



CARING FOR CARERS SURVEY [C4C]: SPOTLIGHT ON UK EXPERIENCES OF FAMILY CAREGIVERS FOR PERSONS LIVING WITH SEVERE MENTAL ILLNESS: AN INTERNATIONAL EXPLORATION¹



1 Introduction & aim of the survey

IN THIS STUDY, THE TYPICAL FAMILY CAREGIVER FOR A PERSON WITH SEVERE MENTAL ILLNESS IN **UK** IS A WOMAN, **60** YEARS OLD CARING FOR HER CHILD WITH SEVERE MENTAL ILLNESS FOR AN AVERAGE OF **16** YEARS.¹

It is widely understood that family caregivers play a central role in the care of a person with severe mental illness. Recent reforms in mental health care, particularly in developed countries, are seeing a gradual move away from hospital-based care to more community-based care, and therefore the demands on family caregivers have increased considerably. Over the past decade there has been some scientific survey-based research data documenting the carer burden. The research is limited, not recent, and often based on single-country samples.

The Caring for Carers Survey (C4C) was designed specifically to address this 'evidence gap': to assess the experiences of family caregivers in caring for their relative with severe mental illness, from an international perspective. The study was conducted by LUCAS, the Centre for Care Research and Consultancy of the University of Leuven, Belgium, in cooperation with the European Federation of Families of People with Mental Illness (EUFAMI).

The first of its kind², the survey was undertaken in **22 countries** and received over **1,000** responses³, the majority (64%) of which were from those caring for people with schizophrenia/psychosis. The research provides a truly global overview and deeper insight into the experience of family carers, the burdens and stigma they face, their needs and necessities, their strengths and support strategies.



A multisite, cross-sectional survey:

Australia, Austria, Belgium, Canada, Cyprus, Denmark, Finland, France, Germany, Greece, Ireland, Israel, Italy, Malta, Netherlands, Norway, Portugal, Russia, Spain, Sweden, Switzerland and **UK**.

The general aim of this study is reflected in three main research questions, which assess the experiences of family caregivers and highlight the central role they play:

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?

The exploratory nature of the research means that one has to be careful with generalisations. Rather than providing definitive answers, the insights gathered in this study provide new hypotheses for further research approaches, as well as triggering carer-focussed initiatives that really will support family caregivers.

About severe mental illness

"HEALTH IS A STATE OF COMPLETE PHYSICAL, MENTAL AND SOCIAL WELL-BEING AND NOT MERELY THE ABSENCE OF DISEASE OR INFIRMITY."

WORLD HEALTH ORGANISATION (WHO)⁴

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."⁴

Those who suffer from severe mental illnesses will often end up living with severe disability and impairments. Typically, these mental illnesses have a chronic impact with a circular course characterised by periods in relatively good health and periods of relapse. People living with a severe affective or psychotic disorder, such as schizophrenia, are likely to 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 for the patient, despite their severe mental health problems.⁵

Estimations indicate that, worldwide about:

- 151.2 million** people have a unipolar depressive disorder
- 29.5 million** people have bipolar affective disorder
- 26.2 million** people are diagnosed with schizophrenia⁴

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.⁴

2 The value of caregivers

“CARERS FOR PEOPLE AFFECTED BY SCHIZOPHRENIA OFTEN FEEL UNDERVALUED. DURING EARLY PSYCHOSIS, INTERVENTIONS AIMED AT THE FAMILY CAN FACILITATE PATIENT IDENTIFICATION, IMPROVE THE EMOTIONAL WELL-BEING OF FAMILY MEMBERS AND SUPPORT CARERS IN THEIR UNQUESTIONABLY IMPORTANT ROLE IN PROMOTING REMISSION AND RECOVERY.”

EUFAMI⁶

Traditionally, people living with a severe mental illness require intensive treatment and, in many countries, may reside in specialised hospitals. However, in between periods of relapse, most people with severe mental illness such as schizophrenia or depression live in the community and are cared for by their relatives. Thus, both in practice, policy and research, there is growing attention to the needs of family caregivers.

In practice – The majority of the family caregivers in UK who took part in the survey do not live with the patient. However, the report reveals that living with the patient or not does not necessarily reduce the burden of the caregiving role.¹

INTERNATIONALLY, 4 OUT OF 10 PEOPLE CARED FOR IN THIS SURVEY LIVE AT HOME WITH THEIR CARER.¹

FROM A GLOBAL PERSPECTIVE, 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.¹

In policy – Mental health policies, especially those in developed countries, are shifting towards more community-based care. This policy shift is also reflected in the growing importance of patient and family support organisations, such as advocacy groups. 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, 38% of these organisations frequently participate in legislation formation and implementation; about 42% are not routinely consulted and 20% of the family associations are rarely or not consulted.⁴

