



# EXPERIENCES OF FAMILY CAREGIVERS FOR PERSONS WITH SEVERE MENTAL ILLNESS

## GERMANY

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# IN 2014, AN INTERNATIONAL SURVEY WAS CARRIED OUT TO GET A **CLEARER PICTURE OF THE EXPERIENCES OF FAMILY CAREGIVERS FOR PERSONS WITH A SEVERE MENTAL ILLNESS**



## The study aimed to clarify

- The burden and well-being
- The satisfaction with professional support
- The need for additional support for family caregivers of persons with a severe mental illness

We provide **country-specific results** for those countries with 46 respondents or more

- 1 Interpretation of country-specific findings
- 2 Specific characteristics of the German respondents
- 3 Major challenges according to the German respondents
- 4 International comparison
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  - b. Positive personal experiences of the carer
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- 5 Need for support according to German respondents
- 6 Full data

To download the full report or to obtain more information, please visit: [www.eufami.org](http://www.eufami.org) or [www.kuleuven.be/lucas](http://www.kuleuven.be/lucas)

LUCAS, the Centre for Care research and consultancy of the KU Leuven (University of Leuven), conducted the study in collaboration with the European Federation of Families of Persons with Mental Illness (EUFAMI). The study was a multi-site, cross-sectional survey undertaken in 22 countries (Australia, Austria, Belgium, Canada, Cyprus, Denmark, Finland, France, Germany, Greece, Ireland, Israel, Italy, Malta, Netherlands, Norway, Portugal, Russia, Spain, Sweden, Switzerland and UK). The survey consisted of an anonymous, self-completion questionnaire administered on paper, by email and online. Questionnaires were completed by 1,111 caregivers.

## Interpretation of country-specific findings

In the full report the total sample of family caregivers (N = 1,111) is reported. As indicated in the full report, it is important to be aware that this sample consists of family caregivers that are mainly associated with a family organisation. The results cannot be generalised for all family caregivers of persons with severe mental illness.

For the country reports, we urge extra caution in interpreting the results because of the low number of respondents. Statistical comparisons between countries or between specific countries and the global sample are difficult. It is not possible to infer strong conclusions on the situation in one specific country.

The aim of a country report is to promote discussion within a country and to generate ideas for further research, policy and practice actions. The results can be a trigger to set up a larger, representative study of family caregivers for persons with severe mental illness. They can help further hypothesis building and can inspire the formulation of new research questions or policy recommendations.

## Specific characteristics of the German respondents

This and previous research show that the burden on family caregivers is determined by the characteristics of the relationship, the condition of their illness, and the cohabitation with the family member with a severe mental illness. For this reason, we highlight the raw data on the distribution of the respondents for these three variables.

### Relationship with patient 1 N = 68

<b>Son/daughter</b>	<b>58</b>
Partner/spouse	4
<b>Brother/sister</b>	<b>2</b>
Parent	1
<b>Friend</b>	<b>0</b>
Other	1

### Illness/condition of patient 1

(multiple responses possible)

<b>Psychosis/schizophrenia</b>	<b>53</b>
Bi-polar disorder/manic depression	11
<b>Depression</b>	<b>4</b>
Anxiety	8
<b>Other mental health problem</b>	<b>5</b>

### Living with patient 1

<b>Yes</b>	<b>16</b>
Some of the time	4
<b>No</b>	<b>46</b>

Data are % based on valid responses

## Major challenges according to the German respondents

We selected the three highest and lowest scoring items of burden or dissatisfaction.<sup>1</sup>



**The respondents in Germany are very dissatisfied with or worry very much about:**

### 1 Caregivers' dissatisfaction with support from medical and/or care staff

**Question:** In general, how satisfied are you with how easy it is to get help and support from staff for the person you care for (e.g. to prevent relapse)?

### 2 Caregivers' dissatisfaction with support from medical and/or care staff

**Question:** In general, how satisfied are you with how well the staff you have contact with are communicating with each other (i.e. that they share important information)?

