

## Value of caring - a 2-year survey-based study on informal caregivers of persons with severe mental illness

The Nordic network for schizophrenia associations started 2019, and consist of Schizofreniförbundet (SWE), Skizofreniforeningen (DK), FinFami (FIN), Rådet for psykisk helse (NO) and Landsforeningen for Pårørende innen Psykisk helse (NO). The network has paid attention to a recent published study entitled: "Value of caring", a 2-year survey-based study, where a questionnaire was sent out to more than 700 informal caregivers of persons with severe mental illness (in particular schizophrenia, bipolar disorder and major depression) across Europe and Canada. The project was a collaboration between the European Federation of Family Associations of people affected by mental illness (EUFAMI), and the researchers David McDaid and A-La Park from the London School of Economics and Political Science (LSE). The aims of the project were firstly, to better understand components of the economic impact of informal care in specific country contexts, and secondly, to make an estimate of the economic value of informal caring, and separately provide a simple tool that can be used to help refine estimates of the value of informal caring. The tool can be find on EUFAMI's homepage: <http://eufami.org/resources/the-value-of-caring-resources-are-now-available/>

Results from the survey show that the majority of informal caregivers are women, caring for a son or a daughter and spending an average of 22 hours per week in caregiving activities. However, their contributions are usually not fully recognized, and this results in insufficient support for their own needs when it comes to health, economy and welfare. Furthermore, approximately 40 percent report worrying about their own physical health, with nearly one third fearing that their role as a caregiver detrimentally affects their physical health (Figure 1). Moreover, as shown in Figure 1, the caregiver's also report effects on their mental health status: nearly one-in-three report being diagnosed with depression or anxiety disorder.

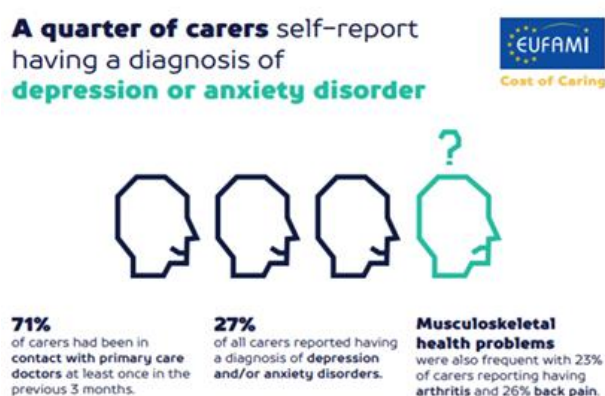


Figure 1. Informal carers provide report worrying about their own physical health and nearly one-in-three report being diagnosed with depression or anxiety disorder. Pictures from: [http://eufami.org/wp-content/uploads/2021/02/value-of-caring-research-survey-key-findings-english\\_.pdf](http://eufami.org/wp-content/uploads/2021/02/value-of-caring-research-survey-key-findings-english_.pdf)

In addition to health stress, financial stress and social isolation/loneliness are frequently reported. The carers do also report reduction in their time in work, education, and leisure activities (Figure 2). On average, informal carers provide more than 43 hours of care every week (Figure 2), and as mentioned before, often without adequate supportive structures. The financial stress is understandable, as each hour of caring time, is valued to be between €23.62 and €28.75. This indicates that the economic value/contribution of informal care is substantial: on a year basis between €61,026 and €74,907 (Figure 3). Sad but not surprisingly, the quality of life for carers were 40 percent lower than if they were not caring (Figure 3). Additionally, the majority of carers have not had a formal assessment of their caring needs, only 23 percent of respondent carers had requested, or had a formal assessment of their care needed.

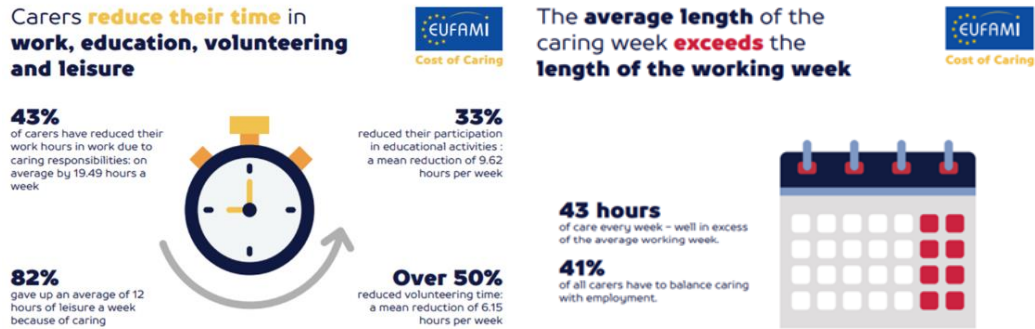


Figure 2. Informal carers provide more than 43 hours of care every week and each hour of caring time, is valued to be between €23.62 and €28.75. Pictures from: <http://eufami.org/wp-content/uploads/2021/02/value-of-caring-research-survey-key-findings-english.pdf>

From the study, it is clear that family members and other informal carers, who support people with mental health problems, are an essential part of the mental health support systems, and the study highlights the tremendous and too often hidden value of caregiving. Without the input from these carers (mainly close family members), some of the support would need to be provided by national health- and social care systems.



Figure 3. Informal carers provide more than 43 hours of care every week and each hour of caring time, is valued to be between €23.62 and €28.75. Quality of life for carers were 40 percent lower than if they were not caring. Pictures from: <http://eufami.org/wp-content/uploads/2021/02/value-of-caring-research-survey-key-findings-english.pdf>

All severe diseases will of course, and to some extent involve family members and other informal carers, but it is unlikely that family members to patients suffering from other diseases, will be responsible for the similar informal care, or financial support as described for caregivers to people affected by severe mental illness and this with insufficient support for their own needs. The Nordic network for schizophrenia associations, wants to highlight the situations for family members and other informal carers who support people with severe mental health problems. Finally, the network wants involved politicians, as well as the national health- and social care systems to answer how these carers can get better support, and also answer, how different systems can be changed and developed to prevent carers to lose quality of life, worsening in physical- and mental health, as well as losses in time and financially.

*The article is advocated by:*  
 Schizofreniförbundet (SWE)  
 Skizofreniforeningen (DK)  
 FinFami (FIN)  
 Rådet for psykisk helse (NO)