

How to *mobilise resources*  
to reduce the *burden of care*  
for the *family members*  
of people suffering from a mental disorder?

Raluca Sfetcu

Sanatatea mintala in secolul XXI. Ajutor si autoajutor pentru membrii fmiliilor

Cluj Napoca, 27 Octombrie 2018





# Outline

1. What type of problems are associated with caring for a mentally ill family member and why are these a burden?
2. Which interventions are effective in reducing the burden of care?
3. What resources are needed to make these interventions accessible and how can these be mobilised?

# Outline

1. What type of problems are associated with caring for a mentally ill family member and why are these a burden?
  1. What is burden of care?
  2. What generates it?
  3. Who is more affected by it?
2. Which interventions are effective in reducing the burden of care?
3. What resources are needed to make these interventions accessible and how can these be mobilised?

# What is burden of care?

- 80% of the family members of persons suffering from a mental illness (MI) experience distress as a result of providing caring activities<sup>1</sup>;
- In average 22,5 hours/week ( 9-32) and 14% of the income is invested in caring activities<sup>2</sup>

1. Magliano et al. 2002; Kuipers & Bebbington, 2005; Parabiaghi et al. 2007

2. Flyckt, Lothman, Jorgensen, Rylander, & Koernig, 2013.

# Ce intelegem prin povara ingrijirilor

- Def. = Atunci cand solicitarile si responsabilitati emotionale, fizice si financiare ce apar ca urmare a imbolnavirii unui individ sunt preluate de membrii familiei, prieteni sau alte persoane apropiate (din afara sistemului de sanatate);
- 80% din membrii familiei PPSM experimenteaza distress ca urmare a activitatii de ingrijire<sup>1</sup>;
- In medie 22,5 ore/saptamana ( 9-32) si 14% din venituri sunt investite in activitati de ingrijire<sup>2</sup>

1. Magliano et al. 2002; Kuipers & Bebbington, 2005; Parabiaghi et al. 2007

2. (Flyckt, Lothman, Jorgensen, Rylander, & Koernig, 2013).

# What generates the burden of care?

1. Activating and monitoring the patient(IEQ<sup>2</sup>)
  - e.g. urging him to take care of himself, to eat, etc.
2. Tense interpersonal relations between the patient and the other family members (e.g. due to sleep disturbances, fighting, irritating behaviors)
3. Supervising the sleep of the patient or his/her dangerous actions (e.g. alcohol use, drug use, suicide attempt)
4. Worrying about the safety, treatment, health, wellbeing or the future of the patient

(1) *Structural stigma, affiliated stigma and consequences of caregiving for the family members of inpatients with dementia: A comparative approach* | Request PDF. Available from: [https://www.researchgate.net/publication/318226065\\_Structural\\_stigma\\_affiliated\\_stigma\\_and\\_consequences\\_of\\_caregiving\\_for\\_the\\_family\\_members\\_of\\_inpatients\\_with\\_dementia\\_A\\_comparative\\_approach](https://www.researchgate.net/publication/318226065_Structural_stigma_affiliated_stigma_and_consequences_of_caregiving_for_the_family_members_of_inpatients_with_dementia_A_comparative_approach) [accessed Oct 26 2018].

(2) Chestionarul de evaluare al Implicarii/Involvement Evaluation Questionnaire (IEQ)





**Problemele membrilor familiilor persoanelor  
cu probleme de sănătate mintală din  
Transilvania**

**Rezultatele unui studiu de evaluare a nevoilor**

Heinz Katschnig<sup>1,2</sup>, Gabriele Niedermayer<sup>2</sup>, Raluca Sfetcu<sup>3</sup>, Paul-Otto Schmidt-Michel<sup>4</sup>

- **At familial level:** no or little time for himself and other family members
- **At financial level:** increased living costs
- **At social level:** shame, social isolation
- **At health status level:** problems sleeping, little energy for other things

<sup>1</sup> Sapoortul a fost organizat de IMEIPS - Improving Mental Health Pathways (Vienna: [www.imeips.at](http://www.imeips.at))

<sup>2</sup> Împreună cu Asociația Transilvanie (Cluj) și Ubuș (Cluj).

<sup>3</sup> IMEIPS - Improving Mental Health Pathways (Vienna: [www.imeips.at](http://www.imeips.at))

<sup>4</sup> Centrul de Cercetare, Universitatea de Medicină, Cluj-Napoca.