INTERNATIONALLY, THE REPRESENTATION OF EUFAMI AND NATIONAL AND REGIONAL FAMILY MEMBER ORGANISATIONS, AT POLICY LEVEL, IS IMPORTANT FOR 90% OF FAMILY CAREGIVERS.¹

FROM A GLOBAL PERSPECTIVE, AROUND 9 IN 10 FAMILY CAREGIVERS WANT MORE OPPORTUNITIES TO MEET, AND SHARE KNOWLEDGE AND EXPERIENCES, WITH PROFESSIONAL CARERS (93%), AS WELL AS OTHER FAMILY MEMBERS AND INFORMAL CARERS (90%).¹

In research – The role of family caregivers has long been recognised. In the early 1950s research focussed on the role of families in the relapse of schizophrenia, examining ‘Expressed Emotion’ as a core theme.⁷ The recent societal trend for reducing in-patient beds in mental health institutions and towards the more rapid discharge of the patient from hospital into the community has re-invigorated research into the role of family caregivers, and this is very much in line with caregiving research in other patient populations.

FROM A GLOBAL PERSPECTIVE, TWO THIRDS OF THE PERSONS CARED FOR BY THE FAMILY CAREGIVER HAVE SCHIZOPHRENIA OR PSYCHOTIC ILLNESS.¹

INTERNATIONALLY, MORE THAN 1 IN 3 (37%) IS ‘QUITE A BIT’ OR ‘A LOT’ CONCERNED ABOUT THE PERSON THEY CARE FOR RELAPSING OR DETERIORATING.¹

3 Study conclusions & UK highlights

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.¹

Advances in treatment, economic pressures and policy shifts in mental healthcare, have resulted in family members being increasingly expected to be present, close by and available for caregiving at all times. The findings of the C4C survey reflect this; that caring for a relative with a severe mental illness, like schizophrenia or bipolar affective disorder, involves an enormous commitment.

The high demands place a heavy burden on caregivers and this research confirms that most family caregivers of persons with severe mental illness are confronted with an accumulation of burden on several areas of their lives. Combining the emotional and relationship burden with lack of sleep, feelings of depression and anxiety or experiencing strains in the relationship with the person they care for, together 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 vital therefore that community-based care should not become a euphemism for the single family caregiver carrying the entire burden.

Not surprisingly, 93 percent¹ of the family caregivers participating in the international study express the need for additional support to help with their role as a caregiver with half asking for significant levels of support. Family caregivers know what it is like to live with mental illness through their daily experiences 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 and further support and information needs to be provided. Whilst information and advice are offered by professional caregivers

there are still many in the **UK** who are concerned about this and other elements of the caregiving role.¹

UK respondents are very dissatisfied or worry very much about¹:

- The person they care for becoming too dependent on them in the future
- Not being able to plan for the future
- The person they care for relapsing or deteriorating, such that it puts their safety at risk

In general, the findings highlight the unmet information and support requirements of carers and a need for greater involvement in the decision making process of professional caregivers. However, internationally, the findings also suggest that, despite the burden on various areas of their lives, family caregiving can also lead to more positive experiences with older carers and those caring more intensively feeling useful, having more understanding and discovering inner strength.

4 Study recommendations – international

For professional caregivers and organisations in mental health care

- Educate healthcare professionals to pay attention to family caregivers in their different roles and apart from the attention given to persons with severe mental illness
- Train healthcare professionals to listen to the individual needs of family caregivers and tune into the specific burdens they are confronted with

For general public and family caregivers in particular

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

For policymakers

- Raise public awareness of the impact of severe mental illness on families to decrease stigma

- Stimulate policy makers to incorporate family caregiver actions and interventions into national mental health care plans
- 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
- Install a diversity of respite opportunities, either through strengthening families to share caregiving responsibilities or to finance professional respite care

About European Federation of Associations of Families of People with Mental Illness [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.

About 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 five years, LUCAS has specialised in a number of crucial topics: social trends in care, care for older persons and people with dementia, mental health care, communication in care relationships, and welfare, poverty and social exclusion. www.kuleuven.be/lucas

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 and Otsuka 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.

To download the full report or to obtain more information, please visit – www.eufami.org or www.kuleuven.be/lucas

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Reference: 1 Vermeulen, B., Lauwers, H., Spruytte, N., Van Audenhove, C., Magro, C., Saunders, J. & Jones, K. (2015) Experiences of family caregivers for persons with severe mental illness: an international exploration. Leuven: LUCAS KU Leuven/EUFAMI. 2 The survey was an anonymous, self-completion questionnaire administered on paper, by email and online. The design was intentionally pragmatic, using only locally available resources in distributing the questionnaire. Data was gathered at all sites from 1st June to 31st December 2014. 3 1,111 responses. 4 WHO, 2011. 5 McGuire e.a. 2014. 6 EUFAMI. 7 Vaughn & Leff, 1985.