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

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/attraction 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, 1995), 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; Heikälä 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, Gerryns, 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...
both negative and positive experiences (Jansen et al., 2014; Joyce et al., 2003). In addition, while earlier studies focused on caregiver distress in terms of its relationship to EE and relapse, recently there has been an increased recognition of the needs of caregivers independent of the course of illness in their ill relative (Kuipers, 2010; Lobban et al., 2013).

However, less is known about the psychological underpinnings of caregiver distress in early psychosis, and there seems to be a limited set of psychological models accounting for variations in caregiver distress. An improved understanding of this would assist in developing need-based support to caregivers of persons with early psychosis. Furthermore, by studying caregiver distress early in the course of illness, findings are less likely to be confounded by duration of the illness and factors associated with more chronic forms of psychosis.

1.1. Aims of the review

Through this current review we sought to identify empirical studies that have investigated psychological factors accounting for caregiver distress in early psychosis, with the aim of summarising key findings and critically evaluating the methodology used.

This review addresses the following questions:

1) What psychological processes, resources or competences within caregivers have been empirically tested in studies to account for variations in caregiver distress and what are the findings?
2) What is the methodological quality of these studies?

2. Material and method

2.1. Search strategy

Systematic searches using Cochrane methodology were performed to find relevant trials and, observational studies from the following databases: PsycINFO, EMBASE and Cochrane Central Register of Controlled Trials (CENTRAL). Databases were searched up to March 2014. The computerised search used the following strategy: ("psychosis/ or exp schizophrenia/) AND (caregiver* OR carer* OR parent* OR famil*) AND (distress* OR burden* OR well-being OR well-being OR stress* OR depression OR anxiety OR loss OR grief) AND (attribution* OR coping OR attachment OR metacognition OR “metacognitive belief” OR “expressed emotion”).

Online titles and abstracts were reviewed after duplicates were removed. Papers that did not meet the inclusion criteria were discarded, and full text papers were retrieved for potentially eligible studies. Electronic searches were supplemented by hand-searching reference lists of retrieved papers, previous reviews and book chapters. We also manually searched relevant journals such as JAMA Psychiatry, Psychiatry Research, Journal of Nervous and Mental Disease, Schizophrenia Bulletin, Schizophrenia Research, Psychology and Psychotherapy: Theory, Research and Practice, Clinical Psychology Review, Early Intervention in Psychiatry, Acta Psychiatrica Scandinavica, Psychological Medicine and British Journal of Psychiatry. Finally, several experts were consulted about potential additional studies.

2.2. Inclusion and exclusion criteria

Inclusion criteria were that studies: 1) reported on caregiver distress or well-being in caregivers of persons with early psychosis and schizophrenia spectrum disorders; 2) empirically tested hypotheses regarding psychological factors within caregivers accounting for caregiver distress and 3) were published in peer-reviewed journals in English. Excluded were: 1) studies with a primary aim of investigating predictors of EE or studies without a hypothesis on how psychological factors within caregivers explain variance in caregiver distress, 2) secondary publications (reviews, commentaries, editorials and letters), (3) theses, dissertations and conference papers, and 4) qualitative studies and case reports. No date restrictions were applied to the selection of studies. Two reviewers (JEJ, JC) independently assessed relevant articles for inclusion, based on a template developed for this purpose. Any disagreements were resolved through discussion.

2.3. Data extraction and tabulation of data

A data extraction template was developed based on the Cochrane Consumers and Communication Review Group’s data extraction template (2011) and the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) checklist (Moher, Liberati, Tetzlaff, & Altman, 2009). Two reviewers (JEJ, JC) tabulated key information independently and discrepancies were reconciled by consensus. The focus of this review was psychological factors predicting caregiver distress; thus where multiple predictor and/or outcome measures were included in a study, consensus was reached amongst the reviewers as to which variables were relevant to the construct of caregiver distress.

2.4. Quality criteria

All selected papers were evaluated in terms of methodological quality to assess risk of bias and generalisability. This was based on the STROBE (STrengthening the Reporting of Observational studies in Epidemiology) guidelines (Epidemiology) guidelines (Von Elm et al., 2007) and PRISMA checklist (Moher et al., 2009). As suggested by Beller et al. (2013), a list of indicators of quality and potential confounding variables in the field were generated by a series of meetings of the reviewers until consensus was reached; these were implemented in the data extraction tool. Amongst these were duration of untreated psychosis, duration of illness, service user characteristics, caregiver and service user demographic variables, time of caregiver assessment and symptomatology, definition of outcome variables, and verification of diagnosis

3. Results

The search and exclusion process are summarised in Fig. 1. The initial data base search produced 870 abstracts. A total number of 15 papers describing 13 studies, published between 1999 and 2014, met the inclusion criteria. These are summarised in Table 1.

