

EXPERIENCES OF FAMILY CAREGIVERS FOR PERSONS WITH SEVERE MENTAL ILLNESS: AN INTERNATIONAL EXPLORATION



Team LUCAS

Bram Vermeulen

Hilde Lauwers

Dr. Nele Spruytte

Prof. dr. Chantal Van Audenhove

Team EUFAMI

Connie Magro

John Saunders

Kevin Jones

Leuven
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Colophon

EUFAMI

The European Federation of Families of People with Mental Illness (EUFAMI) is a European non-profit organisation registered in Belgium that advocates and works on behalf of families and family carers. EUFAMI is recognised as the 'credible voice' of families and carers in Europe. It was founded in 1992 and represents 41 family member associations in 22 European countries and one non-European country. For further information, please visit:

www.eufami.org

LUCAS KU LEUVEN

LUCAS is the interdisciplinary Centre for Care Research and Consultancy of KU Leuven. Its mission is threefold: research, training and consultancy. In all three areas, LUCAS brings together insights from policy, practice and research, and this in constant dialogue with all stakeholders. Over the past twenty years, LUCAS has specialised in a number of crucial topics: social trends in care, care for the (demented) elderly, mental health care, communication in care relationships, and welfare, poverty and social exclusion.

www.kuleuven.be/lucas

Team LUCAS

Bram Vermeulen
Hilde Lauwers
Dr. Nele Spruytte
Prof. dr. Chantal Van Audenhove

Team EUFAMI

Connie Magro
John Saunders
Kevin Jones

Administrative support

Kevin Agten
Lut Van Hoof

Contents

EXECUTIVE SUMMARY.....6

CHAPTER 1

Family caregiving & severe mental illness

- 1** _____ Severe mental illness.....8
- 2** _____ Family caregiving for persons with severe mental illness.....9

CHAPTER 2

Aim & methodology of this study

- 1** _____ Aim of the study.....11
- 2** _____ Research Methods.....12
 - 2.1 _____ Study design.....12
 - 2.1.1 _____ Participants.....12
 - 2.1.2 _____ The questionnaire.....13
 - 2.1.3 _____ Statistical analysis.....14
 - 2.2 _____ Role of the partners.....14

CHAPTER 3

Results

- 1** _____ Caregiver characteristics.....15
- 2** _____ Family caregivers' experiences: perceived stigma, burden and positive caregiving experiences.....17
 - 2.1 _____ Perceived stigma.....17
 - 2.2 _____ Burden.....20
 - 2.2.1 _____ Emotional burden.....20
 - 2.2.2 _____ Social burden.....20
 - 2.2.3 _____ Concerns about safety.....21
 - 2.2.4 _____ Physical burden.....21
 - 2.2.5 _____ Financial burden.....22
 - 2.2.6 _____ Relationship burden.....22
 - 2.2.7 _____ Overview of most frequent burden.....23
 - 2.2.8 _____ Cumulative burden across multiple life domains.....24
 - 2.2.9 _____ Risk factors of caregiver burden.....25

- 2.3** _____ Positive caregiving experiences.....27
- 3** _____ Satisfaction with information, advice & support from professional caregivers.....29
 - 3.1 _____ Satisfaction with support received from different disciplines and parties.....30
 - 3.1.1 _____ Satisfaction with involvement in care.....31
 - 3.1.2 _____ Satisfaction with information and advice for family caregivers.....31
 - 3.1.3 _____ Satisfaction with support from medical and/or care staff.....32
 - 3.2 _____ Risk factors of dissatisfaction with professional support.....32
- 4** _____ The need for support and respite for caregivers.....34
 - 4.1 _____ Unmet need of support.....34
 - 4.2 _____ Expectations of EUFAMI and family member organisations.....35
 - 4.3 _____ Use of respite.....36
 - 4.4 _____ Risk factors for being unable to take a break from caregiving.....37

CHAPTER 4

Summary, conclusions & recommendations

- 1** _____ Summary and conclusions.....38
- 2** _____ Recommendations.....42

REFERENCES AND APPENDICES

References.....43

Appendices.....44

- 1** _____ Family caregiver organisations that distributed the questionnaire.....44
- 2** _____ The Questionnaire.....45

LIST OF TABLES

- Table 1:** Response by country.....12
- Table 2:** Socio-demographic and caregiving-related characteristics of family caregivers of persons with severe mental illness (n=1111).....16
- Table 3:** Mean caregiver scores on the items of the perceived stigma scale.....18
- Table 4:** Univariate and multivariate associations of caregiver characteristics with intensity of perceived stigma as dependent variable.....19
- Table 5:** Overview of most frequent burden of family caregivers of persons with severe mental illness, across life domains.....23
- Table 6:** Illustration of cumulative burden of caregivers across multiple life domains.....24
- Table 7:** Bivariate relations between caregiver characteristics and burden.....26
- Table 8:** Mean scores of family caregivers on the items of the positive subscale of the Experience of Caregiving Inventory.....28
- Table 9:** Univariate and multivariate associations of family caregiver characteristics with intensity of positive caregiving experiences as dependent variable.....28
- Table 10:** Overview of caregiver satisfaction with professional support.....29
- Table 11:** Bivariate relations between caregiver characteristics and dissatisfaction with professional support.....33
- Table 12:** Bivariate relations between caregiver characteristics and being unable to take a break from caring.....37
- Table 13:** Family caregiver organisations that distributed the questionnaire.....44

LIST OF FIGURES

- Figure 1:** Being treated differently (in %, N=1111).....17
- Figure 2:** Perceived stigma (in %, N=1111).....18
- Figure 3:** Emotional burden (in %, N=1111).....20
- Figure 4:** Social burden (in %, N=1111).....20
- Figure 5:** Concerns about safety (in %, N=1111).....21
- Figure 6:** Physical burden (in %, N=1111).....21
- Figure 7:** Financial burden (in %, N=1111).....22
- Figure 8:** Quality of the relationship between caregiver and patient (in %, N=1111).....22
- Figure 9:** Positive caregiving experiences (in %, N=1111).....27
- Figure 10:** Satisfaction with the support received from different disciplines and parties (in %, N=1111).....30
- Figure 11:** Satisfaction with involvement in care (in %, N=1111).....31
- Figure 12:** Satisfaction with information and advice for carers (in %, N=1111).....31
- Figure 13:** Satisfaction with support from medical and/or care staff (in %, N=1111).....32
- Figure 14:** Unmet need of support (in %, N=1111).....34
- Figure 15:** Expectations of EUFAMI and family member organisations (in %, N=1111).....35
- Figure 16:** Taking a break from caring (in %, N=1111).....36
- Figure 17:** Types of support caregivers use to take a break from caring (in %, N=1111).....36

Executive Summary

Family caregivers (relative, family member, non-paid caregiving and support) play a central role in the care of persons with severe mental illness. Following the current mental health reform in developed countries – from hospital-based care to community-based care – the expectations of family caregivers has increased. Scientific survey-based research on the experiences of family caregivers has been done, however results are not recent, is often based on single-country samples, and only covers a limited scope of life domains.

This exploratory study aims to assess the experiences of family caregivers in caring for a relative with severe mental illness, from an international perspective. LUCAS, the Centre for Care Research and Consultancy of the KU Leuven conducted the study in cooperation with the European Federation of Families of People with Mental Illness (EUFAMI). The study is a multisite, 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). Questionnaires were completed by 1,111 family caregivers, caring for a person with a severe mental illness. All these family caregivers are linked with a family caregiver organisation.

Who are the family caregivers of persons with severe mental illness?

The typical family caregiver for a person with severe mental illness participating in this study is a woman around 60 years old caring for her child with schizophrenia.

The typical nature of family caregiving in mental illness is a long-standing (ca. 15 years) and time-consuming task (22 hours a week). Additionally, family caregivers often do not have other relatives to share these caregiving responsibilities with (36% of carers are the only caregiver).

What can be said about caregiving burden, positive caregiving experiences and stigma?

Family caregivers of persons with severe mental illness experience burden on several life domains. One in four feel unable to cope with the constant anxiety of caring (emotional burden), and one in three feel isolated and lonely (social burden). Typical for mental illness are worries about relapse, such that it puts their safety at risk. One third of family caregivers feel that the caring role makes their own physical health worse (physical burden). One in two worries about the financial situation of the person they care for (financial burden) and is also concerned about the person becoming too



dependent on them in the future (relationship burden). One in three family caregivers experience burden on at least three life domains.

Caregiving can also involve positive experiences. Seven out of 10 family caregivers state that they have become more understanding of others with problems, and more than half has discovered inner strength. However, although the experience of caregiving has both negative (burden) and positive (resilience) aspects, this balance is precarious. More than one in three family caregivers are at the point of reaching a 'breaking point'

Several risk factors can be identified. Special attention should be given to female caregivers, younger caregivers and caregivers who have difficulties getting by.

Mental illness carries stigma and these stigmatising processes extend to caregivers. Around 15% of family caregivers feel they are treated differently because of the mental illness of the person they care for.

Are family caregivers of persons with severe mental illness satisfied with the information, advice and support received from professional caregivers?

With regards to 'satisfaction with support' reported by different disciplines and parties, we found that there are two sides to the story. For instance, 39% of the family caregivers are dissatisfied with the support received from doctors, but 39% are satisfied.

There is a similar picture with respect to information and advice available for family caregivers. Family caregivers find information provided easy to understand (58%), and they know who to go to for information and advice (42%), yet we see that one third are dissatisfied with information on who to contact in case of an emergency (36%). Almost half of the family caregivers are dissatisfied with information given on how the illness of their relative will develop in the longer-term (46%). One third of the family caregivers are satisfied with the involvement in, and the ability to influence, important decisions (37–38%), while four in 10 feel dissatisfied about this (43–44%).

All in all, we see that information and advice are appreciated by family caregivers, but that the highest dissatisfaction is present in respect of the support they receive from professionals. Only four in 10 carers feel that medical and care staff takes them seriously. Half of the caregivers are dissatisfied with the ability to seek help and support from professional staff for their own needs. (49%).

Do family caregivers of persons with severe mental illness need other support and respite?

Almost all family caregivers of persons with severe mental illness who participated in this study would appreciate some additional support in their role as a carer (93%), and nearly half would like a significant amount of additional support (46%). If they do use respite, family caregivers rely mostly on friends and family (36%). The use of paid respite care is very low (6–8%).

In summary, this international survey reconfirms that caring for a relative with a severe mental illness like schizophrenia or depression, involves an enormous commitment, leading to a culmination of burden but also to more positive caregiving experiences. Family caregivers acknowledge the information and advice that is offered to them, but are mainly asking for additional support.

These results confront us all with the reality that there is inadequate recognition of caregivers in mental health care. Therefore, we recommend advancing a paradigm shift that views family caregivers of persons with severe mental illness as a resource and a partner in the care requirements of persons with severe mental illness around the world.

This international study focuses on just over 1000 family caregivers of people with severe mental illness who are linked with a family caregiver organization. Research participants filled in a questionnaire about their experiences, well-being and needs.

In the first chapter, we briefly contextualise what is already known about severe mental illness and family caregiving. In the second, we describe the method used in this research, i.e. a quantitative survey. The third chapter contains the results from the survey. Finally, we summarise the main conclusion of this study.

CHAPTER 1: FAMILY CAREGIVING & SEVERE MENTAL ILLNESS



1 Severe Mental Illness

According to the World Health Organization (WHO), “health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity”. Mental health is an essential component of health, and the WHO defines it as “a state of well-being in which every individual realizes his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to her or his community.”

However, many people suffer from severe mental illness and often these conditions lead to chronic disability and impairments. The WHO states that neuropsychiatric conditions are the most important causes of disability, accounting for around one third of Years Lost due to Disability (YLD) among adults aged 15 years and over. The YLD measures the equivalent years of healthy life lost through time spent in states of less than full health.

Estimations indicate that, worldwide, about 151,2 million people have a unipolar depressive disorder, about 29,5 million of people have bipolar affective disorder, and 26,2 million people are diagnosed with schizophrenia (WHO, 2011).

Many people experience depressive feelings at some period in their life, however, the diagnosis of unipolar depressive disorder and severe depression can put serious burden on patients. Depression is the leading cause of burden of disease in high-income countries, representing 10 million of Disability-Adjusted Life Years (DALY's). One DALY represents the loss of the equivalent of one year of full health. Depression is the leading cause of disease burden for women in both high-income and low- and middle- income countries (WHO, 2008).

Bipolar disorder, formerly called manic depression, causes extreme mood swings that include emotional highs (mania or hypomania) and lows (depression). Bipolar disorder is the sixth leading cause of disability worldwide and has a lifetime prevalence of about 3% in the general population. Up to 2% of Europeans will have a bipolar disorder at some point in their life. Bipolar disorder, associated with considerable treatment needs, is associated with a high level of social and occupational burden for both the individual and family in a substantial number of cases (Pini et al, 2005; Tsuchiya et al, 2003; Weissman et al, 1996).

Schizophrenia is another severe mental illness, ‘characterized by abnormal thinking, perceptual disturbances, and diminished or exaggerated emotional expression’ (Fleischhacker et al., 2014). Diagnosis is typically established in adolescence or early adulthood and may lead to long-term support and care in various domains of psychosocial functioning. Incidence of schizophrenia is around 3 per 10.000, but prevalence is higher as schizophrenia is a chronic illness. It affects around 7 per 1.000 of the adult population, mostly those between 15 and 35 years (Chan, 2011). Worldwide, estimates are that schizophrenia affects at least 26 million people (Fleischhacker et al., 2014). Twice as many family caregivers are indirectly affected by this severe mental illness of their loved one. In the European Union, about 5 million people face schizophrenia (Wittchen et al., 2011). The World Health Organization has listed schizophrenia as one of the 10 leading global causes of disability (Murray et al., 1997; Murray et al., 2013).

In summary, severe mental illness such as depression, bipolar affective disorders or schizophrenia are serious conditions that disable the person for a long period of time. Typically, these mental illnesses have a chronic impact; with a circular course of periods in relative health and periods of relapse. People with severe affective or psychotic disorders need lifelong treatment and follow-up, combining medical treatment with rehabilitation and recovery-oriented approaches. These recovery-oriented interventions aim to maintain an optimal quality of life of the patient, despite the severe mental health problems (McGuire et al., 2014).

2 Family Caregiving for Persons with Severe Mental Illness

Traditionally, persons with severe mental illness require intensive treatment and often reside in specialised hospitals. However, in between periods of relapse, most persons with severe mental illness such as schizophrenia or depression live in the community and are cared for by their relatives.

Both in practice, policy and research there is a growing attention to the needs of family caregivers of persons with severe mental illness.

In practice, most of the care given to persons with severe mental illness is provided at home, when people reside in the community. In Western European countries the number of hospital beds for mental health problems has been steadily declining since the 1950s.

Mental health policies, especially those in European countries, are shifting towards more community-oriented care. This policy shift is also reflected in the growing importance of user and family organisations. The WHO Mental Health Atlas clarifies that family associations are present in 80% of the high-income countries and 39% of the low-income countries. In countries with family associations, these organisations frequently participate in legislation formation and in implementation in 38%. About 42% is not routinely consulted and 20% of the family associations are rarely or not consulted (WHO, 2011).

In research, this shift towards more support for persons with severe mental illness in the community, and more attention to the role of family members as caregivers, is also present. For instance, in the early 1950s increased research attention was given to the role of families in the relapse of schizophrenia, with the concept of 'Expressed Emotion' as core theme (Vaughn & Leff, 1985). The recent societal trend for the

reduction of in-patient beds in mental health institutions, and towards the more rapid discharge of the patient from hospital into the community has re-opened the research attention given to the role of family caregivers. There is a new line of inquiry on the experiences of family caregivers, which is in line with the bulk of caregiving research of other patient populations.

Currently, with the advances in treatment, the economic pressures and policy shifts towards community care, the expectation of family members has been profoundly modified. Increasingly, family members are expected to be present, close by and available. The family home has become an additional place for treatment. Frequently, the family is solicited as soon as the patient is discharged; even though he or she is often still in a fragile state, and the responsibility for medication often falls on the family members. In summary, more and more is expected of family caregivers, who have become a pillar in the recovery of the patient alongside formal caregivers (Jungbauer et al., 2003).

Yet, most families are poorly prepared for the increasing demands they face. Research evidence consistently shows that family caregivers of persons with schizophrenia generally lack adequate help and support (Chan, 2011). Overall, family caregivers of persons with severe mental illness experience moderate to high levels of burden (e.g. Caqueo-Urizar et al., 2014; Awad & Voruganti, 2013; Maldonado et al., 2005; Magliano et al., 1998; De Rick et al., 2000).

This concept of caregiver burden has broadened in recent years. The World Federation of Mental Health (2010) also highlights the physical, psychological, social, and financial problems experienced by families caring for a relative with a chronic or mental illness. Significantly, depressive disorders in family caregivers of schizophrenic patients are higher, which could indicate that mental health services should also be directed to the caregivers (El-Tantawy et al., 2010).