### 3 Caregivers' general well-being: financial situation

**Question:** During the past four weeks, how concerned were you about the financial situation of the person you care for?



**The respondents in Germany are very satisfied with or have very few worries about:**

### 1 Caregivers' satisfaction with support

**Question:** In general, how satisfied are you with the support you received from patient/caregiver organisations?

### 2 Caregivers' general well-being: their emotional well-being

**Question:** During the past four weeks, how concerned were you about lack of sleep caused by the person you care for keeping you awake at night?

### 3 Caregivers' general well-being: stigma and discrimination

**Question:** During the past four weeks, how concerned were you about persons treating you differently because of the illness/condition of the person you care for?

1. Burden is defined as a combination of the answers 'quite a bit' and 'a lot' on the 5-point Likert Scale items. Dissatisfaction is defined in this study as a combination of the answers 'very dissatisfied' and 'somewhat dissatisfied' on the 5-point Likert Scale items.

No burden and satisfaction are likewise defined in this study as a combination of respectively 'not at all' and 'a little', and 'somewhat satisfied' and 'very satisfied' on the 5-point Likert Scale items.

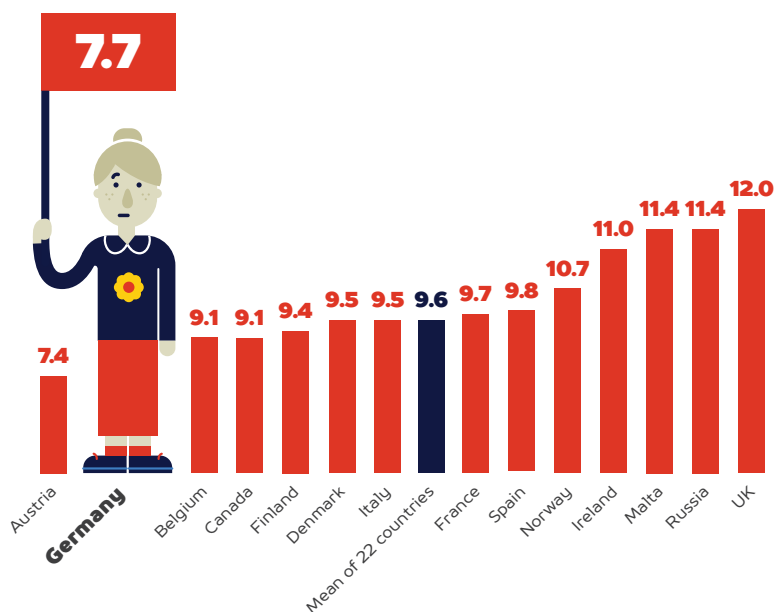


# INTERNATIONAL COMPARISON

## Perceived stigma of family caregivers because they got in contact with professional help

Mean scores on the perceived stigma scale, which consists of the following items:

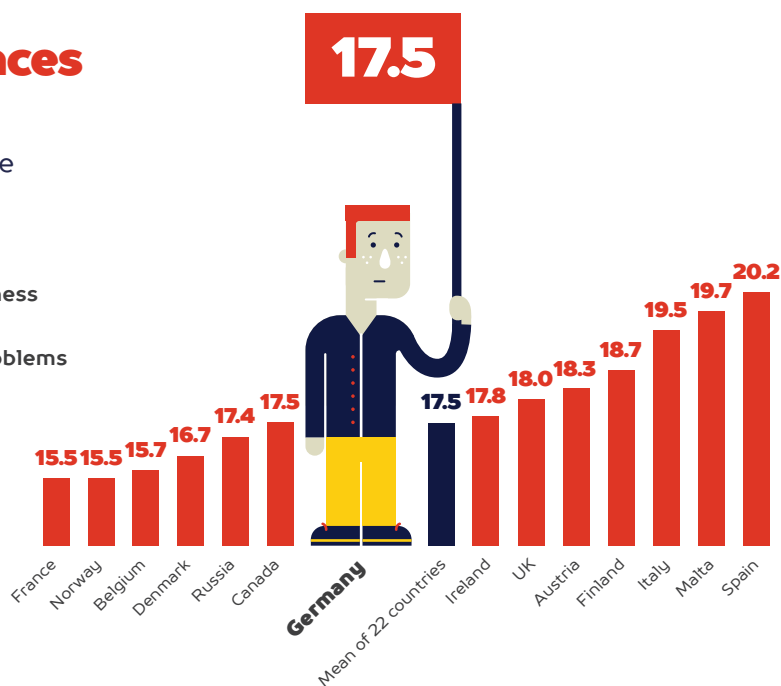
- I started to feel inferior
- I sometimes started feeling useless
- I sometimes am ashamed of this
- I started feeling less capable than before
- I started doubting myself



## Positive personal experiences of the carer

Mean scores on the positive personal experience scale, which consists of the following items:

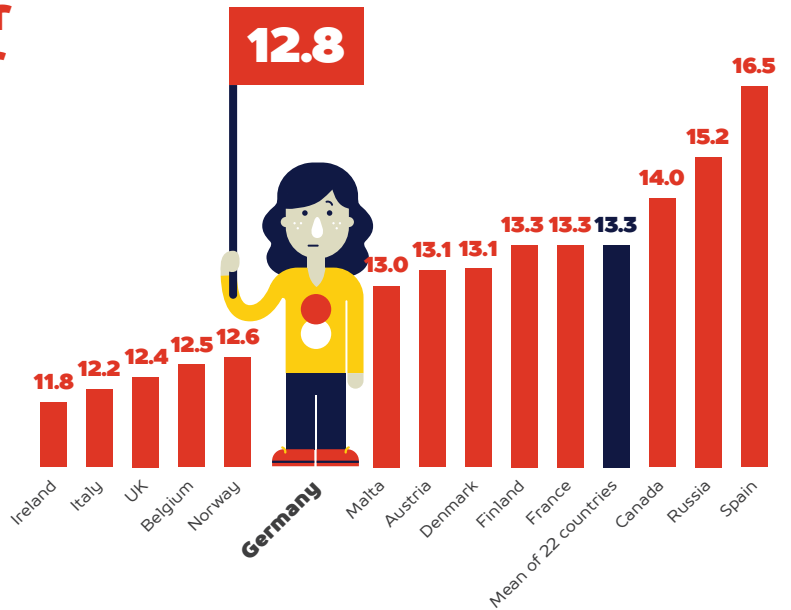
- I have learnt more about myself
- I have contributed to others' understanding of the illness
- I have become more confident in dealing with others
- I have become more understanding of others with problems
- I have become closer to some members of my family
- I have become closer to friends
- I have met helpful persons
- I have discovered strengths in myself



## Good aspects of the relationship between carer and person being cared for

Mean scores on the good aspects of the relationship scale, which consists of the following items:

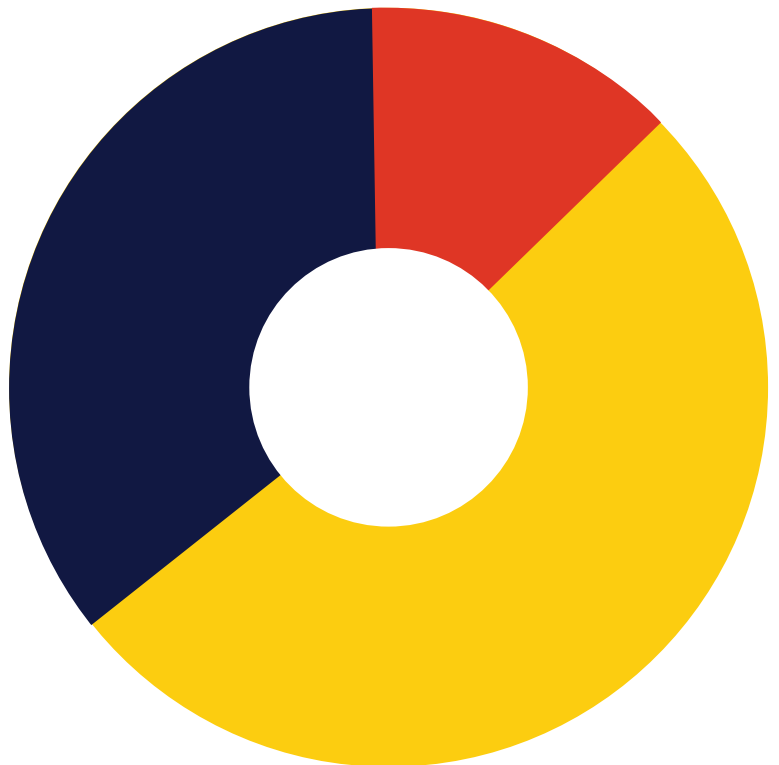
- I have contributed to his/her wellbeing
- That he/she makes a valuable contribution to the household
- That he/she has shown strengths in coping with his/her illness
- That he/she is good company
- I share some of his/her interests
- I feel useful in my relationship with him/her



## Need of support according to German respondents

Need for support for family caregivers of persons with severe mental illness in their role as a carer (N=68)

- No, not at all
- Yes, a little
- Yes, a lot





# FULL DATA

## Socio-demographic and caregiving-related characteristics of family caregivers of persons with severe mental illness in Germany (N=68)

### Age (mean)

Female	51
<b>male</b>	<b>14</b>

### Employment status

<b>Full-time</b>	<b>15</b>
Part-time	10
<b>Self-employed</b>	<b>4</b>
Unemployed	3
<b>Retired</b>	<b>30</b>
Student	2
<b>Unable to work due to caring responsibilities</b>	<b>0</b>
Unable to work due to ill-health/disability	1
<b>Other</b>	<b>0</b>

### Getting by

Getting by is (very) difficult	8
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### How many persons with a mental health problem do you currently care for?

<b>1</b>	<b>50</b>
2	11
<b>3 Or more</b>	<b>4</b>

### Living with patient 1

<b>Yes</b>	<b>16</b>
Some of the time	4
<b>No</b>	<b>46</b>

### Relationship with patient 1

<b>Son/daughter</b>	<b>58</b>
Partner/spouse	4
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Other	1

### Illness/condition of patient 1 (multiple responses possible)

<b>Psychosis/schizophrenia</b>	<b>53</b>
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<b>Other mental health problem</b>	<b>5</b>

### Time caring

Hours spent looking after someone with a mental health problem last week (mean)	19
<b>Years since first started taking care for someone with mental health problem (mean)</b>	<b>16</b>

### Role as a carer

<b>Only caregiver</b>	<b>34</b>
Main caregiver	14
<b>Sharing caring responsibilities equally with others</b>	<b>8</b>
Someone else is the main caregiver	5
<b>Other</b>	<b>3</b>

## Experiences of family caregivers of persons with severe mental illness in Germany (N=68)

“During the past four weeks, how concerned were you about ...” 1 – 2 3 4 5 +

### Your role as a carer

<b>Not having enough time to yourself?</b>	<b>7</b>	<b>12</b>	<b>25</b>	<b>14</b>	<b>8</b>
Having to put the needs of the person you care for ahead of your own needs?	5	12	20	21	7
<b>Not being able to take a break from caring?</b>	<b>8</b>	<b>14</b>	<b>16</b>	<b>18</b>	<b>10</b>
Not being able to plan for the future?	8	9	17	19	12
<b>Not being able to continue caring due to reasons beyond your control?</b>	<b>7</b>	<b>12</b>	<b>20</b>	<b>15</b>	<b>11</b>