3.1. Study characteristics

Most of the studies used consecutive sampling from a defined catchment area (92.3%, n = 12), except for one, which recruited a convenience sample (Möller-Leimkühler, 2005, 2006; Möller-Leimkühler & Obermeier, 2008). Most studies recruited from a specialist early psychosis service setting (69.2%, n = 9) and one study (7.7%) did not specify the recruitment site. One study (7.7%) recruited from a psychiatric hospital and two (15.4%) from general outpatient mental health services. The characteristics of the participants who chose not to participate were not reported in the studies included.

3.1.1. Persons with psychosis

There were a total of 1081 persons with early psychosis in the included studies. Their mean age was 24.7 years (SD = 6.5), based on data from nine studies (72.5%, n = 784). Of the participants with psychosis included, 65.3% (n = 430) were male and 34.7% (n = 229) were female. Six studies reported no data regarding gender (422 participants). Six of the studies (50.1%, n = 542) reported verification of the psychiatric diagnoses using standardised instruments such as the Schedule for Clinical Assessment in Neuropsychiatry (SCAN; WHO, 1992), Operational Criteria Checklist (OPCRIT; McGrath, 1991) or the Structured Clinical Interview (SCID-I; Spitzer, 1992).
3.1.2. Caregivers

There was data on a total of 1056 caregivers in the studies included. Based on data from ten studies the mean age was 47.2 (SD = 9.8). No data regarding age were reported on 341 caregivers (32.3%). Based on the data from eight studies, 71.5% (n = 422) were female and 28.5% (n = 168) were male. Five studies reported no data regarding gender (44.1%, n = 466). Most of the caregivers were parents (74.4%, n = 786) and 80.9% (n = 786) were living with the person with early psychosis. Two studies did not report on cohabitation (n = 70). Education level of caregivers was reported in only three studies, which precludes any meaningful description. Based on the data from seven studies, 62% (n = 358) of caregivers were employed either part- or full time. No data regarding employment status were provided in six studies (63.4%, n = 670).

3.2. Study quality

There were a number of strengths in the studies included, such as reliable and valid distress measures, recruitment from early psychosis specialist service, which increased the likelihood of a representative sampling, and hypotheses that were derived from a stress-appraisal-coping framework. However, there were some considerable methodological issues with regard to the variables we set out to evaluate. There were few studies on caregiver distress in early psychosis and logical issues with regard to the variables we set out to evaluate. There were some considerable methodological issues with regard to the variables we set out to evaluate. There were few studies on caregiver distress in early psychosis and logical issues with regard to the variables we set out to evaluate.

3.3. Measurement of caregiver distress

Only one of the studies included had an explicit definition of distress (Möller-Leimkühler, 2005), and the studies used a variety of overlapping concepts and descriptions of caregiver experiences (see Table 2 for an overview). Across the 13 studies, 15 different measures of caregiver distress or psychological well-being were employed. The number of distress measures included within each individual study ranged from one to four and three studies used more than two different measures. None of the studies included used measures of physical illness or visits to the general practitioner as indicators of distress. Caregivers’ distress was the main variable of interest in six (50%) of the studies, while three (25%) defined EE as the main focus. In the remaining studies it was not made clear whether distress was to be considered as a dependent or an independent variable.

Of the 15 measures, the Experience of Caregiving Inventory (ECI) (Szmukler et al., 1996) and the General Health Questionnaire (GHQ) (Goldberg & Williams, 1988) were the most frequently used and will be described below.

The ECI is a measure of caregivers’ appraisal of the impact of the illness and comprises ten subscales: eight negative (difficult behaviours, negative symptoms, stigma, problems with service, effects on the family, the need to provide back-up, dependency and loss) and two positive (rewarding personal experiences and good aspects of the relationship). The ECI has been shown to have excellent psychometric properties (Szmukler et al., 1996). Eight of the included studies used the ECI (66.7%), five as a dependent measure (Alvarez-Jiménez et al., 2010; Cotton et al., 2013; Jansen et al., 2014; Patterson et al., 2005; Raune et al., 2004) and three as an independent measure (Addington et al., 2003; Gleeson et al., 2010; Tomlinson et al., 2013) predicting depression, scores on GHQ and impact of illness. Only five reported on the positive subscales (Addington et al., 2003; Cotton et al., 2013; Gleeson et al., 2010; Jansen et al., 2014; Patterson et al., 2005).

