

The economic value of caring: a preliminary analysis

David McDaid & A-La Park

Associate Professor, Care Policy & Evaluation Centre, Department of Health Policy, London School of Economics and Political Science, UK

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E-mail: d.mcdaid@lse.ac.uk

Aims

- To capture the value and impacts of informal care for people with mental health difficulties
- Understanding approaches and methods used to value informal care
- Cross-country survey looking at a range of dimensions of impact and value
- Placing results in contexts of other studies on informal care
- Implications for policy and practice

Survey methods

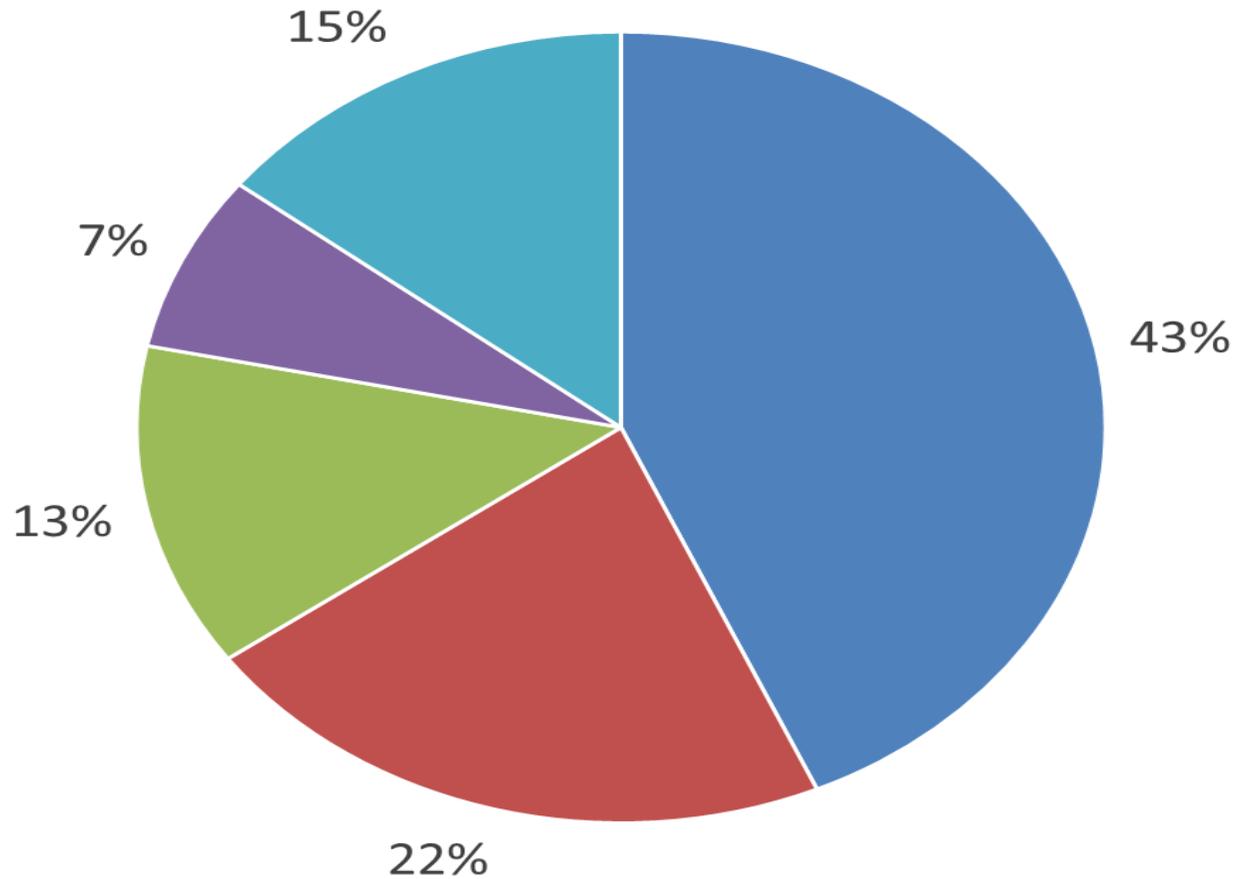
- Online survey predominantly targeted at informal carers in 8 countries: Canada, Denmark, France, Ireland, Italy, Malta, Spain & the UK.
- Comprehensive survey - including several validated instruments.
- Different dimensions of caregiving experience covered: e.g. loneliness, quality of life, time spent caring, value of caring, carer use of health services,
- Placing results in contexts of other studies on informal care

