



# A systematic review of randomised controlled trials of interventions reporting outcomes for relatives of people with psychosis



Fiona Lobban <sup>a,\*</sup>, Adam Postlethwaite <sup>a</sup>, David Glentworth <sup>b</sup>, Vanessa Pinfold <sup>c</sup>, Laura Wainwright <sup>a</sup>, Graham Dunn <sup>d</sup>, Anna Clancy <sup>e</sup>, Gillian Haddock <sup>f</sup>

<sup>a</sup> Spectrum Centre for Mental Health Research, Lancaster University LA1 4YG, UK

<sup>b</sup> Bolton EIS, Hulton Centre for Health, Linnyslaw Close, Bolton BL3 4HW, UK

<sup>c</sup> 15th floor, 89 Albert Embankment, London SE1 7TP, UK

<sup>d</sup> Health Sciences Research Group, Jean McFarlane Building, Oxford Road, Manchester M13 9PL, UK

<sup>e</sup> Division of Health Research, Lancaster University LA1 4YT, UK

<sup>f</sup> School of Psychological Sciences, University of Manchester, M139PL, UK

## HIGHLIGHTS

- ▶ Family interventions can improve outcome for relatives of people with psychosis.
- ▶ Methodological quality of trials is poor with wide variation in outcomes measured.
- ▶ No family intervention components distinguished effective from ineffective interventions.
- ▶ Future research should focus on what works for whom, when and why.

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## ABSTRACT

Relatives play a key role in supporting people with psychosis at all stages of recovery, but this can be associated with high levels of distress. Family interventions, with an international evidence base, improve outcomes for service users but little is known about their impact on relatives' outcomes. This review of published evaluations aimed to assess whether family interventions are effective in improving outcomes for *relatives* of people with psychosis, to identify the key components of effective intervention packages, and to identify methodological limitations to be addressed in future research. Fifty studies were identified which evaluated an intervention to support relatives against a control group, and in which outcomes for the relatives were reported. Thirty (60%) studies showed a statistically significant positive impact of the intervention on at least one relatives' outcome category. Eleven key intervention components were identified across all 50 studies, but there was no evidence that the presence or absence of any of these key components reliably distinguished effective from ineffective interventions. Methodological quality of studies was generally poor with only 11 studies rated as adequate using the Clinical Trial Assessment Measure (CTAM). Recommendations to improve future research include larger samples; better defined interventions and controls; true randomisation and blind assessors; clearly specified primary outcomes; pre-published analysis plans that account appropriately for missing data and clustering of data; a consensus on the most relevant outcomes to assess and valid and reliable measures to do so. Alternative research designs need to be considered to evaluate more recent approaches which focus on family support, personalised to meet individual need, and offered as an integral part of complex clinical services.

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\* Corresponding author at: Spectrum Centre for Mental Health Research, Department of Health Research, Faculty of Health & Medicine, Lancaster University, Lancaster, LA1 4YG, UK. Tel.: +44 1524 593756; fax: +44 1524 592113.

E-mail address: [f.lobban@lancaster.ac.uk](mailto:f.lobban@lancaster.ac.uk) (F. Lobban).

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## 1. Introduction

Families are an important part of the support network for those developing psychosis. This is because late adolescence or early adulthood is typically when the onset of psychosis first occurs (Lieberman & Fenton, 2000), with the majority of people living at home with family members. Psychotic symptoms, such as hallucinations, delusions and disorganised behaviour (American Psychiatric Association, 2000) can be very stressful for both the person with psychosis and their family (Addington, Coldham, Jones, Ko, & Addington, 2003). Carers of people with psychosis typically display increased rates of anxiety, depression and distress compared to the general population (Kuipers, Onwumere, & Bebbington, 2010), highlighting the need to support relatives in their caring role. Supporting carers also makes financial sense. For example, in the UK, it has been estimated that relatives, friends and neighbours providing unpaid care save the National Health Service £119 billion per year (Buckner & Yeandle, 2011), with approximately 24% of these carers supporting someone with a mental health problem (Arksey, 2003). Therefore, there are both strong moral and financial arguments for supporting carers in their roles, protecting their wellbeing. Governments do recognise the value of families, producing carer strategies and guidelines expressing commitments to support families through information and service provision though not all get implemented widely in practice (Australian Government, 2010; Department of Health, 2010; SAMHSA, 2009).