In the past decades, various studies have been published regarding the experience of family members of persons with severe mental illness: Fujino N. & Okamura H. (2009), Lloyd M. & Carson A. (2005), Pinfold V., Rapaport J. & Bellringer S. (2007), Rapaport J., Bellringer S., Pinfold V., et al. (2006), Roick C. et al. (2007), Rowe J. (2012), Wilkinson C. & McAndrew S. (2008).

However, a continuous and systematic registration in different Western countries of the experience of these family members, their problems and level of burden, is lacking. Although the family caregivers' experiences in mental illness has been well documented, we lack recent data and it is possible that differences between countries still persist, even after controlling individual or patient characteristics. Cultural

THE CARING FOR CARERS SURVEY REPORT 2015: RESULTS FROM 22 COUNTRIES

differences, on the views of mental illness and care practices, may explain the differing experiences of family caregivers (Bhugra, 2006).

The balance between taking on the role and responsibility as a carer for a relative with severe mental illness and preserving one's own quality of life is fragile. Especially, in the context of severe mental illness, where the caregiving demands are high, cumulative and long-standing, it is of importance to capture the nature of the caregiving burden and potential buffering factors. An updated review on burden on caregivers of schizophrenia patients illustrates that not all caregivers are able to cope with their caregiving role and responsibilities (Caqueo-Urizar et al., 2014). This is a topic of societal debate around the organisation of mental health systems across countries. Policy makers have to find a balance between shifting responsibilities to family caregivers on the one hand and providing support to these caregivers on the other. Some researchers formulate that a call-to-action to better support family caregivers of schizophrenic patients is also sensible from a clinical point of view.

"From a clinical point of view, little attention has been paid until now to the chronic, excessive demands on many parents that often continue for years and strongly influence family life. In practice, the main focus of the work with relatives was

on informing and giving instruction to the family members taking care of the patients during acute illness episodes. The continuous support of relatives of chronic mentally ill people, however, has been neglected in many places and is almost exclusively the responsibility of self-help groups." (Jungbauer et al., 2003, p.133)

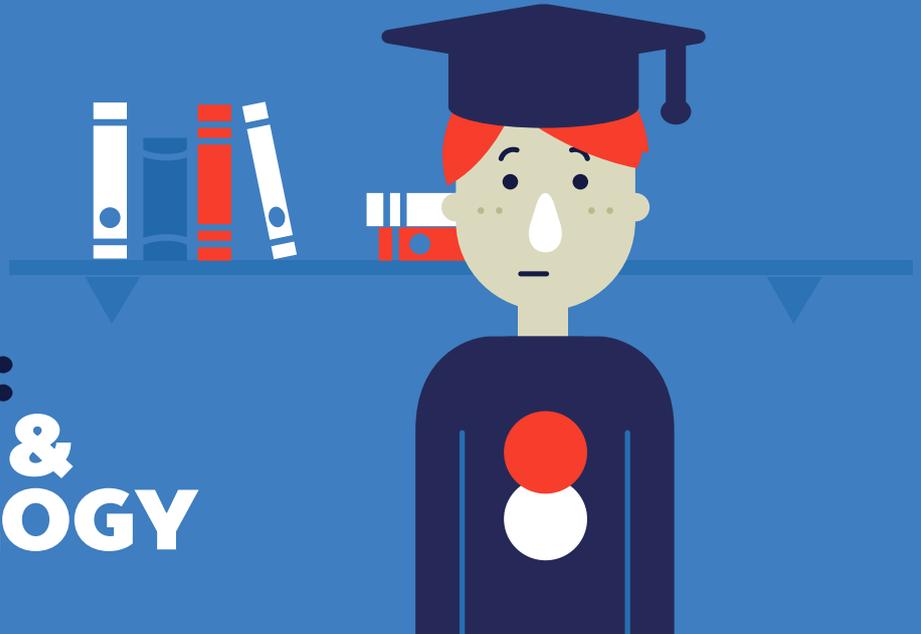
Apart from this burden, family caregivers can also have positive experiences – such as growth in competence, finding inner strength, closer family relationships, etc. These positive caregiving experiences contrast the dominance of the stress-burden model that focuses on the negative aspects of caring (Nolan, 2001).

In summary, it is time for an international exploration of the experiences of family members taking care of a parent, partner or child with severe mental illness like depression or schizophrenia. Such an explorative study can serve as a trigger for deeper investigations on particular experiences, needs and solutions that support these family caregivers in their role.

“The continuous support of relatives of chronic mentally ill people, however, has been neglected in many places and is almost exclusively the responsibility of self-help groups.”



CHAPTER 2: STUDY AIM & METHODOLOGY



1 Aim of the Study

The goal of this international study is an exploratory review of the experiences of family caregivers of persons with severe mental illness. If family members are to become an important partner in the treatment alliance for severe mental illness, we need to expand our knowledge on their care experience, the burdens they face, their needs and necessities, their strengths and support strategies.

It is not the aim to be representative of individual countries, but to be able to capture the collective experiences and therefore the essential needs. Furthermore, the intention was not to be able to grasp the experiences of all family members, since this study was conducted principally amongst family caregivers mainly associated with EUFAMI and its national member organisations. In that way, the results of this study can potentially serve as a basis for more in-depth research, either focusing on specific topics, on a more general population of family caregivers of persons with severe mental illness or on country-specific aspects.

The aim of this research is reflected in three main research questions:

- 1. What are the caregiving experiences of family caregivers, including their well-being, burden, strengths and perceived stigma?*
- 2. How satisfied are family caregivers with the professional support they receive?*
- 3. What are the needs for further support of family caregivers?*

These research questions offer more insight into the family caregiver's role in mental health care. Because of its exploratory nature, no definite answers can be found in this study. Rather it is our intention to serve as hypotheses generation for further research and a trigger for initiatives that support family caregivers of persons with severe mental illness.

2 Research Methods

2.1 Study Design

In order to answer the three main research questions, a survey was developed. The study was a multisite, 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 was an anonymous, self-completion questionnaire administered on paper, by email and online. The design for this study was intentionally pragmatic, using only locally available resources in distributing the questionnaire.

2.1.1 Participants

The survey was distributed to a sample of carers through EUFAMI's member organisations in Europe. Lundbeck and Otsuka were responsible for data collection in Australia and Canada. The questionnaire is available in Danish, Dutch, English, Finnish, French, German, Greek, Italian, Lithuanian, Norwegian, Russian and Spanish. Individuals invited to participate were intended to be representative of the sampling frame, i.e. carers who are linked with a family caregiver organisation. There were no other specific inclusion or exclusion criteria.

With respect to EUFAMI and the process used to distribute and collect the completed questionnaires, the following is a brief summary. EUFAMI identified one or more key contacts at the majority of the European family caregiver organisations detailed in appendix 1 on p44. A detailed explanation of the survey outlining the objectives of the survey, methodology to be used to collect completed questionnaires and delivery method was provided to these contact persons. The local contact persons then distributed the survey amongst their own members and requested that those family carers who were interested should complete the questionnaire. Family carers then started the completion of the questionnaires and returned them to the contact person who then returned the completed questionnaires to LUCAS KU Leuven. In addition, EUFAMI also publicised the survey through its webpage www.eufami.org, where the questionnaire was available for download in the languages already outlined, as well as through its Facebook page and on Twitter. The majority of questionnaires were returned via the countries' family caregiver's associations; a minority were returned to EUFAMI and passed directly to LUCAS KU Leuven.

TABLE 1 Response by country

Country	Respondents
Australia	26
Austria	49
Belgium	93
Canada	106
Cyprus	2
Denmark	146
Finland	48
France	124
Germany	68
Greece	18
Ireland	53
Israel	10
Italy	46
Malta	52
Netherlands	21
Norway	49
Portugal	11
Russia	48
Spain	59
Sweden	7
Switzerland	4
UK	71
Total	1111

It is important to keep in mind that this sample cannot be considered as representative of all family caregivers of persons with severe mental illness in their specific country, as not all caregivers are linked with family organisations.

Lundbeck and Otsuka distributed the questionnaires by open invitation through patient support groups; advertisement through the Mental Health Council of Australia blog; email and request to Mental Health Carers Arafmi Australia, as well as their member organisations and associated groups (e.g. MHCA) to advertise the questionnaire.

Data was gathered at all sites from 1st June to 31st December 2014. **Table 1** gives an overview of the response by country. Questionnaires were completed by 1,111 family caregivers of persons with severe mental illness.

2.1.2 The questionnaire

The questionnaire was developed in collaboration between EUFAMI and LUCAS KU Leuven. EUFAMI suggested the main themes and LUCAS built on previous studies of family caregiving for persons with dementia and schizophrenia (De Rick et al. 2000; Spruytte, et al. 2000). The questionnaire consisted of multiple items on caregiver well-being, burden and stigma; caregiver satisfaction with professional support and the need for further support.

The questionnaire also includes validated scales.

The Experience of Caregiving Inventory (ECI) was used to measure positive caregiving experiences (Szmukler et al., 1996). The ECI is a 66-item self-report measure of caregiving, developed within the stress-coping paradigm, and designed as a simple measure of the experience of caring for relatives of patients with a serious mental illness. Construct validity and internal consistency of the ECI are high (Joyce et al., 2000). The ECI consists of 52 items measuring negative appraisal and 14 measuring positive appraisal. Only the positive subscale is

included in the questionnaire. The ECI measures how often caregivers thought about a specific experience during the past month (e.g., I have become closer to some of my family). Participants rated all items with a 5-point Likert scale, ranging from 0='never' to 4='nearly always'. The overall positive scale score ranges between a minimum of 0 and a maximum of 56, with higher scores indicating more positive experiences.

To measure feelings of perceived stigma, we use a scale of Verhaeghe & Bracke (2007). This scale is a 5-item self-report measure of stigma. All items start with the following sentence: 'Because I got in contact with professional help for the person I care for...'. The 5 items are 'I started to feel inferior'; 'I sometimes started feeling useless'; 'I started feeling less capable than before'; 'I started doubting myself; and 'I sometimes am ashamed for this'. Participants rate all items with a 5-point Likert scale, ranging from 1='totally disagree' to 5='fully agrees'. The overall scale ranges between a minimum of 5 and a maximum of 25, with higher scores indicating more stigma and rejection experiences.



Sociodemographic (age, sex, work status, making ends meet) and caregiving-related information are also recorded (living with patient, relationship with patient, mental illness of patient, hours spent looking after someone with mental health problem last week, years since first started taking care for someone with mental health problem and role as a carer).

2.1.3 Statistical analysis

The main results of this report are for the global sample of family caregivers. It is important to be aware that this sample consists of family caregivers that are mainly associated with a family organisation. The main results cannot be generalised to all family caregivers of persons with severe mental illness.

Additionally we provide separate country fact sheets for those countries with a minimum of 46 respondents and greater. The aim of these separate country fact sheets is to promote in-country discussion and generate ideas for further research, policy and practice actions. These results could be, for instance, a trigger within countries to set up a larger, representative study of family caregivers for persons with severe mental illness.

The country fact sheets are offered to help further hypothesis building and can inspire the formulation of new research questions or policy recommendations. We want to stress the fact that the results presented in the country fact sheets need to be interpreted with caution, because of the low number of respondents. This is also the reason why no statistical comparisons are made between countries or between specific countries and the global sample. It is not possible to infer strong conclusions on the situation in a specific country, because of this low number of respondents, who themselves are limited to family members that are linked with family organisations and thus not representative for all family members of persons with severe mental illness.

In summary, the results presented in this report serve as an international exploration of the experiences of family members of persons with severe mental illness, limited to family members mainly associated with family organisations.

Statistical analyses were completed with SAS version 9.3. All percentages reported are based on valid responses. All items on caregiver well-being and satisfaction with professional support use a 5-point Likert Scale. All figures use colours to visualize negative and positive results. The results of this probability survey are valid within a statistical margin of

error. We use a 95% confidence interval, which means that the margin of error includes the true value of the population in 95 out of 100 surveys. With a sample size of 1,111 the margin of error is at most ± 3 percentage points at 50%.

All p values are two-tailed with an accepted significance level of 0,05. Summary statistics for independent groups were compared with chi-squared test for categorical variables and Mann-Whitney U test for continuous variables with non-

For multivariate analysis, first, we estimated a series of univariable regressions with the dependent variables of interest (i.e. the validated scales) and the following set of potential explanatory variables:

- Gender of caregiver
- Age of caregiver
- Getting by
- Working
- Living with patient
- Relationship with patient
- Hours of caregiving last week
- Years since first started caring
- Role as caregiver
- Number of people with MH problems you care for

Subsequently, we estimated multivariable regression models, introducing as independent variables only those that were significantly associated bivariately ($p < 0,05$) with the dependent variable. We used PROC SURVEYREG (for continuous dependent variables) This SAS procedure incorporates the sample design into the analysis. All models had the cluster option, which specified that the observations were independent between groups (i.e. the 22 countries in this survey), but not necessarily independent within groups.

2.2 Role of the partners

EUFAMI and LUCAS KU Leuven were involved in determining the study design and developing the questionnaire. EUFAMI coordinated data-gathering in Europe. Lundbeck coordinated data-gathering in Australia and Canada. Data-processing, analysis and interpretation, as well as writing of the report were, performed independently by LUCAS KU Leuven. The corresponding authors had full access to all the data in the study.

CHAPTER 3: RESULTS



The results of the survey are presented in four sections. In the first, the characteristics of the participating caregivers are presented. The second describes the experiences of the family caregivers: the perceived stigma, the burden and positive appraisal of caregiving. How satisfied the family caregivers are with professional support is described in the third. The final section highlights the need for support and respite.

1 Caregiver Characteristics

Questionnaires were completed by 1,111 family caregivers (Australia 26; Austria 49; Belgium 93; Canada 106; Cyprus 2; Denmark 146; Finland 48; France 124; Germany 68; Greece 18; Ireland 53; Israel 10; Italy 46; Malta 52; Netherlands 21; Norway 49; Portugal 11; Russia 48; Spain 59; Sweden 7; Switzerland 4; UK 71). **Table 2** shows the overall characteristics of the study participants.

In total, 80% of the carers surveyed were female. The mean age was 58 years ($SD = 13$), with 33% aged over 65 years, 53% aged between 55–64 years and 14% younger than 55. Almost half are retired (43%) and 42% were working (26% in full-time employment, 10% part-time and 6% self-employed). Around 3% were not working due to their role as a carer. One in four caregivers (28%) has difficulties making ends meet.

Almost 1 in 5 (19%) family caregivers care for more than one person with mental health problems. 4 in 10 of people cared for in this survey lived at home with their carer. More than 3

out of 4 (76%) were caring for their son or daughter, 10% were caring for a partner or spouse and 7% for their brother or sister. Around two-thirds (64%) of the persons cared for have psychosis/schizophrenia, followed by bi-polar disorder/manic depression (18%), depression (15%), anxiety (13%) or another mental health problem (18%).

On average, study participants first started caring for someone with mental health problems 15 years ago ($SD = 11$) which emphasizes the long-term consequences of mental illness and being a caregiver. Two-thirds first started caring more than 10 years ago. Caregivers spend an average of 22 hours weekly ($SD = 29$) looking after someone with mental health problems. Six out of 10 spend more than 10 hours weekly caring. Over one third (36%) of caregivers are the only caregiver for their family member. Another third (35%) takes on the role of main caregiver, which means they can share caring responsibilities with others. One in 5 (18%) shares caring responsibilities equally with others.

TABLE 2 Socio-demographic and caregiving-related characteristics of family caregivers of persons with severe mental illness (N=1111)

All Participants ALL PARTICIPANTS N= 1111

Age (years)	58,1 (13,0)
Female	861 (80%)

Employment status

Full-time	271 (26%)
Part-time	108 (10%)
Self-employed	59 (6%)
Unemployed	47 (4%)
Retired	457 (43%)
Student	21 (2%)
Unable to work due to caring responsibilities	36 (3%)
Unable to work due to ill-health/disability	39 (4%)
Other	22 (2%)

Getting by

Getting by is (very) difficult	325 (28%)
---------------------------------------	------------------

How many people with a mental health problem do you currently care for?

