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

Raluca Sfetcu

Sanătatea mintală în secolul XXI. Ajutor si autoajutor pentru membrii familiilor
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) experiment distress as a result of providing caring activities\(^1\);

• In average 22.5 hours/week (9-32) and 14% of the income is invested in caring activities\(^2\)

1. Magliano et al. 2002; Kuipers & Bebbington, 2005; Parabiaghi et al. 2007
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 mebrii familiei, prieteni sau alte persoane apropiate (din afara sistemului de sanatate);

• 80% din membrii familiei PPSM experimenteaza distress ca urmare a activitatii de ingrijire¹;

• In medie 22,5 ore/saptamana (9-32) si 14% din venituri sunt investite in activitati de ingrijire²

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$^2$)  
   - 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. Worring about the safety, treatment, health, wellbeing or the future of the patient


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

- INFORMATION FOR CARE
  - GUIDANCE AND ASSESSMENT
  - INFORMATION
- SELF-HELP AND VOLUNTARY CARE
  - NON-PROFESSIONAL STAFF
  - PROFESSIONAL STAFF
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“Resource Mobilization” or organizing social movements

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

JOHN D. MCCARTHY
Yale University

MAYER N. ZALD
Yale University

American sociologists have been intrigued with the phenomenon 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 neglected moderate movements with intermediate goals or movements with no apparent political goals or implications (i.e., movements related to individual decisions 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 turned to the study of strategic and tactical implications of leadership and membership roles. The development of group consciousness, the relation of a group’s life situation to the formation of strategy and to social action, and the relationship between strategy and action and the consequences of this study and analysis.

We adopt a different approach. Our “resource mobilization” approach emphasizes the resources needed to maintain and manage, that may become available to potential movement organizations. By contrast, the resource mobilization approach emphasizes the growth and stability 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 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.
HILFE ANSCHÖRIGE
PSYCHISCH ERKRANKTER

40 Jahre
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

(Fuchs, 2006)

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  - Abendgesellschaft: Sa 19.5.1979, 9-18 Uhr
  - Generalversammlung und Abend: Do 21.6.1979, 19.30 Uhr
- **ERGEBNISSE** ............................ 3
  - Treffen über gemeindezugehöre Psychiatrie in Graz
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  - "Mein Sohn bewacht eine Hausnützen"

Angehörigenvereinigung "Hilfe für psychisch Erkranke" (HPE):
Telefon 15 87 56 (9-18 Uhr), Stiftungskonto 7449.153
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<td>Arbeiterkammerrsaal Amstetten, 1. Stock Sitzungs- saal, Wiener Straße 55</td>
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<td>Elisabeth Wallner: T 0676/933 60 08</td>
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<td>PSD, Kühlschelmgasse 5</td>
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<td>PSD, Bahnhalle1</td>
<td>DSA Kaindl: T 0676/83 84 45 14</td>
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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.

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