Family Carers Health Survey

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in collaboration with the Carer's Association

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The College of Psychiatry of Ireland
Coláiste Síciatrachta na hÉireann

THE CARERS ASSOCIATION
THERE TO CARE

Background to Study

- Very few Irish studies of carer experience in Ireland

- **Limited by:**

1. Focusing on carers of those people suffering from particular problems
2. Small numbers
3. Sample bias

Nevertheless, found that carers were concerned about their own health and lack of financial supports available.

Background to Study

International Perspective

- ***WHO (Europe) Report on “Lay Participation in Healthcare”***

- **Recommended:**

1. “Research should find the common features of lay groups in different countries and help them to become more effective.
2. Objective research should be fostered which gives comparable data for different societies.
3. There is a need for research into lay participation in professional decision-making”

Background to Study

International Perspective

- ***Princess Royal Trust (UK): "Carers Health Survey"***

- 2002-2003: collected 1066 self-completed questionnaires by carers.

- **Reported**:

a. Carers health and quality of life significantly compromised by caring role.

b. Many carers did not have in place appropriate social, health and financial structure required to adequately carry out their role.

Background to Study

- Collaboration between Public Education Sub-Committee of Irish College of Psychiatrists and Carers Association.

- **Aims:**

1. Obtain an accurate reflection of what lay carers experience while looking after someone with a mental and/or physical disability or other condition.
2. Form a clear picture of the issues, concerns and support required for voluntary carers.
3. Use the results so-obtained to influence forward planning of service delivery to carers by all organisations involved in such care-provision.

Study Method

1. Questionnaire designed to examine the experience of lay carer and effects (if any) on their physical and mental health initiated by PESC and finalised in collaboration with Carers Association.
2. Research Proposal submitted to Research Ethics Committee of the Royal College of Surgeons in Ireland for review and approved.
3. A **random sample** of 10,000 carers identified from Carers Association national database of carers.
4. April 2008: Survey sent to 10,000 carers with return pre-paid SAE.
5. Free-phone help-line set up by Carers Association for carers who may wish to discuss any of the issues raised in the survey.

Results

- 1990 responses received (20% response rate).
- Data entered manually into “Survey Monkey” (online survey management).
- Data downloaded as Excel spreadsheet and converted into SPSS (computerised statistical package) for analysis.
- Results presented as percentages of respondents, with confidence intervals, to allow extrapolation of data to the wider population of carers.

Section A: The Person(s) Cared For (PCR)

Q1: **How many people do you care for?**

Number of People	Percentage (%)	95% Confidence Intervals (CI)
1	**81**	79.7, 83.2
2	**15**	13.4, 16.6
3	1	1.0, 2.2
4	1	0.4, 1.2
5	1	0.3, 1.0

Q2: **Average age of main person cared-for (standard deviation) years**:
62 (28) years; Range: 1-102 years.
Second person: 58 (30); Range: 2-97 years.

Q3: **Gender:** 54% female (CI: 51.3, 55.8)
46% male (CI: 44.0, 48.6)

Q4: Relationship to cared-for person:

Relationship	%	95% CI
Spouse	**26**	24.5, 28.4
Long-term partner	1	1.0, 2.2
Parent	**35**	33.3, 37.6
Grand-parent	1	0.6, 1.6
Sibling	4	3.5, 5.3
Child	**23**	21.6, 25.4
Other relative	6	5.1, 7.3
Non-relative	2	1.3, 2.6

Q5: Do you live with the cared-for person?

Living Arrangement	%	95% CI
Lives with person cared for in carers home	**69**	67.0, 71.1
Lives with person cared for in their home	11	9.8, 12.7
Doesn’t live with person being cared-for	**20**	18.0, 21.6

Q6: For those not living with the PCR, how often they visit to care for them.

Frequency of visits	Percentage (%)	95% Confidence Intervals (CI)
Daily	**79**	74.5, 82.6
2-3 times/week	15	11.8, 18.9
Weekly	4	2.6, 6.8
Less frequently	2	0.9, 3.9

Q7: The medical/mental condition of the PCR

Classification of cared-for person's condition	Percentage (%)	95% Confidence Intervals (CI)
Medical Illness/disorder	**84**	82.8, 86.0
Mental Illness	**39**	36.5, 40.8
Developmental Disorder	21	19.6, 23.3
Addiction	2	1.6, 3.0

Q8: How many others are living in the household of the person being cared-for?