1	884 (81%)
2	158 (15%)
3 Or more	46 (4%)

Living with patient

Yes	425 (40%)
Some of the time	117 (11%)
No	508 (48%)

Relationship with patient

Son/daughter	805 (76%)
Partner/spouse	105 (10%)
Brother/sister	72 (7%)
Parent	45 (4%)
Friend	5 (0%)
Other	23 (2%)

Illness/condition of patient (multiple responses possible)

Psychosis/schizophrenia	686 (64%)
Bi-polar disorder/manic depression	191 (18%)
Depression	161 (15%)
Anxiety	135 (13%)
Other mental health problem	195 (18%)

Time caring

Hours spent looking after someone with a mental health problem last week (mean)	21,8 (28,9)
Years since first started taking care for someone with a mental health problem (mean)	15,0 (10,6)

Role as a carer

Only caregiver	370 (36%)
Main caregiver	360 (35%)
Sharing caring responsibilities equally with others	185 (18%)
Someone else is the main caregiver	83 (8%)
Other	22 (2%)

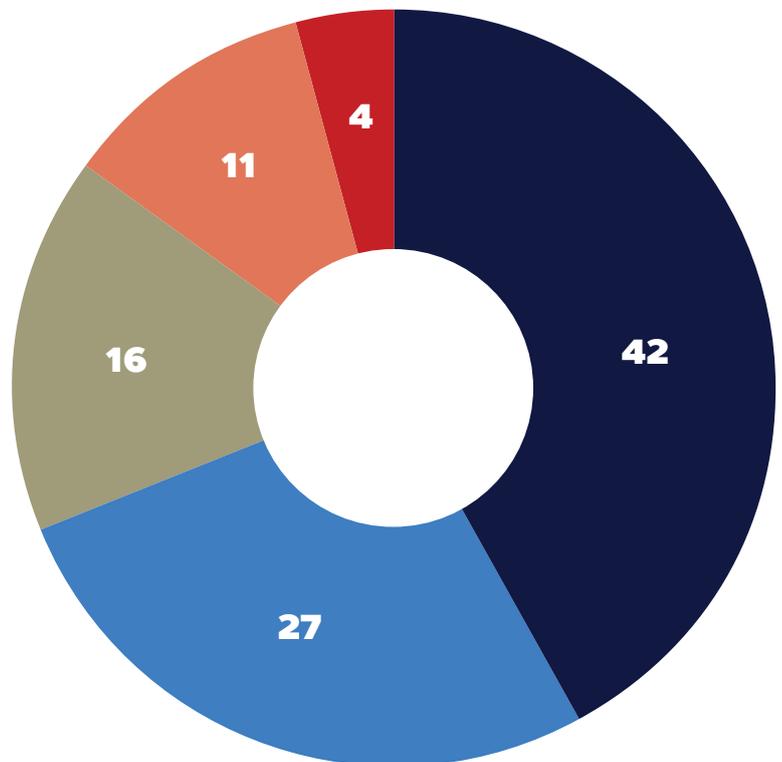
Data are number (%) or mean (SD), based on valid responses.
Total numbers of observations per category do not equal 1111 because of missing responses.

2 Family Caregivers' Experiences: Perceived Stigma, Burden and Positive Caregiving Experiences

In this section the descriptive results of all questions related to caregivers' experiences are presented. Subsequently, the themes of perceived stigma, burden and positive appraisal of the caregiving situation are described. For each of these three themes, we look at risk factors of caregiver burden by analysing the relationship between characteristics of the caregivers.

FIGURE 1 Being treated differently (in %, N=1111)

During the past 4 weeks, how concerned were you about people treating you differently because of the illness/condition of the person you care for?



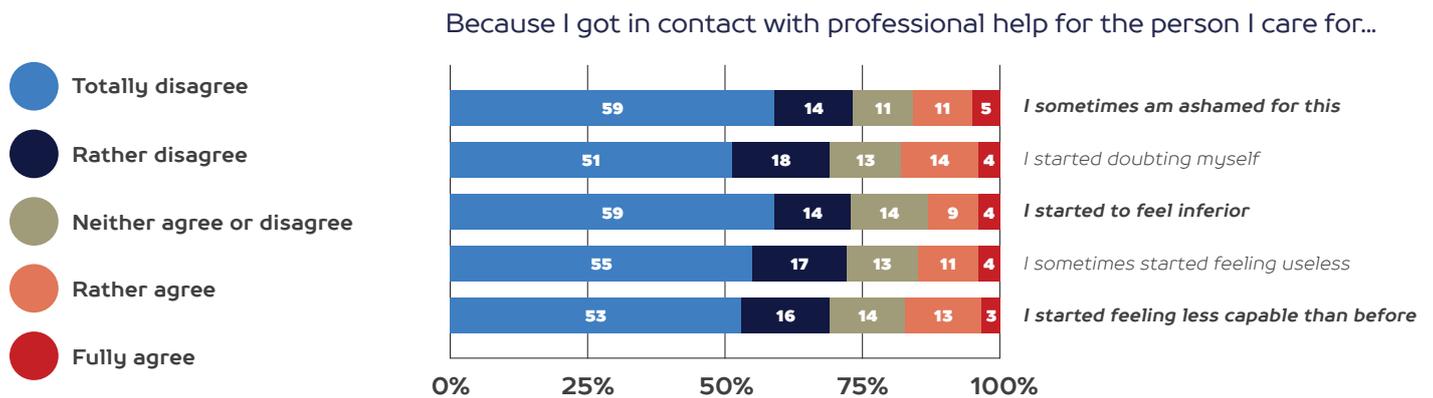
2.1 Perceived Stigma

The stigma of mental illness marks not only the patients, but also their family caregivers. **Figure 1** shows that around 15% of the family caregivers feel they are treated differently because of the mental illness of the person they care for.

Not all caregivers feel empowered by professionals. **Figure 2** shows feelings of perceived stigma of family caregivers because they got in contact with professional help. Some carers began doubting themselves (18%), began feeling less

capable than before (16%), sometimes began to feel useless (15%) and began to feel inferior (13%). More than one in 7 (16%) sometimes feels ashamed because of their contact with professionals.

FIGURE 2 Perceived stigma (in %, N=1111)



The Cronbach's alpha for the 5 items of the self-rejection scale was 0.92. The total mean score of this scale for the family caregivers was 9.6 (SD = 5.3) (n=1094; min=5 max=25). The mean scores for each item are reported in **table 3** below, sorted from low to high.

TABLE 3 Mean caregiver scores on the items of the perceived stigma scale

	MEAN (SD)
I started to feel inferior	1.8 (1.2)
I sometimes started feeling useless	1.9 (1.2)
I sometimes am ashamed for this	1.9 (1.2)
I started feeling less capable than before	2.0 (1.2)
I started doubting myself	2.0 (1.2)

What caregiver characteristics are associated with higher feelings of perceived stigma? Univariate models were fitted with the perceived stigma scale as dependent variable. Participants who experienced most stigma were female; had difficulties getting by; were the only caregiver; and spent

more hours caring last week. In a multivariate model, the variables gender and hours spent caring remained significantly associated with more perceived stigma. Overall, gender and hours spent caring last week accounted for 4.5% of the variance in perceived stigma (*see table 4*).

TABLE 4 Univariate and multivariate associations of caregiver characteristics with intensity of perceived stigma as dependent variable

	Univariable models		Multivariable model	
	Regression Coefficient (95% CI)	P value*	Regression Coefficient (95% CI)	P value*
Male sex	-1.332 (-2.293 to -0.371)	0.00089	-1.255 (-2.180 to -0.330)	0.010
Age	-0.008 (-0.037 to 0.021)	0.582		
Getting by is (very) difficult	1.905 (0.908 to 2.901)	0.001	1.070 (-0.086 to 2.225)	0.068
Working	0.385 (-0.201 to 0.970)	0.186		
Relationship with patient				
Sibling	Ref			
Child	0.512 (-0.634 to 1.658)	0.363		
Friend/other	-0.875 (-2.609 to 0.859)	0.306		
Parent	0.567 (-2.131 to 3.264)	0.667		
Partner/spouse	0.761 (-0.610 to 2.131)	0.261		
Caring for more than one person with mental health problems	0.269 (-0.617 to 1.155)	0.535		
Being the only caregiver	0.970 (0.056 to 1.885)	0.039	0.373 (-0.589 to 1.335)	0.429
Living with patient	0.631 (-0.221 to 1.483)	0.138		
Hours spent caring last week	0.022 (0.011 to 0.034)	0.001	0.019 (0.004 to 0.035)	0.004
Years since first started caring	-0.019 (-0.051 to 0.015)	0.241		

Ref =reference. *Adjusted for clustering by country (22 sites, 1111 participants)

2.2 Burden

The burden of caregiving consists of burden on several life domains. First, the descriptive results are presented. Then, the most frequent burdens faced by caregivers are summarised.

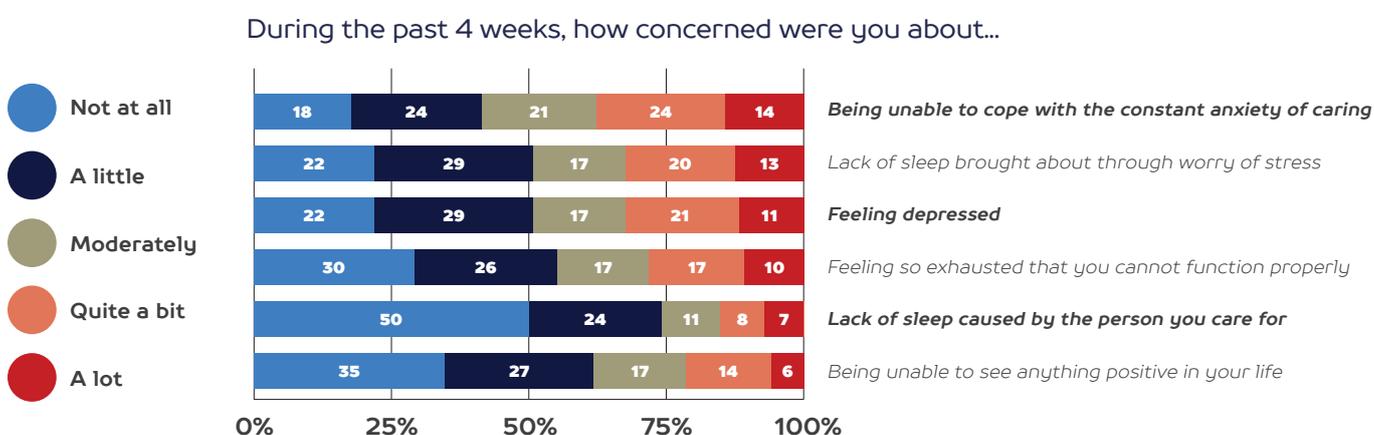
Next, the degree of cumulative burdening experiences across multiple life domains is illustrated. Finally, we look at risk factors associated with caregiver burden.

2.2.1 Emotional Burden

Figure 3 below shows the emotional burden of family caregivers of persons with severe mental illness in the past four weeks. Almost four in 10 (38%) felt unable to cope with the constant anxiety of caring and experienced this feeling 'quite a bit'. One third of family caregivers lack sleep, because

of worry or stress, and one third (32%) feel depressed. One in five family caregivers (20%) is unable to see anything positive in their life and feel so exhausted that they cannot function properly (17%) and around one in seven (15%) lacks sleep through caregiving.

FIGURE 3 Emotional Burden (in %, N=1111)

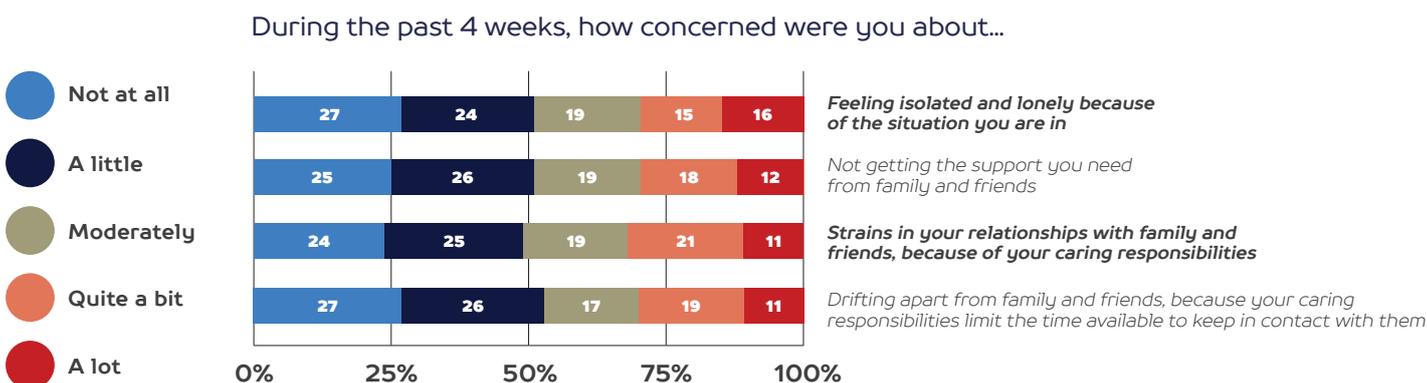


2.2.2 Social Burden

Three in 10 family caregivers of persons with severe mental illness feel isolated and lonely because of the situation they are in. Similar percentages indicate that family caregivers do not get the support they need from family and friends (30%), that they have strains in relationships with family and friends,

because of their caring responsibilities (32%) and that they are concerned about 'drifting apart' from family and friends, because caring responsibilities limit the time available to keep in contact (30%). (**Figure 4.**)

FIGURE 4 Social Burden (in %, N=1111)

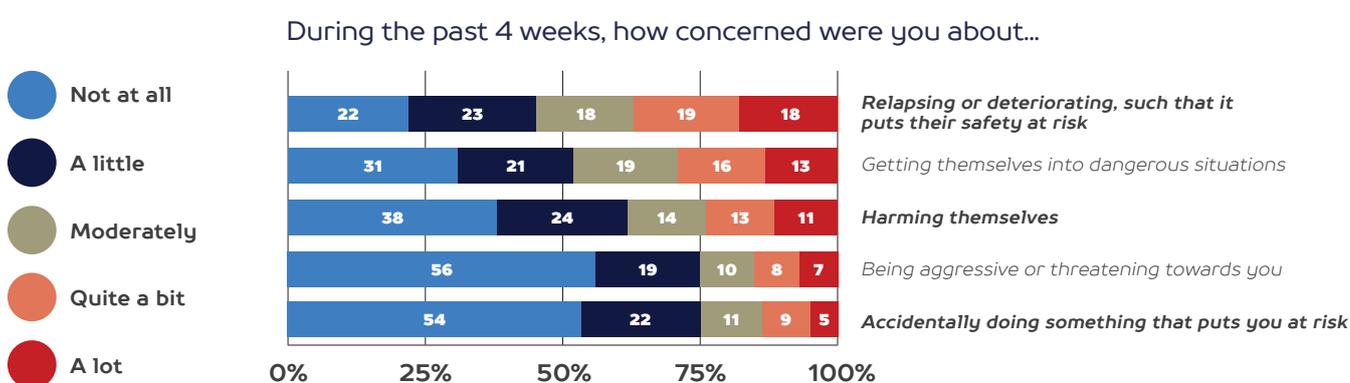


2.2.3 Concerns about safety

Figure 5 shows that more than one in three family caregivers of persons with severe mental illness (37%) is 'quite a bit' or 'a lot' concerned about the person they care for relapsing or deteriorating, such that it puts their safety at risk. One in four worries about the person with schizophrenia harming themselves. Besides concerns about the safety of the person they care for, family caregivers also have concerns about their

own safety, albeit to a smaller degree. For example 15% were concerned about the person being aggressive or threatening towards them. One third (29%) has concerns about getting themselves into dangerous situations and 14% have concerns about the person accidentally doing something that puts them at risk.

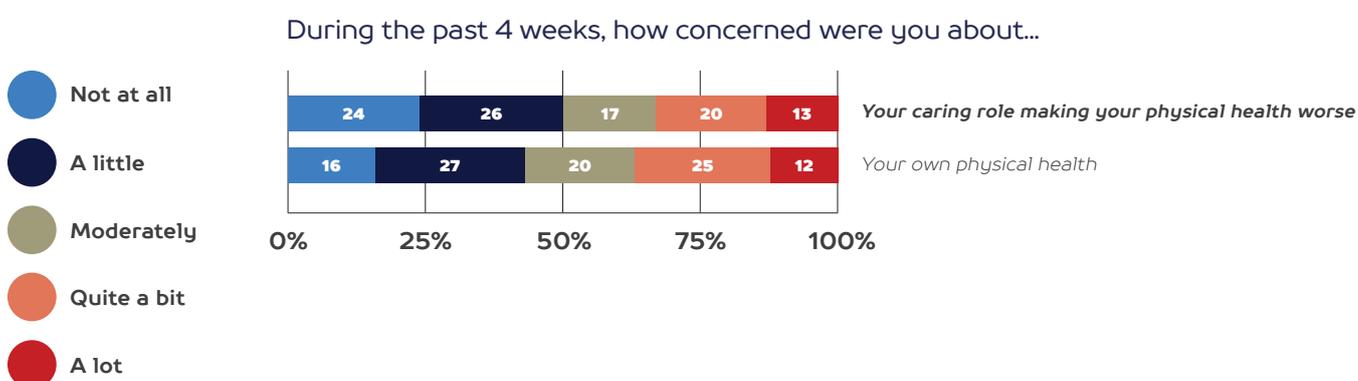
FIGURE 5 Concerns about safety (in %, N=1111)



2.2.4 Physical Burden

One third of the family caregivers of persons with severe mental illness (33%) feel that the caring role makes their physical health worse. Nearly four out of ten family caregivers (37%) are concerned about their own physical health. (Figure 6.)