Preliminary Results

Preliminary results

- Ongoing Online survey predominantly targeted at informal carers in 8 countries: Canada, Denmark, France, Ireland, Italy, Malta, Spain & the UK.
- Responses included in preliminary analysis from 108 consenting carers, mainly in Spain, UK and Ireland
- Results here presented for whole cohort as a whole rather than at country level

Caregiver role

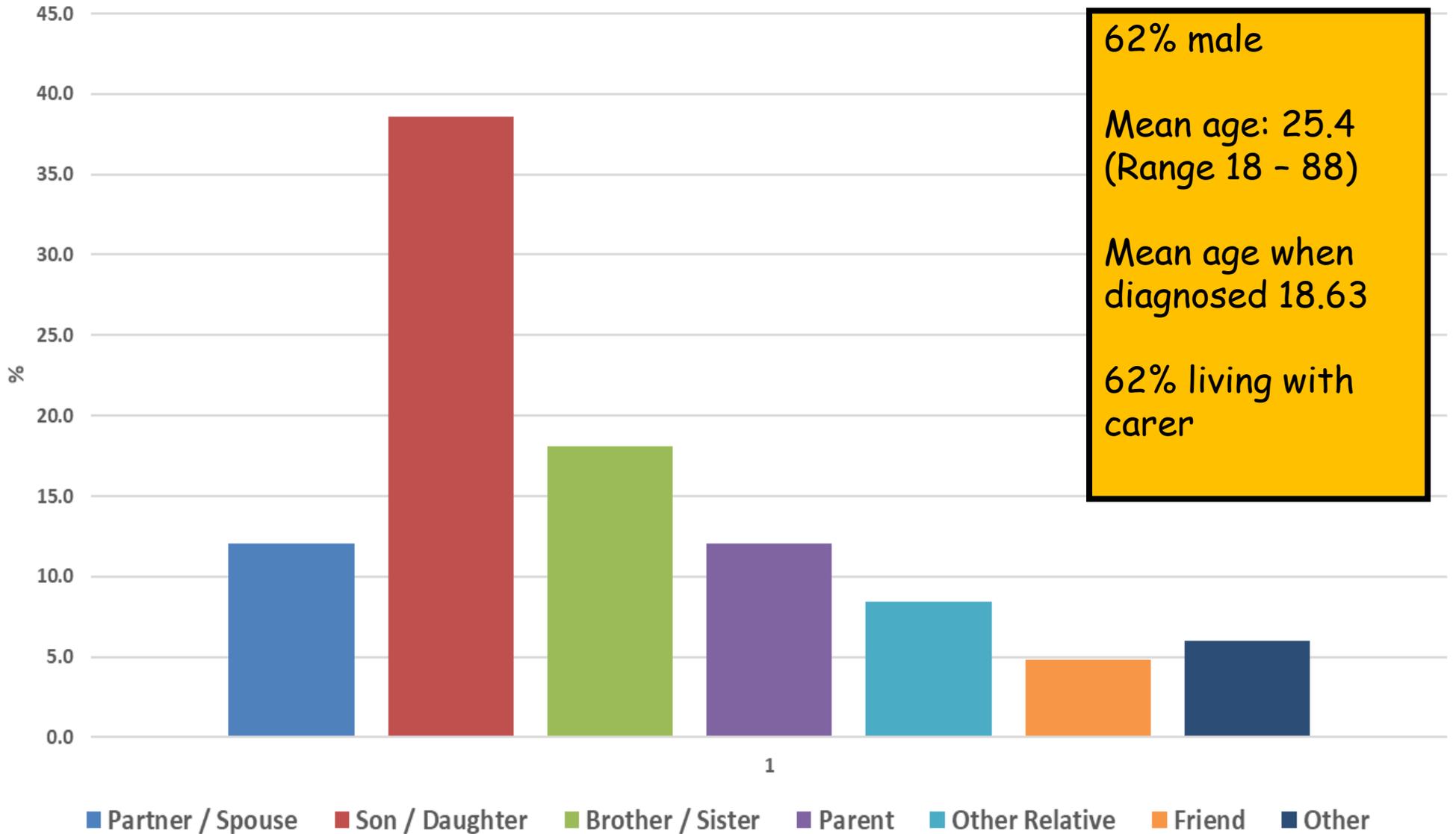


- I am the only unpaid caregiver
- I share caring responsibilities with others, but I am the main unpaid caregiver
- I share caring responsibilities equally with other unpaid carers
- I share caring responsibilities, but someone else is the main unpaid caregiver
- Other

