, 1995; Taylor *et al.*, 1995). Consequently, reliable findings that can be applied at the population level are relatively scarce.

The resulting uncertainty is clearly expressed in the government's strategy for carers:

'... the evidence on whether carers suffer disproportionately more health problems than other people of the same age is not conclusive.'
(DH, 1999a, p. 55)

Such uncertainty may have influenced thinking in other policy domains; for example, the potential effects of caring on health are not considered in the government's health inequalities agenda (DH, 1999c) though since this project began, caregiving has been identified as a risk factor for women's mental health (DH, 2002, p. 17).

The present study sought to overcome many of the criticisms made of previous research, and aims to extend knowledge of the health effects of caregiving by using a population-based design, longitudinal techniques, and robust health measures (see further Section 2).

1.4 Justification for the study

Although support for carers is high on the government's health and social care agenda, and enabling them to maintain their own health is a key element of it's strategy towards carers, can another study of carers' health be justified?

Some commentators have questioned the value of maintaining a focus on carer burden and carer stress, criticising that approach for pathologising the caring relationship and ignoring how people cope with their caring responsibilities (Twigg and Atkin, 1994, p. 5; Zarit, 1989). A more useful approach, it is argued, is to concentrate on what helps carers sustain their caring role, and to identify the factors that reduce the stress of caregiving (Parker, 1992; Twigg and Atkin, 1994). To develop effective support, we need to know what interventions prevent, alleviate or remedy stress in particular care situations.

Research conducted within the stress-coping paradigm indicates that how people appraise stressors is key to understanding carer distress and developing appropriate policy responses (Aneshensel *et al.*, 1995; Nolan *et al.*, 1996). Carer distress is viewed as an outcome of how carers deal with and adjust to the caregiving situation, the physical, social and emotional resources available to them including support from family and friends, and the coping strategies they deploy. An important implication is that carer distress is neither a necessary nor inevitable consequence of caregiving, and could be prevented or ameliorated through appropriate interventions.

Understanding more about the health risks faced by carers is important for several reasons. On grounds of fairness or social justice, it matters whether carer distress provides evidence of inequalities in health and access to or unmet need for health and social care services. Caring-related inequalities in health may be unfair or unjust where the decision to provide unpaid care is not freely chosen, or the circumstances under which care is provided, including the prevailing social and political environment and local service provision, limit or prevent healthy outcomes for carers.

Clearly, carers have the same entitlement to health care as other citizens. That some groups of carers are drawn disproportionately from the manual social classes (and therefore have fewer economic, social or material resources) suggests that care-giving often arises out of constrained choices and unfair circumstances (Arber and Ginn, 1992, 1993; Glaser and Grundy, 2002). Indeed, poor health may be a selection factor for taking on a caring role (Parker and Lawton, 1994, p. 46). In addition, the limited service response to heavily involved carers, including spouse carers, may not be appropriate, and the experiences of minority ethnic carers points to inequities in service and practitioner responses to their particular needs (Katbamna *et al.*, 1997, 1998, 2002; Parker, 1993; Parker and Lawton, 1994). For these sorts of reasons,

inequalities in health associated with caregiving are probably unfair and warrant further study.

Quantitative research on carers' health at the population level is required for developing and implementing policy towards carers. Policy makers and service planners require estimates not only of the population of carers but also of how many experience poor health and caring-related health problems. National estimates are required for reviewing policy measures and monitoring service improvements. Understanding which caring roles are associated with poor health would strengthen the evidence base and help target those carers at greatest risk.

Maintaining the health of carers is also important in supporting the people they care for and maintaining the quality of care relationships. Coping with the demands of care, and a willingness to continue caring, are both associated with lower levels of stress in carers (McKee *et al.*, 1999). Equally, carer ill health or distress is often an important contributory factor in older people's use of health services including: admission to, delayed discharge from, or unplanned readmission to hospital; referral to a day hospital or geriatric unit; and admission to residential care or nursing homes (Armstrong, 2000; Bannister *et al.*, 1998; Liston *et al.*, 1995; Morris *et al.*, 1988; Nolan and Dellasega, 2000; Pearson *et al.*, 2002; Williams and Fitton, 1988, 1991). Key turning points in the caring role, including the transition of disabled young people from childhood to adult life, hospital discharge, or the death of the cared-for person, can also have an adverse impact on carers' health (Bass and Bowman, 1990; Given *et al.*, 1999; Heaton *et al.*, 1999; Hirst, 1985). Distressed carers, and those who feel unable to cope, often have unmet service needs and may elicit support from formal community provision, including services for carers to take a break from caring (Kersten *et al.*, 2001; Morris *et al.*, 1988). Poor health in the carer population can therefore have important implications for service planning in the formal health and social care sectors.

We do not have a well-based understanding of:

- How many carers present health problems arising from their caring activities?
- Which carers are most at risk of poor health and adverse health changes?
- How big is the risk for adverse health effects associated with caring?
- What kinds of health problems are most likely to be associated with a caring role?
- Are health inequalities related to the onset, intensity, and duration of caring activities?
- How do health inequalities change during the course of a caring episode?
- Have health inequalities associated with caregiving widened, narrowed, or remained constant in recent years?
- Are health inequalities related to former episodes of caregiving?

Answers to questions like this could help create a framework for more appropriate service responses to the support needs of carers. As well as policy towards carers and the health inequalities agenda, the study is also relevant to:

- The role of primary care trusts in primary care development by including carers explicitly in plans to extend the range of services, improve access to services, enhance the capacity of the workforce, implement health improvement initiatives, and build operational partnerships with local social services authorities.
- The role of GPs and the primary care team in identifying carers, supporting them in their caring activities, monitoring their health, and referring them for a social services assessment.
- Improvements in mental health care services around the needs and preferences of different population groups, including carers and former carers.

These policy domains are informed by the findings of a major survey on the mental health of carers, which was published by the Office for National Statistics (ONS) during the course of this research (Singleton *et al.*, 2002). The ONS study interviewed carers identified in the 2000 General Household Survey (Maher and Green, 2002). Its main purpose was to estimate the prevalence of common mental disorders among adults who were providing unpaid care in England in 2001. It also considers the impact of caring responsibilities on carers' health and the support they receive for maintaining their mental and emotional well-being. The present study complements the ONS study in two important respects. Firstly, it examines trends in carers' psychological well-being throughout the 1990s and relates changes in their health to transitions into and out of care (Section 2.4). Secondly, it includes a matched comparison group of non-carers for estimating the extent of health inequalities associated with variations in the caregiving role (Section 2.6).

1.5 Aims of the study

The broad objective is to provide a quantitative framework at the population level for measuring and monitoring health inequalities between carers and non-carers over time. Specifically, the research aims to:

- Examine inequalities in carers' health before, during and after spells of caregiving. As well as comparing carers and like non-carers, the analysis differentiates carers by their relationship to the cared-for person, the intensity of caregiving, and whether caregiving takes place within or between households.
- Investigate the cumulative impact of caregiving on health inequalities by relating health variations in carers and former carers to the timing, duration and intensity of current and former caregiving episodes.
- Quantify the extent to which providing unpaid care is associated with the onset of or delayed recovery from the most common mental health problems, namely

anxiety and depression, identifying those carers at greatest risk of mental health problems, and providing population estimates.

- Estimate the use of GP services associated with caring-related inequalities, and the impact on GP consultation rates of taking on a caregiving role.
- Chart trends in carers' health and their use of GP services during the 1990s. The aim here is to understand better how recent trends have evolved and anticipate the future impact of changes in patterns of caregiving, especially the growth of elderly spouse care and the care of elderly parents.