When professional support is provided to relatives, it is often by way of family intervention. The original rationale for the majority of family interventions was based on evidence that people with schizophrenia living with families that display high levels of expressed emotion (EE) tend to have higher relapse rates than those living in low EE families (Bebbington & Kuipers, 1994), coupled with the evidence that lowering EE in families reduces relapse rates (Butzlaff & Hooley, 1998). As a result many family interventions were developed with the aim of reducing EE (Budd & Hughes, 1997). Today there is greater emphasis within clinical services on supporting service users and relatives through a process of recovery, and family intervention models have been elaborated to reflect this. Principles from cognitive behavioural therapy and from systemic family therapy, have been incorporated into these models and the focus has shifted from reducing EE in order to reduce relapse rates for service users, towards reducing distress and improving wellbeing for all family members (Addington, Collins, McCleery, & Addington, 2005; Burbach & Stanbridge, 2002; Kuipers et al., 2010).

Some family intervention models have informed treatment manuals that have been evaluated in randomised controlled trials (C.M. Anderson, Reiss, & Hogarty, 1986; Barrowclough & Tarrrier, 1992; Clarkin, Haas, & Glick, 1988; Falloon, Boyd, & McGill, 1984; Kuipers, Leff, & Lam, 1992; McFarlane, 1983). Reviewing these studies has been difficult because although some studies are strict in their adherence to model being used, most are not. The most commonly reported intervention models used to inform evaluated interventions are: psycho educational workshops based on the work of Anderson, Hogarty, and

Reiss (1980) which aimed to decrease family stress, improve family confidence and knowledge about schizophrenia, and facilitate constructive reactions to service user behaviour; Behavioural Family Therapy developed by Falloon et al. (1985) which advocates working with the whole family to promote positive communication, problem solving skills and stress management; and multi-family groups as outlined by McFarlane and colleagues (1983) which emphasises the benefits of families learning from and supporting each other. The blending of approaches was not uncommon and thus testing model fidelity across a number of studies is not possible.

Many studies have assessed the impact of family interventions on service users with psychosis and there is strong evidence that these interventions have a positive effect, particularly on service user relapse, hospitalisation rates, and compliance with medication (Pfammatter, Junghan, & Brenner, 2006; Pharoah, Mari, Rathbone, & Wong, 2010; Pitschel-Waltz, Leucht, Bauml, Kissling, & Engel, 2004). Relatives' outcomes in these studies are sometimes assessed but rarely as the main outcome by which the effectiveness of the treatment is evaluated. As such, family outcomes are often reported in less detail than service user outcomes and it is consequently difficult to draw any firm conclusions about the impact of family interventions on relatives, or to explore the mechanisms by which such interventions are operating. However, it is important to address these issues because interventions that improve outcomes for service users may do so because of increased support provided by relatives, and this may be at an increased cost to their own well being. Families in the widest sense – parents, partners, siblings, and all significant others – need support themselves to care effectively and we need to know if family interventions are an effective way to provide this care.

Thus the aim of this review is to assess whether family interventions are effective in improving outcomes for relatives of people with psychosis, and to identify the key components of effective intervention packages. This information can then be used to inform the development of clinical services aimed at supporting relatives. An additional aim is to assess the methodological rigour of the trials included in the review, firstly as a key step in determining what conclusions can be drawn from this data, and secondly to identify the limitations of existing research in order to make recommendations to improve the design of future evaluations.

## 2. Method

### 2.1. Literature search

An electronic search of four databases (AMED (Allied and Complementary Medicine Database), CINAHL (Cumulative Index to Nursing and Allied Health Literature), Medline and PsycINFO) was conducted including papers published up to April 2010. The reference lists of the papers returned by the search were then explored for relevant papers. The reference list for the Cochrane review of family

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