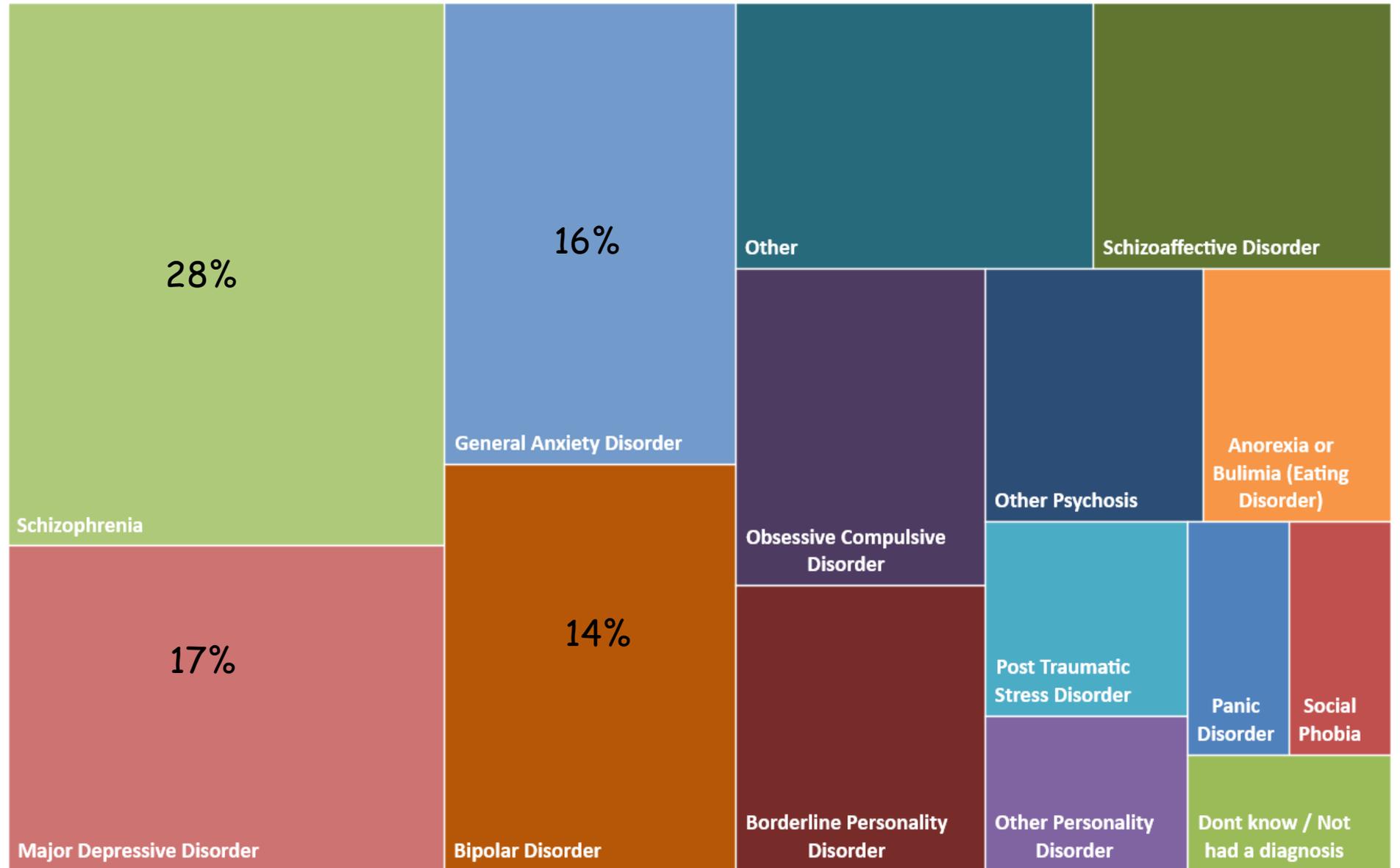
Caregiver Characteristics

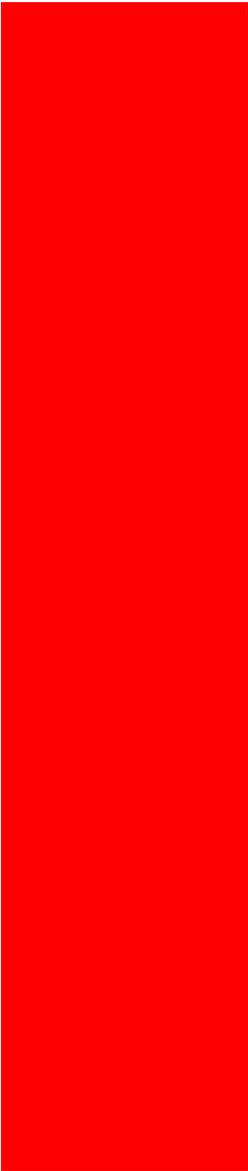
- Men account for 25% carers
- Mean age 38.6 Range: 13 - 80
- 44% married / co-habiting; 32% single; 18% separated / divorced
- 49% carers in employment; 18% retired; 11% registered disabled
- 70% caring for more than 3 years