The study also provides baseline data at the national level against which to monitor the impact of recent and emerging policy initiatives on maintaining carers' health and reducing health inequalities. From the policy-maker's perspective, the findings are relevant to the Strategy for Carers, National Service Frameworks, Health Improvement Programmes, Health Inequalities Agenda, and partnerships between primary health and social care.

1.6 Structure of this report

The purpose of this report is to summarise the key findings from the study and outline the implications for policy and practice. It draws on seven research reports that were published as the study progressed. These reports, which are summarised in an Appendix, provide a much fuller account of the research design and data analyses. The conclusions presented here draw on that more detailed evidence base. The remainder of this report is set out as follows:

- The next chapter describes the study design drawing particular attention to how the carer's situation is defined, the health measures used, and the interpretation of caring-related health inequalities.
- Chapter 3 provides an overview of the key findings from the research focusing on the nature, extent, timing and persistence of caring-related health inequalities.
- The fourth chapter presents the implications for policy and practice towards carers and the evaluation of health outcomes in carers.

2 Study design

This chapter discusses some of the methodological issues that should be borne in mind when assessing the validity of the findings from this study and the confidence that can be placed in them. Some readers may prefer to skip directly to the findings presented in the next chapter.

2.1 Data source

This study uses data from the British Household Panel Survey (BHPS) covering the years 1991 to 2000. The BHPS is the only longitudinal survey of the population in Britain that follows individuals in all age groups over time by repeated monitoring of their personal circumstances and household characteristics. It is ideally suited for investigating health inequalities associated with the provision of unpaid care. The advantages of the BHPS for the present study can be summarised under four headings: representativeness of the sample, identification of carers, temporal perspectives on caregiving, and validity of health measures. Each is discussed in turn before considering the study's approach to measuring and assessing health inequalities associated with caregiving.

2.2 Representativeness

The first wave of the BHPS was designed as a large-scale, general-purpose survey of the population of England, Scotland and Wales living in a representative sample of around 5,000 private households in 1991. The sample has been augmented each year since then (including for example adults who join the households of existing panel members) to ensure that it remains broadly representative of the non-institutional population as it changes over time (Buck *et al.*, 2002).

Thus, the BHPS provides representative samples of carers and non-carers and, within the usual margin of error in such surveys, the findings are generalisable to the carer population. This is an important advance on most studies of the health effects of caring that have relied on samples of carers in contact with particular services or support groups, identified through self-referral, or caring for people with particular conditions (Baumgarten, 1989; Schulz *et al.*, 1990, 1995; Taylor *et al.*, 1995). In contrast to those recruitment methods, the BHPS sample is unlikely to be biased towards carers who are distressed or who present poor health, making it possible to quantify the association between health and caregiving at the population level.

2.3 Identification of carers

The standard survey approach to measuring unpaid care is to ask respondents to identify themselves as carers and then follow up with questions about their caring responsibilities. The BHPS questions are modelled on those developed for the General Household Survey, which is considered the gold standard for gathering information on this topic (ONS, 1998). As well as identifying respondents who provide care, these questions distinguish key sub-groups of carers that previous research has found to be associated with important variations in the impact of caring (Parker, 1992). It is recognised however, that reliance on self-report may underestimate the true extent of unpaid care because some carers, especially those looking after a spouse or child, do not readily identify themselves as such because they regard care-giving as part of their normal everyday activities, as simply fulfilling family obligations (Parker, 1993).

Caregiving is defined in the BHPS as looking after, giving special help, or providing some regular service that is not provided in the course of paid employment, to someone who is sick, elderly or disabled. This definition includes carers who look after clients of voluntary organisations but these carers are excluded here because what motivates them to care, and the choices available to them, are quite distinct from those of family members and friends who take on caring responsibilities (Leat, 1992).

Every adult aged over 16 years in the BHPS sample is asked personally about the provision of unpaid care. Thus, carers and non-carers are individually identified and the composition of the carer population at each wave is readily determined. By linking respondents across successive waves and comparing their responses to the questions on caregiving over time, it is possible to identify would-be carers (non-carers who provide unpaid care at the next wave) and former carers (non-carers who looked after someone at the previous wave). Care provided by children and young people is not recorded in the BHPS.

Sub-groups of adult carers are distinguished according to:

- **Locus of care**, which distinguishes between co-resident carers who live in the same household as the cared-for person and extra-resident carers who look after someone living in a different household.
- **Care relationship** describes the relationship of the cared-for person to the carer. The analysis focuses on three co-resident relationships (caring for a spouse or partner, parent or parent-in-law, and son or daughter) and three extra-resident relationships (caring for a parent or parent-in-law, other relative, and friend or neighbour). Other relationships are identified but the numbers are too small for separate analysis.

- **Time devoted to caring activity** records the number of hours per week that carers spend helping the person they look after.

These aspects of the caregiving situation are closely linked and, in the absence of information on caring activities and detailed knowledge of the carer's role and responsibilities, provide useful proxies for some of the factors that are likely to be associated with adverse effects on carers' health. Thus, locus of care largely reflects the intensity of caregiving demands and the closeness of caring relationships. Co-resident carers often provide the more demanding forms of physical and personal care (bathing, dressing or using the toilet, for example), and help with mobility. Out-of-household care is generally less intensive, concentrating on the provision of practical help such as housework, shopping or collecting prescriptions rather than intimate or personal care (Parker and Lawton, 1994). Co-resident carers are more likely to be sole carers and least likely to be receiving any service support (Parker, 1992). Moreover, caregiving within households is usually based on close kinship ties that are associated with intimacy, emotional commitment, and a sense of duty or obligation (Twigg and Atkin, 1994).

Counting the number of care hours is a way of measuring carers' involvement in caring activities or the intensity of caregiving. This measure has assumed considerable importance in identifying those who provide care in the more demanding situations and assessing their support needs (Bytheway and Johnson, 1998; Social Services Inspectorate, 1996). Support for its validity comes from an association between decreases in paid work hours around the start of caregiving and increasing care hours in midlife women (Spiess and Schneider, 2003). The number of hours devoted to caregiving may also represent self-perceived burden or strain.

2.4 Temporal perspectives on caregiving

The longitudinal design of the BHPS enables investigation of the association between health and caregiving over time. Temporal perspectives are important for both practical and methodological reasons. At the practical level, a temporal understanding of caregiving can have implications for targeting appropriate interventions by focusing attention on the considerable changes that carers typically experience in terms of their support needs, coping resources, choices, and strategies for sustaining their caring role (Aneshensel *et al.*, 1995). At the methodological level, longitudinal analysis is required to gather robust evidence of a genuine association between health and caring, and point to underlying causal pathways (Burton *et al.*, 2003). A key advantage of the BHPS is that it enables the health effects of caring to be investigated prospectively: representative samples of non-carers can be followed until those who become caregivers are compared with those who do not take on a caring role. Thus, common baseline measures can be established before caregiving

starts. A longitudinal design can also help to distinguish between transient health problems and unremitting symptoms.

In this study, the health effects of caregiving over time are assessed in three ways:

- First, **health changes** are assessed as individuals take on a caring role, as their care episodes lengthen, and when they cease providing care.
- Secondly, **health outcomes** in late 1999 are related to the experience of caregiving during the previous nine years.
- Thirdly, **health trends** in the carer population are monitored from 1991 to 2000.

As well as investigating the health effects of transitions into and out of a caring role, the impact on health of the duration of care episodes, level of involvement in caregiving over time, and changes in hours spent caring are also explored.

