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Towards a better understanding of caregiver distress in early psychosis: A systematic review of the psychological factors involved

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HIGHLIGHTS

- Better understanding of the psychological underpinnings of caregiver distress
- Development of a broader intervention repertoire in caregivers of persons with first-episode psychosis
- Relationship between emotional over-involvement and caregiver distress
- Highlights gaps in literature and points to new research areas

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ABSTRACT

Objectives: We sought to review empirical studies of psychological factors accounting for distress in caregivers of young people with early psychosis.

Method: Following the PRISMA guidelines, we included studies that empirically tested psychological models of caregiver distress in early psychosis by searching the following databases up until March 2014: PsycINFO, EMBASE and Cochrane Central Register of Controlled Trials (CENTRAL). This was followed by additional manual searches of reference lists and relevant journals.

Results: The search identified 15 papers describing 13 studies together comprising 1056 caregivers of persons with early psychosis. The mean age of caregivers was 47.2 years (SD = 9.8), of whom 71.5% were female and 74.4% were parents. Nine different psychological variables were examined in the included studies, which were categorised in the following non-mutually exclusive groups: coping, appraisal/attribution and interpersonal response. There was considerable data to support the link between distress and psychological factors such as avoidant coping, appraisal and emotional over-involvement. However, the possibilities of drawing conclusions were limited by a number of methodological issues, including cross-sectional data, small sample sizes, confounding variables not being accounted for, and a wide variation in outcome measures.

Discussion: The strengths of the review were the systematic approach, the exclusion of non-empirical papers and the rating of methodological quality by two independent raters. Limitations were that we excluded studies published in languages other than English, that data extraction forms were developed for this study and hence not tested for validity, and that there was a potential publication bias in favour of significant findings.

Conclusion and implications: A better grasp of the psychological factors accounting for caregiver distress early in the course of illness may help us understand the trajectory of distress. This is an important step in preventing long-term distress in caregivers and supporting recovery in the whole family.

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1. Introduction

Caregivers of persons with early psychosis or schizophrenia play an important role in the process of recovery but often experience high levels of distress, including depression, anxiety and subjective experience of burden (Martens & Addington, 2001). Barrowclough and Parle (1997) found that fifty-seven percent of the caregivers were clinically significantly distressed, and Raune and Kuipers (2000) found one third to suffer from depression. This is of great importance since the majority of service users live at home (50–70%) with their families at the early stages of illness (Addington, Addington, Jones, & Ko, 2001). An early understanding and assessment of this, followed by appropriate support, is an important part of a comprehensive early intervention programme to prevent chronic problems and long-term distress in the whole family following the onset of psychosis (McGorry, Killackey, & Yung, 2008).

While early studies often described the caregiver situation in terms of “objective” burden (Baronet, 1999; Yarrow, Schwartz, Murphy, & Deasy, 1955), later studies seem to agree on a stress-appraisal-coping framework in understanding how subjective experience of distress develops (Lazarus & Folkman, 1984; Szmukler et al., 1996). In other words, the extent to which these stressors are related to a caregiver's negative mental health is dependent on the caregiver's appraisal, or subjective evaluation, of the stressors and his/her ability to cope with them. A number of illness characteristics have been found to be associated with caregiver distress, including negative symptoms, reduced levels of functioning and ‘disruptive behaviour’ (Addington, Coldham, Jones, Ko, & Addington, 2003; Boye et al., 2001; Tennakoon et al., 2000; Wolthaus et al., 2002). However, the findings are inconclusive and others have not found these to be related (Carrà, Cazzullo, & Clerici, 2012; Heikkilä et al., 2002). Studies have also looked at caregiver demographics such as age, gender and ethnicity, but the findings here are also inconclusive (Baronet, 1999; Boydell et al., 2013).

While there are a limited number of studies looking at early psychosis, data suggest that caregivers at this stage report higher levels of distress compared to family members of individuals who have a more chronic course of illness (Martens & Addington, 2001). In the early phase of psychosis, caregivers face a number of issues, such as shock, grief and poor understanding of illness and the psychiatric system (Addington & Burnett, 2004). Also, incidences such violence, disruptive behaviour and forced admission can be traumatising, sometimes warranting a diagnosis of posttraumatic stress disorder in caregivers themselves (Onwumere, Bebbington, & Kuipers, 2011).

In relation to reducing the distress, and helping caregivers to help their psychotic relatives, one of the most influential concepts in psychosocial research on psychosis has been Expressed Emotion (EE). EE refers to interactions between persons with psychosis and their caregivers that are characterised by either critical comments (CC)/hostility or emotional over-involvement (EOI) (Brown, Monck, Carstairs, & Wing, 1962). EE is a robust predictor of relapse and symptom exacerbation in schizophrenia and other mental illnesses (Butzlaff & Hooley, 1998; Wearden, Tarrier, Barrowclough, Zastowny, & Rahill, 2000). The concept has been of considerable importance in the development of family intervention and family support programmes in psychosis (Glynn, 2012; Pfammatter, Junghan, & Brenner, 2006). However, the relevance of the concept in the early phase of psychosis has been questioned. Findings relating to the association between EE and relapse are mixed in early psychosis (Bird et al., 2010; Linszen et al., 1996) and certain aspects of EE, especially EOI, might be useful for persons with psychosis in the early phase of illness (Bentsen et al., 1996). As an example, EOI has been associated with greater participation in care, including supporting adherence to treatment and attention to needs that are unmet by the treatment system (Van Os, Marcelis, Germeys, Graven, & Delespaul, 2001). For this reason some researchers caution against relying too much on EE-focused interventions in early psychosis, and argue that, if EE is too crudely targeted in this population, it may have detrimental effects (Gleeson et al., 2010; Jansen et al., 2014; Linszen et al., 1996).

In the current research literature, the experience of caregiving is conceptualised as a complex phenomenon, influenced by characteristics of the person with psychosis as well as the caregiver, and comprising