<sup>5</sup> Asociația Transilvanie (Cluj): contact: [asociatia\\_transilvania@yahoo.com](mailto:asociatia_transilvania@yahoo.com)

# Who is more affected?

- Parents (mothers)
- Who live in the same home as the person suffering from a mental illness (PSMI)
- PSMI had a recent episode
- PSMI manifests psychotic symptoms or abnormal behaviors
- PSMI has a low level of functioning
- Spend a lot of time in caring activities
- Other family members also need support or care
- They do not receive practical help with caring from other family members
- They do not have a perceived support from formal care systems

Grandon, Jenaro, & Lemos, 2008; Magliano et al., 1998; Parabiaghi et al., 2007

Kumar, Suresha, Thirthalli, Arunachala, & Gangadhar, 2015; Parabiaghi et al., 2007

Lauber, Eichenberger, Luginbuhl, Keller, & Rossler, 2003; McCullagh, Brigstocke, Donaldson, & Kalra, 2005; Parabiaghi et al., 2007; Winefield & Harvey, 1993.

# Outline

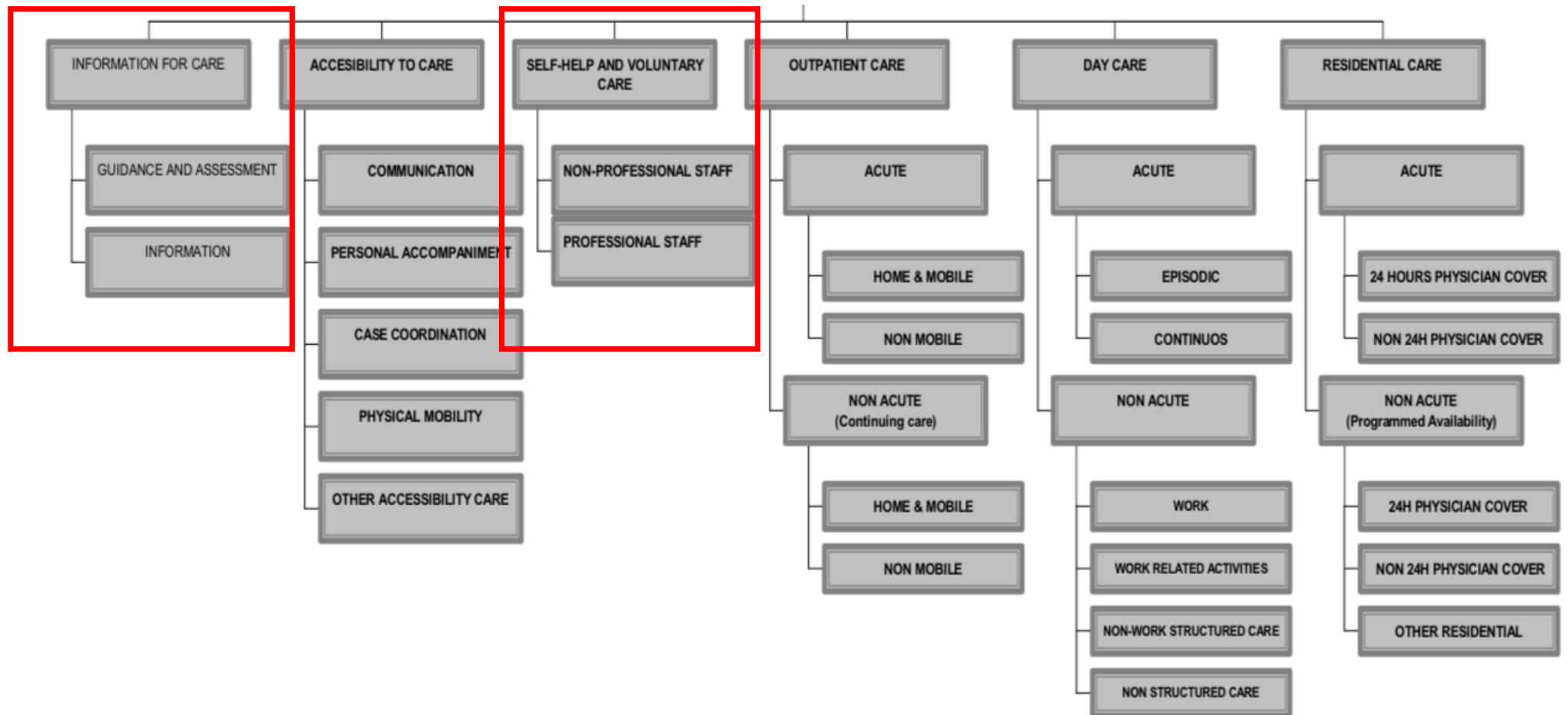
1. What type of problems are associated with caring for a mentally ill family member and why are these a burden?
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# Interventions to improve the experience of caring for people with severe mental illness: systematic review and meta-analysis