2.5 Health measures

The BHPS includes two, well-attested health measures that provide valid and reliable assessments of the health of a wide variety of patient groups and general population samples:

- The *Short-Form 36* health status questionnaire (SF36, UK version 1) measures general aspects of health that are considered important by most people. It asks whether, and to what extent, everyday activities and behaviours are adversely affected by illness and impairment, and covers eight health domains. These include physical functioning, health limitations affecting usual role, emotional and mental health, energy or fatigue, and an overall evaluation of health status (Jenkinson *et al.*, 1996).
- The *General Health Questionnaire* (GHQ) measures the prevalence and severity of psychological distress by asking respondents about their recent experience of symptoms known to be indicative of anxiety and depression, social dysfunction, loss of confidence and self-esteem (Goldberg and Williams, 1991). Because the GHQ covers a wide range of symptoms, it is considered more appropriate for measuring the mental health of carers than instruments for detecting depression alone (Pot *et al.*, 1997).

Both health measures are administered independently of the questions on unpaid care in the BHPS; the GHQ forms part of a self-completion module.

2.6 Caring-related health inequalities

The term health inequality is used to designate variations, differences or disparities in health between individuals and groups (Kawachi *et al.*, 2002). The aim of this study is

to measure differences in health between carers and non-carers and to assess whether, and to what extent, those differences can be attributed to the caregiving role. This approach assumes that health differences between carers and non-carers are not attributable to other factors that are themselves associated with health and caregiving.

The difficulty here is that carers and non-carers often differ in other ways that can affect their health. Carers are generally older for example, and more likely to have characteristics associated with the social determinants of poor health (e.g. out of paid work; financial strain). Men and women often differ in the way they present ill-health and are likely to respond in different ways to the stresses of providing care (MacIntyre *et al.*, 1996; Yee and Schulz, 2000). Thus, differences between carers and non-carers in the proportions of women, of those in older age groups or in paid employment, would produce health inequalities that are not necessarily related to the caring role.

To compare the health of carers with that of non-carers in similar circumstances and with like characteristics, differences between them are controlled in the analysis. In effect, comparisons are drawn between carers and non-carers with 'average' social, economic, demographic and other characteristics. Health differences that remain after taking account of age and other social determinants of health can then be interpreted as ***caring-related inequalities***. Thus, caring-related inequalities refer to the additional health problems that carers present compared with like non-carers, and may be attributable to their caring responsibilities.

It is not possible to infer that health differences between matched groups of carers and non-carers are caused by caregiving because the comparisons between them rely on statistical measures of association or correlation. Nor is it possible to identify those aspects of the caring role or the care situation that actually cause health inequalities. The question of probable causality, which would require an experimental design rather than a prospective observational study, is not addressed directly in this research.

It is further acknowledged that structured questions in large-scale surveys like the BHPS are rather blunt instruments for understanding the diverse impacts of caregiving. However, support for the quantitative analysis of broad survey categories comes from qualitative research and case studies (e.g. Aneshensel *et al.*, 1995; Jenkinson, 2003; Leat, 1992; Parker, 1993; Twigg, 1992; Twigg and Atkin, 1994). These studies confirm that caregiving is a valid construct that may influence health outcomes and thus necessitate carer-specific interventions. They further indicate that locus of care, hours spent caring and relationship to the carer, differentiate the carer population in ways that are associated with some of the factors affecting the health of carers (e.g. the intensity of care, emotional involvement with the cared-for person, social isolation).

Whilst recognising that the findings from this study cannot define or explain the causal pathways between caregiving and carers' health, additional criteria were considered to ensure that the identification of caring-related health inequalities would support a causal interpretation (Twisk, 2003, p. 2). Briefly, these criteria include:

- Temporal relation between health inequalities and caregiving.
Prospective longitudinal analysis allows health status (and potential confounding variables) to be assessed before taking on a caring role, reducing the possibility of bias in the identification of carers and non-carers, establishing the temporal order of an effect, and providing an important indication of causality. Thus, the existence of a causal pathway would be indicated by wider health inequalities following the transition into a caring role (Burton *et al.*, 2003).
- A progressive relation between health inequalities and involvement in a caregiving.
One would expect health inequalities to widen with the amount of time spent on caring activities, with increases in the time devoted to caregiving, and with the duration of care episodes. Associations like this are called dose-response relationships between they describe a progressive relation between the intensity of care provision and increased health risk (O'Reilly *et al.*, 1996).
- Sub-group differences in caring-related health inequalities.
Carers are a diverse group of people, care situations are extremely varied, and the demands of the caregiving role vary considerably (Atkin, 1992; Parker and Lawton, 1994). Consequently, one would expect caring-related health inequalities and the risk of adverse health changes to vary between carer sub-groups differentiated, for example, according to the amount of time spent on caring activities or emotional involvement with the cared-for person.
- Specific health domains.
As noted in Section 1.3, reviews of the literature draw attention to evidence linking caregiving and psychological distress; effects on physical health are elusive. The strength of association between health inequalities and caregiving was therefore expected to vary across health domains with greater risk for carers' mental and psychological health.
- Strength of association.
In general, the stronger the association between health inequalities and caregiving, the more confidence one has inferring an underlying causal link and discounting alternative explanations or bias in the research design. Although the clinical significance of associations between caregiving and health is beyond this analysis, the strength of association can be compared with that of other factors that are more widely recognised as underlying social determinants of health inequalities.

2.7 Conclusions

The BHPS provides a rich source of data and analysis for understanding the association between health inequalities and the provision of unpaid care. The study design overcomes many of the uncertainties about detecting the effects of caring on health identified in previous research, and provides more robust evidence than is currently available for policy and service planning at the population level.

3 Summary of key findings

The purpose of this chapter is to provide an overview of the study's findings. These are distilled from the detailed analyses and results presented in the individual research reports and summarised in the Appendix. Here the findings are brought together and organised around key questions addressed by the research. The chapter concludes by considering needs and priorities for further research.

3.1 Key findings

3.1.1 Caring-related health domains

The study indicates that caregiving is most likely to be associated with inequalities in mental and emotional health. These findings are consistent with the literature briefly reviewed in Section 1.3, which shows that carers are more likely than non-carers to report psychological symptoms of stress and minor psychiatric morbidity (anxiety, depression, sleeplessness, for example). Although other health domains are associated with caregiving to a lesser degree than mental and psychological health, they may be important for understanding the carers' situation and their adjustment to the caregiving role. The additional caring-related inequalities identified in the study include fatigue or lack of energy, and health problems that limit social participation. Taken together, these findings draw attention to the physical and emotional stresses that some carers face and the personal and social isolation that often accompanies a demanding caring role.

3.1.2 Caring-related health inequalities

At the population level, caregiving is a relatively important, independent predictor of variations in psychological distress – that is, after taking account of other underlying social determinants of health. Indeed, health inequalities associated with particular care situations (see Section 3.1.4) may be as important as those attributed to more widely acknowledged determinants such as employment status, socio-economic group, or ethnicity. Moreover, caregiving may exacerbate existing inequalities; for example, differences in psychological and mental well-being commonly observed between women and men in the general population are significantly larger in the carer population.

As might be expected, some of the factors taken into account in the analyses are also important in accounting for variations in carer distress, including financial strain, physical health problems, age, marital status, educational qualifications, number of consumer durables, smoking behaviour, employment status, and social class. Taken together, the findings draw attention to the context and diversity of caregiving. One

implication is that a thoroughgoing understanding of caring-related health inequalities depends as much on the carer's personal, household and wider circumstances as on the nature of their caring responsibilities and the care situation.