The GHQ is a screening instrument covering a range of psychiatric symptoms. It was originally developed as a 60-item questionnaire, and was later adapted into 30-, 28- and 12-item versions. The GHQ can be scored as a continuous measure with higher scores indicating increased levels of mental distress. It can also be scored as a ‘case-score’, indicating
Table 1
Summary of studies investigating psychological factors accounting for caregiver distress in early psychosis.

<table>
<thead>
<tr>
<th>Study</th>
<th>Location</th>
<th>N Caregivers</th>
<th>Age (SD)</th>
<th>% Female</th>
<th>Design</th>
<th>Distress measures</th>
<th>Psychological constructs</th>
<th>Measure of psychol. constructs</th>
<th>Key findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Addington et al. (2003)</td>
<td>Calgary, Canada</td>
<td>238</td>
<td>–</td>
<td>–</td>
<td>Cross-sectional</td>
<td>PCWB</td>
<td>Appraisal</td>
<td>ECI</td>
<td>The family's appraisal of the impact of the illness was associated with their psychological well-being. EOI predicted family distress and burden at baseline and follow-up.</td>
</tr>
<tr>
<td>Alvarez-Jiménez et al. (2010)</td>
<td>Melbourne, Australia</td>
<td>63 (48)</td>
<td>44.4</td>
<td>–</td>
<td>Prospective, 7 month follow-up</td>
<td>GHQ-28</td>
<td>Coping model</td>
<td>FQ</td>
<td>Increased perceived coping efficacy, lower age in caregivers and less severe symptoms predicted a reduction in distress.</td>
</tr>
<tr>
<td>Barrowclough, Gooding, Hartley, Lee, and Lobban (2014)</td>
<td>Manchester, UK</td>
<td>79 (9.9)</td>
<td>46.5</td>
<td>–</td>
<td>Prospective, 6 months follow-up</td>
<td>ECI</td>
<td>Attachment model</td>
<td>IPQ-R</td>
<td>Avoidance coping strategies were related to psychological distress, EOI and burden.</td>
</tr>
<tr>
<td>Cotton et al. (2013)</td>
<td>Melbourne, Australia</td>
<td>124</td>
<td>47.2</td>
<td>82.3</td>
<td>Cross-sectional</td>
<td>ECI</td>
<td>Coping style</td>
<td>WOC</td>
<td>There were significant group effects for aspects of the appraisal of caregiving (RPT vs. TAU). There were no significant effects for caregiver distress.</td>
</tr>
<tr>
<td>Gleeson et al. (2010)</td>
<td>Melbourne, Australia</td>
<td>63 (21)</td>
<td>45.5</td>
<td>–</td>
<td>RCT</td>
<td>GHQ-28</td>
<td>Appraisal</td>
<td>ECI</td>
<td></td>
</tr>
<tr>
<td>Hinrichsen and Lieberman (1999)</td>
<td>NY, USA</td>
<td>63 (35 F20)</td>
<td>46.8</td>
<td>44.4</td>
<td>Cross-sectional</td>
<td>FQ</td>
<td>Attribution</td>
<td>SVF</td>
<td>ADHD, FQ, DMSS, MAS-R, FQ, FQ</td>
</tr>
<tr>
<td>Jansen et al. (2014)</td>
<td>Roskilde, Denmark</td>
<td>40 (60)</td>
<td>49.1</td>
<td>66</td>
<td>Cross-sectional</td>
<td>GHQ-28</td>
<td>Attribution</td>
<td>SVF</td>
<td>Greater levels of general distress and EOI were related to more negative experience of caregiving; greater metacognitive capacity was related to more positive experiences of caregiving. Distress was associated with utility beliefs (beliefs about the utility of self-sacrifice and person-focused criticism) and EOI.</td>
</tr>
<tr>
<td>McNab, Haslam, and Burnett (2007)</td>
<td>Melbourne, Australia</td>
<td>53 (5.3)</td>
<td>49.1</td>
<td>66</td>
<td>Cross-sectional</td>
<td>GHQ-28</td>
<td>Attribution</td>
<td>SVF</td>
<td>Caregiver burden was predicted by EE, neuroticism, generalised negative stress response (negative coping) and life stressors.</td>
</tr>
<tr>
<td>Müller-Leimkühler (2005)</td>
<td>Munich, Germany</td>
<td>83 (35 F20)</td>
<td>46.8</td>
<td>44.4</td>
<td>Cross-sectional</td>
<td>FQ</td>
<td>Negative stress response (coping)</td>
<td>SVF</td>
<td>The most relevant predictors of burden were EE, emotion-focused coping strategies and generalised negative stress response. Illness characteristics were not predictive of distress.</td>
</tr>
<tr>
<td>Müller-Leimkühler (2006)</td>
<td>Munich, Germany</td>
<td>70 (34 F20)</td>
<td>49.2</td>
<td>48.6</td>
<td>Prospective, 1 year follow-up</td>
<td>FQ</td>
<td>Negative stress response (coping)</td>
<td>SVF</td>
<td>Caregiver burden was predicted by EE, neuroticism, generalised negative stress response (negative coping) and life stressors.</td>
</tr>
<tr>
<td>Müller-Leimkühler and Obermeier (2008)</td>
<td>Munich, Germany</td>
<td>63 (34 F20)</td>
<td>48.3</td>
<td>47.6</td>
<td>Prospective, 2 year follow-up</td>
<td>FQ</td>
<td>Negative stress response (coping)</td>
<td>SVF</td>
<td>Caregiver burden was predicted by EE, neuroticism, generalised negative stress response (negative coping) and life stressors.</td>
</tr>
<tr>
<td>Onwumere, Kuipers et al. (2011)</td>
<td>London and East Anglia, UK</td>
<td>141</td>
<td>50.2</td>
<td>79.3</td>
<td>Cross-sectional</td>
<td>GHQ-28</td>
<td>Coping</td>
<td>COPE</td>
<td>Caregiver distress was associated with avoidance coping strategies but not with duration of illness. Subjective burden was linked to loss and not EE status. The appraisal of loss was linked to EOI but not CC at baseline. Loss was reduced in those who changed EE status from high CC or low EE. High EE was associated with avoidance coping, subjective burden and lower perceived patient interpersonal functioning. High EE might be a way of coping with the burden.</td>
</tr>
<tr>
<td>Patterson, Birchwood, and Cochrane (2005)</td>
<td>Birmingham, UK</td>
<td>50 (39)</td>
<td>43.9</td>
<td>79.3</td>
<td>Prospective, 9 month follow-up</td>
<td>CDSS</td>
<td>Loss</td>
<td>TRIG</td>
<td></td>
</tr>
<tr>
<td>Raune, Kuipers, and Bebbington (2004)</td>
<td>London, UK</td>
<td>46</td>
<td>47.2</td>
<td>72</td>
<td>Cross-sectional</td>
<td>GHQ-28</td>
<td>Coping</td>
<td>CFI</td>
<td></td>
</tr>
<tr>
<td>Tomlinson, Onwumere, and Kuipers (2013)</td>
<td>London, UK</td>
<td>24</td>
<td>51.7</td>
<td>83.3</td>
<td>Cross-sectional</td>
<td>HADS</td>
<td>Social cognition</td>
<td>FEEST</td>
<td>Negative experience of caregiving was related to high EE, anxiety and depression. Both patients and carers showed impaired social cognition, but social cognition was not related to burden or EE.</td>
</tr>
</tbody>
</table>

