

Supplementary file: Protocol for a Systematic Review

Implementing family involvement in treatment of psychosis: A Systematic Review of facilitating and hindering factors

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Background and rationale for a review

Due to the move of psychiatric care from hospitals to community, nowadays informal caregivers (i.e. family or friends) have taken some functions performed in the past by psychiatric institutions. Consequently, "informal care" plays a significant role in development and evaluation of health programs and policies (Clark & Drake, 1994; Simpson, 2008; Caqueo-Urizar et al., 2009).

An estimated 40-50% of almost six million carers in the United Kingdom provide care for another family member or friend with a mental health problem (Office for National Statistics 2003). In particular, it has been estimated that carers of people with schizophrenia save the public purse £1.24 billion per year (Schizophrenia Commission Report, 2012).

Many psychiatric policies and guidelines stipulate that families should be supported and actively involved in psychiatric treatment (Department of Health, 2006; National Institute of Mental Health in England, 2004; NICE, 2011). The Schizophrenia Commission Report (2012) states that "Services need to make a fundamental reappraisal of how they treat families and put them at the centre of their thinking and practice". This document also emphasizes that "carers are seen as resource, experts, partners in care". Recent evidence from large scale European and UK studies has documented that relatives wish to be more involved in the care of their ill relatives, also during acute phases of their illness (Jankovic et al., 2011; Giacco et al., 2012).

Family involvement in treatment is often seen as intrinsically worthwhile; however some positive consequences in terms of patients' outcomes and patients and families' satisfaction with treatments have also been hypothesized (Simpson and House, 2003).

However, a number of barriers to family involvement in treatment and problems in its implementation in routine practice have been also identified (Simpson and House, 2003) such as: danger of increasing burden related to caregiving, role strain, lack of experience and/or interest. Also, specific problems may arise in different phases of the illness (e.g. when the patient is acutely ill and requires involuntary treatment).

This study will systematically review the available studies exploring family involvement in routine psychiatric treatment. Assessing barriers, problems and facilitating factors related to family involvement will help better define and implement family involvement in clinical practice.

Research questions

The review will aim at answering the following research questions:

1. What are the barriers that may prevent family involvement?

2. What are the problems that may arise during implementation of family involvement?
3. What are the facilitating factors for family involvement?

The different perspectives of patients, their family members and staff will be assessed.

Selection criteria

1) Study type

Conducted in general public mental health services
Any type of study design (qualitative, quantitative and mixed)
Published in Latin script

2) Participants

Patients

People with psychotic disorders (F20-29 and F31 according to ICD-10)
Age 18-65/ any gender/nationality

Family/Carers

Family and informal (i.e. non-professional) carers: relatives, friends, others
Any age /gender/nationality
Either main carer (i.e. spending most time with the patient) or other carers

Staff

Any mental health professional (psychiatrists, psychologists, nurses, social workers, care coordinators, occupational therapists)

3) Family involvement

Explicit description of family involvement (i.e. information, support, involvement in decision making, preparation of crisis plans, etc.)
Assessment of carer's involvement through assessment of barriers or problems or facilitating factors or feasibility

Exclusion criteria

- 1) Studies assessing family involvement in planning of services will be excluded
- 2) Studies not reporting clear information on how family involvement was implemented (services' catchment area, description of activities, i.e. information, support, involvement in decision making, preparation of crisis plans, etc.)
- 3) Studies into general experience, opinions, satisfaction or needs, unless related to a clearly described carer involvement in treatment
- 4) Studies reporting on therapy for the family or group psychoeducation, i.e. the carer involvement will have to be in the context of the treatment of an individual patient

Methods

In order to gather relevant literature, electronic searches of electronic databases will take place. In addition, the articles included as references in the review papers found will be hand searched too.

Databases to be searched include:

- BNI
- CINAL
- EMBASE
- MEDLINE
- PsychINFO
- CENTRAL
- AMED
- Social Sciences Citations in Web of Knowledge

Hand searching of review articles on the topic and of included studies

Grey literature will also be searched, including:

- Dissertations/PhDs
- Contacting authors in the field
- Forward and backward snowballing related to citations

The abstracts of the papers identified will be examined to determine papers potentially relevant to the review. Based on this initial screening, selected full-text articles will be obtained for a second-stage screening. Studies will be included and submitted for data extraction if they specifically address family involvement in the treatment of patients with psychosis and if the tasks in which the family is involved are specifically described.

Extraction process

Search terms will be a mixture of family/carers' involvement descriptors, psychosis descriptors and outcomes.

Family/Carers' involvement descriptors	Psychosis descriptors	Outcome descriptors	
Carers	Psychosis	Clinical outcomes	Experiences
Caregivers	Schizophrenia	Symptoms	Benefits
Relatives	Psychotic disorders	Hospitalizations	Rewards
Friends	Schizoaffective disorder	Quality of life	Failures
Family support	Schizophreniform disorder	Adherence	Challenges
Family burden	Severe mental illness	Satisfaction with treatment	Difficulties
Involvement	Acute phase	Care	Barriers
Social support	Crisis	Satisfaction	Stress
Practical support		Experiences	Empowerment
Inpatient treatment		Service provision	
Outpatient treatment		Psychiatric services	
Involuntary hospitalization		Opinions	
Psychoeducation		Attitude	

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