Living in Household	Percentage (%)	Confidence Intervals (CI)
Male Adults		
0	55	52.7, 57.1
1	**32**	30.3, 34.4
2	10	8.3, 10.9
3 or more	3	
Female Adults		
0	66	63.7, 67.9
1	**24**	22.4, 26.2
2	8	6.7, 9.1
3 or more	2	
Children		
0	**80**	78.6, 82.1
1	9	8.1, 10.7
2	7	5.6, 7.8
3 or more	4	

Q9: Do other persons in the cared-for person's household provide care/support for them?

Provide Care/Support to person being cared-for?	Percentage (%)	95% Confidence Intervals (CI)
Yes	35	33.0, 37.9
No	**65**	62.1, 67.0

And, of those who do help/support Carer:

Helps regularly with your caring role	Percentage (%)	95% Confidence Intervals (CI)
Male Adults	**67**	62.7, 70.5
Female Adults	30	26.3, 34.0
Children	11	8.9, 14.2

Summary of information on person being cared-for

- Slightly more likely to be female
- Average age 62 years
- Most likely to be parent of Carer and living in Carer’s home
- The vast majority of those carers not living with person being cared for visit daily
- Most have a medical illness, but mental illness also very prevalent.
- More than half of those being cared-for had only their carer living with them

  - where some-one else living with them, most (65%) did not provide care

  - of those living with them who could help, males were more likely to (be able to) help out.

Section B: Questions about the Carer

Q1: Marital Status:

Marital Status	Percentage (%)	95% Confidence Intervals (CI)
Single	16	14.2, 17.6
Married/Co-habiting	**76**	74.0, 78.0
Divorced/Separated	7	6.2, 8.6
Widow/Widower	1	0.5, 1.5

Q3: Gender:

Gender	Percentage (%)	95% Confidence Intervals (CI)
Female	**82**	80.0, 83.5
Male	18	16.5, 20.1

Q2: Age Group

Age Group (Years)	Percentage (%)	95% Confidence Intervals (CI)
Under 15	0.2	0.0, 0.5
15-24	**0.4**	0.2, 0.8
25-34	3.4	2.7, 4.3
35-44	20.8	19.0, 22.7
45-54	**30.3**	28.3, 32.4
55-64	24.2	22.3, 26.2
65-74	14.0	12.5, 15.6
>75	6.6	5.6, 7.8

Or, alternatively:

0.6% of carers under 25

78.7% of carers between 25-64 years

20.6% of carers over 65 years

Q4: Employment Status:

Employment Status	Percentage (%)	95% Confidence Intervals (CI)
Paid-work full-time	10.3	8.8, 12.0
Paid-work: 20-34 hours/week	8.7	7.3, 10.3
Paid-work <20 hours/week	**16.7**	14.8, 18.7
At College/University full-time	0.7	0.3, 1.3
At school full-time	0.1	0.0, 0.4
Retired	**40.3**	37.8, 42.9
Unemployed	**23.3**	21.1, 25.6

Q5: Ethnic Descent:

Ethnic Descent	Percentage (%)	95% Confidence Intervals (CI)
White/Caucasian	**99.2**	98.7, 99.6
Black-African	0.4	0.2, 0.8
Travelling Community	0.2	0.0, 0.5
Asian	0.1	0.0, 0.5

Q6: Geographical Distribution of Carer sample

County where Carer Lives	Percentage (%)	95% Confidence Intervals (CI)
Dublin	**15.1**	13.5, 16.8
Wexford	**13.6**	12.1, 15.2
Cork	11.1	9.7, 12.6
Tipperary	10.6	9.3, 12.1
Waterford	5.2	4.3, 6.3
Westmeath	4.7	3.8, 5.8

Every county in the Republic - at least one respondent
Ulster: (Donegal, Monaghan, Cavan) = 0.9% (0.5, 1.5)
Munster: 35.8% (33.7, 38.0)
Leinster: 55.1% (52.8, 57.3)
Connaught: 8.2% (7.0, 9.5)

