The Change of Perspective in the Associations of families

22nd of November, 2018
Barcelona, Spain

Miia Männikkö
EUFAMI President
president@eufami.org
Founded in 1992

Represents circa 25 million families in Europe

37 member organisations in 23 countries

EUFAMI’s mission is to represent all family members of persons affected by severe mental illness at European level so that their rights and interests are protected and promoted
Caring for carers

CARING FOR CARERS SURVEY (C4C)

Experiences of family caregivers of persons with severe mental illness: An international exploration.

The aim of the Caring for Carers (C4C) survey was to assess the experiences of family caregivers in caring for their relative with severe mental illness from an international perspective, and to highlight the central role they play. The C4C survey was undertaken in 22 countries and received over 1,000 responses, the majority (64%) of which were from those caring for people with schizophrenia/psychosis.
What do families say?

#C4Csurvey – voices of 1111 carers of a family member with severe mental health problems throughout Europe

Full results:
www.caringformentalhealth.org

Spain: www.eufami.org/c4c/region/spain.html

and general info in Spanish:
http://www.eufami.org/c4c/spain/themes.html
Family caregivers have typically cared for their loved one for 15 years. Caring can also involve positive experiences with more than half of caregivers discovering inner strength.

More than 1 in 3 family caregivers are at the point of reaching breaking point. 4 in 10 feels unable to cope with the constant anxiety of caring and experience these feelings “quite a lot” or “sometimes.”

1. THE HIGHS AND LOWS OF CARING

Family caregiving for people with severe mental illness involves feelings of stigma and burden, however, these experiences can be coupled with positive caregiving experiences.
Caring can often have a detrimental impact on the caregiver's own health.

\[ \frac{1}{3} \] feels that the caring role make their own physical health worse.

Nearly \( \frac{4}{10} \) are concerned about their own physical health.
2. THE REAL-LIFE CARER

The typical family caregiver for a person with severe mental illness is female (80%) and around 60 years old, with:

- 76% taking care of a son or daughter
- 7% for a brother or sister
- 10% for a partner or spouse
- spending an average of 22 hours each week caregiving
The job of caring is **often solitary** and with little respite

- Nearly half (**47%**) never take a break from caring
- **36%** of carers are the only caregiver

- Only **6-8%** rely on paid respite care
- **36%** rely on friends and family
3. CARER SUPPORT IS LACKING AND THEIR VOICE OFTEN UNHEARD

Caregivers were **equally satisfied and dissatisfied** with the support from healthcare professionals nevertheless:

- **4 in 10** are dissatisfied with support from doctors
- A **1/3** are dissatisfied with support from nurses
- And only **3 in 10** were satisfied with support from their social workers
- **Half** are dissatisfied with the ability to seek help and support from professional staff for their own needs
- **1 in 4** is dissatisfied with the support they receive from their workspace
- Caregivers were more satisfied with the support from patient/caregiver organisations (6 out of 10)
Caregivers don't feel involved in important decisions

Only 1/3 are satisfied with their involvement in important decisions in treatment and care planning.

4 in 10 are dissatisfied with their involvement and ability to influence important decisions.

Less than 4 in 10 carers feel that medical and care staff take them seriously.

Fewer than 1 in 4 feel communication between healthcare professionals is going well.
Families need information and education

Further **essential information** is critical

1/3 of family caregivers are dissatisfied with the information on who to contact in case of an emergency.

Almost **half** of the family caregivers are dissatisfied with information on how the illness of their relative will develop in the longer term.
The worry and stress means that

1 in 5 feel so exhausted that they cannot function properly

1/3 lack sleep because of the worry and stress

1/3 feel depressed

1 in 5 are unable to find anything positive in their life
Around 9 in 10 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%
4. CRITICAL SUPPORT FOR CAREGIVERS - WHAT THEY ARE TELLING US THEY NEED

A staggering 93% would appreciate some additional support in their role as caregiver.

With nearly half requesting a significant amount of additional support.

Only 7% need no additional support.
Family caregivers have special knowledge and experience to contribute to the whole process of diagnosis, treatment, care and recovery of the service user.

At the diagnostic stage they will usually be the first to notice the possible warning signs and have essential relevant information to communicate.

They also become the main if not sole source of the care provided, often full time.

The transfer of care and treatment from hospital to community settings significantly expands this role.
TRIALOGUE
Open communication and mutual understanding

Service users

Professionals

Families

www.eufami.org
“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”
Listening to family members (not using them as a means to observe/control their family members affected by mental ill health; also listen to their needs and concerns and respond to them.
Family members and carers play an important role. Their contributions must be acknowledged appropriately.

Carers should have the right and opportunity to state their needs.

They should be allowed to define the role they are willing and able to play.

Carers should be provided with quality information in their own language.

But how can these objectives be achieved? One way is to empower family members.
policies in mental health offer family members a choice to care or not to care

- deinstitutionalisation accompanied by investment in local support services, including for family members.
- flexible working hours & financial & other support measures so it is possible to choose to be a working carer – (for which EUFAMI looks to the EU)
8 out of 10 want **individual support** from EUFAMI and family member organisations by providing/offering:

- **Information**: 88%
- **Emotional support**: 83%
- **Respite care**: 78%
- **Financial support**: 62%
Thank you

#C4Csurvey