Acquired brain injury: The psychological and physical health effects on carers

Introduction

In spring 2012 Headway undertook a research project designed to examine various aspects of caring for someone with an acquired brain injury. Here we present a summary of the results and their implications.

We set out to analyse the impact caring duties have on carers' psychological, physical, financial and social wellbeing. We also tried to ascertain how much support carers are receiving from statutory services and whether that support is meeting people's needs. In order to do this, we designed a questionnaire hosted on the Survey Monkey website, which people could complete online or on printed copies downloaded from the Headway website.

The response we received was exceptional, with over 350 carers taking part. Headway would like to take this opportunity to thank everyone who took the time to participate and to the Headway Groups and Branches who helped with recruitment. Thanks also to the following organisations for advertising the survey on their websites: Carers Federation, Samantha Dickson Brain Tumour Trust, Different Strokes, Brain and Spine Foundation, Connect, Stroke Association, Encephalitis Society, Epilepsy Society, UKABIF, Meningitis Trust, Epilepsy Action, Carers UK, Princess Royal Trust for Carers and Crossroads Association.

Special thanks go to Professor Alan Tennant and Robin Waxman at the University of Leeds for their invaluable support with putting together the survey scales and analysing the results.

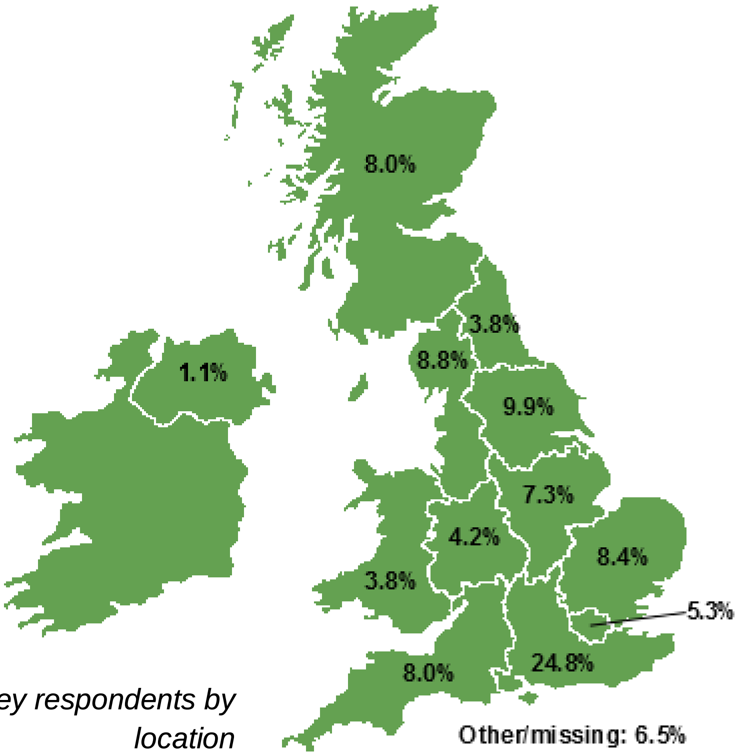
If you would like to discuss any aspect of the research please contact Richard Morris on info.officer@headway.org.uk.

Demographics

The survey was available to anyone providing care for someone with a brain injury, excluding professional carers. We asked a number of questions to help us identify who is providing care, and to find out more about the people they are caring for.

Participants

- 366 people participated in our survey
- 81% of participants are female
- The average age of the participants is 50
- 21% of carers are aged under 40, 56% aged 40-59, and 22% over 60
- Survey respondents were spread throughout the UK



