



The Princess Royal Trust for Carers Carers Health Survey

Main Findings
January 2004



Supported by



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In 2002-3, a comprehensive research study was conducted throughout Great Britain to look into the health of carers across the country. More specifically, we wanted to understand the main health problems that carers suffer from; how the health of carers varies by the condition(s) of the people that they care for, and how carer's health is affected by the caring functions they undertake.

We were able also to establish what they experience whilst caring, both physically and emotionally, and we monitored the help and support they get from the medical world, the community and the voluntary organisations and how they rate that.

This summary of the research will concentrate mainly on issues around mental health. The study was sourced by The Princess Royal Trust for Carers, sponsored by GlaxoSmithKline and designed and run by Q2 Research & Consultancy.

Findings are based on a total of 1066 interviews among carers who identify themselves as such. Thus, many have some contact with a carer organisation. A self-completion questionnaire was used, filled in via the Internet or on paper.

This summary reports on the carers' experience with the main person cared for.

The profile of carers

The characteristics of the carers who took part in this study are as follows and show a different profile to that of the adult population of this country:

- Significantly biased to women (77% of the sample). There is a higher proportion of male carers in the general population, but this level of a quarter of carers being male matches other data for male carers who identify themselves as such and use caring services.
- Women carers tend to be aged 35-64yrs and male carers, 45-64 yrs.
- Not working/retired (42/16%) or working part-time (16%).
- Married or cohabiting (69%).
- Readers of broadsheets (for example, The Daily Telegraph or The Times) and mid-market newspapers (e.g. Daily Mail), generally reflecting a more educated profile.

A very high proportion (80%) have access to a car, whilst 67% are a driver, which is over the national average. This may be because of the mobility component contained in the Disability Allowance received by many of the people who are cared for. The remainder are passengers, who also take local buses or taxis.

Caring

The overwhelming majority care for one person (77%). Those caring for someone with a mental illness or learning disability are a little more likely to be caring for more than one person and these carers are more likely to be younger mums, looking after children.

More than half of the carers have spent the last six years caring for someone.

- Those caring for well over 10 years are mainly looking after people with learning disabilities although for both mental illness and long term physical conditions, the duration is greater than the average.

70% of all carers spend at least 50 hours caring per week.

- Those spending more than the average number of hours per week are 35-44 year old carers, those looking after under-25 yr olds with learning disabilities, and to some extent those looking after older people with dementia.
- 35% do share the caring, particularly male carers in the young or middle age bracket who are looking after people younger than themselves with mental illness or learning disabilities.

Over 50% of carers look after people who have mental health illnesses of any type:

- mental illnesses e.g. schizophrenia, depression, autism (27%)
- learning disabilities or disorders (15%)
- dementia (11%)

The remainder are looking after long term deteriorating physical illnesses or physical disability

Most carers (86%) live with the person they care for and, for the vast majority (90% of these), it is in the carer's home; for the remainder, the (single) carer tends to live with the cared-for parent. The 13% of carers who do not live with the cared-for person, tend to be young and caring for older parents for less than 50 hrs per week. Nevertheless, 58% visit daily and only 15% once a week or less.

Carers regularly do a wide variety of tasks. 'Cooking', 'shopping' and 'ensuring appointments are kept' are the most frequent (80%+). 'Dealing with medical staff', and 'organising transport' also are common (70%+). 'Administering medicines', 'managing their money' 'personal tasks', 'getting them to take their medicines', 'washing clothes/bed clothes' occupy more than 60% and even 'physical tasks', 'dealing with the DSS/Housing' 'getting up in the night', and 'coping with bizarre behaviour' involve more than half the carers surveyed. What is more, of those surveyed, 44% are dealing with verbal/emotional abuse and 28% with physical aggression/violence.

There are clearly correlations between these mental illnesses and certain tasks:

- Dementia creates demands because the carers themselves are older. They also frequently have to get up in the night, suffer verbal abuse and have to think and plan for the person they care for.
- Those caring for people with learning disabilities often encounter physical aggression. They also provide a high level of personal care.
- Those caring with people who are suffering from mental illness are often required to cope with bizarre behaviour, verbal and physical abuse. They also often have to take financial responsibility, dealing with benefits on behalf of the person they care for and other practical issues such as housing.

Carers' own health

Overall, 52% say that their health is 'good' (only 7% say it is 'very' good), but 37% say it is 'not very good' and 10% 'not at all good'. Those carers who are caring for people with mental illness and dementia (less so, with learning difficulties) are more likely to say their own health is not very good or not at all good.

Specific activities that are perceived to cause ill health are:

- Getting up in the night (37%) and physical tasks such as lifting (27%)
- Coping with inconsistent/bizarre behaviour and dealing with verbal and mental abuse (27%) and physical aggression (16%)

But even dealing with benefit and housing problems and medical staff (both 16%) is seen to cause health problems.

Health conditions perceived to have been caused by caring responsibilities are:

- Stress/nervous tension: 38%, with a slightly higher level amongst those caring for someone with learning disabilities.
- Depression: 28%, with a slightly higher level amongst those caring for someone with mental health difficulties.
- Anxiety: 27%, with a slightly higher level amongst those caring for those with learning difficulties.
- Back injury: 20%. This is obviously mainly amongst carers doing heavy physical caring for those with physical disabilities, but also is significant higher amongst those people caring for someone with high dependency because of learning disabilities.
- High blood pressure: 10%. Those caring for someone with dementia have this complaint more than other carers.

Within the overall group of carers, depression is more likely among men and 15-34 year olds, and anxiety and high blood pressure is more common among women and those who are older.