FIGURE 6 Physical burden (in %, N=1111)

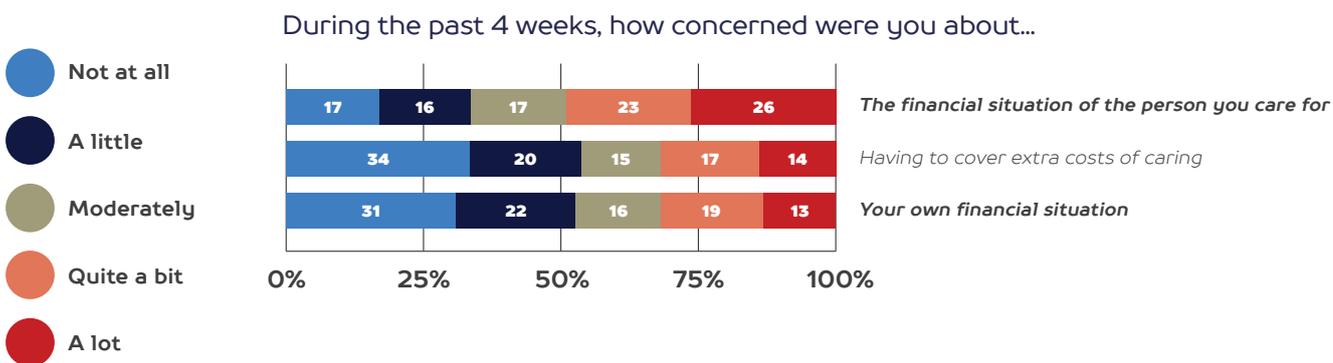


2.2.5 Financial burden

Figure 7 shows that family caregivers of persons with severe mental illness are most concerned about the financial situation of the person they care for. Almost half of the sample (49%) were 'quite a bit' or 'a lot' concerned about this issue during the

past four weeks. Around three in 10 also worry about having to cover the extra costs of caring in the context of their own financial situation.

FIGURE 7 Financial burden (in %, N=1111)

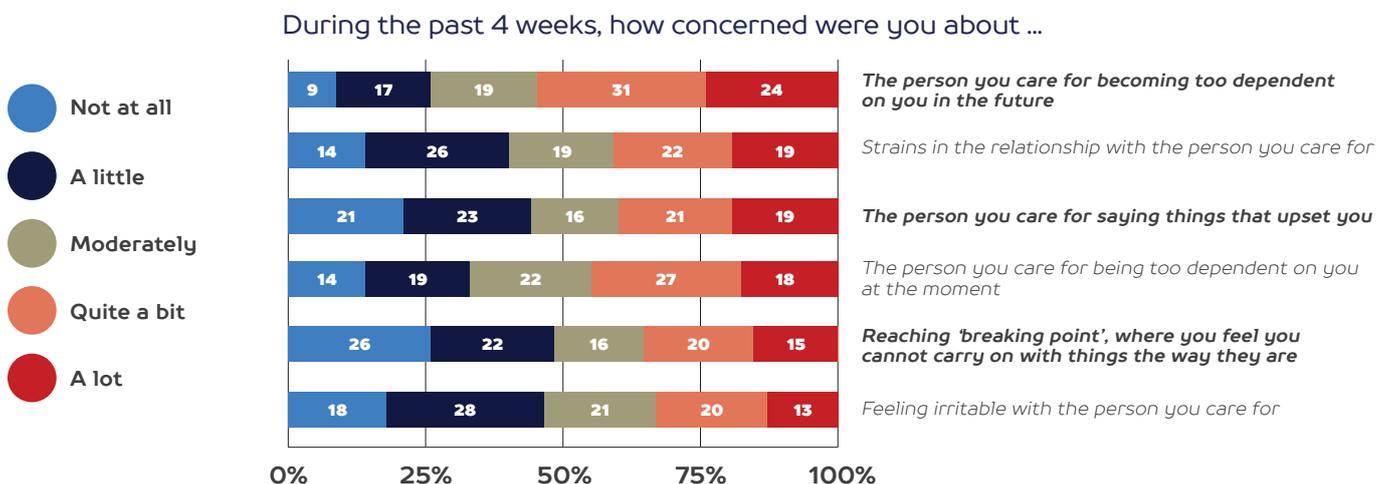


2.2.6 Relationship Burden

Family caregivers of persons with severe mental illness worry most (55%) about the person becoming too dependent on them in the future. At the moment, 45% are concerned about the person they care for being too dependent on them. Four out of 10 (41%) experience 'quite a bit' or 'a lot' of strain in the

relationship with the person they care for. More than one in three (35%) family carers is reaching 'breaking point'; where they feel they cannot carry on with things the way they are. Caregivers also sometimes feel irritable with the person they care for (33%) or get upset by things they say (40%). (Figure 8.)

FIGURE 8 Quality of relationship between caregiver and patient (in %, N=1111)



2.2.7 Overview of most frequent burden

Table 5 lists all items about family caregivers' experiences and well-being where overall concern is 33% or higher. This means at least one in three family caregivers of persons with severe mental illness were concerned 'quite a bit' or 'a lot' about this

specific issue during the past month. This provides a view on the life domains and aspects that contribute most to the burden placed on family caregivers caring for someone with severe mental health problems.

TABLE 5 Overview of most frequent burden of family caregivers of persons with severe mental illness, across life domains

Domain of burden	Specific item	All caregivers (n=1111)
Future role as a caregiver and future care	the person you care for becoming too dependent on you in the future	55%
Financial	the financial situation of the person you care for	49%
Future role as a caregiver and future care	not being able to plan for the future	47%
Lack of time and attention for oneself (non-care)	having to put the needs of the person you care far ahead of your own needs	46%
Lack of time and attention for oneself (non-care)	the person you care for being too dependent on you at the moment	45%
Relationship quality	strains in your relationship with the person you care for	41%
Relationship quality	the person you care for saying things that upset you	40%
Emotional coping	being unable to cope with the 'constant anxiety' of caring	38%
Physical health	Your own physical health	37%
Safety risks	relapsing or deteriorating, such that it puts their safety at risk	37%
Lack of time and attention for oneself (non-care)	not being able to take a break from caring	36%
Emotional coping	reaching 'breaking point', where you feel you cannot carry on with things as they are	35%
Future role as a caregiver and future care	not being able to continue caring due to reasons beyond your control	34%
Lack of time and attention for oneself (non-care)	not having enough time to yourself	33%
Physical health	your caring role making your physical health worse	33%
Physical health	lack of sleep brought about through worry or stress	33%
Relationship quality	feeling irritable with the person you care for	33%

Burden is operationalized as a combination of the answers 'quite a bit' and 'a lot' on the following 5-point Likert Scale items: "During the past 4 weeks, how concerned were you about..."

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The most frequent burdens family caregivers face are mostly situated within the domain of their role as carer of a person with severe mental illness now and in the future (greens) and within the domain of emotional burden and coping strategies (blues).

More than half of the family caregivers worry about the future: 'Will the person they care for become too dependent

and will they be able to continue caring?' Family caregivers experience emotional burden through lack of personal time, of putting the needs of the person they care for ahead of their own needs. One in three feels he or she has reached 'breaking point'. These burdens can have an effect on the carer's physical health.

2.2.8 Cumulative Burden Across Multiple Life Domains

Caregiver burden is a multidimensional concept and intensive caregiving situations can lead to feelings of burden on several life domains. To illustrate the degree of cumulative burdening experiences across multiple life domains,

Table 6 combines emotional, social, physical, financial and relationship burden. Almost one third of the family caregivers of persons with severe mental illness (28%) experience no

burden in any of these five life domains and one in four (23%) experience burden on only one life domain. So, half of the family caregivers face burden on diverse life domains. On the extreme negative side, 6% of the family caregivers of persons with severe mental illness face burden in all five life domains, i.e. emotional, social, financial, physical and relational burden and 11% experience burden in four of the five life domains.

TABLE 6 Illustration of cumulative burden of caregivers across multiple life domains

Life domain	During the past 4 weeks, how concerned were you about ...	% of caregivers with burden ('quite a bit' / 'a lot' combined)	Cumulative burden across these 5 domains
Emotional	Feeling depressed	31	0 Domains 28% 1 23% 2 16% 3 15% 4 11% 5 Domains 6%
Social	Strains in your relationships with family and friends, because of your caring responsibilities	32	
Physical	Your caring role making your physical health worse	33	
Financial	The financial situation of the person you care for	49	
Relationship	Strains in the relationship with the person you care for	41	

2.2.9 Risk Factors of Caregiver Burden

Are family caregiver characteristics associated with the experienced burden of caregiving?

Table 7 shows bivariate relationships between characteristics of the caregivers and burden on different life domains.

For this analysis, burden is operationalized as a combination of the answers 'a lot' and 'quite a bit' for the following 5-point Likert Scale items:

“During the past 4 weeks, how concerned were you about...

- ... *feeling depressed?*” (= emotional burden)
- ... *strains in your relationships with family and friends, because of your caring responsibilities?*” (= social burden)
- ... *your caring role making your physical health worse?*” (= physical burden)
- ... *having to cover extra costs of caring?*” (= financial burden)
- ... *strains in the relationship with the person you care for?*” (= burden on relationship)

Several caregiver characteristics are clearly associated with increased burden.

Female caregivers experience more emotional, social, physical and relationship burden. They also have higher levels of perceived stigma than male caregivers.

Younger caregivers seem to have more problems with emotional burden. Overall, caregivers aged 65+ have the lowest level of caregiver burden and they have more positive personal experiences related to their caregiving.

Not getting by is linked with burden across all life domains e.g. 42% of the family caregivers who have difficulties getting by feel depressed, compared to 28% of the caregivers without financial difficulties.

Working is not closely related to caregiver burden, although working family caregivers experience more strains in the relationship with the person they care for.

Living with the patient or not is not associated with burden. Those family caregivers who live with the patient however, experience more perceived stigma on the one hand and they experience more often the good aspects of their relationship on the other hand.

The kinship relationship between the family caregiver and the patient is not crucial for understanding caregiver burden, although the level of financial burden differs between familial ties. Family caregivers are more often concerned about having to cover the extra costs of caring when they care for their children (53%) or parents (47%) compared to their partner (38%) or sibling (38%). Family caregivers have more positive personal experiences when they care for their sibling or child as compared to family caregivers that take care of their partner.

The number of hours of caregiving last week is clearly associated with increased burden in all life domains. For example, 40% of family caregivers who took on more than 10 hours of care last week experienced strains in relationships with family and friends, compared to 20% of the caregivers who took on fewer hours.

Caregivers who started caring more than 10 years ago experience less emotional burden as opposed to those with less than 10 years of caring.

Being the only caregiver is linked to overall higher levels of burden. Caregivers who can share caring responsibilities have lower levels of perceived stigma.

TABLE 7 Bivariate relations between caregiver characteristics and burden

Caregiver characteristics		Distribution in sample (%)	% with burden in different life domains *				
			Emotional	Social	Physical	Financial	Relationship
Gender of caregiver	female	80	34	34	35		43
	male	20	21	23	26		34
Age of caregiver	<55	14	41	37	35	35	46
	55-64	53	34	35	36	35	45
	65+	33	24	25	27	25	35
Getting by	not difficult	72	28	29	28	22	39
	(very) difficult	28	42	40	46	58	49
Working	no	58					38
	yes	42					45
Living with patient	no/sometimes	48					
	yes	51					
Relationship with patient	son/daughter	76				53	
	partner/spouse	10				39	
	brother/sister	7				38	
	parent	4				47	
Illness/condition of patient	schizophrenia	64	30	28	31	29	38
	bi-polar disorder	18	34	30	37	37	46
	depression	15	33	40	38	36	51
	anxiety	13	43	38	47	41	55
Hours of caring last week	<10 hours	41	22	20	22	17	30
	10+	59	37	40	40	42	58
Years since first started caring	<10 years	35	37				
	10+	65	28				
Role as caregiver	Only caregiver	36	37	37	43	40	48
	not the only one	64	28	28	28	27	37

* Percentages are only shown if bivariate relationship is significant (p-value of Chi-squared test is <0,05)

Burden is operationalized as a combination of the answers 'quite a bit' and 'a lot' on the following 5-point Likert Scale items: "During the past 4 weeks, how concerned were you about...

... feeling depressed?" (= emotional burden)

...strains in your relationships with family and friends, because of your caring responsibilities?" (= social burden)

... your caring role making your physical health worse?" (= physical burden)

... having to cover extra costs of caring?" (= financial burden)

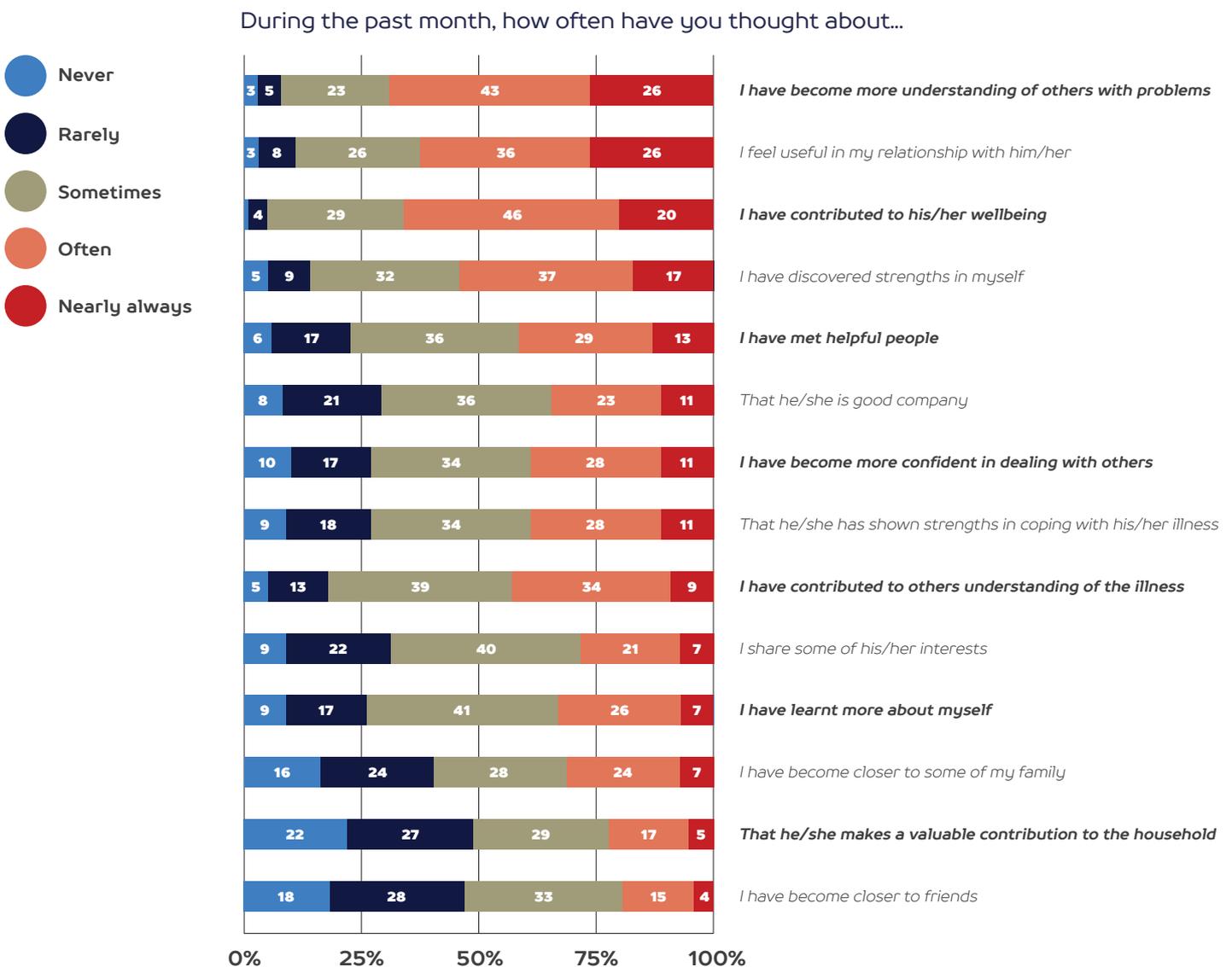
... strains in the relationship with the person you care for?" (= burden on relationship)

2.3 Positive Caregiving Experiences

Family caregiving for persons with severe mental illness involves feelings of stigma and burden; however, these experiences can be coupled with positive caregiving experiences. Governments need to strengthen existing positive caregiving experiences to moderate negative aspects of caregiving.