Person receiving informal care



MENTAL HEALTH PROBLEMS REPORTED





The Economic Value of Time Spent Caring

Value of caring

- One way of identifying value of caring is to ask carers how much either they would be:
- Willing to pay for someone else to provide an extra hour of caring tasks
- Willing to accept in order to provide an extra hour of caring tasks
- Reflects personal values placed on care by carers rather than simply estimating replacement costs

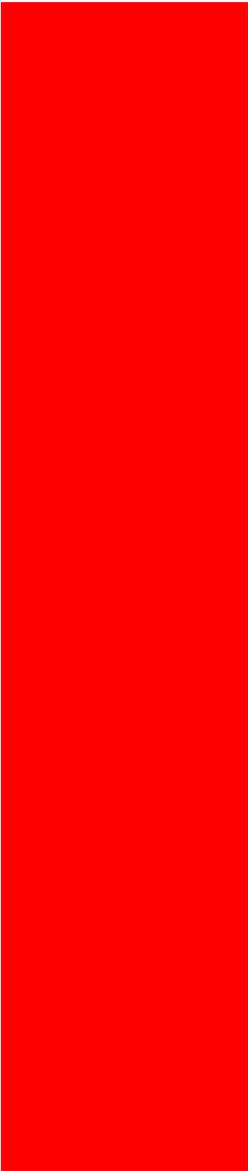
Mean hours of care per week



Mean Hours

- Schizoaffective Disorder
- Bipolar Disorder
- Major Depressive Disorder
- Personality Disorders