Q7: Length of Time Being a Carer

Length of Time being a Carer	Percentage (%)	95% Confidence Intervals (CI)
Less than 1 year	3.8	3.0, 4.8
1-5 years	**38.6**	36.4, 40.1
6-10 years	**26.7**	24.8, 28.7
11-20 years	18.4	16.7, 20.2
Greater than 20 years	12.4	11.0, 14.0

Q8: Hours per week spent Caring

Hours Spent per week	Percentage (%)	95% Confidence Intervals (CI)
1-9 hours	3.6	2.8, 4.6
10-19 hours	6.1	5.1, 7.3
20-34 hours	**11.0**	9.6, 12.5
35-49 hours	8.6	7.4, 10.0
More than 50 hours	**70.7**	68.6, 72.8

Summary of Information about the Carer

- Vast majority of carers female and married/cohabiting
- Over half between 45-64 years of age; One fifth are over 65 years.
- Most retired and over one fifth are unemployed.
- Almost 40% of all Carers have carried out caring role for between 1 and 5 years; 57% for over 6 years.
- Vast majority (80%) of Carers spend more than 35 hours per week caring.
- 71% of Carers spend more than 50 hours per week caring.

Carer Role & Health

Q9: Tasks done on a regular basis while caring: do they cause ill-health?

Task done regularly	%	C.I.	Cause Ill-Health (%)	C.I.
Cooking/meals	**89.1**	87.6, 90.4	5.2	4.2, 6.4
Domestic	**88.4**	86.9, 89.8	6.2	5.1, 7.5
Deal with services	**83.4**	81.7, 85.0	11.4	9.9, 13.0
Transport tasks	**75.9**	73.9, 77.7	7.6	6.3, 9.1
Manage finances	70.1	68.0, 72.1	8.2	6.8, 9.8
Medical tasks	67.1	65.0, 69.1	6.5	5.3, 8.0
Personal tasks	64.6	62.4, 66.7	14.5	12.6, 16.6
Deal with verbal or emotional abuse	**30.3**	28.3, 32.4	**42.2**	38.2, 46.3
Cope with inconsistent or bizarre behaviour	**36.1**	34.0, 38.3	**40.0**	36.4, 43.7
Get up at night	43.1	40.9, 45.3	**38.5**	35.2, 41.8
Deal with physical aggression	**21.5**	19.7, 23.4	**35.5**	31.0, 40.2
Physical tasks	56.9	54.7, 59.1	**30.8**	28.1, 33.6

Q10: How the Carer described their own health

Description of Health	**Percentage (%)**	**95% Confidence Intervals (CI)**
“Very Good”	17.2	15.5, 19.0
“Quite Good”	**54.1**	51.8, 56.4
“Not very good”	24.1	22.2, 26.1
“Not at-all good”	4.5	3.6, 5.6

71.3% described their health as “very good” or “quite good”.

28.6% described their health as “not very good” or “not at-all good”

Q11: Diagnosed Illness in Carers & has their work as Carer caused or worsened their condition?

Medical Problem	%	C.I.	Caused or worsened their condition (%)	C.I.
Back injury/Backache	**32.6**	30.5, 34.7	**58.6**	54.7, 62.4
Anxiety Disorder	**30.7**	28.7, 32.8	**68.6**	64.7, 72.2
High Blood Pressure	**23.5**	21.7, 25.4	**46.3**	41.7, 50.9
Arthritis	**23.0**	21.8, 25.0	37.8	33.4, 42.4
Depressive Disorder	**20.0**	18.3, 21.8	**66.2**	61.3, 70.8
Osteoporosis	9.8	8.5, 11.2	27.7	21.7, 34.6
Heart Problems e.g., Angina	8.4	7.2, 9.7	33.1	26.1, 40.9
Asthma	8.0	6.9, 9.3	20.7	14.9, 28.0
Peptic Ulcer Disease	7.0	5.9, 8.2	**48.9**	40.4, 57.5
Diabetes Mellitus	5.0	4.1, 6.1	19.0	12.1, 28.3
Other mental disorder	4.0	3.2, 5.0	31.6	21.8, 43.1
Bruising, cuts, injury	2.8	2.1, 3.6	**53.6**	39.9, 66.8
Illness caused by chronic infection e.g., hepatitis	0.6	0.3, 1.1	25.0	6.7, 57.2