Survey respondents by location

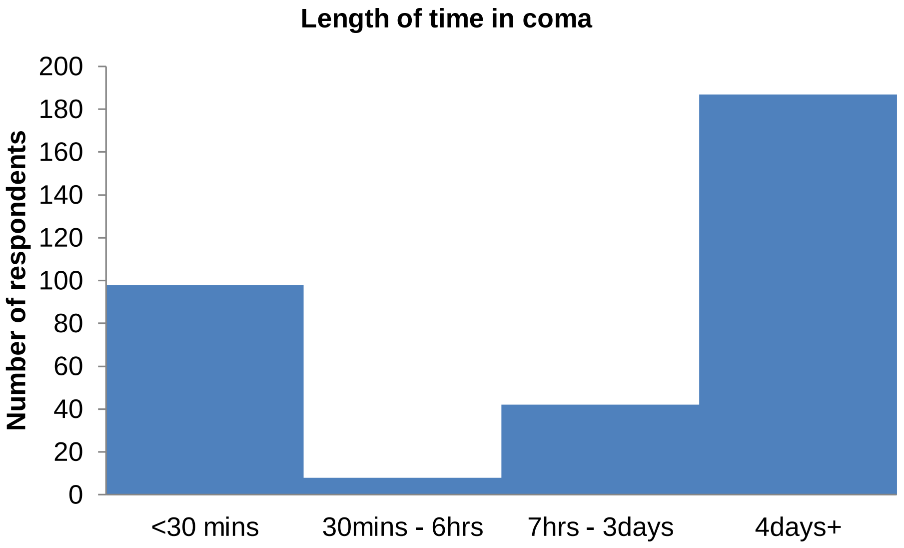
People with brain injury

We asked a number of questions to help us identify characteristics of the people being cared for.

- The mean age of people being cared for is 43
- 68% are male
- 53% of people sustained a traumatic brain injury, while a quarter sustained a stroke
- The majority of people sustained their injury over three years ago, with 10% having lived with a brain injury for over 20 years

Length of time in coma is often used as a measure of injury severity, so questions based on coma duration were designed to indicate people living with minor, moderate or severe brain injuries.

- 62% were in a coma for seven hours or more
- 27% were in a coma for less than 30 minutes



- The amount of care the person receives is not associated with coma duration

These results indicate that even people with seemingly minor injuries can require a high level of ongoing care.

Brain injury causes a wide variety of difficulties, so we attempted to identify the symptoms that people were trying to cope with, and the level of their severity.

- Cognitive symptoms such as memory, concentration and decision making problems are the most commonly reported and severe effects
- The most commonly reported severe symptoms are planning and organisation problems, fatigue and concentration problems

Impact of caring

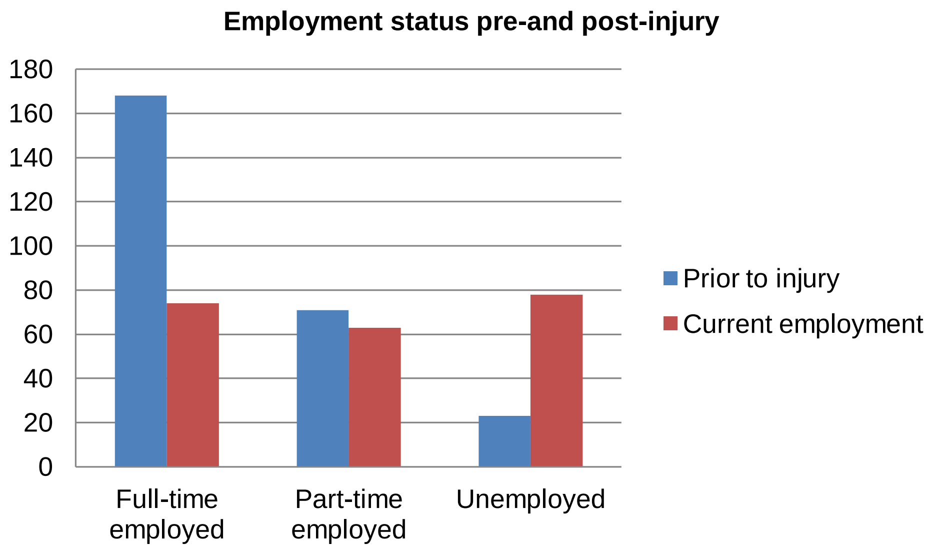
Caring for someone with a brain injury can impact upon almost any area of regular life. We designed a series of questions to look at how people's caring duties had affected their relationships, employment, finances and social life. We also assessed how much help people received from statutory services, friends and family.