This survey has found that family caregivers of persons with severe mental illness feel that they have become more understanding of others with problems (69%). They also feel useful in the relationship with the person they care for (62%). More than half of the family caregivers (54%) have discovered inner strength, and around four in 10 thought often about meeting with helpful people during the past month. Some caregivers have also become closer to some of their family (31%) or to friends (19%). (Figure 9.)

FIGURE 9 Positive caregiving experiences (in %, N=1111)



The Cronbach's alpha for the fourteen items of the positive subscale of the ECI was 0,84. The mean score of the family caregivers on the positive scale was 30.8 (SD = 8,5) (n=1003;

min=2 max=56). The mean scores for each item of the ECI positive subscale are reported in **table 8**, sorted from high to low.

TABLE 8 Mean scores of family caregivers on the items of positive subscales of the Experience of Caregiver Inventory

	MEAN (SD)
I have become more understanding of others with problems	2.8 (1.0)
I have contributed to his/her wellbeing	2.8 (0.9)
I feel useful in my relationship with him/her	2.7 (1.0)
I have discovered strengths in myself	2.5 (1.0)
I have contributed to others understanding of the illness	2.3 (1.0)
I have met helpful people	2.3 (1.1)
That he/she has shown strengths in coping with his/her illness	2.2 (1.1)
I have learnt more about myself	2.1 (1.0)
I have become more confident in dealing with others	2.1 (1.1)
That he/she is good company	2.1 (1.1)
I share some of his/her interests	2.0 (1.0)
I have become closer to some of my family	1.8 (1.2)
That he/she makes a valuable contribution the household	1.6 (1.2)
I have become closer to friends	1.6 (1.1)

Here too, the associations between caregiver characteristics and positive caregiving experiences were investigated. Univariate models were fitted with the positive appraisal scale of the ECI as dependent variable. Participants who experienced most positive caregiving experiences were those who were older; spent more hours caring last week; and first started caring for a person with mental health problems more years ago. The number of years

since first started caring was not included in the multivariate model since it is highly correlated with age ($r=0.40$). However, age and hours spent caring last week are not associated ($r=-0.09$). In a multivariate model, the variables age and hours spent caring remained significantly associated with more positive caregiving experiences. Overall, age and hours spent caring last week accounted for 1% of the variance. **Table 9,**

TABLE 9 Univariate and multivariate associations of family caregiver characteristics with intensity of positive caregiving experiences as dependent variable

	Univariable models		Multivariable model	
	Regression Coefficient (95% CI)	P value*	Regression Coefficient (95% CI)	P value*
Male sex	-0.696 (-1.725 to 0.333)	0.174		
Age	0.057 (0.012 to 0.102)	0.015	0.045 (0.008 to 0.082)	0.018
Getting by is (very) difficult	-0.167 (-1.558 to 1.218)	0.802		
Working	-1.069 (-2.190 to 0.052)	0.061		
Relationship with patient				
Sibling	Ref	Ref		
Child	0.956 (-0.783 to 2.754)	0.260		
Friend/other	-1.721 (-6.133 to 2.692)	0.427		
Parent	-1.766 (-5.119 to 1.588)	0.286		
Partner/spouse	-1.098 (-3.608 to 1.412)	0.373		
Caring for more than one person with mental health problems	0.729 (-0.919 to 2.376)	0.368		
Being the only caregiver	-0.079 (-1.485 to 1.327)	0.908		
Living with patient	0.587 (-0.772 to 1.945)	0.379		
Hours spent caring last week	0.015 (0.001 to 0.028)	0.035	0.017 (0.002 to 0.032)	0.031
Years since first started caring	0.037 (0.002 to 0.073)	0.041		

Ref =reference. *Adjusted for clustering by country (22 sites, 1111 participants)

3 Satisfaction with Information, Advice and Support from Professional Caregivers

Table 10 provides an overview of all questions related to caregiver satisfaction with professional support, which we describe further in detail.

TABLE 10 Overview of caregiver satisfaction with professional support

“In general, how satisfied are you with ...”	Very dissatisfied	Somewhat dissatisfied	Not satisfied and not dissatisfied	Somewhat satisfied	Very satisfied
Information and advice for carers					
That you have enough information about how their condition/illness is likely to develop in the longer-term	20	26	22	23	10
With the amount of advice available to you	17	24	22	26	11
That you can get whatever information you need when you need it	17	26	19	25	12
With how easy it is to understand the information you have	6	15	22	44	13
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	13	22	19	31	14
That you are clear about who to call if you have a routine inquiry	16	19	19	32	14
That you are clear about who to go to for the information and advice you need	17	22	18	27	15
That you are clear about who to contact if there is an emergency and you need help right away	19	17	18	30	17
Your involvement in treatment and care planning					
Your ability to influence important decisions	21	22	19	27	11
Your involvement in important decisions	22	22	19	25	12
Support from medical and/or care staff					
How well the staff you have contact with are communicating with each other	23	24	28	18	7
How easy it is to get help and support from staff for yourself	25	24	24	19	8
The level of understanding staff have of what it must be like to be in your situation	19	21	30	21	9
How easy it is to get help and support from staff for the person you care for	22	23	21	24	9
The quality of help and support from staff for the person you care for	16	23	24	26	10
Your relationships with key staff who support the person you care for	16	18	26	27	12
How seriously staff take what you say to them?	16	19	25	27	13

Continued on the next page ...

THE CARING FOR CARERS SURVEY REPORT 2015: RESULTS FROM 22 COUNTRIES

"In general, how satisfied are you with ..."	Very dissatisfied	Somewhat dissatisfied	Not satisfied and not dissatisfied	Somewhat satisfied	Very satisfied
Support you received from					
Insurance company	16	11	60	9	4
Pharmaceutical companies	18	12	56	10	4
Social workers	18	16	36	21	9
Workplace	16	10	46	16	12
Nurses	12	16	35	25	13
Doctors	18	21	22	26	13
Patient/caregiver organisations	7	10	25	33	25

Data are row percentages, with each row totaling 100%. Percentages are based on valid responses. All items use the same 5-point Likert Scale (1= very dissatisfied, 5= very satisfied). All items start with "In general, how satisfied are you with ..."

3.1 Satisfaction with Support Received from Different Disciplines and Parties

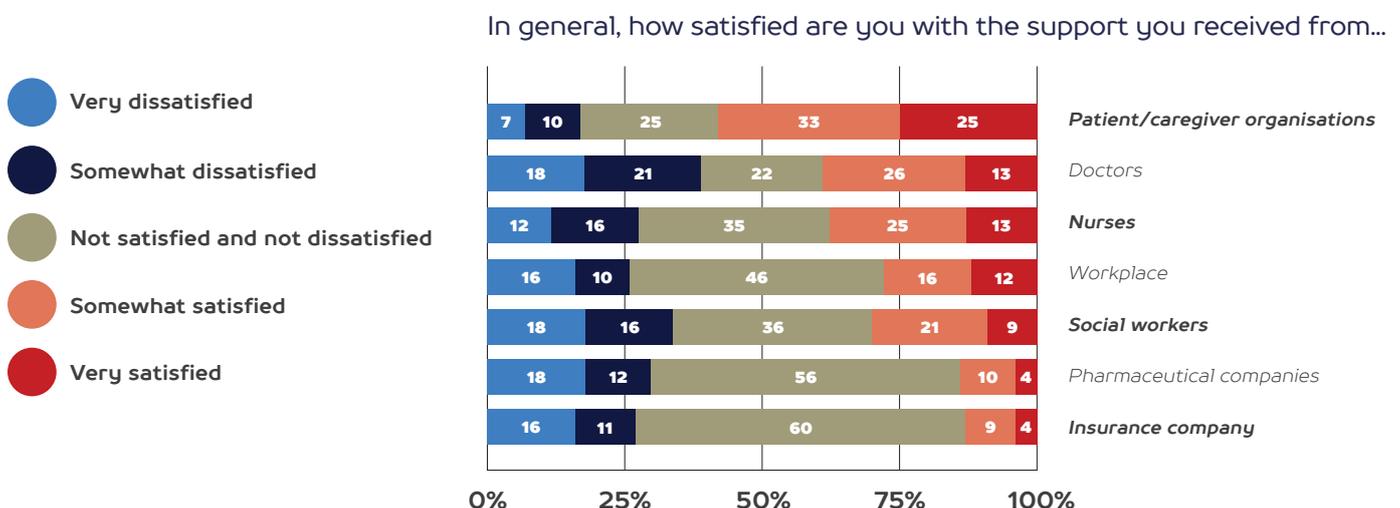
Figure 10 below illustrates that satisfaction with the professional support received by family caregivers from persons with severe mental illness varies between professional disciplines. Family caregivers are most satisfied with the support they receive from patient/caregiver organisations. Six out of 10 feel (very) satisfied with their support, but still 17% feel dissatisfied.

This contrasting picture is emphasised further in respect of the support received from doctors. Four in 10 family caregivers are (very) satisfied with their doctors, but the same percentage also feel dissatisfied.

Satisfaction with support from nurses is also mixed: a third are satisfied, a third feel dissatisfied and a third are neutral. Only three in 10 family caregivers are satisfied with support from their social worker. More than half of carers reported feeling neither dissatisfied nor satisfied with pharmaceutical companies (56%) and insurance companies (60%). Feelings of dissatisfaction are similar when compared with other professional groups, but comparatively fewer carers are very satisfied with pharmaceutical (4%) or insurance companies (4%).

Additionally, one in four caregivers feels dissatisfied with the support they received from their workplace of the mental illness of the person they care for.

FIGURE 10: Satisfaction with the support received from different disciplines and parties (in %, N=1111)

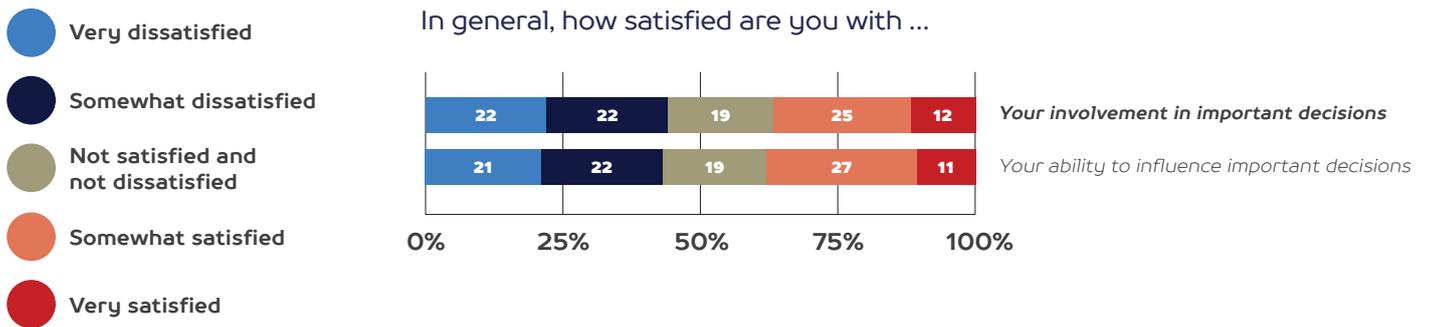


3.1.1 Satisfaction with Involvement in Care

Only a third of the family caregivers of persons with severe mental illness (37%) feel satisfied with their ability to influence important decisions in treatment and care planning. Four out of ten caregivers are satisfied with their involvement in

important decisions. However, an almost equal share of family caregivers experiences dissatisfaction with their involvement and ability to influence important decisions (43–44%) (Figure 11.)

FIGURE 11 Satisfaction with involvement in care (in %, N=1111)

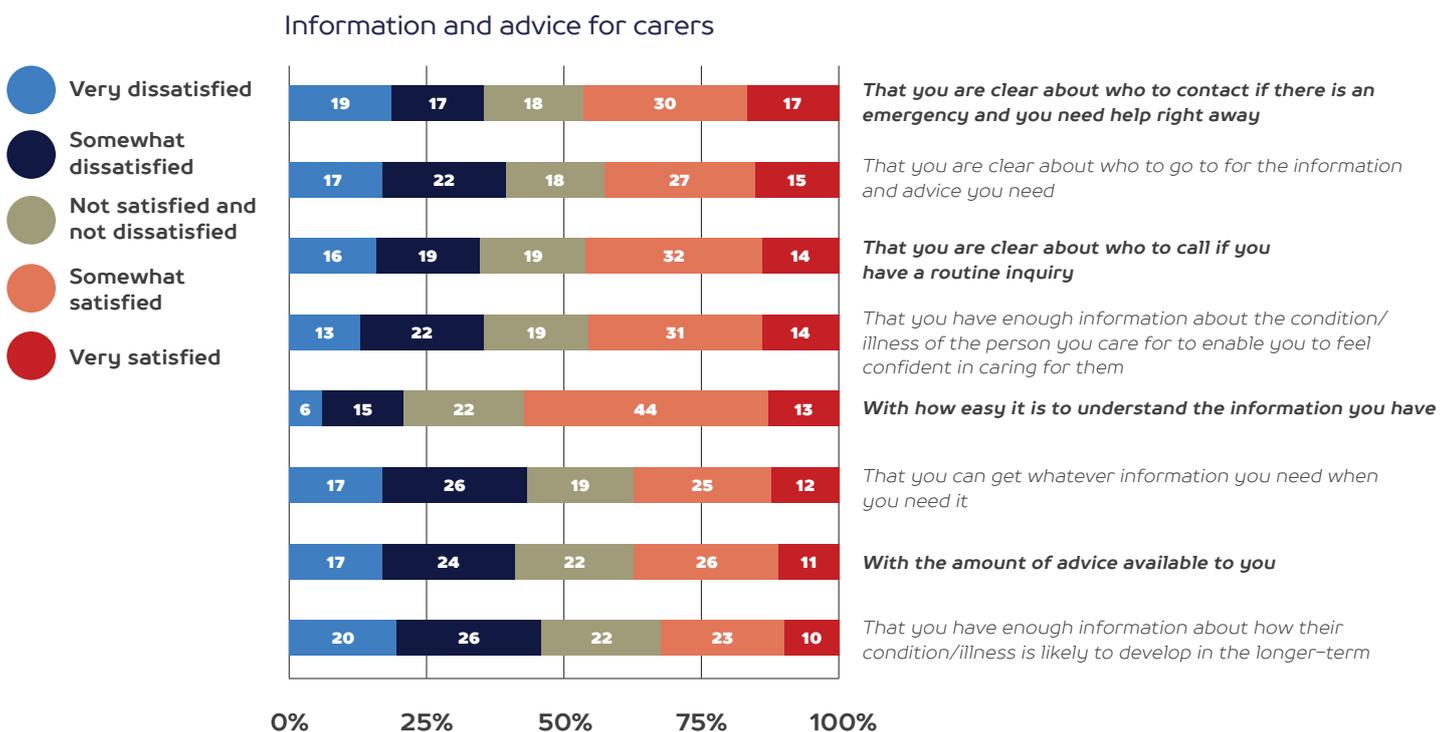


3.1.2 Satisfaction with Information and Advice for Family Caregivers

More than half of the family caregivers (52%) are clear about who to contact if there is an emergency and immediate help is needed, and more than four out of ten (43%) are clear about who to go to for information and advice. Three out of four also

find the information they have easy to understand. However, family caregivers are least satisfied (33%) about having enough information on how the illness is likely to develop in the longer-term. (Figure 12.)