- Psychoses
- Overall
- General Anxiety or Panic Disorder

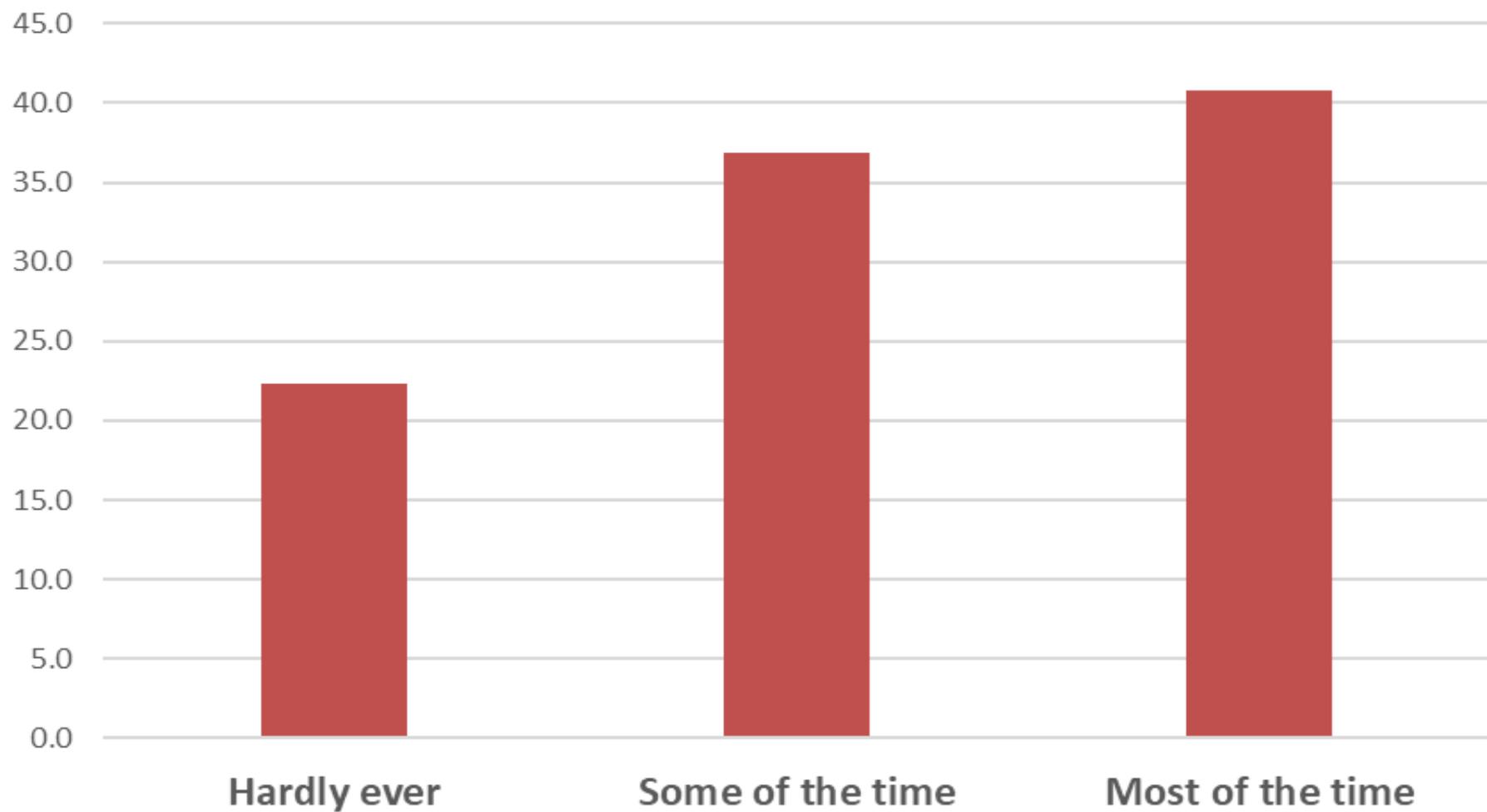


Impacts of caregiving on loneliness

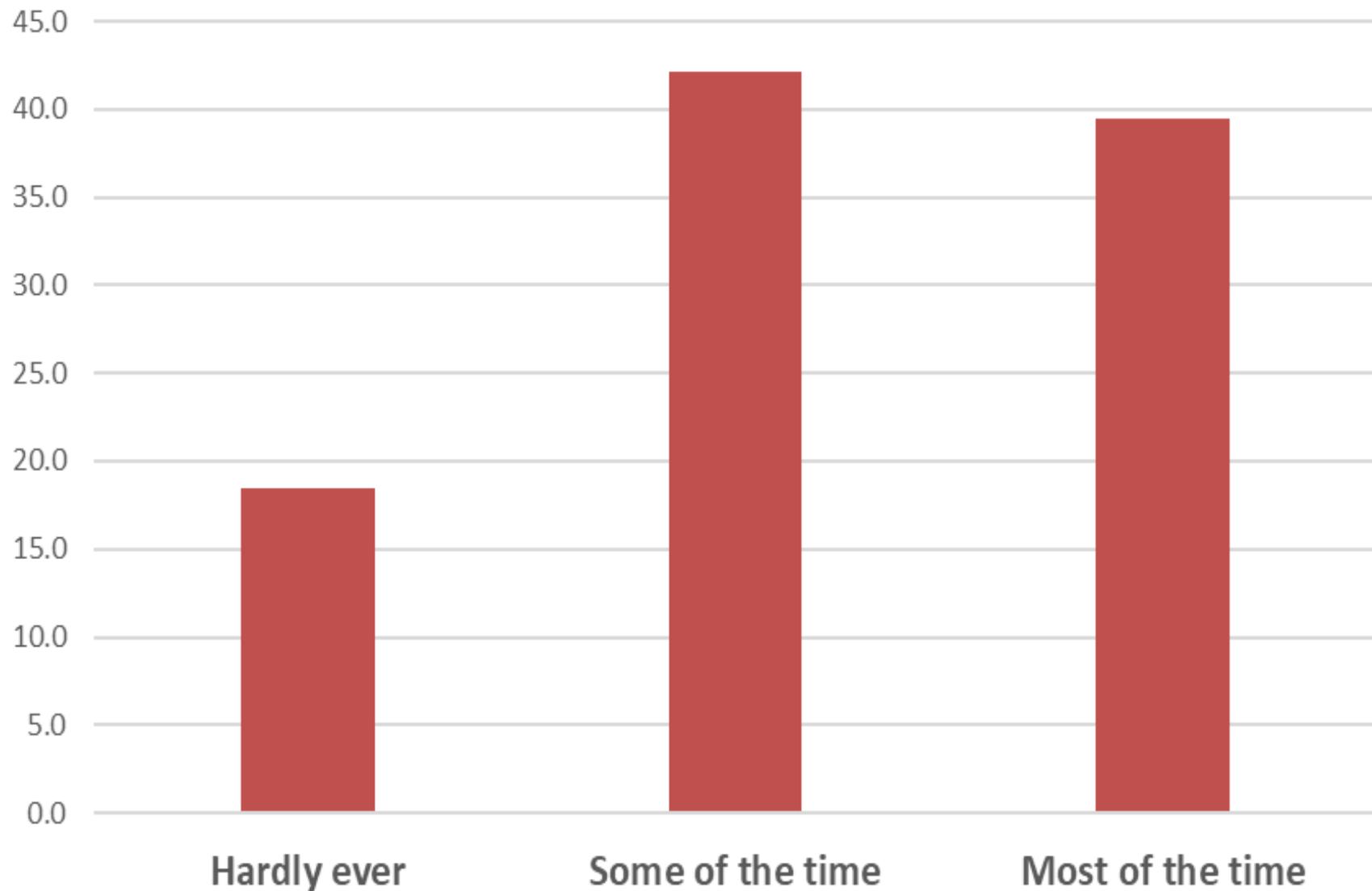
Caring and Loneliness

- Loneliness is associated with higher risks of poor physical and mental health
- Increasingly recognised in policy discussions
- Survey included 3 item short form UCLA-3 loneliness instrument. Used in a number of population surveys in Europe and beyond