There is also wide range of negative emotions experienced by many carers, with a really significant level of each. The most frequent are:

- Mentally/emotional drained (ever 77%; experienced nowadays 70%)
- Frustration (ever 74%; experienced nowadays 61%)
- Sadness for the person (ever 68%; experienced nowadays 56%)
- Physically drained (ever 66%; experienced nowadays 61%)
- Disturbed sleep/sleep deprivation (ever 66%; experienced nowadays 57%)
- Stress/nervous tension (ever 65%; experienced nowadays 61%)
- Anger (ever 59%; experienced nowadays 41%)
- Loneliness (ever 54%; experienced nowadays 46%)
- Guilt (ever 53%; experienced nowadays 38%)

Lack of concentration, headaches, fear, panic attacks, sexual problems are also experienced nowadays by over a quarter of carers. Many of these emotional concerns correlate most with those dealing with dementia, and to a lesser extent those dealing with mental illness.

It is interesting to note that there is a wide variation between those carers experiencing negative emotions ever and those experiencing them when the question was asked, except for experiencing stress/nervous tensions where the gap between the two was quite small.

Concerns and issues for carers

The greatest concern amongst carers, whatever the condition of the person cared for, is worrying about what happens if they (the carer) die or cannot cope because of their own illness and lack of support from the professionals in general (63 and 61% respectively). Over 50% are worried that the illness may go on forever or that they will not have enough money in future (particularly those caring for someone with mental illness or learning disability).

On a more practical note, 47% of carers say they do not understand how to react in certain situations and 40% do not know how to deal mentally with the person, particularly with sufferers from mental illness and dementia. 47% of carers looking after those with mental illnesses are also worrying about the cared-for person self-harming or attempting suicide. Carers, particularly those looking after someone with dementia, also worry that they do not know enough about the condition.

When asked if they ever thought about 'harming' the person that they are caring for, 27% admitted that they thought about it at some point. This was largely out of frustration and stress, rather than actually wanting to stop that person suffering.

Most carers have experience of a wide variety of organisations and people who help them in their caring responsibilities. They are mainly medical, such as GPs, therapists and hospital consultants. Of those, satisfaction is highest with the GPs and lowest with hospital nurses.

Well over 50% have never dealt with social workers, care workers, district community nurses or psychiatric nurses. Of those that have, the district community nurses are seen as most helpful, particularly for carers coping with long term physical disability, dementia/old age. Social workers are seen as the least helpful. The housing department has the worse ratings of any organisation experienced.

Less than half of the carers surveyed had already contacted charities or voluntary organisations, and they are generally satisfied with the help they receive. A carer centre is rated second overall to the GP in terms of support and help (above any hospital, community staff or voluntary organisations for special conditions)

- Specialist schools are the best-rated organisation for learning disabilities.
- The GP and the district nurse, closely followed by care workers, are valued for dementia and old age, although psychiatric nurses are rated third for those caring for someone with dementia.

Carers currently make use of some facilities, but it is by no means widespread and 53% use none of those put into the questionnaire.

- Telephone contact with Carers' Centres (20% ever;14% currently) is rated as most important for those caring for learning disabilities
- Transport facilities (12% currently)
- Visiting regional Carers' Centres (12%)
- Irregular respite arrangements (11%)
- Regular respite arrangements (11%)
- Having a counsellor to talk to (9%) is rated as most important, especially when caring for someone with mental illness
- Being part of a self-help group (8%) especially for those caring for someone with learning disabilities and mental illness

Hours of help required

Carers currently receive an average of four hours help a week, comprising two hours free or paid for by others plus two hours paid for by carer or the cared-for. Those who receive more than average are men, the elderly and those from non-white ethnic groups.

The minimum help perceived to be required to improve carers' own health is a further seven hours a week on average.

Attitudes

The core attitudes to caring are that the outside world does not really understand because there is not enough publicity about caring and carers. Carers worry how long they can carry on without more help (significantly higher amongst those caring for someone with mental illness), and 48% believe that professionals do not spend sufficient time listening to the views of the carer. As carers are reluctant to ask for more help, this can lead to serious difficulties.

Getting paid would relieve some of the pressure say 41%, but the same number do not even know where to go to get more help. Only a third say there are positive aspects to caring and the same proportion that friends are supportive and understanding.

Conclusions

Many carers complain about the fact that nothing is done to raise awareness and understanding of caring.

They are caring for very long periods of time each week (around 60 hours on average) over many years, and they largely live with the person they care for. They are doing many physical, practical and liaison tasks. They consider that certain aspects do correlate directly with their own health problems, particularly getting up in the night/personal care and coping with verbal, bizarre and physically aggressive behaviour.

Nearly half of the total surveyed believe their health is not very good or not at all good, especially amongst those looking after people with mental illness, long-term physical illness and dementia. Ill health manifests itself in both physical and mental complaints – nearly a third claim to suffer from depression. Not only do they have certain diagnosed illnesses but many feel drained and suffer from stress, frustration and sleep deprivation. Just under 30% say they have, at some point, wanted to harm the person cared for, largely out of frustration.

There are serious concerns about the future: their capability of continuing to look after the person (after all, many people they care for are direct relatives), including their financial capability. Specific concerns on what happens to the person if they die, and a lack of understanding about the condition of the person they are looking after, are other reasons for further anxiety and stress.

There is clearly a perceived lack of support from professionals in the medical and community area (less so regarding GPs). In particular, carers are not being sufficiently informed on what to do, and how to react in certain situations.

Those carers who require more help than average tend to have contact with carer centres. Carer centres are as well rated as the GP and are seen to be more useful than many other helpers.

Carers are getting little respite from the caring. At the moment they tend to get only a couple of hours per week paid for by others and a couple paid for by themselves or the person they care for. They say an average of an **extra seven hours** help a week would make a significant difference to their **own** health.