### Your relationship with the person you care for

<b>Strain in your relationship with the person you care for?</b>	<b>6</b>	<b>22</b>	<b>10</b>	<b>13</b>	<b>15</b>
The person you care for being too dependent on you at the moment?	7	12	20	16	10
<b>The person you care for becoming too dependent on you in the future?</b>	<b>4</b>	<b>9</b>	<b>14</b>	<b>28</b>	<b>10</b>
The person you care for saying things that upset you?	19	13	11	12	10
<b>Feeling irritable with the person you care for?</b>	<b>13</b>	<b>17</b>	<b>16</b>	<b>10</b>	<b>9</b>
Reaching “breaking point”, where you feel you cannot carry on with things as they are?	8	14	13	16	14

### Your relationship with family and friends

<b>Strain in your relationship with family and friends, because of your caring responsibilities?</b>	<b>15</b>	<b>21</b>	<b>15</b>	<b>9</b>	<b>7</b>
“Drifting apart” from family and friends, because your caring responsibilities limit the time available to keep in contact with them?	12	21	14	17	3
<b>Feeling isolated and lonely because of the situation you are in?</b>	<b>20</b>	<b>15</b>	<b>14</b>	<b>9</b>	<b>8</b>
Not getting the support you need from family and friends?	11	23	15	14	4

### Your financial situation

<b>Your own financial situation?</b>	<b>20</b>	<b>16</b>	<b>14</b>	<b>12</b>	<b>5</b>
The financial situation of the person you care for?	6	11	9	20	20
<b>Having to cover extra costs of caring?</b>	<b>18</b>	<b>14</b>	<b>15</b>	<b>14</b>	<b>5</b>

### Your physical health situation

<b>Your own physical health?</b>	<b>4</b>	<b>18</b>	<b>15</b>	<b>18</b>	<b>12</b>
Your caring role making your physical health worse?	9	18	13	14	13

**Experiences of family caregivers of persons with  
severe mental illness in Germany (N=68) – continued**

	1 –	2	3	4	5 +
<b>Your emotional well-being</b>					
<b>Being unable to cope with the “constant anxiety” of caring?</b>	<b>7</b>	<b>13</b>	<b>17</b>	<b>20</b>	<b>10</b>
Feeling depressed?	10	17	15	15	9
<b>Being unable to see anything positive in your life?</b>	<b>20</b>	<b>18</b>	<b>13</b>	<b>11</b>	<b>4</b>
Lack of sleep brought about through worry or stress?	13	14	16	17	6
<b>Lack of sleep caused by the person you care for keeping you awake at night?</b>	<b>28</b>	<b>23</b>	<b>8</b>	<b>3</b>	<b>4</b>
Feeling so exhausted that you cannot function properly?	16	14	19	11	6

**Stigma and discrimination**

<b>Persons treating you differently because of the illness/condition of the person you care for?</b>	<b>26</b>	<b>20</b>	<b>12</b>	<b>5</b>	<b>4</b>
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**Safety ‘how concerned were you about the person you care for...’**

<b>Accidentally doing something that puts you at risk?</b>	<b>18</b>	<b>20</b>	<b>11</b>	<b>13</b>	<b>4</b>
Being aggressive or threatening towards you?	30	18	7	5	6
<b>Harming themselves?</b>	<b>17</b>	<b>20</b>	<b>15</b>	<b>9</b>	<b>5</b>
Getting themselves into dangerous situations?	11	9	25	13	8
<b>Relapsing or deteriorating, such that it puts their safety at risk?</b>	<b>8</b>	<b>8</b>	<b>21</b>	<b>14</b>	<b>14</b>

Data are N, based on valid responses.

All items use the same 5-point Likert Scale (1=not at all, 2=a little, 3=moderately, 4=quite a bit, 5=a lot).