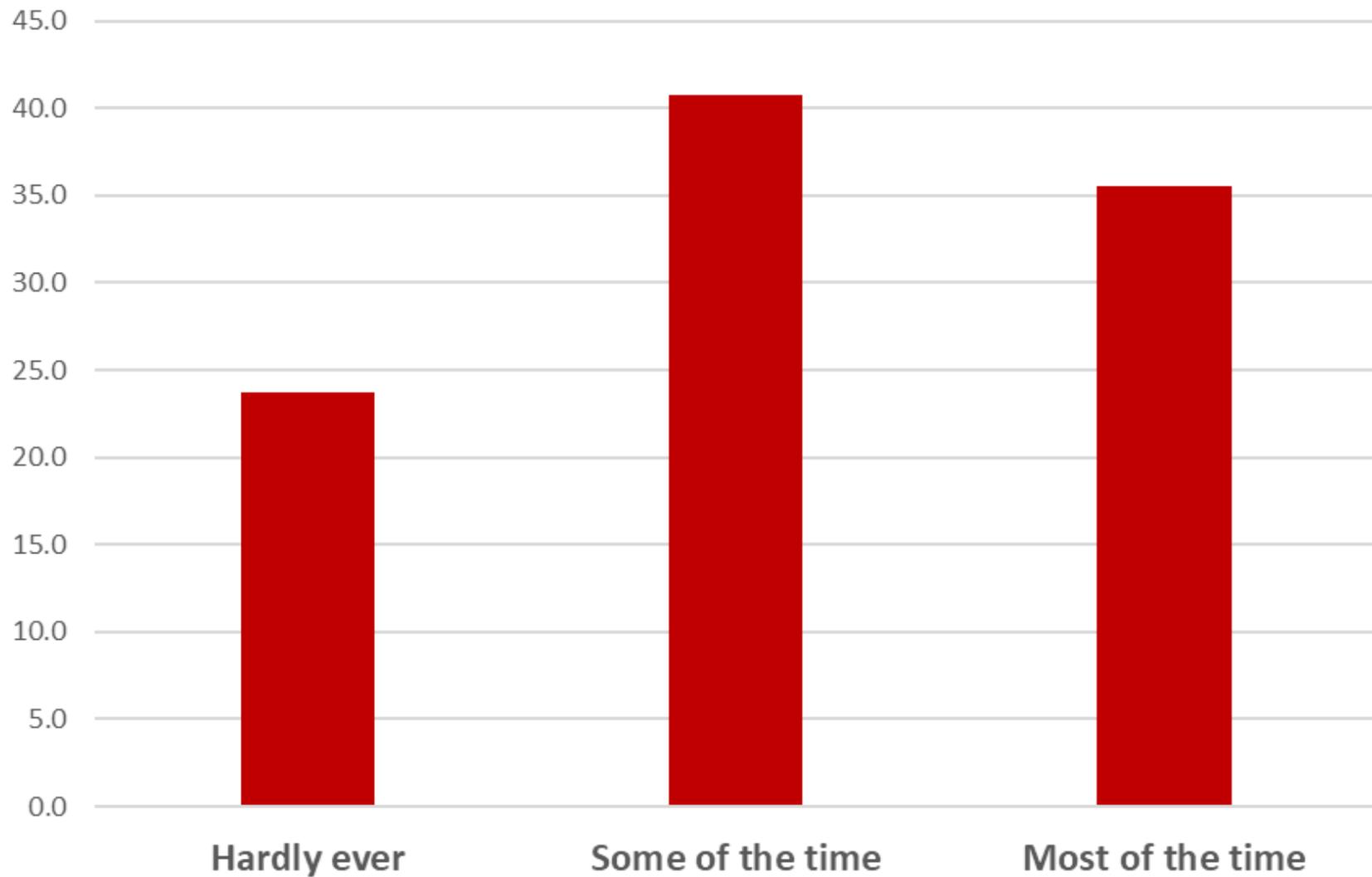
How often do you feel you lack companionship? (%)



How often do you feel left out? (%)