FIGURE 12 Satisfaction with information and advice for carers (in %, N=1111)

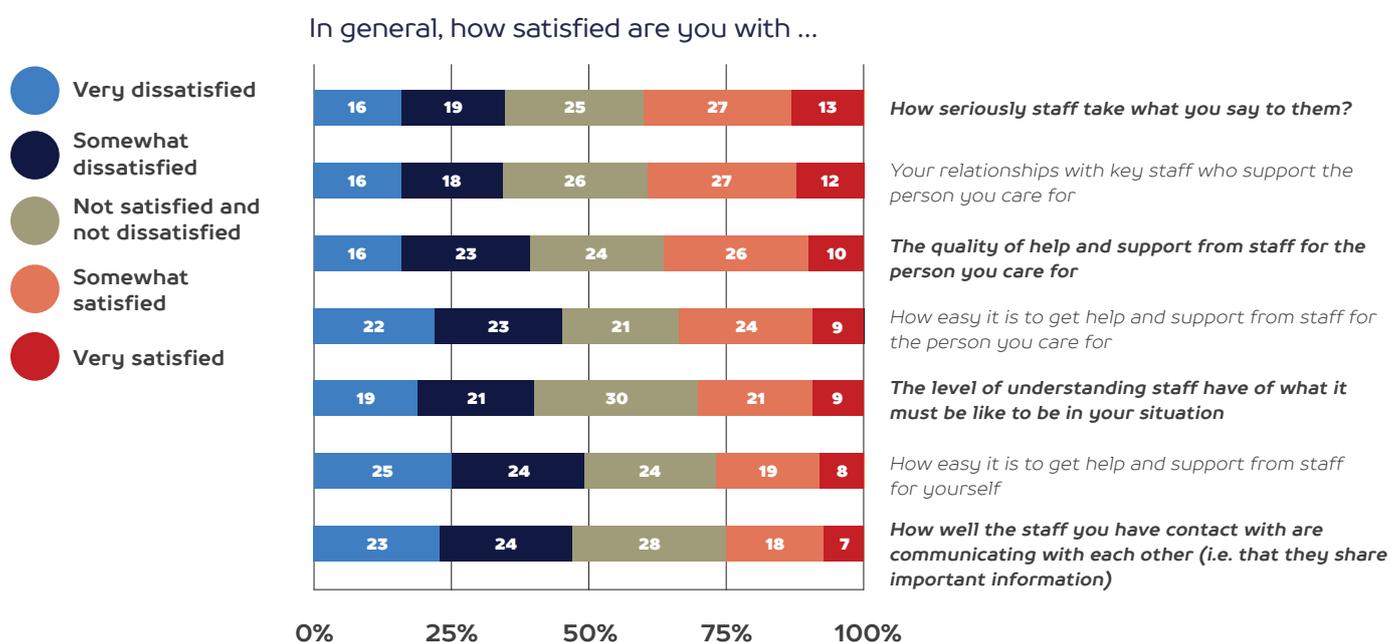


3.1.3 Satisfaction with Support from Medical and/or Care Staff

Family caregivers of persons with severe mental illness are less satisfied with the support they receive from professionals compared to the information and advice they get. For example, less than 4 out of 10 feels that medical and/or care staff take what they say seriously. However, around three in 10 family caregivers are satisfied with the level of understanding what it must be like in their situation. All in all, only one in four family caregivers (26%) is satisfied with how easy it is to get help and

support from professional staff for themselves. Getting help for the person with a severe mental illness is somewhat easier for family caregivers, but not significantly (33%). Dissatisfaction with professional support may be linked to ineffective communication between professionals. Less than one in four family caregivers feel communication is going well (23%).

FIGURE 13 Satisfaction with support from medical and/or care staff (in %, N=1111)



3.2 Risk Factors of Dissatisfaction with Professional Support

Table 11 shows bivariate relationships between the characteristics of the family caregivers and the dissatisfaction with professional support. Dissatisfaction is operationalised as a combination of the answers 'very dissatisfied' and 'somewhat dissatisfied' for the following 5-point Likert Scale items:

- Support received from doctors**
- Support received from pharmaceutical companies**
- Support received from patient/caregiver organisations**
- Involvement in important decisions**
- How seriously staff take what you say to them**
- How easy it is to understand the information you have**

Several caregiver characteristics are clearly associated with dissatisfaction with professional support.

Female caregivers experience more dissatisfaction with support received from doctors. Female family caregivers also feel that staff take what they say less seriously.

Age is not associated with these selected items.

Not getting by is linked with increased dissatisfaction with professional support. For example 24% of the caregivers who have difficulties getting by feel dissatisfied with support from patient/caregiver organisations, compared to 15% of the caregivers without financial difficulties. Information is also more difficult to understand for caregivers that have difficulties getting by and feel they are taken less seriously by professional staff if they say something.

Working is not closely related to family caregiver satisfaction with professional support.

Family caregivers that don't live permanently with

the patient are more often dissatisfied with the support received from doctors, and their involvement in important decisions, than family caregivers living with the person with severe mental illness.

The kinship relationship between the carer and the patient is linked with how seriously staff takes what family caregivers say. Sibling caregivers have the highest dissatisfaction (48%). Those caring for their partner have the lowest dissatisfaction (23%).

More intensive caregiving is associated with increased dissatisfaction; e.g. carers with more than 10 hours of caregiving last week were more dissatisfied with support received from pharmaceutical companies and from patient/caregiver organisations. Caregivers who provide more weekly hours of care are also more dissatisfied with how seriously staff takes what they say to them.

Being the only caregiver is linked to overall higher levels of dissatisfaction; e.g. caregivers who can share caring responsibilities are more satisfied with their involvement in important decisions and how seriously staff takes what they say to them.

TABLE 11 Bivariate relations between caregiver characteristics and dissatisfaction with professional support

Caregiver characteristics		Distribution in sample (%)	Dissatisfaction* with professional support (%)					
			Support received from doctors	Support received from pharmaceutical companies	Support received from patient/caregiver organisations	Involvement in important decisions	How seriously staff take what you say to them	How easy it is to understand the information you have
Gender of caregiver	female	78	40				37	
	male	22	32				27	
Age of caregiver	<55	8						
	55-64	50						
	65+	42						
Getting by	not difficult	75		27	15		33	19
	(very) difficult	25		40	24		43	25
Working	no	64						
	yes	36						
Living with patient	no/sometimes	58	44			51		
	yes	42	34			38		
Relationship with patient	son/daughter	84					36	
	partner/spouse	7					23	
	brother/sister	5					48	
	parent	3					30	
Hours of caregiving last week	<10 hours	39		25	13		31	
	10+	61		34	20		39	
Years since first started caring	<10 years	33						
	10+	67						
Role as caregiver	only caregiver	38	44			48	41	
	not the only one	62	36			41	32	

Percentages are only shown if bivariate relationship is significant (p-value of Chi-squared test is <0,05)

*Dissatisfaction is operationalized as a combination of the answers 'very dissatisfied' and 'somewhat dissatisfied' on the 5-point Likert Scale item

4 The Need for Support and Respite for Caregivers

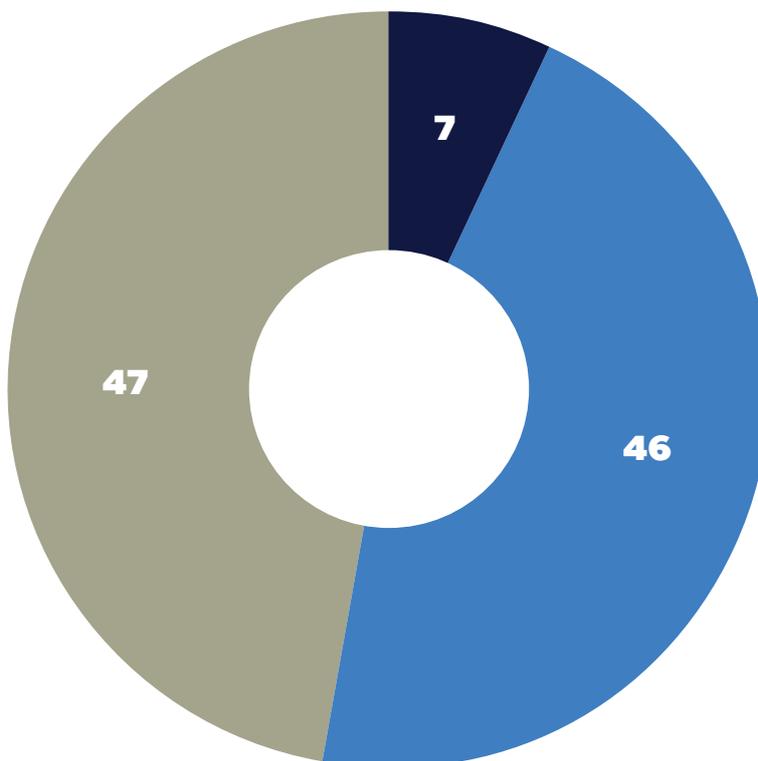
4.1 Unmet Need for Support

More than 9 out of 10 caregivers (93%) would like additional support to help in their role as a family caregiver, 46% would like a lot of additional support and 47% a little. Only 7% need no additional support at all. **(Figure 14.)**

FIGURE 14 Unmet need of support (in %, N=1111)

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

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



4.2 Expectations of EUFAMI and Family Member Organisations

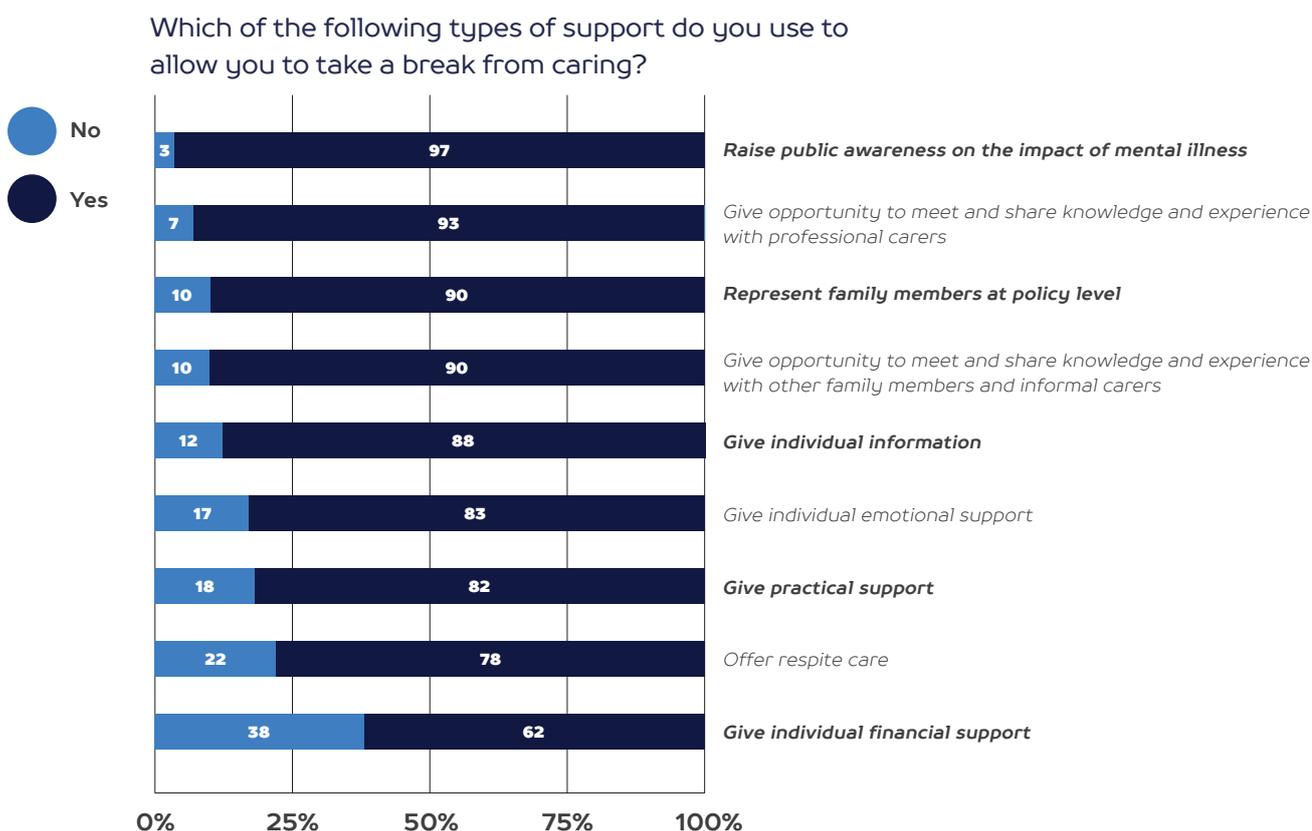
The survey also asked about the expectation of family caregivers towards EUFAMI and other family member organisations. **Figure 15** shows that nearly all family caregivers (97%) expect that EUFAMI and other family member organisations raise public awareness of the impact of mental illness. Representing family members at policy level is important for 90% of the family caregivers.

Besides weighing on the societal issues of mental illness at a macro level, family caregivers want EUFAMI to be a connector.

Around 9 in 10 caregivers want more opportunities to meet, and share knowledge and experiences, with professional carers (93%), as well as with other family members and informal carers (90%).

Around 8 in 10 caregivers also want individual support from EUFAMI and family member organisations, e.g. by providing information (88%), emotional support (83%) and offering respite care (78%). More than half of the family caregivers (62%) want financial support.

FIGURE 15 Expectations of EUFAMI and family member organisations (in %, N=1111)

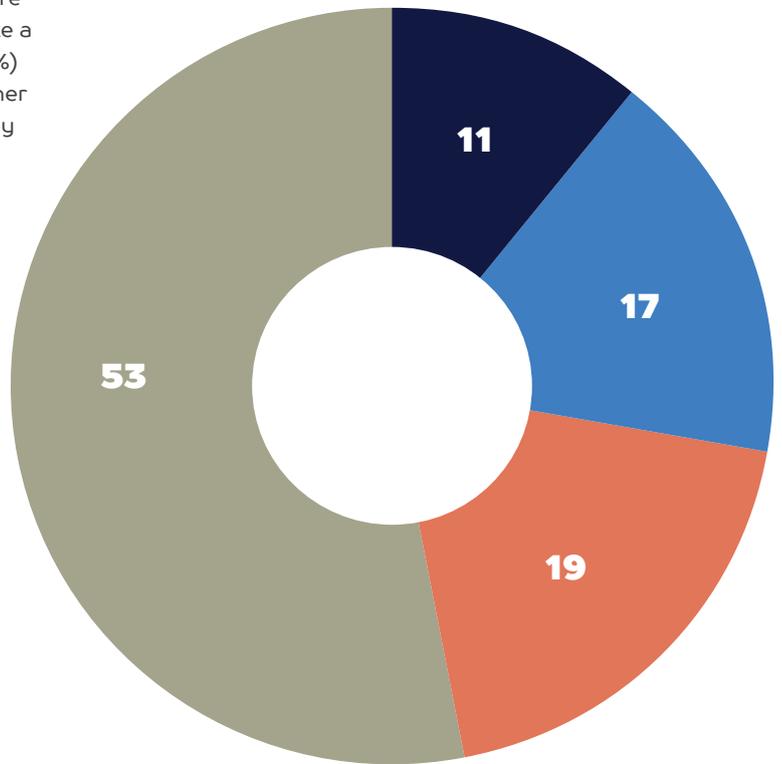
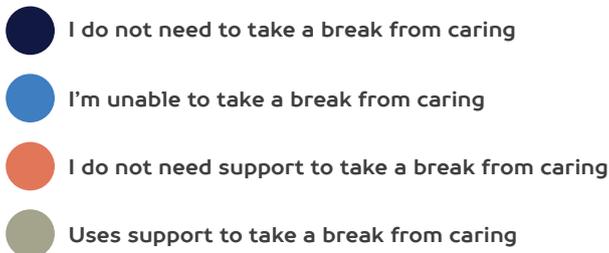


4.3 Use of Respite

Family caregivers of persons with severe mental illness were asked what types of support they use to allow them to take a break from caring. **Figure 16** shows that half of carers (53%) use support to take a break from caring. Therefore, the other half of carers do not take a break from caring, because they are unable to take one (17%), because they do not need a break (11%) or because they do not need support to take a break from caring (19%).

FIGURE 16 Taking a break from caring (in %, N=1111)

Taking a break from caring



In order to take a break from caring, more than one third of all caregivers questioned (36%) relies on friends and family to provide temporary care. One out of five (20%) uses supported activities out of the home. Few family caregivers pay others to

come into the home (6%) or to provide care away from home (8%). Around one in 10 family caregivers use other respite care (13%) or supported breaks for themselves and the person they care for away from home (9%). **(Figure 17.)**

FIGURE 17 Types of support caregivers use to take a break from caring (in %, N=1111)



4.4 Risk Factors for Being Unable to Take a Break from Caregiving

Which family caregivers of persons with severe mental illness are unable to take a break from caregiving? Can we find associations with other caregiver characteristics?

Table 12 shows that having difficulties getting by, living with the patient, caring for your parent, caring more hours and being the only caregiver are all factors that increase the risk of not being able to take a break from caring.

TABLE 12 Bivariate relations between caregiver characteristics and being unable to take a break from caring

Caregiver characteristics		Distribution in sample (%)	Being unable to take a break from caring (%)
Gender of caregiver	female	78	
	male	22	
Age of caregiver	<55	8	
	55-64	50	
	65+	42	
Getting by	not difficult	75	12
	(very) difficult	25	30
Working	no	64	
	yes	36	
Living with patient	no/sometimes	58	12
	yes	42	22
Relationship with patient	son/daughter	84	17
	partner/spouse	7	17
	brother/sister	5	11
	parent	3	30
Hours of caregiving last week	<10 hours	39	7
	10+	61	23
Years since first started caring	<10 years	33	
	10+	67	
Role as caregiver	only caregiver	38	24
	not the only one	62	13

Percentages are only shown if bivariate relationship is significant (p-value of Chi-squared test is <0,05)

CHAPTER 4: SUMMARY, CONCLUSIONS & RECOMMENDATIONS

1 Summary and conclusions

Why was this research conducted?

Developed countries are shifting their mental health policies away from hospital-based care towards community-based care and family caregivers play an essential role in making living in the community with a severe mental illness possible. Although mental health services have contact with the family caregivers of patients with mental illness, evidence exists that there is a need for more support for the carers themselves; besides the necessary treatment and guidance for the patient. This evidence is often anecdotal, based on individual stories of an unbalanced, burdensome experience of family caregiving. Scientific survey-based evidence of these experiences of family caregivers exists, but these results are not recent, are often based on single-country samples and only cover a limited scope of life domains.