Caring and relationships

- 76% of carers live with the person they care for
- 31% of participants are caring for their husband, while 26% are caring for their son
- 34% of participants reported that their relationship status had changed as a direct result of their caring duties
- Two thirds of people felt that their caring duties have placed a strain on their relationship

Changes to employment

- Only 20% of carers are currently in full-time employment, compared to 46% prior to the person's brain injury
- 21% of carers are currently unemployed, compared to only 6% before the person's brain injury



- 20% are currently retired, compared to only 6% before the injury
- 54% of respondents told us that their employment status changed as a result of their caring duties
- 37% of people who were in full-time employment prior to the injury felt they did not receive adequate support from their employer

Financial status

- 71% of carers reported that their financial situation has been adversely affected by their caring duties
- Only 24% of participants receive carers allowance
- Of the carers whose financial situation was adversely affected, 73% still do not receive carers allowance
- The more hours spent caring the more likely that the financial situation is adversely affected

Support from others

- 64% receive less than 21 hours of help per week with their caring duties
- 29% of carers receive less than two hours of help per week with their caring duties
- 60% of brain injury carers feel they do not receive adequate support in their caring duties.
- Just 7% of brain injury carers receive help from social workers

The effect of caring on social life

- 56% of participants feel socially isolated
- 56% of carers have lost friends as a result of their caring duties

Level of care need

- 71% of participants provide care for more than 21 hours a week, with 54% providing care for more than 40 hours a week
- 41% of carers only feel that they will be able to provide care for a maximum of five more years
- 79% of carers believe that the person with a brain injury will not be able to cope when they are no longer able to provide support

Carers' rights

There are currently two pieces of government legislation in place which are designed to ensure carers receive the support they need. Under the Carers and Disabled Children Act 2000, everyone providing a 'regular and substantial amount of care for someone aged 18 or over' has a right to a carer's assessment. Under the Carers (Equal Opportunities) Act 2004 it is a legal requirement for local authorities to ensure carers are made aware of their right to an assessment.

We asked participants to tell us whether they were aware of these rights and whether they had received an assessment.

- Half of participants are unaware that they have a right to a carer's assessment
- Only 27% of participants have had a carer's assessment

Scientific measures

In order to fully analyse the effect caring for someone with a brain injury has on the psychological and physical health of carers, we employed the following battery of validated scientific scales.

Zarit Burden Scale: 12-item version (Bedard et al, 2001)

This scale requires caregivers to indicate the extent of burden experienced while providing care for a loved one.

- Burden is defined as the extent to which a caregiver perceives emotional, physical health, social life, and financial consequences that impairs one's ability to provide care
- Responses range from 'not at all' = 0 to 'extremely' = 4
- Total scores are obtained by summing all items

The range is therefore minimum = 0 and maximum = 48

Table one: Zarit Burden Scale results

Stats	Male	Female	Age <40	40-49	50-59	60+	Total
Mean	22	26	23	25	27	24	25
Min-max	0-48	0-48	2-40	0-48	0-48	1-44	0-48

According to Bedard et al (2001) a score above 16 suggests clinically significant caregiver burden. The mean and median average totals both equal 25, which is well above the clinically significant burden cut off score. This compares to previous research by Higginson et al (2010) which looked at burden scores of caregivers for ABI, cancer and dementia:

Table two: Zarit Burden Scale results by condition

Stats	Cancer	Dementia	ABI
Mean	12.0	15.1	21.7

ABI caregiver scores in both this study and the current Headway research therefore indicate higher burden than for any of these populations.

Depression, Anxiety and Stress Scale (DASS-21) (Lovibond & Lovibond, 1995)

The 21-item measure consists of three separate sub-scales measuring depression, anxiety and stress. Respondents are asked to indicate how much each statement applied to them over the past week. Each sub-scale has seven items each scored from 'Did not apply to me at all' = 0, to 'Applied to me very much, or most of the time' = 3. The range for each sub-scale is 0-21.