All items start with “During the past four weeks, how concerned were you about ...”.

**Satisfaction with professional support of family caregivers  
of persons with severe mental illness in Germany (N=68)**

“In general, how satisfied are you with ...”

	1 –	2	3	4	5 +
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**Information and advice for carers**

<b>That you have enough information about the condition/illness of the person you care for to enable you to feel confident in caring for them?</b>	<b>6</b>	<b>23</b>	<b>9</b>	<b>24</b>	<b>6</b>
That you have enough information about how their condition/illness is likely to develop in the longer-term?	6	21	21	16	4
<b>That you can get whatever information you need when you need it?</b>	<b>16</b>	<b>19</b>	<b>14</b>	<b>13</b>	<b>6</b>
With how easy it is to understand the information you have?	3	15	22	21	7
<b>With the amount of advice available to you?</b>	<b>12</b>	<b>15</b>	<b>17</b>	<b>19</b>	<b>5</b>
That you are clear about who to go to for the information and advice you need?	12	22	10	16	10
<b>That you are clear about who to contact if there is an emergency and you need help right away?</b>	<b>13</b>	<b>16</b>	<b>14</b>	<b>17</b>	<b>7</b>
That you are clear about who to call if you have a routine inquiry?	13	10	13	23	8



**Satisfaction with professional support of family caregivers of persons with severe mental illness in Germany (N=68) – continued**

**1 – 2 3 4 5 +**

**Your involvement in treatment and care planning**

<b>Your involvement in important decisions?</b>	<b>25</b>	<b>16</b>	<b>7</b>	<b>18</b>	<b>2</b>
Your ability to influence important decisions?	22	19	7	18	2

**Support from medical and/or care staff**

<b>How easy it is to get help and support from staff for the person you care for?</b>	<b>17</b>	<b>29</b>	<b>9</b>	<b>12</b>	<b>0</b>
How easy it is to get help and support from staff for yourself?	15	27	15	10	1
<b>The quality of help and support from staff for the person you care for?</b>	<b>15</b>	<b>22</b>	<b>16</b>	<b>14</b>	<b>0</b>
Your relationships with key staff who support the person you care for?	19	13	14	18	3
<b>How well the staff you have contact with are communicating with each other?</b>	<b>18</b>	<b>27</b>	<b>15</b>	<b>8</b>	<b>0</b>
How seriously staff take what you say to them?	20	18	11	17	2
<b>The level of understanding staff have of what it must be like to be in your situation?</b>	<b>25</b>	<b>16</b>	<b>16</b>	<b>10</b>	<b>1</b>

**Support you received from**

<b>Doctors?</b>	<b>19</b>	<b>17</b>	<b>16</b>	<b>13</b>	<b>2</b>
Nurses?	20	11	31	7	0
<b>Patient/caregiver organisations?</b>	<b>1</b>	<b>2</b>	<b>11</b>	<b>37</b>	<b>16</b>
Insurance companies?	9	16	29	12	2
<b>Social workers?</b>	<b>8</b>	<b>18</b>	<b>24</b>	<b>17</b>	<b>1</b>
Workplace?	6	7	37	13	5
<b>Pharmaceutical companies?</b>	<b>12</b>	<b>7</b>	<b>46</b>	<b>3</b>	<b>0</b>

Data are N, based on valid responses.  
All items use the same 5-point Likert Scale (1= very dissatisfied, 2= somewhat dissatisfied, 3= not satisfied and not dissatisfied, 4= somewhat satisfied, 5= very satisfied).  
All items start with "In general, how satisfied are you with ...".

**Need of support for family caregivers of persons with severe mental illness in Germany in their role as a carer (N=68)**

Would you like more support to help you in your role as a carer?

<b>Germany</b>	<b>N = 68</b>
<b>No, not at all</b>	<b>10</b>
Yes, a little	33
<b>Yes, a lot</b>	<b>19</b>

Data are N, based on valid responses.