Note. N = number; “–” = not reported; PCWB = Psychological General Well-being Scale; GHQ-28 = General Health Questionnaire, 28-item version; ECI = Experience of Caregiving Inventory; FQ = Family Questionnaire; FQ* = Family Questionnaire (Wiedemann, Rayki, Feinstein, & Hahlweg, 2002); FQ = Family Questionnaire (Quinn, Barrowclough, & Tarrier, 2003); EOI = Emotional over-involvement; CC = Critical comments; EE = Expressed emotion; K10 = Kessler Psychological Distress Scale; WOC = Ways of Coping Checklist; TAU = Treatment As Usual; RPT = Relapse Prevention Therapy; RCT = Randomised controlled trial; PRS = Patient Rejection Scale; BI = The Burden Interview; SCL-90 = Symptom Checklist-90; IPQ = Illness Perception Questionnaire; HDLFC = Health and Daily Living Form Indices of Coping; DMSS = Dementia Management Strategies Scale; GHQ-30 = General Health Questionnaire, 30-item version; MAS-R = Metacognition Assessment Scale-Revised; IPQ-SCV = Illness Perception Questionnaire-Relatives; UB = Utility beliefs; FQ = Family Burden Questionnaire; LQCP = Lancashire Quality of Life Profile; BF-S = Befundrichtigkeitskala; SVF = Stressverarbeitungsbogen; FFK = Fragebogen zu Kompetenz- und Kontrollüberzeugungen; NEO-FFI = Neo Five-Factor Inventory; FMSS = Five-Minute Speech Sample; COPE = The Coping Instrument; CDSS = Calgary Depression Scale for Schizophrenia; TRIG = Texas Revised Inventory of Grief; CFI = Camberwell Family Interview; SFS = Social Functioning Scale; BDI = Beck Depression Inventory; HADS = Hospital Anxiety and Depression Scale; FEEST = Facial Expression of Emotion Stimuli Test; FAS = Family Attitude Scale; IPQ-R = Illness Perception Questionnaire-Relatives.
Table 2