3.1.3 Extent of caring-related health inequalities

Despite firm evidence for the existence of caring-related inequalities, the findings indicate that most carers do not have additional health problems that could be attributable to their caring responsibilities. Although a substantial minority of carers present poor physical, emotional and mental health, morbidity levels in the carer population are, in large measure, no different than would be observed if the same people were not providing unpaid care. Raised levels of mental and psychological health problems can be attributed to the caring activities of only a relatively small minority of carers. For example, up to one in four carers present high levels of psychological distress, and half that number present recurring symptoms of distress, but these rates are only marginally higher than would be observed in the general population. Overall, no more than one in twenty carers present symptoms of anxiety and depression that might be attributed solely to their caring responsibilities; that is, over and above the level of distress observed in the general population.

Caring-related inequalities vary considerably within the carer population however, and substantial minorities, between 10 and 20 per cent, in key groups of carers report much higher than expected levels of distress. Carers who are most at risk of psychological distress are often found in the more demanding care situations, providing the bulk of unpaid care over extended episodes (see further Section 3.1.4). Caring-related inequalities increase progressively with the amount of time devoted to caring activities each week. Both cross-sectional associations (focusing on current carers at one point time) and longitudinal associations (monitoring transitions to care-giving over time) between level of involvement in caregiving and the extent of caring-related inequalities are highly significant. Carers' cumulative involvement in care-giving over time, the number of care episodes (or multiple transitions), and marked increases in the intensity of caring activities are also associated with a raised risk of emotional and mental health problems in carers.

3.1.4 High risk or priority groups of carers

As noted above, carers in the more demanding care situations face additional risk for psychological distress. Carers who look after someone in the same household are more at risk than those providing support to someone living in a different household, and those providing at least 20 hours care per week are often at greatest risk of poor health and adverse health changes because of their caring responsibilities. At any one time, the risk of psychological distress for carers in these care situations is between 20 per cent and 70 per cent higher than that of like non-carers. Caring for a spouse or partner is particularly associated with additional health problems beyond those that might be attributable to other health determinants. Those heavily involved in looking after a parent or caring for a sick or disabled child also present an

increased risk of psychological distress. In contrast, carers who support a friend or neighbour often present better health than non-carers. Overall, women face greater risk of psychological distress because of their caring responsibilities than men.

Although these high risk groups form a minority of the carer population, they are responsible for providing the bulk of unpaid care. No more than one in four carers provide 20 hours or more care per week but they account for around 75 per cent of the hours devoted to caregiving. Likewise, fewer than one in three carers look after someone in the same household but they supply over 70 per cent of care hours each week.

3.1.5 Transitions into and out of care

Raised levels of distress are observed around the start of care episodes and when caregiving comes to an end, especially in those carers most at risk of poor health (Section 3.1.4). The start of a caregiving role is associated with both the onset of anxiety and depression and recurring symptoms of distress in these carers, more so for women than for men. The high risk groups of carers often present raised distress levels before providing regular help with practical, physical and personal tasks, drawing attention to the uncertainties and challenges facing those about to take on a demanding caring role. Health inequalities associated with former care episodes are most likely to be found in the high risk groups of carers who have recently ceased caregiving; around three or four years into the post-care period caring-related inequalities are unlikely to be detected. Adjustment to the loss of a demanding caring role is likely to be complicated by the death of the cared-for person.

3.1.6 Health inequalities during care episodes

Rates of psychological distress in some groups of carers vary according to their position in the caregiving trajectory. For example, following an initial increase around the start of heavy caregiving, levels of distress in women decline as their care episodes lengthen although they continue to be significantly more distressed than like non-carers. By comparison, distress levels in men who provide out-of-household care, especially those looking after an elderly parent living in a different household, rise steadily as caregiving extends suggesting a dose-response relation between caring-related inequalities and duration of care. In contrast, rates of psychological distress in the general population are relatively stable over time and distress levels in other groups of carers often fluctuate within a narrow range or show no consistent pattern over time.

Irrespective of the duration of their care episodes, carers are significantly more likely than expected to present recurring or persistent symptoms of psychological distress. Those who have been heavily involved in caregiving over an extended period, whether continuously or repeatedly, are likely to present the highest levels of psychological distress in the carer population.

3.1.7 Recent trends in caring-related inequalities

Inequalities in psychological distress between the high risk carer groups and non-carers did not diminish during the ten years to 2000. The persistence of caring-related inequalities during the 1990s indicates that the evidence for supporting heavily involved carers is as compelling as it ever was. Charting recent trends in caring-related inequalities also provides a national baseline against which to monitor the impact of prevention strategies and health promotion aimed at maintaining carers' health and well-being, and can help to identify emerging problems.

3.1.8 Caring-related inequalities and GP services

The study confirms that GP surgeries are likely to provide the most productive settings in which to identify adult carers, provide advice and information, and refer them for a social services assessment. Most carers consult a GP at least once a year and a substantial minority do so more often, including the high priority groups of carers who present raised levels of psychological distress.

Women who provide care are more likely than men in similar care situations to contact a GP, reflecting gender differences in GP consultation rates in the general population. However, men increase their level of contact with GPs when taking on a caring role; as their caregiving continues, particularly in the high priority groups identified above, an increasing proportion of men see their GP and do so more often, narrowing the gender gap in GP consultation rates. By comparison, women who look after someone in the same household or carry heavy caring responsibilities do seem relatively to have less contact with GPs than expected, including those who present symptoms of anxiety and depression. This was because women in these care situations reduced their level of contact with GPs as their care episodes lengthened.

3.1.9 Estimating needs and resources

A question on caregiving was included in the 2001 Census so that local social services authorities could estimate the number of carers in their area to allocate resources and plan service developments. These counts are likely to underestimate the number of carers across service planning, commissioning and budgeting cycles because they relate to a single point in time and ignore the extent to which carers move into and out of their caring roles. The findings of this study indicate that some carers have additional needs for support around these transitions and beyond (Section 3.1.5). The implication is that resources cannot be readily switched from those whose care episodes end to those about to take on a caring role, even if the total number of carers were static. Therefore, the number of would-be and former carers in the high risk groups should be considered, alongside those who currently provide care, when estimating service needs.

To include in population counts those who take on a caring role or cease providing care, the number of adults involved in caregiving at any time during a 12-month period was estimated. Key sub-groups in the carer population were distinguished,

including those who present raised distress levels and recurring symptoms of anxiety and depression. These estimates are considerably higher than those based at a single point in time, and provide a more reliable basis for planning the service response.

3.1.10 Measuring and monitoring caring-related inequalities

Two health measures with known psychometric properties, the SF36 and the GHQ, are used in this study (Section 2.5). Both appear to be acceptable to carers and non-response does not vary significantly across different groups of carers. The SF36 indicates that psychological well-being and mental health are the key domains for caring-related inequalities, and the GHQ seems to be particularly appropriate for measuring important aspects of carer distress and social dysfunction. The GHQ is sensitive to variations in the carer's situation and the intensity of care, as well as to changes over time, including short-term and recurring problems around transitions into and out of the caring role, and as care episodes lengthen.

Although the GHQ was developed in part to aid clinical observations, this study did not evaluate the GHQ as a guide to decisions about individual carers. In primary care settings, practitioners are likely to prefer simpler screening instruments (Arroll *et al.*, 2003). However, the findings indicate that the GHQ might have a useful function in measuring and monitoring caring-related inequalities at the population level. It may also be useful as an outcome measure when evaluating interventions to support carers because it is responsive to changes in the care situation over time.