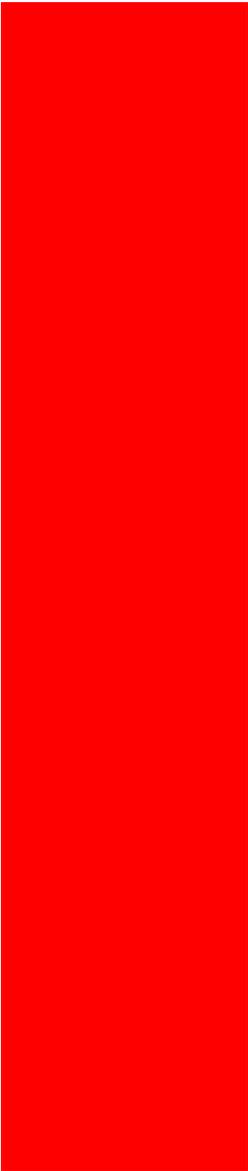


How often do you feel isolated from others? (%)



Caring and Loneliness

- Loneliness scores range from 3 (lowest level of loneliness) to 9 (highest levels of loneliness)
- No consensus on score that indicates substantive loneliness - rule of thumb - 6 to 9 indicates substantive loneliness
- Mean score in our survey is **6.51**
- This is **significantly higher than that seen in general population surveys** in Europe e.g. Finland, Poland and Spain (3.51, 3.79, 3.74) ($p=0.001$) 1,000 bootstrap samples



Impacts of caregiving on quality of life

Caring and Quality of Life

- Survey includes validated CareQOL quality of life instrument specifically focused on 7 different aspects of caring
- Developed in Netherlands; tested and validated in several European countries including UK
- Can be used to generate quality of life scores
 - 0 = worst possible carer quality of life
 - 100 = caring has no detrimental impacts on carer quality of life
- Individuals also rated happiness between 0 & 100

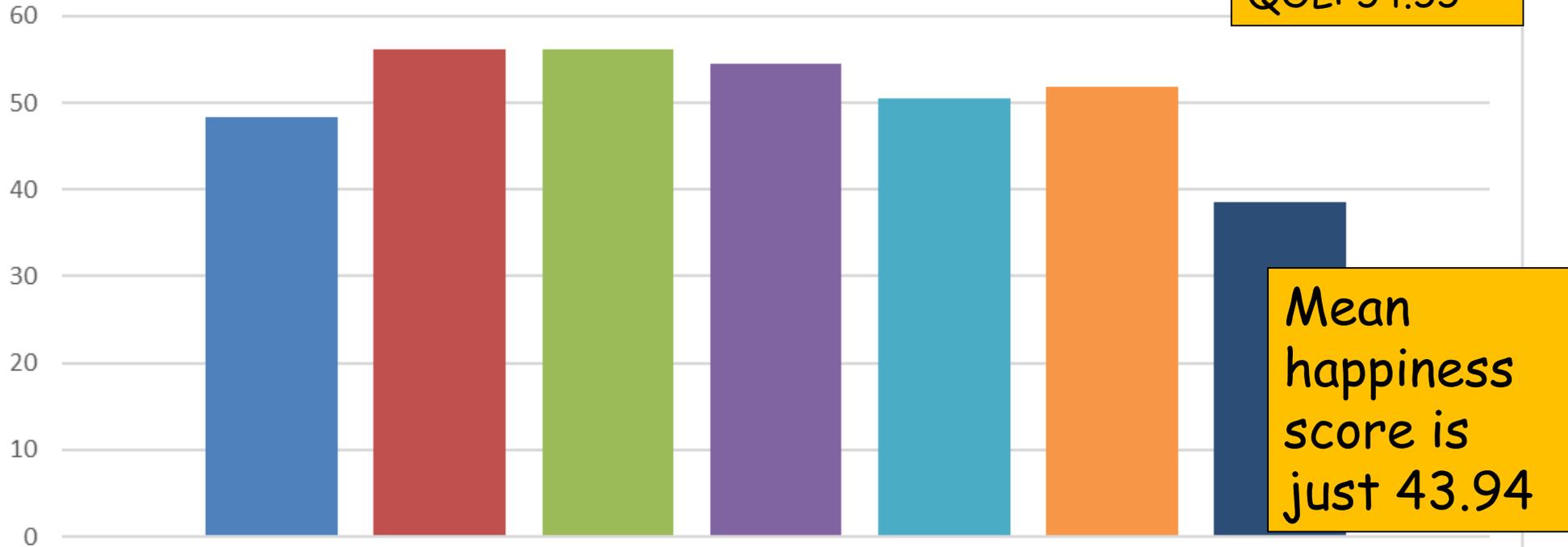
CarerQOL 7-D instrument

↓

	No	Some	A Lot of	
I have				fulfilment from carrying out my care tasks
I have				relational problems with the care receiver (e.g. he/she is very demanding or he/she behaves differently; we have communication problems)
I have				problems with my own mental health (e.g. stress, fear, gloominess, depression, concern about the future)
I have				problems combining my care tasks with my daily activities (e.g., household activities, work, study, family and leisure activities)
I have				financial problems because of my care tasks
I have				support with carrying out my care tasks, when I need it (e.g. from family, friends, neighbours, acquaintances)
I have				problems with my own physical health (e.g. more often sick, tiredness, physical stress)