<table>
<thead>
<tr>
<th>Description in paper</th>
<th>Measurement</th>
<th>Authors</th>
</tr>
</thead>
<tbody>
<tr>
<td>“Appraisal of impact of illness/stressors/caring experience”</td>
<td>ECI</td>
<td>Addington et al. (2003); Alvarez-Jiménez et al. (2010); Cotton et al. (2013); Gleeson et al. (2010)</td>
</tr>
<tr>
<td>“Subjective experience of caregiving”</td>
<td>ECI</td>
<td>Tomlinson et al. (2013); Raue et al. (2004)</td>
</tr>
<tr>
<td>“Psychological distress”</td>
<td>K10</td>
<td>Cotton et al. (2013); Möller-Leimkühler (2005); Möller-Leimkühler (2006); Möller-Leimkühler and Obermeyer, 2008</td>
</tr>
<tr>
<td>“Burden of care/subjective burden”</td>
<td>FBQ and LQJP</td>
<td>Patterson et al. (2005); Raue et al. (2004)</td>
</tr>
<tr>
<td>“Caregiver distress”</td>
<td>GHQ-28 or GHQ-30</td>
<td>Barrowclough et al. (2014); Jansen et al. (2014); McNab et al. (2007)</td>
</tr>
<tr>
<td></td>
<td>GHQ-28 or GHQ-30</td>
<td>Onwumere, Kuipers et al. (2011); Onwumere, Kuipers, et al. (2011); Raue et al. (2004)</td>
</tr>
<tr>
<td>“Level of stress”</td>
<td>PGWB</td>
<td>Addington et al. (2003); Addington et al. (2003)</td>
</tr>
<tr>
<td>“General well-being”</td>
<td>PGWB</td>
<td>Jansen et al. (2014); McNab et al. (2007)</td>
</tr>
<tr>
<td></td>
<td>GHQ-30</td>
<td>Onwumere, Kuipers et al. (2011); Onwumere, Kuipers, et al. (2011); Raue et al. (2004)</td>
</tr>
<tr>
<td>“Emotional adjustment to the care of the patient”</td>
<td>PRS</td>
<td>Hinrichsen and Lieberman (1999)</td>
</tr>
<tr>
<td>“Career symptoms”</td>
<td>GHH-28</td>
<td>Alvarez-Jiménez et al. (2010)</td>
</tr>
<tr>
<td>“Depression”</td>
<td>CDSS</td>
<td>Patterson et al. (2005); Raue et al. (2004)</td>
</tr>
<tr>
<td></td>
<td>HADS</td>
<td>Tomlinson et al. (2013);</td>
</tr>
</tbody>
</table>

Note. PGWB = Psychological General Well-being Scale; GHQ-28 = General Health Questionnaire, 28-item version; ECI = Experience of Caregiving Inventory; K10 = Kessler Psychological Distress Scale; PRS = Patient Rejection Scale; BI = The Burden Interview; SCL-90 = Symptom Checklist-90; DMSS = Dementia Management Strategies Scale; GHQ-30 = General Health Questionnaire, 30-item version; FBQ = Family Burden Questionnaire; LQJP = Lancashire Quality of Life Profile; BF-S = Befindlichkeitsskala; CDSS = Calgary Depression Scale for Schizophrenia; BDI = Beck Depression Inventory; HADS = Hospital Anxiety and Depression Scale.

the presence or absence of clinically significant distress. The GHQ has also been shown to have excellent psychometric properties (Goldberg & Williams, 1988). Seven of the included studies used the GHQ (53.8%). Six studies used the GHQ-28 (Alvarez-Jiménez et al., 2010; Barrowclough et al., 2014; Gleeson et al., 2010; McNab et al., 2007; Onwumere, Kuipers, et al., 2011; Raue et al., 2004) and one study used the GHQ-30 (Jansen et al., 2014).