3.2 Implications for research

The findings of this study have implications for further research on the health effects of caring, and on caregiving in general. The most important are:

3.2.1 Carer diversity

While the study demonstrates that health inequalities between carers and non-carers can be detected at the population level, the adverse effects of caregiving on health and well-being are neither widespread nor constant throughout the carer population. The extent of caring-related inequalities only becomes fully apparent when the carer population is differentiated by locus of care for example, or level of involvement. Poor health in carers, especially raised levels of distress, is associated with particular care situations and caring relationships, and is more prevalent in women than men. To understand the diverse effects of caregiving, or evaluate the effectiveness of interventions, it is crucial to differentiate the carer population as far as possible according to the factors that have been shown to account for key differences in carers' experiences. Failure to distinguish between sub-groups of carers in particular care situations is likely to obscure outcomes, and unlikely to produce results that

have any useful application. Equally, findings based on particular groups of carers will not be generalizable to the population of carers.

3.2.2 Temporal perspectives on caregiving

As noted in Section 2.4, other researchers have highlighted the practical and theoretical importance of adopting a temporal perspective on caregiving. Caring takes place within a time trajectory and carers typically experience considerable changes in their responsibilities and activities before, during and after care episodes (Aneshensel *et al.*, 1995; Nolan *et al.*, 1996; Twigg and Atkin, 1994, p. 133). An important advantage of using data from the BHPS is the ability to track changes in carers' health over time.

The temporal framework constructed from the BHPS produced two key insights:

- First, adverse health changes and poor health in the high risk carer groups are closely associated with transitions into and out of the caring role.
- Second, the extent of caring-related inequalities (and use of GP services) is related to the location of carers in the caring trajectory.

Longitudinal analysis also produced new evidence of the cumulative effects of caregiving on the health of carers, the persistence of psychological distress during care episodes, and the nature of health legacies in former carers. Temporal perspectives are required to appreciate the health effects of caring (and other outcomes); indeed, caring-related inequalities might be misrepresented by analyses conducted at a single point in time or study designs that ignore the care trajectory.

The value of a prospective design is that it provides not only a common baseline for carers and non-carers alike, but can also identify people before the start of their care episodes and help to establish the temporal order of health effects. Longitudinal designs may also be required for monitoring time trends in carers' health. However, longitudinal designs can be costly and time consuming. Secondary analysis of panel data and birth cohorts will continue to provide cost-effective alternatives for investigating caring-related inequalities.

3.3 Research needs

By removing some of the methodological uncertainties about the nature and extent of caring-related health inequalities, the findings of this study move the research agenda towards prevention and the investigation of specific risk factors for carers. The study also echoes calls for evaluations of 'what works' in carer support. The findings indicate that the acceptability and effectiveness of interventions to help carers maintain their own health and well-being, and prevent ill-health, are likely to depend on being tailored to individual care situations and their location in the caring trajectory, as well as the carer's wider circumstances and other roles (Sections 3.1.2,

3.1.4, 3.1.5, and 3.1.6). Evidence shows for example, that individual coping styles and expectations can be as important as service responses and social support in modifying the health effects of caring (Nolan *et al.*, 1996; Twigg and Atkin, 1994). Enabling carers and former carers to remain in, or take up paid employment can promote health benefits by tackling social isolation, financial strain, lack of confidence and other determinants of carer stress (Arksey, 2002). Thus, further evaluation of the underlying pathways between caregiving and health, and the factors associated with good and poor outcomes, is required to inform policy, service development and practice.

Specific topics where further research was felt to be required were also identified during the course of this project. These include:

3.3.1 Identifying carers

The study identifies in a population-based sample those situations in which carers are most likely to be at risk of poor mental and emotional health because of their caring responsibilities. At the same time, it has shown that relatively simple indicators (such as locus of care, hours caring per week, and how these combine with gender) are good predictors of inequalities in psychological distress. Spouse carers present the highest risk of psychological distress while parents looking after sick or disabled children often provide the longest spells of care. Caring for parents who live in the same household can present different strains and stresses to providing care for parents living in a different household. Including such indicators would enhance the identification of priority groups of carers in routine practice. Particular combinations of care situations and relationships should also be piloted in the development of risk assessment protocols for health promotion interventions, to evaluate their reliability and effectiveness for identifying individuals at risk.

3.3.2 Carers' help-seeking behaviour

The analysis of carers' contact with GPs was hampered by lack of information on why they were consulting a GP and whether, and in what ways, consultations were linked to their caring role. The study also lacked information on carers' use of other services including respite care, carers' centres and carer support projects, as well as the reasons why some carers do not seek help with their caring responsibilities. Further investigation of these factors is warranted because of the finding that women who are heavily involved in looking after a spouse or close relative inside their own households consult GPs less often over time than might be expected.

Government policy assigns a pivotal role to GPs in identifying and supporting carers, and enabling them to maintain their own health (DH, 1999a). The success of this strategy depends in part on understanding how caregiving influences the ways in which people manage their own health and seek help from GPs and members of the primary care team. Such an understanding will, in turn, underpin the effectiveness of advice and support to carers, and the prospects for developing a genuine partnership

between them and professional carers. Both qualitative and quantitative research is required to understand better the effects of caregiving on carers' help-seeking for health care and use of services, and to evaluate the implications.

3.3.3 Caregiving in the life course

A life course approach is especially relevant for maintaining health and function in an ageing population and for implementing positive interventions earlier in life (Davey Smith, 2003). This study has focused on the health effects of transitions into and out of care and changes in caregiving over time, implicitly abstracting such events and episodes from a broader consideration of people's lives. A life course approach would increase understanding of the cumulative and longer-lasting effects of caregiving on health; it would also underpin a more proactive and positive approach to carer support both during and beyond their caregiving episodes. The health legacies of caregiving are likely to be an important factor in the lives of individuals who are heavily involved in caring over many years (McLaughlin and Ritchie, 1994).

The contribution of caregiving to health inequalities across the life course would require a more thoroughgoing analysis – one that recognised that the health effects of caregiving may be associated with other changes and outcomes in people's lives. For example, taking on the care of an elderly parent or a severely disabled child may be associated with partnership dissolution, giving up paid work, or additional costs. Such changes of circumstances are potential stressors and should be considered when assessing their independent and joint effects on people's health. To do so would indicate more precisely the impact of caregiving on health and address a potential weakness of this study: that it treats potential confounding variables as invariant over time.

Relating health inequalities to events and changes over the life course, including adaptation and adjustment to a caregiving role, would require a complex conceptual and analytical framework that recognises health as a potential selection factor and an outcome variable. As well as the BHPS, secondary analysis of birth cohort data and the recently launched longitudinal study of ageing would provide new insights into the health effects of caregiving over the life course.

3.3.4 Former carers

The findings of this study indicate that carers in the high risk groups, who have recently ceased providing care, often present levels of distress comparable to those of carers who are currently looking after someone in similar circumstances. Moreover, transitions out of care are associated with increased rates of psychological distress in some carers that can take several years to return to levels found in the general population.

However, little is known about the support needs of former carers and the extent to which they are able to resume their lives and face new challenges and opportunities

for fulfilment. Bereavement studies rarely follow-up past carers to see how they adjust to their changed circumstances and loss of role, yet the consequences can be especially profound and far reaching in those under pension age (Jenkinson, 2003; Long *et al.*, 2000). The support needs of carers for people who have moved into long-term institutional care have also been recognised as a research priority (Bond *et al.*, 1999; Nolan and Dellasega, 2000). In the first instance, qualitative studies are required to understand better the experiences and needs of former carers, and to ascertain their views on what interventions might provide appropriate and acceptable support in the post-care period.