Mean quality of life scores

Overall mean
QOL: 54.55



Mean
happiness
score is
just 43.94

Mean QOL

Schizoaffective Disorder

Psychoses

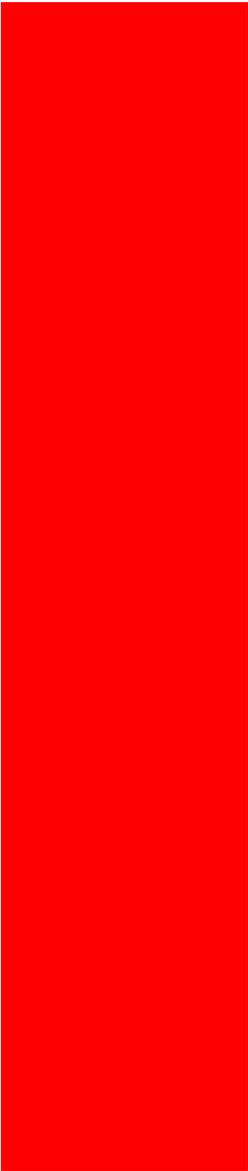
Bipolar Disorder

Overall

Major Depressive Disorder

General Anxiety or Panic Disorder

Personality Disorders



Impacts of caregiving on work, volunteering, leisure and education

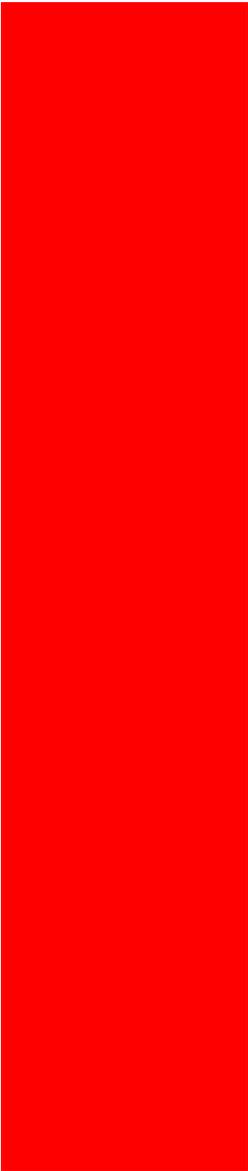
Impact on everyday activities

- 57.4% of carers report reduced work time (mean reduction 22 hours per week)
- 52.2% report reduced volunteering time (mean 7.94 hours per week)
- 46.3% report reduced education opportunities (mean 13.97 hours per week)
- 85.1% reported reduced leisure time (15.78 hours per week)

Impacts on carer health

Impact on carer health

- 80% of carers report contact with primary care doctor in past 3 months
- 29% report contact with social worker in past 3 months
- 23% have formal diagnosed depression or anxiety;
- 33% in contact with mental health professionals for own mental health
- 11% had hospital inpatient stays in past 3 months
- Only 15% of carers have had an assessment of carer needs & 30% receive help from paid carers



Areas where carers
would like help

Carers support needs

- We asked carers to identify top three support needs
- Top priorities
- 53.1% for help with supervision and monitoring
- 50.0% for more emotional support and encouragement
- 50.0% for more help with finances, paying bills, paper work etc

Other observations

Other selected observations

- 46% of carers have a lot of concern for finances of person they are caring for
- 47% of employed carers have a lot or quite a bit of concern over future employment opportunities
- 42% of carers think they will have (or have had) to postpone retirement because of caring
- 61% of carer say relationship with families has been weakened - 28% say this has strengthened
- 23% of carers are caring for more than one person with mental health problems

Informal carers: Key points

- Substantial economic value of informal care
- But vulnerable to adverse substantial impacts for wide range of mental disorders
- Much higher levels of loneliness than general population
- Low quality of life and happiness levels
- Loss of earnings, career and education opportunities

To conclude

- Preliminary findings, but consistent across countries
- Consistent with findings reported elsewhere in literature
- Important to highlight value of informal care
- Important to provide carers with routes to support
- Important to invest in protecting emotional and mental wellbeing of carers