Q12: Experiences of the Carer while carrying out their role

Experience	**Percentage (%)**	**95% Confidence Intervals (CI)**
Mentally/emotionally drained	**63.4**	61.2, 65.5
Physically drained	**56.5**	54.3, 58.7
Disturbed sleep/sleep deprivation	**55.3**	53.1, 57.5
Frustration	54.7	52.5, 56.9
Stress/nervousness/panic attacks	42.7	40.5, 44.9
Anger	35.6	33.6, 37.7
Fear	29.1	27.1, 31.2

Q13: What Carers worry about:
a. The person they care-for

Worry	Percentage (%)	95% Confidence Intervals (CI)
"What happens if I die or can't care any longer because of my own illness"	**56.3**	54.1, 58.5
"What happens if they die"	**38.8**	36.7, 41.0
The cared-for person's illness "may go on forever"	**34.8**	32.7, 36.9
Not understanding enough about how to deal with the person being cared-for	22.1	20.3, 24.0
Not understanding enough about the cared-for person's condition	20.5	18.8, 22.4
The cared-for person's self-harming or trying to commit suicide	8.3	7.1, 9.6

Q13: What Carers worry about:

b. Themselves

Worry	Percentage (%)	95% Confidence Intervals (CI)
Not having enough money for the future	46.3	44.1, 48.5
“Money worries as I cannot work/work full-time”	39.8	37.6, 42.0
“Loss of my career/job”	25.9	24.0, 27.9
“No time for personal hobbies/social life”	59.0	56.8, 61.2
“Can’t have normal intimate relations with partner”	30.5	28.5, 32.6

Q14: Has the Carer ever wanted to “harm” or neglect the person cared-for?

“Yes, to stop their suffering”	1.1	0.7, 1.7
“Yes, out of annoyance, anger, stress or tiredness”	8.1	6.9, 9.5
“No, never”	90.8	89.4, 92.1

Summary of Information about Carer Role & Health

- Most Carers (71%) reported their health as “quite good”* or “very good”,
- But, well-over half experienced being mentally & physically “drained” by their role.
- Regular carer tasks most reported to cause ill-health reported as:
  - dealing with verbal/emotional abuse
  - coping with bizarre/inconsistent behaviour
  - getting up in the night
- Over half of Carers had a medical problem (most frequent being back injury)
- Over half of Carers reported a significant mental health problem, the most frequent being anxiety disorder.
- **Anxiety and depressive disorder** reported as the medical conditions most highly associated with their caring role.
- Most carers worried how the person being cared-for would cope if they could not care any longer due to illness/death, and that they had no time for themselves due to caring.

Carer Experience of Services

Q15: Professionals/Organisations encountered in relation to caring

Professional or Organisation	Ever Experienced (%)	C.I.	Ongoing Support (%)	C.I.
General practitioner	**67.0**	64.9, 69.1	**69.1**	68.5, 71.6
Community PHN	**59.3**	57.1, 61.5	58.3	55.4, 61.1
Care workers	**29.4**	27.4, 31.5	**67.9**	63.9, 71.6
Any Carer charity or organisation	28.5	26.5, 30.5	**64.5**	60.4, 68.4
Social workers	13.0	11.6, 14.6	33.7	28.3, 39.9
Special schools	11.0	9.7, 12.5	57.5	50.6, 64.1
Community psychiatric nurse	10.0	8.7, 11.4	52.3	45.1, 59.4
Housing department	7.6	6.5, 8.9	33.0	25.7, 41.1
Religious groups	7.5	6.4, 8.8	58.4	50.0, 66.3
Support groups for mental health problems	4.9	4.0, 6.0	43.9	34.0, 54.3
Ethnic groups	1.0	0.6, 1.6	10.1	1.8, 33.2

Q16: Problems experienced by Carers in relation to services

Response	Proportion (%)	C.I.
No problems with services	13.8	12.1, 15.7
Cannot Access Services	12.2	10.6, 14.0
- no access to any service	**28.8**	22.5, 36.0
- no support for carer (e.g., psychological/support services)	**16.3**	11.4, 22.6
- no financial assistance from government	9.8	8.1, 15.3
- no access to home help/nursing	8.7	5.2, 13.9
- no access to occupational therapy	8.2	4.8, 13.4
Others: SLT, suitable accommodation, necessary supplies & equipment	3.5	2.7, 4.6