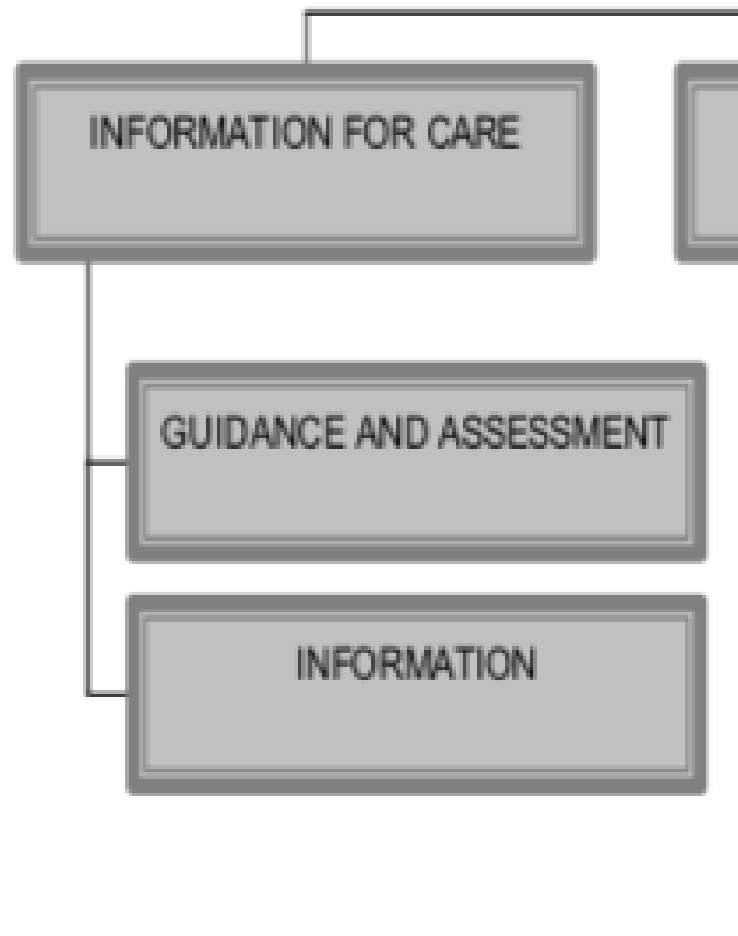
Amina Yesufu-Udechuku, Bronwyn Harrison, Evan Mayo-Wilson, Norman Young, Peter Woodhams, David Shiers, Elizabeth Kuipers\* and Tim Kendall\*

- **Support groups**
  - Discussions about the PSMI and his disease
  - Behavioural problems and symptom management of the PSMI
  - Own wellbeing importance & management (self-help)
  - Understanding and accessing mental health services as well as information about resources, benefits and support
  - Adopting new and positive roles and improving the relationship with the PSMI
- **Psychoeducation**
  - Coping abilities training
  - Communication training
  - Problem solving training

# REFINEMENT



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# “Resource Mobilization” or organizing social movements

## The Trend of Social Movements in America: Professionalization and Resource Mobilization

JOHN D. MC CARTHY  
Vanderbilt University

MAYER N. ZALD  
Vanderbilt University

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AMERICAN sociologists have been intrigued with the phenomena of social movements. They have studied and analyzed movements ranging from those on the left wing aimed at overturning the social order to those on the right wing aimed at restoring an earlier order. But they have not neglected moderate movements with ameliorative goals or movements with no apparent political goals or implications (e.g., movements related to individual deviance such as alcoholism or to a belief in the end of the world). To understand the rise and fall of all of these movements—and their related movement organizations, which normally are the unit of analysis—sociologists have focused upon members. Leites and Wolf [1970] call this a “hearts and minds of the people” approach, which assigns primary importance to the state of consciousness of members and potential members. The development of group consciousness, the relation of a group’s life situation to the formation of ideology and to social action have been primary concerns of this study and analysis.

We stress a different approach. Our “resource mobilization” approach emphasizes the resources, beyond membership consciousness and manpower, that may become available to potential movements. These resources support the growth and vitality of movements and movement organizations. This view does not necessarily deny the existence of grievances. It stresses the structural conditions that facilitate the expression of grievances.