Table three: DASS Depression, Anxiety and Stress Scores

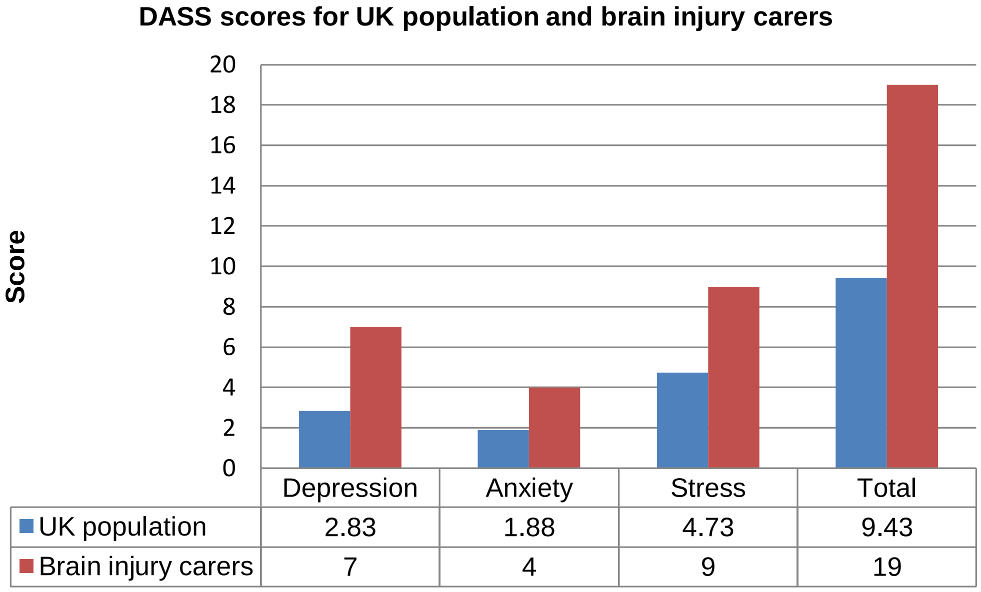
		Male	Female	Total
DASS Depression Score	Mean	6	7	7
	Median	4	6	6
DASS Anxiety Score	Mean	3	4	4
	Median	1	3	3
DASS Stress Score	Mean	8	9	9
	Median	7	8	8
DASS Total Score	Mean	17	20	19
	Median	14	17	17

These compare against the following results from a study of 1,794 members of the general UK adult population.

Table four: General UK population (Henry & Crawford, 2005)

Scale	Mean
Depression	2.83
Anxiety	1.88
Stress	4.73
Total scale	9.43

The chart below shows that the ABI carers scored significantly higher on all measures than the general population.



	Depression	Anxiety	Stress	Total
🟦 UK population	2.83	1.88	4.73	9.43
🟥 Brain injury carers	7	4	9	19

Further context is provided on the following page, by the analysis of clinical cut-off scores for depression within respondents to the current study.

Table five: Depression severity by level of care provided (scores derived by multiplying original scores by two)

	How much time per week do you spend helping the person?							
	<21 hrs		21-40 hrs		>40 hrs		total	
	n	%	n	%	n	%	n	%
DASS Depression - the higher the burden of care the higher the DASS Depression score. (p=0.004)								
Normal 0-9	43	54.4	22	37.3	66	37.3	131	41.6
Mild 10-13	11	13.9	10	16.9	23	13.0	44	14.0
Moderate 14-20	15	19.0	16	27.1	42	23.7	73	23.2
Severe 21-27	4	5.1	4	6.8	17	9.6	25	7.9
Extremely severe 28+	6	7.6	7	11.9	29	16.4	42	13.3
Total	79	100.0	59	100.0	117	100.0	315	100.0
DASS Anxiety - the higher the burden of care the higher the DASS Anxiety score. (p=0.002)								
Normal 0-7	56	70.9	34	57.6	94	53.7	184	58.8
Mild 8-9	7	8.9	5	8.5	11	6.3	23	7.3
Moderate 10-14	9	11.4	10	16.9	28	16.0	47	15.0
Severe 15-19	4	5.1	5	8.5	13	7.4	22	7.0
Extremely severe 20+	3	3.8	5	8.5	29	16.6	37	11.8
Total	79	100.0	59	100.0	175	100.0	313	100.0
DASS Stress - the higher the burden of care the higher the DASS Stress score. (p=0.003)								
Normal 0-14	46	58.2	29	49.2	75	42.4	150	47.6
Mild 15-18	12	15.2	9	15.3	30	16.9	51	16.2
Moderate 19-25	14	17.7	8	13.6	26	14.7	48	15.2
Severe 26-33	6	7.6	7	11.9	25	14.1	38	12.1
Extremely severe 34+	1	1.3	6	10.2	21	11.9	28	8.9
Total	79	100.0	59	100.0	177	100.0	315	100.0

A selection of important results from the DASS-21 is as follows:

- 59% of respondents indicate signs of clinical depression, with 21% in the severe or extremely severe range
- 41% indicate possible clinically significant levels of anxiety, with 18% in the severe or extremely severe range
- 52% indicate possible clinically significant levels of stress, with 21% in the severe or extremely severe range
- The more care provided the higher the average levels of depression, anxiety and stress
- Of those who provide over 40 hours care per week, 26% indicate severe or extremely severe depression, 24% severe or extremely severe anxiety and 26% severe or extremely severe stress

World Health Organisation Quality of Life (WHOQOL-BREF) Physical domain (WHOQOL, Group, 1998)

This scale assesses quality of life within the context of an individual's culture, value systems, personal goals, standards and concerns. The physical domain sub-scale looks at aspects of health and physical activity. It has seven questions with scores calculated on an algorithm. Scores range from 4-20 with higher scores indicating higher quality of life.

Table six: WHOQoL Physical domain: ABI carers and UK general population (n=475) (Skevington, Lofty & O'Connell, 2004)

Population	Mean
ABI carers	14
UK general population	15.8

This indicates a lower physical quality of life on average for ABI carers than among the general population. Further evidence for reduced quality of life is provided by the following results from the Headway study.

- Just 24% of brain injury carers are 'satisfied' or 'very satisfied' with their own health
- A worrying 40% are 'dissatisfied' or 'very dissatisfied' with their own health
- 18% of brain injury carers rate their quality of life as 'poor' or 'very poor'

The feelings of carers

It is important to remember that brain injury carers are not necessarily a homogenous group and the experience of being a carer is very subjective. Different people encounter different problems and cope with them in a variety ways. For this reason, we gauged the more personal thoughts and feelings of our participants by asking for any further comments they would like to make.

The following quotes are reproduced anonymously with participants' permission. They are very powerful and moving, illustrating the challenges carers face every day:

"Even with lots of supportive family and friends it can be extremely lonely".

"I find I become very frustrated with the lack of motivation shown by my husband and I resent being seen as the nag when trying to make him see this behaviour is inappropriate. I become extremely angry at his alcohol consumption as he appears not to appreciate the dangers and how his behaviour deteriorates".

"One thing that continually affects my family is the coming to terms with the change in our family member. The grief of losing someone we still have, but is not the same".

"My husband went from being very active, sporty etc to someone of very low confidence due to physical problems and loss of speech. I have had to take on everything and still find it difficult to accept... I could weep seeing how my husband is now".

"I am devastated that my once excellent marriage has been ruined. I feel more like his mother every day. The thing I miss most is having someone to rely on/lean on - now everything is down to me. I am very bitter about his treatment and the complete lack of care he received. Can't see life ever being good again".

"It drains you and [you] feel you need time away to recharge and be able to carry on with your caring role".

"We have to live on the government money, which we find hard to do. I have not only lost my husband, business, I have lost my worth and identity".

"Due to the support we get from the care agency we are able to do some things we want to. There are times when caring gets too much but when you look back and see how far our son has come, we just thank God that he is alive as he could have died when he had the accident".

"I feel that my experience as a carer is very hard work and I am on call 24 hours a day... but I do find it rewarding even though I don't have a lot of time for myself to do the things I would like to do".

"I love caring for my son and seeing him smile everyday is so heart warming"

Conclusion

The results presented provide a striking illustration of the challenges faced by carers. This sample does not represent all brain injury carers, but the high reported levels of depression, anxiety, stress and burden are nevertheless extremely concerning.

Headway intends to use the data we have gathered to raise awareness of the issues during our 2012 ABI Week campaign. We also intend to further analyse the information and to produce a paper for submission to an academic journal.

It is vitally important that better support is provided for carers by local authority and NHS services. Too many carers are risking psychological and physical health problems because of the strain they are under with little support to alleviate the burden. However, it is also important to remember that in order to get help you have to ask for help.

Carers should try to remember to care for themselves as well as others. It is important to be aware of signs of psychological and physical health problems and to discuss them with a GP. There are a lot of psychological therapy services available in the UK and it will very often be possible for a GP to make an NHS referral to a local therapist.

Further information

For information about depression and what to do about it visit www.nhs.uk/Conditions/Depression/Pages/Introduction.aspx.

For information about anxiety and what to do about it visit www.nhs.uk/conditions/Anxiety/Pages/Introduction.aspx.

For information about stress and what to do about it visit www.nhs.uk/Conditions/Stress/Pages/Introduction.aspx.

References

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