Q16: Problems experienced by Carers in relation to services

Response	Proportion experiencing problem (%)	C.I.
Services are inadequate to meet need	**74.0**	71.7, 76.2
- inadequate services “across the board”	**15.2**	13.2, 17.5
- inadequate public health nurse service	**15.3**	13.3, 17.6
- poor/inadequate communication with health-care staff	11.8	10.0, 13.9
- inadequate home-help service	11.7	9.9, 13.8
- inadequate response to requests for help	10.2	8.5, 12.2
Others: lack of understanding of carer needs by Government Agencies/care providers; inadequate information provided to Carers on services provided and their entitlements; inadequate equipment/supplies; lack of respite facilities	11.3	9.8, 13.0

Q17: Do you know whether person you care for has opportunities for respite care?

Opportunities for respite care	Proportion of respondents (%)	C.I.
Response to question	**89.9**	88.4, 91.2
No	42.8	40.6, 45.0
Yes	57.2	55.0, 59.4

If yes, what are those opportunities?

Respite Opportunities	Percentage (%)	95% Confidence Intervals (CI)
Respite not availed of/available		
Cared-for person “refuses to go”	**20.8**	**17.8, 24.1**
Respite not availed of (generally)	**16.7**	**14.0, 19.8**
Respite is not available	**4.5**	**3.1, 6.4**
Respite is available		
Less often than 1 week yearly	4.2	2.8, 6.1
1-7 days per year	5.5	3.9, 7.6
8-14 days per year	15.3	12.7, 18.3
15-28 days per year	**14.3**	11.8, 17.3
29-48 days per year	8.0	6.1, 10.4
More than 48 days per year	8.3	6.4, 10.7
Day hospital respite only	2.1	1.2, 3.6

Q18: The help Carers Receive

Help paid-for by yourself or the person cared-for	Percentage (%)	95% Confidence Intervals (CI)
No extra care received	**83.6**	81.8, 85.2
Up to 4 hours per week	5.8	4.8, 7.0
5-10 hours per week	5.4	4.4, 6.5
11-20 hours per week	2.6	1.9, 3.4
21-40 hours per week	1.8	1.3, 2.5
More than 40 hours per week	0.8	0.5, 1.3

Help which is paid by others	Percentage (%)	95% Confidence Intervals (CI)
No extra care received	**57.6**	55.3, 59.8
Up to 4 hours per week	13.8	12.3, 15.4
5-10 hours per week	16.8	15.2, 18.6
11-20 hours per week	8.1	6.9, 9.4
21-40 hours per week	3.0	2.3, 3.9
More than 40 hours per week	0.7	0.4, 1.2

Summary of Information about Carer Experience of Services

- The services providing the most ongoing support to carers are G.P., care workers & Carer organisations.
- Vast majority (74%) of respondents reported that services made available to them for their role as carer are inadequate.
- 12% of carers reported that they could not access services.
- Just over half of Carers knew whether the person cared-for has opportunities for respite care. The availability of respite was variable. Over one in five respondents reported that the person cared-for refuses to go into respite care.
- While at least half of Carers reported not receiving any extra help with caring, the average amount of weekly help received by Carers is:
  - 4.1 hours (SD 11.3 hours) (paid-for by Carer or person cared-for)
  - 6.8 hours (SD 10.0 hours) (free or provided by others).

What would help Carers?

Q19: “How many extra hours per week would be the minimum you think you would need to improve your own health

Extra help needed to improve own health (hours)	Percentage (%)	95% Confidence Intervals (CI)
No extra care received	**26.0**	23.6, 28.6
Up to 4 hours per week	12.6	10.8, 14.6
5-10 hours per week	34.2	31.6, 36.9
11-20 hours per week	17.1	15.1, 19.3
21-40 hours per week	8.1	6.7, 9.8
More than 40 hours per week	1.9	1.2, 2.9

Min extra hours per week

Average (standard deviation): 9.6 (13.8) hours

Q20: What type of support or help would improve your own health?