3.3.5 Minority ethnic carers

Like other general-purpose household surveys, the BHPS sample is not large enough for systematic investigation of issues of race or ethnicity yet these factors mediate the carer's experience and needs as well as their relationship with services and service providers (Atkin and Rollings, 1993). Demographic factors, culturally-held beliefs and practices, a recent history of migration and settlement, and social, economic and material disadvantage shape the demand for and supply of unpaid care in minority ethnic groups (Katbamna *et al.*, 1998). Survey evidence highlights the diversity of patterns of caregiving within and between minority ethnic groups and the white population (Hirst, 2000). Demographic trends in minority ethnic groups point to significant changes in family and household size and structures, and an imminent increase in the number of older people from the cohort who migrated to Britain in the late 1950s and 1960s; expectations about marriage and inter-generational responsibilities are also changing (Owen, 1993, 1995). Higher rates of long-term conditions and morbidity in some sections of the minority ethnic population are likely to shape both the prevalence and nature of caregiving, and the carer's response (Nazroo, 1997). For these reasons, much more needs to be known about health inequalities among minority ethnic carers to inform policy thinking and service development.

3.4 Conclusions

The study summarised here provides new evidence on the nature, extent, timing and persistence of health inequalities associated with unpaid care. Taken together, the findings increase knowledge of the diverse impacts of caregiving and help to disentangle the effects of caring on health. They also begin to validate caregiving as an underlying social determinant in the creation of health inequalities, and to identify the circumstances in which caregiving might be an important variable in epidemiological analysis.

There will always be a need to refine our understanding of the health effects of caregiving, not least because the demands on unpaid carers are changing and their responses and expectations are likely to evolve. Further research is required to

evaluate the mechanisms for caregiving and health outcomes and how adverse effects are modified by individuals' coping skills and expectations, family resources and service responses. In the meantime, the findings of this study indicate that some carers present particular health care needs because of their caring responsibilities: the practical implications are considered in the next chapter.

4 Implications for policy and practice

The findings of this study show the challenge to public health policy that tackling the inequalities associated with caregiving represents. Although the vast majority of carers do not present additional health problems because of their caring activities, the adverse effects of caregiving on carers' psychological well-being are quantifiable and significant. They are most pronounced around transitions into and out of care, and in the more demanding care situations. The risk for psychological distress increases with involvement in and intensity of caring activities. Ongoing care further increases the risk for recurring distress, and adverse health effects can persist beyond the end of caregiving. An increased risk of mental and psychological distress attributable to caring responsibilities affects a substantial minority of carers who provide the bulk of care over extended spells. Several groups of carers face an increased health risk, especially those looking after a spouse or partner, and women who provide care for a child or a parent in the same household. Moreover, caring-related inequalities in psychological distress did not diminish during the 1990s: the evidence for addressing carers' health needs is as compelling as it ever was.

The adverse effects of caring on health are, in principle, avoidable and amenable to policy interventions. Although this study was not designed to develop or evaluate policy options and directions for good practice, the findings have implications for carer support, and could inform service planning and resource allocation decisions. Key messages for policy and practice include:

4.1 Prioritising needs

The findings indicate that the adverse health effects of caring are primarily psychological. Health promotion measures that address carers' particular needs and the prevention of carer ill health should give priority to maintaining their emotional and mental well-being. The importance of psychological well-being for public health is well recognised in policy thinking, good practice in the workplace, and at particular stages of the life course. Explicit consideration of the role of unpaid caregivers could increase the effectiveness and acceptability of health improvement programmes.

The research literature indicates that there are likely to be multiple causes of carer distress. Each may require different types of intervention, geared to individuals' circumstances and to differences in the way men and women present psychological needs and mental health problems.

4.2 Targeting resources

Carers are a diverse group of people so the service response and interventions will need to be flexible and wide based. Thus, services to improve emotional support to carers will depend for their acceptability and effectiveness on their responsiveness to the context and diversity of caring relationships. Interventions will need to be sensitive to the nature of the care situation and the carer's role, as well as to the other social, economic, demographic, and cultural factors associated with the psychological well-being of women and men.

The study identifies some simple aspects of the care situation that focus attention on those carers who are most likely to report adverse health effects. The high risk groups include carers who are heavily involved in their caring activities, especially those looking after someone inside their own household. On the face of it, these carers are most likely to benefit from support to maintain and promote their health and psychological well-being. Assessment protocols to identify vulnerable carers are required because targeted interventions are likely to be more cost effective.

The needs of the priority groups of carers should be considered explicitly in local population health assessments, both to inform the targeting of resources and the planning, development, commissioning and delivery of carer support. The provision of community health, social services and palliative care for the cared-for person, should also take into account the needs of carers in the high risk groups. In addition, GPs, members of the primary care team and social care practitioners should actively seek to identify those carers providing a lot of care to monitor their health and treat or prevent ill health.

4.3 Timing interventions

The government's strategy for carers recognises their need for emotional support, which can include counselling, befriending, help lines, telephone contacts, internet links, support groups, social events and other activities. Such support may be accessed on a regular or periodic basis as carers' needs arise. Additionally, the findings point to particular times or circumstances when carers are most at risk of psychological distress and may gain particular benefit from such sources of support. The priority groups of carers identified in this study are most likely to benefit from emotional support around the start of their care episodes. The caring trajectories of carers most at risk should also be monitored for adverse effects on their psychological well-being. Heavily involved carers may have particular needs for ongoing emotional support throughout their care episodes, especially where caregiving extends beyond three or four years. Emotional support, including bereavement care, may be beneficial when caring comes to an end, especially for spouse carers and others who have been heavily involved in their caring activities.

4.4 Identifying carers

Identification of carers is the first step towards helping them. This study confirmed that GP surgeries are likely to provide the most productive settings for identifying adult carers and advising them of their rights to a social services assessment. Most carers talk to or visit a GP every year and a substantially minority consult a GP about their own health several times a year. Carers with raised distress levels are more likely to consult a GP than those who do not present symptoms of anxiety and depression. Thus, GP surgeries often present the best opportunity for signposting carers to support services. Additionally, specific interventions to enable carers to maintain their own health and receive training in basic nursing tasks might be appropriately located in primary care settings.

Carers need to be actively identified because those in the high priority groups often do not readily self-identify (Leat, 1992). Various approaches to the identification of carers have been tried. Brainstorming with colleagues working in both general practice and community settings can identify patients already known to have caring responsibilities or who are looked after at home by a relative or friend. 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 further 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 that includes a question about caring responsibilities. Others have attached an invitation on prescriptions asking carers to identify themselves. The time is ripe for a trial of all these methods.

The challenge is to develop effective methods for identifying carers that are acceptable to GPs (Keeley and Clarke, 2003). Introducing carer support workers or social care staff alongside GPs can improve the identification of carers and boost service responses to their particular needs (Lankshear and Hodges, 1999). Carers who are not in regular contact with a GP may require different approaches: one possibility is to involve community pharmacists in identifying hidden or hard-to-reach carers (Princess Royal Trust for Carers, 2003). Once carers are identified, practice nurses or another member of the primary care team might telephone or visit those in the high risk groups when they have not contacted the surgery for some time.

4.5 Estimating the carer population

The findings of this study indicate that individuals in the priority groups of carers often present particular support needs around transitions into and out of a caring role. The findings also indicate that some would-be carers present raised distress levels well

before identifying themselves as carers and there is evidence of complicated grief long after caregiving has ceased. Consequently, when developing carer support services and estimating the resources required it is important to estimate not only the number of people providing unpaid care at any one time but also to estimate the number of would-be and former carers. Such estimates can be calculated from longitudinal data such as the BHPS provides. They are obviously higher than the estimates based on cross-sectional censuses and surveys but are likely to give a more realistic indication of the health care and support needs associated with caregiving across budgeting cycles. The population estimates developed in this study could also provide a yardstick against which to assess the efficacy of methods for identifying carers at the local level (Section 4.4).