What was the aim of this study?

The goal of this study was to explore the experiences of family caregivers of persons with severe mental illness from an international perspective. LUCAS, the Centre for Care Research and Consultancy of the KU Leuven, conducted the study on behalf of the European Federation of Families of People with Mental Illness (EUFAMI).

The study is a multisite, 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 the UK). The survey is an anonymous, self-completion questionnaire administered on paper, by email and online. The questionnaire consists of multiple items on caregiver well-being, burden and stigma; caregiver satisfaction with professional support and the need for further support. Data was gathered at all sites from 1st June to 31st December 2014. Questionnaires were completed by 1,111 family caregivers for someone with a severe mental illness. All these family caregivers are linked with a family caregiver organisation.

This exploratory survey addresses three research questions:

- 1. What are the caregiving experiences of family caregivers, including their well-being, burden, strengths and perceived stigma?*
- 2. How satisfied are family caregivers with the professional support they receive?*
- 3. What are the needs for further support of family caregivers? Results are mainly descriptive, although risk factors through statistical analyses were also explored.*

2 Who are the family caregivers of persons with severe mental illness?

The typical family caregiver for a person with severe mental illness, who participated in this study, is a woman around 60 years of age, caring for her child with schizophrenia. Eighty percent of the family caregivers who completed the survey were female. The mean age is 58 years, with one in six caregivers younger than 55 years (14%) and one third older than 65 years (33%). This diversity is also reflected in the working situation, with 43% of the family caregivers being retired, as opposed to 42% working.

Three quarters of the family caregivers takes care of a child with severe mental illness (76%), 10% for a partner or spouse and 7% for a sibling. Almost one in five takes caregiving responsibility for more than one person with mental health problems (19%).

Two thirds of the persons cared for by the family caregiver have schizophrenia or psychotic illness (64%), while other patients have a bipolar affective disorder (18%), a depressive disorder (15%), an anxiety disorder (13%) or other mental health problem (18%).

On average, family caregivers first started caring 15 years ago. In a given week, caregivers spent an average of 22 hours looking after someone with mental health problems. About one third of the caregivers (36%) are the only caregiver for the person with severe mental illness.

These figures point to the typical nature of family caregiving in mental illness: it is a long-standing and time-consuming task with few other relatives to share these caregiving responsibilities with.

3 What can be said about caregiving burden, stigma and positive caregiving experiences?

Family caregivers of persons with severe mental illness experience burden on several life domains. Almost four in 10 (38%) feel unable to cope with the constant anxiety of caring (emotional burden). One third feel isolated and lonely because of the situation they are in (social burden). Typical for mental illness are the worries about relapse, such that it puts their safety at risk (37%). One third of the family caregivers (33%) feel that the role of caring worsens their physical health (physical burden). Half of the family caregivers (49%) worry about the financial situation of the person they care for (financial burden) and is concerned about the persons becoming too dependent on them in the future (55%) (relationship burden). Around 6% of the family caregivers surveyed face emotional, social, physical and relationship burden, as well as financial worries, and more than one in three experiences burden on at least three life domains. Cumulative burdening experiences across life domains can weigh upon the balance, and upon the quality of family life.

Family caregiving in mental illness can involve simultaneous feelings of burden and positive caregiving experiences. For instance, seven in 10 family caregivers state that they have

become more understanding of others with problems (69%), and more than half (54%) have discovered inner strength. Being older and spending more hours in caregiving are significantly associated with more positive experiences. Caregiving is thus not all doom and gloom. These positive caregiving experiences, like growth in competence or finding strength in oneself, or with family or friends, contrast the dominance of the stress-burden model in caregiving research. However, although the experience of caregiving has both negative (burden) and positive (resilience) aspects, this balance is precarious. More than one in three (35%) family caregivers is reaching 'breaking point', where they feel they cannot carry on with things the way they are. Bivariate analyses showed that several risk factors can be identified for becoming increased burdened. Special attention should be given to female caregivers, younger caregivers and caregivers who have difficulties getting by. Being the only caregiver and having more hours of caregiving during the last week both are associated with more burden on all life domains (emotional, physical, social, relational, financial). The kinship relationship between the family caregiver and the patient, living with the patient and working as a caregiver do not seem to be related to this increased burden.

Mental illness confronts persons with stigma and these stigmatising processes also mark family caregivers of persons with severe mental illness – around 15% of the family caregivers feel they are treated differently because of the mental illness of the person they care for. Female caregivers, caregivers living with the patient, and caregivers who cannot share the caregiving responsibilities with other relatives or informal caregivers, experience more stigma.

4 Are family caregivers of persons with severe mental illness satisfied with the information, advice and support received from professional caregivers?

Regarding 'satisfaction with support', reported by different disciplines and parties, there are two differing sides to the story. For instance, 39% of the family caregivers are dissatisfied with the support from

doctors, but another 39% are satisfied. Not surprisingly, considering the selection of participants, the highest satisfaction is for the support received from patient and caregiver organisations (58%).

With respect to information and advice for family caregivers, a variable picture is presented. On the one hand, family caregivers find the information given easy to understand (58%), or they know who to go to for information and advice (42%). But, on the other, we see that one third of the family caregivers are dissatisfied with information provided in the case of an emergency (36%). Almost half of the family caregivers are dissatisfied with the information given on how the illness of their relative will develop in the longer-term (46%).

The same picture is presented in respect of the family caregiver's involvement in care: one third of the family caregivers are satisfied with the involvement in and the ability to influence important decisions (37–38%), while four in 10 feels dissatisfied with this (43–44%).

All in all, we see that information and advice are appreciated by family caregivers, but that the highest dissatisfaction is present in relation to support family caregivers receive from professionals. Only four in 10 carers feel that medical and care staff take them seriously, and half are dissatisfied with getting help from professional staff in respect of their own needs (49%).

Being the only caregiver, having more hours of caregiving tasks and not getting by are the main factors that are associated with dissatisfaction with professional support. Family caregivers living with the patient or caring for their partner are relatively most satisfied as compared to those not living with the patient or those with another kinship relationship.

5 Do family caregivers of persons with severe mental illness need other support and respite?

Almost all family caregivers of persons with severe mental illness participating in this study would prefer additional support to help themselves in their role as a carer (93%), and nearly half would like significant additional support (46%).

Seventeen percent state they are unable to take a break from caring; and this is associated with having serious difficulties of getting by, living with the patient, being the only caregiver, caring for a parent and caring for an increased number of hours. If family caregivers do use respite, they rely mostly on friends and family (36%). The use of paid respite care is very low (6–8%).

Family caregivers of persons with severe mental illness have high expectations of EUFAMI and family member organisations. More than eight out of 10 want these organisations to raise public awareness, to connect them with professional caregivers and other informal caregivers, to represent them at policy level and to give individual information, emotional and practical support. Only the offer of respite care (78%) and the offer of individual financial support (62%) scored lower.

6 What conclusions can be made?

This research raises important questions about the role of family caregivers of persons with severe mental illness in the ongoing push for mental health care to be facilitated in the community. Community-based care should not be a euphemism for a single-family caregiver carrying the entire burden.

Family caregivers of persons with severe mental illness should not be painted as victims. This study confirms that most offer care to a relative with mental illness for several years, and with a great intensity (hours of care per week). This is evidence of intense engagement and commitment to the person with severe mental health problems. The study also identified that older caregivers, and those caring more intensively (hours per week), experienced more positive caregiving experiences, besides the feelings of burden on different life domains. It seems that throughout these long-standing years of caregiving (a mean of 15 years) many caregivers feel useful, have more understanding and discover inner strengths.

Nevertheless, this nuanced picture of positive caregiving experiences paralleling the high demands on family caregivers should not conceal the heavy burdens faced by family

caregivers. This international survey confirms what already is known from previous studies: most family caregivers of persons with severe mental illness are confronted with the accumulation of burden on several life domains. Thirty two percent of the family caregivers experience burden on at least three of five life domains (social, emotional, physical, relational and financial). Although further research is necessary, some characteristics seem to be predictive for this high cumulative burden: female caregivers, younger caregivers, caregivers who have difficulties getting by, being the only caregiver and having more hours of caregiving during the last week. Interestingly, and contrary to our expectations we did not find significant associations between increased burden and the kinship relationship between the family caregiver and the patient, living together with the patient and being a working caregiver. Future research could elaborate on these factors that either support positive caregiving experiences or contribute to a higher feeling of total burden.

Of course, over the last decades there have been efforts to tackle this caregiving burden, and the professional health care system does come into contact with family caregivers of persons with severe mental illness such as schizophrenia, depression or bipolar disorders. In this survey, family caregivers acknowledge that information and advice is offered, although there are still approximately one third who are dissatisfied with this. The greatest need of family caregivers lies in the recognition that they are a full partner in care, and in the need to be listened to and taken seriously by professional caregivers. Family caregivers know what it is to live with mental illness through their daily experience with the patient. They especially worry about the future and what will happen with their ill relative in the long-term. These worries need to be taken seriously.

Combining the emotional and relational burden with lack of sleep, feelings of depression and anxiety or experiencing strains in the relationship with the person they care for, with the social isolation and stigma that these family caregivers are confronted with, gives an idea of the chronic stress that family caregivers are exposed to. It is not surprising that 93% percent of the family caregivers participating in this survey express the need for additional support, and half asking for a significant amount.

The results of this survey do point to another specific problem, that of the financial and physical burden from family caregivers. Half of the caregivers are seriously concerned about the financial situation of their mentally ill relative. Family caregivers not getting by are significantly more vulnerable for increased burden than family caregivers having less financial problems.

Despite the long-standing nature of severe mental illness, family caregivers seem to undertake their caregiving responsibility in relative silence: many do not take a break from caring and, if they do so, they prefer to accept – or are obliged to use – the help of family or friends above paid professional respite care. Family caregivers who can share caregiving responsibilities have

lower levels of perceived stigma.

In summary, this international survey reconfirms that caring for a relative with a severe mental illness, such as schizophrenia, bipolar disorder or depression, involves an enormous commitment, leading to a culmination of burden and, throughout the years, to more positive caregiving experiences. Family caregivers of persons with severe mental illness acknowledge the information and advice that is offered to them, but are mainly asking for additional emotional support. Family caregivers of persons with severe mental illness need more recognition and proper support on the different life domains that burden them.

This survey offers several hypotheses on what can be done to support family caregiving for mentally ill persons. Before formulating our recommendations we want to discuss the limitations of this study.

This study has several limitations.

Firstly, the study design could be more elaborate instead of pragmatic. For instance, this pilot study offers limited insight into the sampling frame, the contact procedures and thus the non-response.

Secondly, it is unclear how family caregivers, without linkage to a family caregiver organisation, differ from the participants in this study. It might be that family caregivers joining a family caregiver organisation are coping in a more positive way, seeking support for themselves through EUFAMI and other family organisations. Therefore, the results in this survey are not fully generalisable to all family caregivers.

Thirdly, it would have been an additional advantage to include more validated scales in the questionnaire to measure central concepts related to caregivers' experiences, in particular on caregiver burden.

Future research could expand on this pilot study by rolling out larger, representative surveys within countries. Longitudinal studies could add depth of understanding of the continuity and change in the caregiving experience. Another line of inquiry involves the implementation of interventions that support family caregivers. Evaluating the effectiveness and cost-effectiveness of these interventions is necessary. Future research should establish whether the survey used in this research is sensitive enough to measure the impact of such interventions. Policy makers need to see the financial impact of burden of family caregiving, together with an understanding of the economic benefit of supporting family caregivers.

Who needs to pay attention to this study and its results?

Obviously policy makers, clinicians and family caregiver organisations; but ideally also social workers and employers. While the results of this study do not come as a surprise to family caregiver organisations, they might astonish other stakeholders.

Although this study does not offer an answer to the question of concrete, cost-effective supporting measures to relieve

caregiver burden, and methods of enhancing communication and interaction skills of professional caregivers towards family caregivers, these findings should be of benefit to inform discussion about priorities for future actions.

Based on the findings from this international exploratory study, we have formulated the following recommendations to strengthen and support family caregivers for persons with severe mental illness:

Recommendations for policy makers

- 1. Raise public awareness on the impact of severe mental illness on families to decrease stigma.*
- 2. Stimulate policy makers to incorporate family caregiver actions and interventions into national mental health care plans.*
- 3. Encourage and support research to stimulate innovative actions and to monitor and evaluate the (cost-)effectiveness of supporting interventions for family caregivers of persons with mental illness.*
- 4. Install a diversity of respite opportunities, either through strengthening families to share caregiving responsibilities, either to finance professional respite care.*

Recommendations for professional caregivers and organisations in mental health care

- 5. Educate professional caregivers to pay attention to family caregivers in their different roles and apart from the attention given to persons with severe mental illness.*
- 6. Train professional caregivers in listening to the individual needs of family caregivers and tune into the specific burdens they are confronted with.*

Recommendations for the general public and family caregivers in particular

- 7. Educate people about mental health and the care this requires.*
- 8. Educate family caregivers on the impact of caregiving and empower them to recognize their own caregiving limits and capacities, their burdens and strengths.*
- 9. Empower families to share caregiving responsibilities and to lower the threshold for using respite care.*
- 10. Sensitise employers to support chronic family caregiving*



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Appendices

1 Family caregiver organisations that distributed the questionnaire

TABLE 13 Family caregiver organisations that distributed the questionnaire

Australia	ARAFMI
Austria	HPE – Hilfe für Angehörige Psychisch Erkrankter
Belgium	Similes Fr – Fédération des Associations SIMILES Francophones a.s.b.l. Similes VI – Federatie van Vlaamse SIMILES kringen v.z.w.
Canada	Société Québécoise de Schizophrénie Schizophrenia Society of Canada
Cyprus	KIPROSIPSA – Advocacy Group for the Mentally Ill KINISI PROASPISIS DIKEOMATON
Denmark	Bedri Psykiatri – Landforeningen Pårørende til Sindslidende
Finland	FinFami – Omaiset Mielenterveystyön Tukena Keskusliitto Ry
France	UNAFAM – Union Nationale des Amis et Familles de Malades Mentaux
Germany	BApK – Bundesverband der Angehörigen psychisch Kranker
Greece	KINAPSI – Siblings of people with mental problems POSOPSI – Panellinia omospondia Syllogon oikogeneion Gia Thn psychiki Ygeia Association of mental health service users and families SOPSI Patras – Patras Panhellenic Association of Families for Mental Health
Ireland	SHINE – Supporting People Affected by Mental Ill Health (Ireland)
Israel	OZMA – המצוּע - מורפּ - הַמְצוּע (ר"ע) שפּנ יעגפּנ תּוּחפּשּמ לּש יצרא מורפּ - הַמְצוּע (The National Forum of Families of People with Mental Illness)
Italy	ARAP – Associazione per la Riforma dell' Assistenza Psichiatrica psiche lombardia – Associazione di famigliari e volontari per la salute mentale UNASAM – Unione Nazionale delle Associazione per la Salute Mentale APAMP – Associazione Parenti ed Amici di Malati
Malta	MHA – Mental Health Association
Netherlands	YPSILON – Vereniging Ypsilon
Norway	LPP – Landsforeningen for Pårørende innen Psykiatri
Portugal	ENCONTRAR + SE – ASSOCIAÇÃO PARA A PROMOÇÃO DA SAÚDE MENTAL
Russia	New Choices – All-Russia society of persons with psychiatric disabilities and their families
Spain	FEAFES – Confederación Española de Agrupaciones de Familiares y Enfermos Mentales
Sweden	SCHIZOFRENIFORBUNDET – Intresseförbundet för personer med schizofreni och liknande psykoser
Switzerland	VASK – Vereinigung der Angehörigen von Schizophrenie-/ Psychisch Kranken
UK	Hafal (Wales) Rethink Mental Illness (England) Support in Mind Scotland (Scotland)

2 The Questionnaire

The survey was distributed to a sample of carers through EUFAMI's member organisations in Europe. Lundbeck and Otsuka were responsible for data collection in Australia and Canada. The questionnaire is available in Danish, Dutch, English, Finnish, French, German, Greek, Italian, Lithuanian, Norwegian, Russian and Spanish.