Type of support or help which would improve Carers health	Percentage (%)	95% Confidence Intervals (CI)
More home help	**22.0**	20.2, 23.8
“Someone who could mind them for a few hours a day (to allow a break/shopping, etc)	**18.4**	16.8, 20.1
More time-out for myself and for my other relationships	**14.3**	12.8, 15.9
More respite care	11.5	10.2, 13.0
Better domestic help	8.3	7.2, 9.6
More financial help from the government	8.0	6.9, 9.3
Psychological/Group support for Carer	5.2	4.3, 6.3
Better out-of-hours home-help	5.1	4.2, 6.2
More family help	2.7	2.1, 3.5
Better transport facilities	2.4	1.8, 3.2
Better communication and multi-disciplinary teamwork between agencies involved in caring	2.1	1.5, 2.8

Q21: Which of these statements do you agree with?

Statement	Ever Experienced (%)	C.I.
“There is not enough publicity about Carers and caring”	**70.4**	68.3, 72.4
“Outsiders do not really understand about caring”	**58.6**	56.4, 60.8
“I wonder if I can carry on indefinitely, without more help”	**46.9**	44.7, 49.1
“Friends are very supportive and understanding”	40.7	38.5, 42.9
“There are plenty of positive aspects to caring”	37.4	35.3, 39.6
“If I was paid to do the caring, it would relieve some of the pressure”	36.3	34.2, 38.5
“It is against my nature to ask for help”	36.1	34.0, 38.3
“Other family members do not get as much attention as I would like”	35.1	33.0, 37.2
“I only receive help from others which I organise/pay for my-self”	33.7	31.6, 35.8
“I feel that I have the right to ask for all possible help”	32.2	30.2, 34.3
“Professionals do not spend enough time listening to my views”	32.0	30.0, 34.1
“I don’t know where to go to get more help”	25.6	23.7, 27.6
“I feel embarrassed or ashamed to ask for help”	15.9	14.3, 17.6

Q22: Financial/Tax benefits received by Carer and person cared-for

Financial/Tax benefit	Received by Carer (%)	C.I.	Received by person being cared-for (%)	C.I.
No benefits received at-all	**15.6**	14.0, 17.3	5.2	4.3, 6.3
CARER-SPECIFIC BENEFITS				
Respite care grant	**48.1**	45.9, 50.3	3.1	2.4, 4.0
Carers Allowance (including half-rate CA)	**47.4**	45.2, 49.6	2.2	1.6, 3.0
Household benefits package	**18.3**	16.6, 20.1	10.9	9.6, 12.4
Carers benefit	7.1	6.0, 8.3	0.5	0.2, 0.9
Domiciliary care allowance	**3.0**	2.3, 3.9	**----**	8.1, 10.7
OTHER BENEFITS/SUPPORTS				
Death benefit	3.5	2.8, 4.4	9.3	8.1, 10.7
Disability allowance	3.3	2.6, 4.2	11.1	9.8, 12.6
Disability benefit	2.8	2.1, 3.6	6.6	5.6, 7.8
Special needs supplements	1.2	0.8, 1.8	**0.5**	0.2, 0.9
Unemployment benefit	1.1	0.7, 1.7	**0.1**	0.0, 0.4
Family income supplement	1.0	0.6, 1.6	**1.0**	0.6, 1.6
Disablement Benefit	0.7	0.4, 1.2	2.5	1.9, 3.3
Others	2.2	1.6, 3.0	1.1	0.7, 1.7

Note: The old age pension was frequently reported. However it was not reliably specified whether the Carer of the person being cared-for (or both) was receiving this.

Q23: Type of Transport mostly used by Carer

Type of Transport	Percentage using it (%)	C.I.
Car/Van	86.9	85.3, 88.3
Local bus/LUAS/train	6.8	5.7, 8.0
Taxi/private bus	5.5	4.6, 6.6
Local Health board transport	1.4	0.9, 2.0
Other	3.1	2.4, 4.0

Q24: “Is there anything else of relevance to the issue of your health & caring not covered in this questionnaire?”

Issue	Spontaneously reported (%)	C.I.
1. Better & more flexible back-up support services needed Specific issues: Needs should be assessed by multi-disciplinary team and linked-in with appropriate services; home care; appropriate respite care; out-of-normal hours cover; supportive housing; 24-hour helpline for Carers; more locally-based services; provision of home-based psychiatric services; directory of services should be made available to Carer	**26.4**	24.0, 29.0
2. More financial support Specific issues: Carers-allowance should not be means-tested & should be increased; allowances should not be taxed; more allowances should be provided to carers e.g., relating to heating & transport	**21.1**	18.9, 23.5
3. There should be more understanding shown to Carers by: Government authorities, health-care professionals, financial institutions & own family members in interaction	**15.1**	13.2, 17.2
4. Psychological support-services for Carers Specific requests were: specific counselling service; courses in Caring; training; help dealing with family friction	12.9	11.1, 14.9

Q24: “Is there anything else of relevance to the issue of your health & caring not covered in this questionnaire?”