4.6 Providing carer-specific support

Most carers' health care needs are probably best met by mainstream service provision. However, caring-related inequalities identify health differences over and above those attributable to other factors and are closely associated with the caring role and the carer's relationship to the cared-for person. Therefore, the detection of caring-related inequalities might support the case for developing specialist or carer-specific services that would allow the carer's needs and experiences to be the sole or principal focus of provision, perhaps with dedicated staff. Such interventions may be provided within mainstream services (e.g. a carer support project within a community-based healthy living initiative or a carer support worker in a GP's surgery), or delivered independently by specialist providers or carers' centres dedicated solely to carer support (Leat, 1992).

One advantage of carer-specific interventions is that they can be more easily tailored to meet the particular needs and circumstances of heavily involved carers. Carer-specific interventions might also be more acceptable to the priority groups of carers identified here, and thus more effective. This study has also drawn attention to the support needs of some former carers: they too are likely to be most effectively supported through carer-specific interventions rather than generic bereavement care for example (Jenkinson, 2003).

4.7 Conclusions

This chapter draws attention to the implications of the study for health promotion, prevention strategies and service responses to the health care needs of carers. Taken together, they indicate that:

- **Caregiving should be recognised as a public health issue.** The aim here would be to release additional health care resources for developing carer support services and encourage a more thoroughgoing approach to policies that promote carers' health and prevent ill health. In particular, primary care trusts should increase carer awareness in primary care settings, improve access for carers, and commission carer support services in partnership with social services. Public health programmes for maintaining health and function across the life course also need to take into account the potential benefits of alleviating the adverse health effects of caregiving.
- **Caregiving should become part of the health inequalities agenda.** This move would have two important consequences: first, it would require consideration of caregiving alongside other social determinants when tackling health inequalities, and monitoring health trends and outcomes. Secondly, it would encourage key government departments (Department for Education and Skills, Department of Trade and Industry, Department for Work and Pensions, Office of the Deputy Prime Minister, HM Treasury, for example) to assess the health impacts of their policies and programmes on carers, and to consider whether and how they can reduce caring-related health inequalities.

Evidence on caring-related health inequalities will continue to accumulate but has probably reached the stage where new opportunities for policy and service developments can be identified. Progress towards genuine partnerships between primary care trusts and local social services authorities is opening up possibilities for jointly commissioned and jointly provided carer services, and improved collaboration between frontline staff around carer support. The challenge will be to find good evidence of their effectiveness and cost effectiveness, their acceptability to carers and their relevance to the caregiving experience.

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Appendix

Seven working papers were produced during the course of this project:

- Caring-related inequalities in self-assessed health.
- A temporal perspective on caring-related health inequalities.
- Caring-related inequalities in psychological distress during the 1990s.
- Carer distress: prospective, population-based study.
- Carers' consultations in general practice.
- Inequalities in psychological well-being and the impact of caregiving.
- Estimating unpaid adult care over time.

These reports were initially prepared for comment and discussion at meetings of the project advisory group, and have since been revised. They describe in more detail the research design, explain how the research was carried out, present the findings in tables and charts, and provide an interpretative commentary. The purpose of this appendix is to outline the scope and content of each report in turn and summarise the key findings. Although each report addresses different aims, they are linked around a common focus on caring-related health inequalities and draw on different analyses of the same dataset; inevitably, there is overlap between the reports and some repetition of key findings.

A.1 Caring-related inequalities in self-assessed health

There is widespread evidence linking caregiving to increased rates of psychological distress, including symptoms of anxiety and depression; however, effects on physical morbidity are generally weak and inconsistent (Schulz *et al.*, 1990, 1995). It was important to establish from the outset how far these conclusions apply to the population of carers identified in the BHPS sample. This report uses data from the ninth interview wave to assess the effects of caregiving in eight health domains measured by the SF36 (Section 2.5). It relates health inequalities to the locus of care, the amount of time devoted to caring activities, and the relationship between the carer and the cared-for person. Key findings indicate that:

- Poor health in carers is more likely to be associated with caring for someone in the same household than with looking after someone living in a different household.
- Caring for someone in the same household is associated with emotional and mental health problems, especially for women who are heavily involved in their caring activities.
- Women who look after a parent or parent-in-law inside their own household are likely to report emotional and mental health problems irrespective of the amount

of time they devote to caring. Men who provide such care often report better health than non-carers.

- Mothers caring for a sick or disabled son or daughter are likely to report fatigue or reduced energy levels, and severe or limiting pain.
- Men who are heavily involved in looking after their wife or partner are more likely to report physical, mental and emotional health problems, and bodily pain, than men who are less involved in spouse care.
- For men and women alike, heavy involvement in caring for a parent or parent-in-law living in a different household is associated with physical and emotional health problems, and with health limitations that affect everyday life and activities.
- Men who are heavily involved in caring for 'other' relatives living in a different household are more likely to report mental health problems, fatigue and poor social functioning than those who are less heavily involved. Women who provide such care often report better health than non-carers.
- Carers who look after a friend or neighbour are often in better health than like non-carers.

A.2 A temporal perspective on caring-related health inequalities

A long sustained period of care may well have different consequences for the carer's health than a brief spell of caregiving, or several intermittent spells over the life course. This report examines the impact on health of caregiving over a nine-year period, covering changes in the caring role and the duration of care episodes; it also investigates the health of former carers. The cumulative experience of caregiving is related to individuals' health in 1999 assessed according to the SF36, and is based on the sub-sample of respondents who gave full interviews at each annual wave from 1991 onwards. The findings show that:

- Health differences between carers and non-carers are partly associated with inequalities of age, gender, socio-economic group, marital status, labour market position, and other factors. Carers are generally older for example, and more likely to have characteristics associated with the social determinants of poor health (e.g. out of paid work; divorced or separated).
- Beyond their socio-demographic circumstances however, carers often face additional health problems compared with non-carers in similar circumstances with like characteristics.
- Adverse health effects associated with caregiving are specific to certain sub-groups of carers and to particular health domains.
- Heavily involved carers, most of whom live in the same household as the person they look after, are more likely than non-carers with similar characteristics, and those who are less heavily involved, to report poor health.

- Health inequalities associated with caring for someone in the same household are typically linked to emotional and mental health problems, fatigue or lack of energy, and health problems that limit social participation.
- Caring-related inequalities in mental and emotional health are more likely to be observed among women; men who provide care are more likely to report physical health limitations than non-carers.
- Health inequalities associated with caregiving are greater for women than for men, for carers living in the same household as the cared-for person than for those looking after someone living elsewhere, and for current rather than former carers.
- Emotional health problems increase with the time devoted to caring activities, with duration of care episodes, and with carers' involvement over time.
- Carers who are heavily involved over extended episodes of care, or face increasing demands over time, are at greatest risk of poor health.
- The effects of several brief, intermittent spells of care may be as harmful to health as those associated with a long continuous episode.
- Carers who have recently ceased looking after someone living in the same household often present health problems to the same extent as current co-resident carers.
- Caring for a spouse or partner is associated with adverse effects across physical, emotional and mental health domains although women spouse carers are more likely to report health problems than their male counterparts.
- Women caring for parents living in the same household are more likely than non-carers of the same age to report emotional and mental health problems.
- Mental or emotional health problems, and fatigue, are associated with caring for a sick or disabled son or daughter.
- This study detected no adverse health effects associated with looking after a parent or parent-in-law living in a different household.
- The health of those who regularly help friends and neighbours is often no different from, and sometimes better than, that of like non-carers.