Contact EUFAMI or LUCAS KU Leuven for further information.

www.eufami.org
www.kuleuven.be/lucas

- This questionnaire is for you as a carer to talk about your own circumstances and needs, and not those of the person you care for. We recognise that carers' needs are closely linked with the needs of the person they care for, but this questionnaire has been designed to find out about YOUR circumstances and YOUR needs. All results will be analysed in order to get a clearer picture of the needs of carers of persons with mental health problem. It will also be helpful for EUFAMI to set out priorities for future actions to support these carers.
- This questionnaire can be filled in by anyone who has a role in caring for someone with a mental health problem. You don't have to be a person's main carer or live at the same address as them.
- Please try to answer every question; there are no wrong or right answers.
- We recognise that some carers may be caring for more than one person. For each question, choose one answer that best reflects your caring responsibilities as a whole. Please, do not leave questions blank, because this makes the questionnaires less useful.
- If you do have any questions for clarification, please contact the family organisation that invited you to cooperate. They will help you further.
- Some parts of the questionnaire ask about how you have been over the past 4 weeks. We recognise that this may have been an unusual time for you. However, we would like you to respond about your well-being in the last 4 weeks specifically. If you would like to tell us why this has been an unusual time, there is space to do so at the end of the questionnaire.
- At the end of the questionnaire you find questions about some basic demographic data. This is necessary to get an idea of the general response of this research.
- All data you give will be analyzed anonymously. Only the researchers will get access to the detailed answers. The results will be reported at an aggregated level and conclusions will be formulated for groups and subgroups of family members.
- Thank you for your valuable cooperation!

A. Well-Being

The questions in Part A are about aspects of **your general well-being**.
All of the questions are about how you have been over the past four weeks.

We recognise that some carers may be caring for more than one person. For each question, **tick one box on each line** that best reflects your caring responsibilities as a whole.

Please write **today's date**: / /

Your role as a carer

The first set of questions asks about your **role as a carer**. *(Please tick one box on each line.)*

During the <u>past 4 weeks</u> , how concerned were you about...	Not at all	A little	Moderately	Quite a bit	A lot
1. Not having enough time to yourself?					
2. Having to put the needs of the person you care for ahead of your own needs?					
3. Not being able to take a break from caring?					
4. Not being able to plan for the future?					
5. Not being able to continue caring due to reasons beyond your control (e.g. becoming ill yourself, looking after very young children)?					

Your relationship with the person you care for

The next questions are about your **relationship with the person you care for**. *(Please tick one box on each line.)*

During the <u>past 4 weeks</u> , how concerned were you about...	Not at all	A little	Moderately	Quite a bit	A lot
6. Strains in your relationship with the person you care for?					
7. The person you care for being too dependent on you <u>at the moment</u> ?					
8. The person you care for becoming too dependent on you <u>in the future</u> ?					
9. The person you care for saying things that upset you?					
10. Feeling irritable with the person you care for?					
11. Reaching 'breaking point', where you feel you cannot carry on with things as they are?					

Your relationships with family and friends

(Please tick one box on each line.)

During the past 4 weeks, how concerned were you about...	Not at all	A little	Moderately	Quite a bit	A lot
12. Strains in your relationships with family and friends, because of your caring responsibilities?					
13. "Drifting apart" from family and friends, because your caring responsibilities limit the time available to keep in contact with them?					
14. Feeling isolated and lonely because of the situation you are in?					
15. Not getting the support you need from family and friends?					

Your financial situation

(Please tick one box on each line.)

During the past 4 weeks, how concerned were you about...	Not at all	A little	Moderately	Quite a bit	A lot
16. Your own financial situation?					
17. The financial situation of the person you care for?					
18. Having to cover extra costs of caring (e.g. extra help in the home, trips to hospital)?					

Your physical health

(Please tick one box on each line.)

During the past 4 weeks, how concerned were you about...	Not at all	A little	Moderately	Quite a bit	A lot
19. Your own physical health?					
20. Your caring role making your physical health worse?					

Your emotional well-being

(Please tick one box on each line.)

During the past 4 weeks, how concerned were you about...	Not at all	A little	Moderately	Quite a bit	A lot
21. Being unable to cope with the "constant anxiety" of caring?					
22. Feeling depressed?					
23. Being unable to see anything positive in your life?					
24. Lack of sleep brought about through worry or stress?					
25. Lack of sleep caused by the person you care for keeping you awake at night?					
26. Feeling so exhausted that you cannot function properly?					

Stigma and discrimination

(Please tick one box on each line.)

During the past 4 weeks, how concerned were you about...	Not at all	A little	Moderately	Quite a bit	A lot
27. People treating you differently because of the illness/condition of the person you care for?					

'Because I got in contact with professional help for the person I care for...'	Totally agree	Rather disagree	Neither agree or disagree	Rather agree	Fully agree
28. ... I started to feel inferior					
29. ... I sometimes started feeling useless					
30. ... I started feeling less capable than before					
31. ... I started doubting myself					
32. ... I sometimes am ashamed for this					

Your own safety

(Please tick one box on each line.)

During the past 4 weeks, how concerned were you about...	Not at all	A little	Moderately	Quite a bit	A lot
33. Accidentally doing something that puts you at risk (e.g. leaving the gas on)?					
34. Being aggressive or threatening towards you (e.g. verbal threats, sexual aggression, physical intimidation)?					

The safety of the person you care for

(Please tick one box on each line.)

During the past 4 weeks, how concerned were you about...	Not at all	A little	Moderately	Quite a bit	A lot
35. Harming themselves?					
36. Getting themselves into dangerous situations?					
37. Relapsing or deteriorating, such that it puts their safety at risk?					

Experience of Caregiving

The following pages contain a number of statements that commonly apply to persons who care for relatives or friends with a serious mental illness.

We would like you to read each one and decide how often it has applied to you over the **past one month**.

Complete by ticking the box under the appropriate heading; for example if it **never happened**, tick the box under Never, if it **rarely** happened, then tick the box under Rarely, if **sometimes**, tick the box under Sometimes, if it has happened **often** then tick the box under Often and finally if it seems to have happened **nearly all the time**, ticking the box under Nearly always.

It is important to note that there are no right or wrong answers. Also, it is best not to spend too long on any one statement. Often your first reaction will usually provide the best answer. While there seem to be a lot of statements, you will find that it won't take more than a moment or so to answer each one.

During the <u>past month</u> , how often have you thought about...	Never	Rarely	Sometimes	Often	Nearly always
38. I have learnt more about myself					
39. I have contributed to others understanding of the illness					
40. I have contributed to his/her wellbeing					
41. That he/she makes a valuable contribution the household					
42. That he/she has shown strengths in coping with his/her illness					
43. I have become more confident in dealing with others					
44. That he/she is good company					

During the <u>past month</u> , how often have you thought about...	Never	Rarely	Sometimes	Often	Nearly always
45. I have become more understanding of others with problems					
46. I have become closer to some of my family					
47. I have become closer to friends					
48. I share some of his/her interests					
49. I feel useful in my relationship with him/her					
50. I have met helpful people					

B. Support

The questions in Part B ask **how satisfied** you are, in general, with the **support you may receive** to help you in your role as a carer. Support may be provided by people working in the voluntary, private or statutory sectors, such as GPs, social workers, housing support workers, community psychiatric nurses, care workers, psychologists, psychiatrists, and carer support services or groups run by the voluntary sector.

Please tick the box on each line that best reflects your level of satisfaction with **the support you receive as a whole**.

Information and advice for carers

The next questions ask about how satisfied you are with **information and advice** for carers. (Please tick one box on each line.)

In general, how satisfied are you with...	Very dissatisfied	Somewhat dissatisfied	Not satisfied and not dissatisfied	Somewhat satisfied	Very satisfied
1. 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?					
2. That you have enough information about how their condition/illness is likely to develop in the longer-term?					
3. That you can get whatever information you need when you need it (e.g. through your doctor or on your own)?					
4. With how easy it is to understand the information you have?					
5. With the amount of advice available to you (e.g. from healthcare workers or other carers)?					
6. That you are clear about who to go to for the information and advice you need?					
7. That you are clear about who to contact if there is an emergency and you need help right away?					
8. That you are clear about who to call if you have a routine inquiry?					

Your involvement in treatment and care planning

(Please tick one box on each line.)

In general, how satisfied are you with...	Very dissatisfied	Somewhat dissatisfied	Not satisfied and not dissatisfied	Somewhat satisfied	Very satisfied
9. Your involvement in important decisions (e.g. medication, hospitalisation)?					
10. Your ability to influence important decisions?					

Support from medical and/or care staff

The following questions ask about **the support you may receive from medical and/or care staff** – that is, the people providing treatment and care for the person you care for (e.g. GPs, social workers, housing support workers, community psychiatric nurses, workers from the voluntary sector, psychologists and psychiatrists). (Please tick one box on each line)(Please tick one box on each line.)

In general, how satisfied are you with...	Very dissatisfied	Somewhat dissatisfied	Not satisfied and not dissatisfied	Somewhat satisfied	Very satisfied
11. How easy it is to get help and support from staff for the person you care for (e.g. to prevent relapse)?					
12. How easy it is to get help and support from staff for yourself (e.g. advice on how to deal with certain behaviours)					
13. The quality of help and support from staff for the person you care for?					
14. Your relationships with key staff who support the person you care for?					
15. How well the staff you have contact with are communicating with each other (i.e. that they share important information)					
16. How seriously staff take what you say to them?					
17. The level of understanding staff have of what it must be like to be in your situation?					

In general, how satisfied are you with the support you received from	Very dissatisfied	Somewhat dissatisfied	Not satisfied and not dissatisfied	Somewhat satisfied	Very satisfied
Doctors					
Nurses					
Patient/care giver organisations					
Insurance company					
Social workers					
Workplace					
Pharmaceutical companies					

C. Your Needs

The questions in Part C are about **your needs for support** to help you in your role as a carer

Information and advice for carers

The next questions ask about how satisfied you are with **information and advice for carers**. (Please tick one box on each line.)

1. Would you like more support to help you in your role as a carer?	
No, not at all	
Yes, a little	
Yes, a lot	

2. EUFAMI and family members organisations take several actions towards relatives caring for persons with mental illness. What support do you need from these organisations? (Several answers are possible)		
Do you want EUFAMI and the family members organisations to ...	No	Yes
Represent family members at policy level		
Raise public awareness on the impact of mental illness		
Give individual emotional support		
Give individual financial support		
Give individual information		
Give practical support		
Offer respite care		
Give the opportunity to meet and share knowledge and experiences with other family members and informal carers		
Give the opportunity to meet and share knowledge and experiences with professional carers (e.g. lectures)		
Other, namely ...		

D. Background Information

The following information will help us to understand your caring situation better and interpret your answers more effectively.

About you

1. Your date of birth?

2. Your gender

Male Female

3. Your nationality?

4. Country of residence?

5. Your environment (the area you live in)?

- Rural
 Semi-urban
 Urban

6. To what extent can you get by on your total available income per month?

- Very difficult
 Difficult
 Not difficult and not easy
 Easy
 Very easy

7. To what extent has the fact that you are a carer contributed to you getting by

- Not at all
 A little
 Moderately
 Quite a bit
 A lot

8. Your employment status?

- Employed full-time
 Employed part-time
 Self-employed
 Unemployed
 Retired
 Student
 Unable to work due to caring responsibilities
 Unable to work due to ill-health /disability
 Other (please specify)

9. How many people with a mental health problem do you currently care for?

- 1 person
- 2 persons
- 3 + persons

The next questions refer to all the persons with a mental health problem you care for.

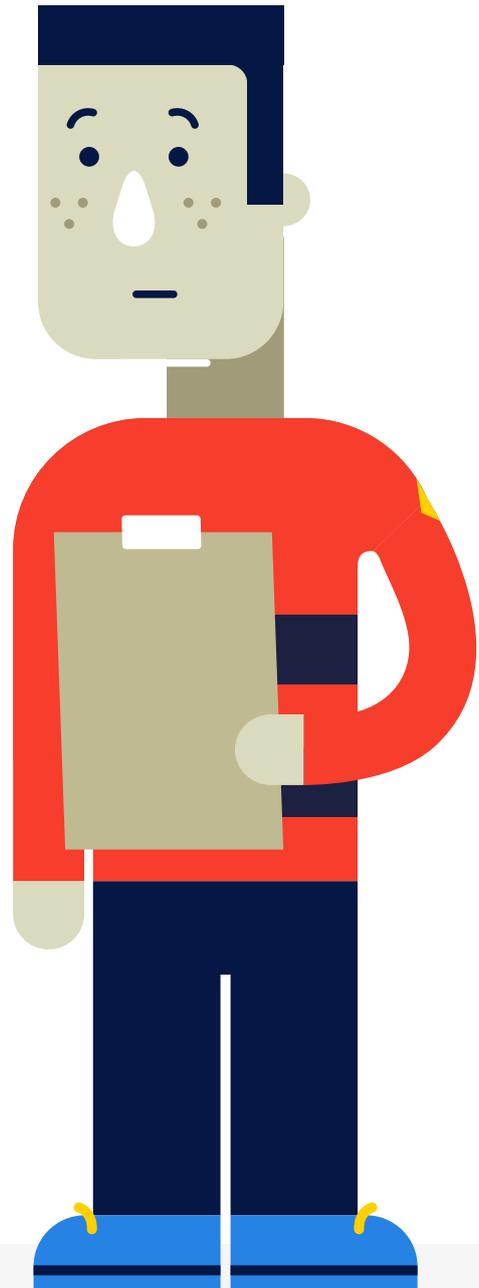
10. Please estimate as best as you can how many hours have you taken off paid work last week to care for the person with a mental health problem?

I estimate this was _____ hours

11. Please estimate as best you can how many hours you spent last week looking after someone with a mental health problem?

I estimate this was _____ hours

12. In what year did you first start caring for someone with a mental health problem? (If you don't remember the exact year, please give an estimate of the year you started caring.)



About the Person or Persons You Care For

This next section asks about the person or persons you care for with a mental health problem. Please respond about the person you care for using the first column of boxes ('Person 1'). If you care for more than one person with a mental health problem, please tick relevant boxes in the other two columns (Persons 2 & 3). There is space at the end of the questionnaire if you would like to tell us about any further caring responsibilities you may have.

13. Who do you care for?

	Person 1	Person 2	Person 3
My son/daughter	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My partner/spouse	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My brother/sister	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My parent	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My friend	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other (<i>please specify below tick box</i>)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	_____	_____	_____
	_____	_____	_____

14. What is their illness/condition?

	Person 1	Person 2	Person 3
Psychosis/schizophrenia	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Bi-polar disorder/manic depression	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Depression	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Anxiety	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other mental health problem (<i>please specify below tick box</i>)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	_____	_____	_____
	_____	_____	_____

15. Do you live with each other at the moment?

	Person 1	Person 2	Person 3
Yes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Some of the time	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<i>If no, where are they currently living?</i>			
Own/rented accommodation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Supported accommodation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
With other family member/friend	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Care home	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Hospital	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other (please specify below tick box)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	_____	_____	_____
	_____	_____	_____

16. Which of the following statements best describes your role as a carer at the moment?

	Person 1	Person 2	Person 3
I am the only caregiver	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I share caring responsibilities with others, but I am the main caregiver	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I share caring responsibilities equally with others	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I share caring responsibilities, but someone else is the main caregiver	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other (please specify below tick box)	_____	_____	_____
	_____	_____	_____

Taking a Break

17. Which of the following types of support, if any, do you use to allow you to take a break from caring?

(Tick more than one box if required.)

- Friends/family providing temporary care
- Paid carers coming into the home
- Paid carers providing care away from the home (e.g. care home)
- Supported activities out of the home, for the person you care for
- Supported breaks for you and the person you care for, away from the home
- Other respite care (please specify below)

- I'm unable to take a break from caring
- I do not need support to take a break from caring
- I do not need to take a break from caring

THE CARING FOR CARERS SURVEY REPORT 2015: RESULTS FROM 22 COUNTRIES



KU Leuven has over 40.000 students and around 8.000 academic staff. It's various faculties and departments are organised into 3 'groups': The Humanities and Social Sciences Group, the Biomedical Sciences Group and the Science, Engineering and Technology Group. Each group has a doctoral school. KU Leuven claims a place among Europe's top centers of learning.

LUCAS is the interdisciplinary Centre for Care Research and Consultancy of KU Leuven. Its mission is threefold: research, training and consultancy. In all three areas, LUCAS brings together insights from policy, practice and research, and this in constant dialogue with all stakeholders. Over the past twenty years, LUCAS has specialised in a number of crucial topics: social trends in care, care for the (demented) elderly, mental health care, communication in care relationships, and welfare, poverty and social exclusion.

Furthermore, LUCAS treats a diversity of research topics such as professional and informal care, quality of care, prevention of suicide, discrepancies between needed and provided care, relations between caretakers and care-receivers, expressed emotion, community support systems, vocational rehabilitation, stepped-care programs, case management, mobbing, discrimination, etc.

The key objective of LUCAS is to improve quality of life by initiating and supporting innovations in care practice and policy. This objective is realized by thorough research that sets national and international standards. A participative research model enables LUCAS to bring together all stakeholders and to initiate and stimulate collaborations. LUCAS encourages critical reflection, methodical action and a research-oriented mentality in the different care sectors.

For the Flemish government LUCAS coordinates the policy research center for health, social welfare and family.

Website: www.kuleuven.be/lucas