- McCarthy si Zald:
  - Resources: time, money, legitimacy, people
  - Mobilization: motivating people to take part and to attract resources
- What does matter is attracting resources and action
- 2 categories of founding members
  - a) motivated by their consciousness (they can contribute without having a direct benefit)
  - b) motivated by the result (they will benefit)



# 40 years of self-help for family members in Austria

## 40 Jahre gemeinsam – 40 Jahre HPE Selbsthilfe

Vor 40 Jahren haben engagierte Angehörige, Eltern von PatientInnen, den ersten HPE Verein in Wien gegründet. Dem sind einige Gruppen-Treffen, gefördert und unterstützt von Sozialpsychiater Heinz Katschnig, vorausgegangen und die Überzeugung, „es muss sich etwas ändern“, waren für die GründerInnen Dorli Simon und Eva Breu und andere die Triebfeder. Standen am Beginn noch die PatientInnen sehr im Fokus (Hilfe für Psychisch Erkrankte) wurde im Austausch untereinander spürbar, wie sehr auch wir Angehörigen Hilfe brauchen und sie uns gegenseitig geben können. (Hilfe für Angehörige psychisch Erkrankter). Also wurde HPE als Selbsthilfegruppe aktiv.

einbringen, wie z.B. das Thema Partnerschaft mit einem psychisch erkrankten Menschen, Kindheit mit einem erkrankten Elternteil, Maßnahmenvollzug u.v.m. und diese mit Leben füllen, und viele, viele andere mehr.

Diese vielen Menschen mit ihren individuellen Eigenschaften und Fähigkeiten prägen das bunte Bild der HPE, wie bunte Teile einer Patchwork-Decke, die unterschiedlich sind, aber zusammenhalten und alle gemeinsam Wärme spenden.

Ein Ziel der HPE ist Veränderung und Entwicklung – als Angehöriger, in der Familie, beim Erkrankten und in der Psychiatrie. Das zu erreichen ist nicht immer einfach und mit Rückschlägen verbunden, aber, wie die letzten 40 Jahre zeigen, möglich. Auch die HPE hat sich in jedem ihrer 40 Jahre weiterentwickelt, sich

- 40 years ago the family members, parents of mentally ill patients have founded the first HPE association in Vienna”.
- It was preceded by a series of group meetings sponsored and supported by the social psychiatrist Heinz Katschnig and by the conviction that “something needs to change”
- And initiated by Dorli Simon, Eva Breu and others.
- In the beginning, the patients were in the middle of the attention but soon it became obvious that the family members themselves need support
- And HPE became active as a self-help group.



# Social movements can mobilize

- Material resources:
  - Money
  - Organizations
  - Human resources
  - Technology
  - Communication and mass-media
- Non-material resources:
  - Information (newsletter)
  - Support network
  - Time
  - Moral support
  - Personal connections
  - Public attention
  - Authority
  - Solidarity

1979

APRIL 1979

NR. 6

# KONTAKT

MITTEILUNGSBLATT FÜR ANGEHÖRIGE PSYCHISCH ERKRANKTER

Ab dieser Nummer hat unser Mitteilungsblatt einen neuen Namen. Wir betrachten es als das wichtigste Ziel für psychisch Kranke und ihre Angehörigen, die Isolation zu überwinden, in der sie von anderen gehalten werden und in die sie sich zurückziehen. Eine wesentliche Voraussetzung für die Verbesserung der Situation psychisch Kranker und ihrer Angehörigen besteht darin, den Kontakt zwischen Patienten und Umwelt, Angehörigen und Umwelt, Patienten untereinander, Patienten und Angehörigen und Angehörigen untereinander zu fördern. Dieses zentrale Anliegen soll sich im Namen unseres Mitteilungsblattes ausdrücken.

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Nächster Jour fixe: Do 3.5.1979, 18.30 Uhr	
Angehörigenseminar: Sa 19.5.1979, 9-18 Uhr	
Generalversammlung und Jour fixe:	
Do 7.6.1979, 18.30 Uhr	
Urlaub für Familien mit psychisch Kranken:	
Juli od. September 1979	
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"Mein Sohn braucht eine Hausmutter"	

Angehörigenvereinigung "Hilfe für psychisch Erkrankte" (HPE)  
Telefon 43 07 55 (9-16 Uhr), Postscheckkonto 7910.155

2018

ZEITSCHRIFT DER HPE ÖSTERREICH

JAHRGANG 41 AUSGABE 4 2018

# KONTAKT
















Informationen  
zu allen HPE-  
Veranstaltungen  
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Rubrik Termine!