Issue	Spontaneously reported (%)	C.I.
5. The government should show more understanding & acknowledge Carer needs and issues	6.9	5.6, 8.5
6. There should be better opportunities available for social outlets/breaks for Carers	6.5	5.2, 8.0
7. There should be better transport facilities and provision made available to Carers	4.3	3.3, 5.6
8. Full-time Carers should be automatically entitled to a medical card	3.8	2.8, 5.0
9. Family members should help out more	1.2	0.7, 2.0
10. When the cared-for person dies, the Carer should receive help with their future financial planning and with employment	1.0	0.5, 1.8

Q25: “Have you ever received training for your role as Carer?”

Training Received	Proportion of respondents (%)	C.I.
Yes	**21.9**	20.1, 23.8
No	78.1	76.2, 79.9

“If yes, what training did you receive?”

Training	Percentage (%)	95% Confidence Intervals (CI)
Carers Course	**75**	68.2, 81.2
Manual handling/lifting	**22**	16.3, 28.8
Nursing training/experience	20	14.9, 27.1
First aid	11	7.4, 17.3
Palliative care, CPR, injections, medication-training, parenting, community care, managing stress, art therapy	4 (0.5 each)	0.0, 3.5

Q26: “What kind of training would be of help to you, if it were available?”

Type of Training	Proportion of requests (%)	C.I.
1. General training for Caring Role Specific issues: manual handling, hygiene, cooking, feeding, dressing	**51.0**	46.3, 55.6
2. Training in medical matters Specific issues: First aid, drug administration, general medical-care, cardio-pulmonary resuscitation (CPR)	**23.9**	20.1, 28.1
3. Coping Skills Specific requests were: stress management, assertiveness training, dealing with professionals, emotional & physical abuse	**9.8**	7.3, 13.0
4. “I have no need of training”	**9.8**	7.3, 13.0
5. “I have no time for training.. I am exhausted”	5.4	3.6, 8.0
6. Education Specific requests were: understanding & managing the condition of the cared-for person, education & training in psychology, education & training in psychiatry, basic speech therapy, basic physiotherapy, therapeutic massage, exercise training, health & safety in the home	0.2	0.0, 1.4

Summary of what Carers say would help them carry out their role

- At least 9.6 extra hours per-week to improve their own health
- Better and more flexible back-up support services, especially home-help & respite care to allow them to have a break.
- More financial support
- More understanding and “joined-up thinking” between agencies relating to caring
- Psychological support
- The vast majority of carers had never received training to help them carry out their role and would like training made available to them.
- Most carers believe that people do not understand what is involved in caring and that there should be more publicity about caring.

Discussion

- This is the first study in Ireland and UK to examine the impact of lay-caring on the mental & physical health of Carers, using a random sampling method. It is also the largest study of its kind to be carried out in Ireland & UK on Carer experience

- Highlights the real challenges faced by Carers in their role and the effects these have on their mental and physical health

- Provides insights into what changes Carers would like to see addressed in present & future planning of services

Some Recommendations

- Greater government awareness & acknowledgement of the valuable work carers do in the community and the challenges they face

- Improve carer support infrastructure:
  - a dedicated, formal forum where all relevant carer support providers meet plan and organise service provision to carers.
  - a new legal and social framework for dynamic assessment of carer needs according to their circumstances
  - Greater education and training regarding carer role (needs government support)
  - Provision of information on caring supports (social and practical) including available services, to carers

Some Recommendations

- Improvement in carer support infrastructure (involving liaison between government and community organisations)

- Improve awareness of the often adverse effects of caring on health among health professionals - improves detection & treatment of stress-related illnesses
  - improve psychological supports to carers
  - regular liaison & communication among health care practitioners regarding health issues of carers – for example, clear “stepped care approach” to management of mental health issues

- Other suggestions..?

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- The Royal College of Surgeons in Ireland Research Ethics Committee

Thank You for your attention!