

# Carer distress: A prospective, population-based study

Michael Hirst\*

*Social Policy Research Unit, University of York, Heslington York YO10 5DD, UK*

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## Abstract

This study investigates whether transitions into and out of unpaid caregiving are associated with increased risk for onset of or delayed recovery from psychological distress, and traces the prevalence of distress across successive years of caring activity and after caregiving has ceased. The analysis is based on data from the British Household Panel Survey covering 3000 would-be carers, 2900 former carers, and 11,100 non-carers during the 1990s; their psychological well-being was assessed at annual intervals using the General Health Questionnaire. Carers providing long hours of care over extended spells present raised levels of distress, women more so than men. Compared with non-carers, risk for onset of distress increases progressively with the amount of time devoted to caregiving each week. Adverse effects on the psychological well-being of heavily involved carers are most pronounced around the start of their care episodes and when caregiving ends. Ongoing care increases their susceptibility to recurring distress, and adverse health effects are evident beyond the end of their caregiving episodes. Several groups of carers experience psychological health inequalities compared with non-carers, especially those looking after a spouse or partner, and mothers caring for a sick or disabled child. The findings underline the importance for effective carer support and health promotion of early identification of carers, monitoring high risk groups, timing appropriate interventions, and targeting resources.

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## Introduction

An existing wealth of studies show that providing unpaid care for disabled and older people is associated with increased rates of anxiety, depression, and psychiatric illness compared with control groups or population norms (Schulz, O'Brien, Bookwala & Fleissner, 1995; Singleton et al., 2002). Carers report that caregiving adversely affects their emotional well-being and social functioning (Maher & Green, 2002). Compromised immune response in carers provides further evidence of emotional distress and may increase susceptibility to physical illness (Kiecolt-Glaser, Dura,

Speicher, Traske & Glaser, 1991); mental or emotional distress may also increase risk of mortality among elderly spouse carers (Schulz & Beach, 1999).

Longitudinal perspectives show that rates of distress vary at different stages in a caring relationship (Aneshensel, Pearlin, Mullan, Zarit & Whitlatch, 1995; Nolan, Grant & Keady, 1996). A handful of studies have followed samples of non-carers until those who become caregivers can be compared with those who do not take on a caring role (Burton, Zdaniuk, Schulz, Jackson & Hirsch, 2003; Lawton, Moss, Hoffman & Perkinson, 2000; Seltzer & Li, 2000). Others have identified carers around key events such as discharge of the cared-for person from hospital (Canning, Dew & Davidson, 1996; Nieboer et al., 1998). Rather more studies have followed existing groups of carers, often covering the period after

\*Tel.: +44 1904 321950; fax: +44 1904 321953.

E-mail address: [spru@york.ac.uk](mailto:spru@york.ac.uk).

the cared-for person dies or enters institutional care (Bass & Bowman, 1990; Collins, Stommel, Wang & Given, 1994; Levin, Sinclair & Gorbach, 1989; Pot, Deeg, & Van Dyck, 1997; Seltzer & Li, 2000; Schulz et al., 2001).

Overall, the longitudinal evidence supports two broad conclusions. First, carers face increased risk of recurrent or persistent distress. A majority of studies report little variation or no systematic change in distress rates during care episodes; coupled with higher than expected levels of distress in the carer population, constant rates would indicate that carers are likely to report recurring symptoms (Ballard, Eastwood, Gahir & Wilcock, 1996; Buck et al., 2000; Kiecolt-Glaser et al., 1991; Pevalin & Goldberg, 2003; Taylor, Ford & Dunbar, 1995). Secondly, transitions into and out of care, and at key turning points, are often associated with significant change in levels of carer distress (Baumgarten et al., 1994; Burton et al., 2003; Cannuscio et al., 2002; Collins et al., 1994; Lawton et al., 2000; Levin et al., 1989; Nieboer et al., 1998; Pot et al., 1997; Seltzer & Li, 2000).

Longitudinal studies of carer distress are often difficult to compare as the groups of carers are different and because some designs have methodological limitations similar to those identified in Baumgarten's (1989) review of earlier cross-sectional studies: small, unrepresentative or non-probability samples, different measures of stress and caregiving, absence of comparison groups, and uncontrolled confounding effects. Evaluating longitudinal studies is further complicated by differences in the number and spacing of follow-up interviews, and lack of baseline measures before caregiving starts.

This study produces new evidence on the extent, timing and persistence of distress across the carer population, and identifies high risk or priority groups of carers. It examines individual change in psychological distress around transitions into and out of caregiving, and traces distress rates across successive years of caring activity and after caregiving has ceased. The findings relate to the experiences of unpaid caregivers in Britain during the 1990s. Throughout that period, there were around 6.5 million adults providing unpaid care for disabled and elderly people, including over 1.5 million who devoted 20 h per week or more to their caring activities (Maher & Green, 2002; Rowlands & Parker, 1998).

## Methods

The study uses data from the first ten waves of the British Household Panel Survey (BHPS) covering the period 1991 to 2000. The BHPS is a general-purpose survey of the population living in a nationally representative sample of around 5000 private households in England, Scotland and Wales (Buck, Burton, Laurie &

Lynn, 2002). When the panel was recruited in 1991, around 10,000 adults aged 16 years and over were interviewed. The sample for subsequent waves, conducted at approximately 1-year intervals, includes all adults enumerated at wave one, plus their natural descendants on turning age 16 and other adults living in their household. Because the sample is augmented in this way, it remains broadly representative of Britain's non-institutional population as it changes over time.

## Study design

The BHPS dataset was reorganised to create a prospective study design around transitions into and out of caregiving in order to compare changes in carers' experience of distress across these transitions with that of concurrent non-carers.

Each year, respondents over 16 years are asked whether they provide care for someone who is sick, elderly or disabled. Caregiving is defined as looking after, giving special help or some regular service that is not provided in the course of paid employment. Unpaid carers who help clients of voluntary organisations are excluded here because what motivates them to care, and the choices available to them, are quite distinct from those of family carers (Leat, 1992). Care provided by children and young people is not recorded in the BHPS.

Respondents were linked across successive interview waves to identify transitions into and out of caregiving. Would-be carers are observed for one wave before providing care (c0) and in the next year (c1) when caregiving is reported (c = care episode). Episodes of increasing duration are observed if caregiving is reported in successive waves (c2, c3, etc.). In like manner, former carers are observed for at least one wave of care provision (p0) and in the following year (p1) when caregiving is no longer reported. The post-care period (p) is extended if no caregiving is reported in the following waves (p2, p3, etc.). Respondents who reportedly did not provide care over equivalent waves (c0 or p0 onwards) make up the comparison group.

The construction of caregiving episodes is based on the assumption that caring activity reported in two or more successive waves describes a continuous spell of care and lasts longer, on average, than caring reported at one wave only. When transitions into or out of care take place between successive waves (c0/c1 and p0/p1 respectively) is not precisely known. Caregiving that starts and ends between successive waves is missed altogether; moreover, no information is available about respondents' caregiving experiences before their first interview for the BHPS.

All transitions into and out of caregiving, and successive years of care provision and beyond were pooled across the ten waves of data analysed here. The sample comprises 17,000 adults who were interviewed

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