**SELBSTHILFE:**

**GEMEINSAM SIND WIR STÄRKER**



Ort	Beratungsstellen und Gruppen	Datum	Zeit	Adresse	Kontakt und Information
St. Pölten	 Angehörigenberatung durch erfahrene Angehörige	Terminvereinbarung		PSD, Brunngasse 23	Karoline Pölzl: T 02755/86 41 T 0676/838 44 88 81 Helma Fuchs: T 0676/838 44 88 82
	 Angehörigengruppe	1. Freitag/Monat	14.00 – 17.00	PSD, Brunngasse 23	Karoline Pölzl: T 0676/838 44 88 81
	 Professionell moderierte Angehörigengruppe	2. Dienstag/Monat	15.00 – 17.00	PSD, Brunngasse 23 Gruppenraum 3.04/3. Stk.	DSA Ingrid Wittchen: T 0676/83 84 45 13
	 TRIALOG	Termin auf Anfrage	16.00 – 17.30	PSD, Brunngasse 23	T 0676/838 44 89 63
Amstetten	 Angehörigengruppe	2. Donnerstag/Monat	18.00	Hauptplatz 37, 1. Stock, RAIBA-Gebäude)	Sandra Scherfler: T 0676/838 44 88 71
	 TRIALOG	Termin auf Anfrage	16.00 – 18.00	Arbeiterkammersaal Amstetten, 1. Stock Sitzungs- saal, Wiener Straße 55	PSD Regionalbüro Mostviertel: T 07472/655 44
Baden	 Angehörigengruppe	2. Dienstag/Monat Anmeldung bei erstmaliger Teilnahme	18.30	Kolpinghaus, Valeriestraße 10	Dr. Waltraud Kress: T 02252/478 17
Bruck / Leitha	 Angehörigengruppe	1. Montag/Monat	16.30	Stadthalle, Leithagürtel	Elisabeth Wallner: T 0676/933 60 08
	 TRIALOG	jeden 1. Dienstag in geraden Monaten	17.00 – 19.00	PSZ Club Wiener Gasse 3/B/1. DG., Bruck /Leitha	Auskunft unter T 02162/639 12
Gänserndorf	 Angehörigenberatung	Termin auf Anfrage		PSD, Wiener Straße 25	DSA Erna Guth: T 02282/87 33
	 TRIALOG	jeden 1. Dienstag einem Monat		PSD, Wiener Straße 25	Auskunft unter T 02282/87 33
Gmünd	 Angehörigengruppe	1. Dienstag/Monat	16.00 – 18.00	PSD, Pestalozzigasse 3	Dr. Irina Taschler: T 0676/83 84 45 11
Hollabrunn	 Angehörigengruppe	1. Montag / Monat	18.00	PSD, Kühschelmgasse 5	Frau Toifl: T 0664/73 76 25 60
Kloster- neuburg	 TRIALOG	letzter Mittwoch/Monat	18.00 – 19.30	BG, Buchberggasse 31	PSD: T 02243/35 201
Krems	 Angehörigengruppe	1 x monatlich Montags Termin auf Anfrage	17.00 -18.30	PSD, Bahnzeile 1	DSA Kaindl: T 0676/83 84 45 14 DSA Pfeiffer: T 0676/83 84 45 20



# Resource Mobilization

*This brief is one in a series of tips for civil society organizations written from a funder's perspective. It is intended to stimulate inquiry, rather than to provide rigid instructions.*

## Tips for Strengthening Organizational Capacity

### **Resource Mobilization**

Tips for mobilizing resources closer to home to strengthen organizational capacity and deliver benefits to the community.

These tips include diverse methods for mobilizing resources starting with preparing for fundraising, assessing and using community strengths, and soliciting external funding sources.

### **Project Development**

Tips for developing and implementing a project and key questions to ask in the process.

### **Budgeting**

Tips for preparing a budget with an emphasis on its purpose, steps, and components.

### **Financial Systems**

Tips for establishing an accountable and transparent financial system to build financial sustainability.

### **Monitoring & Evaluation**

Tips for reviewing and assessing progress towards objectives, identifying problems and strategies, and making adjustments to plans.

### **Grant Proposal Writing**

Tips for developing and writing a proposal, including critical elements to facilitate project success.

### **Reporting to Funders**

Tips for maintaining and strengthening your relationship with funders following a grant award.

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- Success depends on the resources but also on the capacity to use them