A.3 Caring-related inequalities in psychological distress during the 1990s

Caring activity intensified during the 1990s associated with increasing amounts of time devoted to the more demanding types of care and to those care relationships that typically make heavy demands on the carer. This report investigates whether the intensification of caring activities had any adverse impact on carers' health over time. It compares trends for the severity and prevalence of psychological distress in carers and non-carers from 1991 to 2000. The analysis is based on the GHQ, which provides a robust measure of psychological distress for each wave of the BHPS (Section 2.5). The results provide a baseline against which to monitor the impact of

policy action on maintaining carers' health and emotional well-being. The key findings are:

- People with caring responsibilities, men and women alike, present higher levels of psychological distress and higher rates of probable psychiatric illness than people who do not currently provide care.
- Self-reported psychological distress increases progressively with involvement in more intensive caregiving.
- Inequalities in psychological distress associated with providing unpaid care are significant when age and other social, economic and demographic differences between carers and non-carers are taken into account.
- Women present higher levels of psychological distress than men in comparable care situations; the health gap between women and men widens with the amount of time they devote to caring activities.
- There is no firm evidence of any increase in caring-related inequalities in psychological distress during the study period.
- Inequalities in psychological distress associated with caregiving persist throughout the 1990s, and had not diminished by the year 2000.
- There is a continuing need to promote the psychological health and well-being of carers, especially those women with heavy caring responsibilities. The evidence for doing so is as compelling as it ever was.

A.4 Carer distress: prospective, population-based study

This report compares the psychological well-being of adult carers before, during and after their care episodes with that of non-carers. The chief aim is to estimate the extent, pattern and timing of inequalities in emotional health associated with the provision of unpaid care. The analysis focuses on the health effects of transitions into and out of a caring role, how carers' psychological health changes during the caregiving trajectory, and which carers are most at risk of adverse health changes and poor psychological health over time. Key findings include:

- People who are engaged in the more demanding caring roles – those looking after someone inside the same household, or heavily involved in their caring activities, or both – are most at risk of anxiety and depression.
- Spouse carers are likely to present the highest rates of psychological distress; people caring for a parent or parent-in-law in the same household, or a sick or disabled child, also face an increased health risk.
- Women who take on these caring roles are more at risk of psychological distress than their male counterparts.
- Elevated rates of distress are observed in these high risk groups of carers often before practical, physical and personal caregiving actually starts.
- For carers in the high risk groups, the start of a caregiving episode is associated with both new and recurring symptoms of distress.

- The risk of psychological distress increases progressively with the amount of time devoted to caring activities.
- After an initial increase, distress levels in the high risk groups fall during the first two or three years of caregiving but remain above those reported by non-carers.
- Men who look after someone living in a different household, usually a parent or parent-in-law, present increasing rates of distress as their care episodes lengthen.
- Heavily involved carers who live in the same household as the care recipient face an increased risk of recurrent or unremitting distress each year of their care episode.
- The end of a heavy caregiving episode is also marked by an increase in rates of distress, especially in spouse carers.
- Thereafter, distress levels fall in the post-care period and, around three or four years after caregiving has ceased, equate with those reported by non-carers.
- Former carers who were heavily involved in their caring activities present the most sustained levels of distress in the post-care period.

A.5 Carers' consultations in general practice

GPs and members of the primary care team have a key part to play in identifying carers, supporting them in their caring role, and helping them to maintain their own health and well-being. This report produces new evidence on carers' use of and access to GP services in comparison with that of non-carers. It investigates the extent of carers' contact with a GP, whether being a carer has an effect on consultation rates, and how far contact levels are associated with their psychological well-being. The analysis also investigates the influence of different care situations and relationships on contact with GPs, and how contact levels change when caregiving starts, during the early years of a care episode and when caregiving comes to an end. The findings indicate that:

- Most carers contact a GP at least once a year and a substantial minority do so more frequently.
- Carers with symptoms of psychological distress are more likely to contact a GP than those without.
- Women who provide care are more likely than men in similar care situations to contact a GP, reflecting gender differences in GP consultation rates in the general population.
- However, gender differences in contacting behaviour are less pronounced in the carer population mainly because men who provide care are more likely than their counterparts in the general population to consult a GP.
- Men increase their level of contact with GPs when taking on a caring role and, as caregiving continues, an increasing proportion consults a GP.

- Women who look after someone inside their own household are less likely to contact a GP, and have fewer consultations, than non-carers of similar age, health and socio-demographic characteristics.
- Women who take on the care of someone inside the same household also report declining contact rates as their care episodes extend to two years and beyond.
- Since 1991, contact between GPs and women with heavy caring responsibilities, or those who look after someone inside the same household, has declined.
- There is no firm evidence of inequalities associated with caregiving in access to, or unmet need for, GP services.
- However, women who look after someone in the same household or carry heavy caring responsibilities do seem relatively to have less contact with GPs than expected, including those who present symptoms of anxiety and depression.

A.6 Inequalities in psychological well-being and the impact of caregiving

Health inequalities across population groups are predominantly a consequence of socially structured differences in the material conditions of people's lives. Such inequalities are usually represented as systematic differences in mortality and morbidity according to socio-economic classifications that encapsulate the underlying determinants of health (covering for example, living and working conditions, access to essential goods and services, environmental influences and community networks). There are also health inequalities associated with gender and ethnicity, as well as variations according to age. As noted above, caregiving is associated with many of these factors and its impact on health inequalities may be confounded with that of other determinants (Section 2.6). This report estimates the relative importance of caregiving in shaping inequalities in psychological well-being compared with socio-demographic, economic and other factors, and investigates the impact of gender differences on rates of distress in the carer population. The analysis also estimates the extent to which raised levels of distress are associated with particular care situations and relationships. The findings show that:

- Caregiving is a relatively important factor in accounting for inequalities in women's psychological well-being, and particular care situations are associated with some of the highest levels of distress reported by women.
- Although caregiving has an independent effect on levels of distress reported by men, providing care is generally less important than other social factors that influence their psychological well-being.

- For women and men alike, the likelihood of psychological distress in carers is greater where they live in the same household as the cared-for person, and rises progressively with the number of hours devoted to their caring activities.
- Women who look after someone in the same household, or provide at least 20 hours of care a week, are disproportionately more likely to report symptoms of psychological distress than men in comparable circumstances.
- Women who provide care for a spouse or partner, a parent or parent-in-law, or a child, are disproportionately likely to present high levels of psychological distress.
- Caring-related inequalities in men's psychological health are relatively small; however, those who provide long hours of care, especially for a spouse or partner, are likely to report raised levels of distress.

A.7 Estimating unpaid adult care over time

This report provides estimates of the prevalence of unpaid adult care, distinguishing between people who start, cease or continue to provide care during a 12-month period. The population of carers in typical catchments or organisational settings, including local social services authorities and primary care trusts, is also estimated. The aim is to provide service planners and practitioners with indicative targets of how many carers they can expect to identify and to show the extent to which the carer population changes from year to year. As well as taking account of transitions into and out of caregiving, attention is drawn to changes in the carer's role, focusing on those who become more heavily involved in their caring activities or who maintain a high level of involvement over time.

Carers are distinguished according to where the cared-for person lives in relation to the carer's usual place of residence, their relationship to the person they care for, and the amount of time they devote to their caring activities. In addition, the number of carers who present high levels of psychological distress is estimated to provide an indication of how many describe themselves as under considerable strain and might benefit from emotional and practical support. The number of carers who contact a family doctor is also estimated to indicate how readily carers might be identified in GP surgeries and, where appropriate, referred for a social services assessment.