The following distress measures were used in one or two studies: The Beck Depression Inventory (BDI; Beck & Steer, 1987); The Psychological General Well-Being Scale (PGWB; Beck, 1993); The Kessler Psychological Distress Scale (K10; Andrews & Slade, 2001); Patient rejection scale (Addington, Addington, Maticka-Tyndale, & Joyce, 1992); The Family Burden Questionnaire (FBQ; Pai & Kapur, 1981); The Symptom Checklist-90 (SCL-90; Derogatis, 1977) (used in two studies); The Burden Interview (Zarit & Zarit, 1983); The Lancashire Quality of Life Profile (LQJP; Oliver, Huxley, Priebe, & Kaiser, 1997); Befindlichkeitsskala (BF-S; Von Zerssen, 1976); The Calgary Depression Scale for Schizophrenia (CDSS; Addington et al., 1992); Texas Revised Inventory of Grief (TRIG; Miller, Dworkin, Ward, & Barone, 1990); The Hospital Anxiety and Depression Scale (HADS; Zigmond & Snith, 1983); and The Social Functioning Scale (SFS; Birchwood, Smith, Cochrane, Wetton, & Copestake, 1990).

3.4. Psychological models and constructs examined and their measurement

Across the thirteen studies, nine different psychological processes, resources or competencies relating to caregivers were examined and empirically tested in terms of their association with caregiver distress. These were: appraisal, coping, attribution, loss, expressed emotion, metacognition, attachment, social cognition and utility beliefs which for the purpose of overview and synthesis, we have organised into three non-mutually exclusive groups below, namely (a) coping, (b) appraisal/attribute and (c) interpersonal response. The various psychological factors were assessed by the following rating scales: The Family Questionnaire (FQ; Wiedemann et al., 2002); The Experience of Caregiving Questionnaire (ECI; Szmucler et al., 1996); The Ways of Coping Checklist (WOC; MacCarthy, Kuipers, Hurry, Harper, & LeSage, 1989); The Psychiatric Disabilities Attribution Questionnaire (PDAQ; Krauss, 1989); The Health and Daily Living Form Indices of Coping (HDLFC; Moos, Cronkite, Billings, & Finey, 1984); The Dementia Management Strategies Scale (DMSS; Hinrichsen & Niederehe, 1994); The Metacognitions Assessment Scale–Abbreviated (MAS-R; Lysaker et al., 2005); The Illness Perception Questionnaire (IPQ; Barrowclough, Lobban, Hatton, & Quinn, 2001); ‘Utility Beliefs’ (McNab et al., 2007); The Stressverarbeitungsbogen (SVF; Janke & Erdmann, 1997); The Fragebogen zu Kompetenz- und Kontrollüberzeugungen (FFK; Krampen, 1991); The Neo Five-Factor Inventory (NEO-FFI; Borkenau & Ostendorf, 1993); The Five-Minute Speech Sample (FMSS; Magaña et al., 1986); The Cope instrument (COPE; Carver, Scheier, & Weintraub, 1989); The Texas Revised Inventory of Grief (TRIG; Miller et al., 1990); The Camberwell Family Interview (CFI; Vaughan & Leff, 1976); The Hinting Task (Corcoran, Mercer, & Frith, 1995); The Facial Expression of Emotion Stimuli (FEEST; Young, Perrett, Calder, Sprengelmeyer, & Ekman, 2002); The Family Attitude Scale (FAS; Kavanagh et al., 1997); The Illness Perception Questionnaire Schizophrenia—relatives (IPQS-R; Lobban, Barrowclough, & Jones, 2005); and The Family Questionnaire (FQ; Quinn et al., 2003).

3.4.1. Coping

Five studies (Cotton et al., 2013; Hinrichsen & Lieberman, 1999; Möller-Leimkühler, 2005, 2006; Möller-Leimkühler & Obermeier, 2008; Onwumere, Kuipers, et al., 2011; Raue et al., 2004) explored associations between coping and distress. In a study that recruited two relatively large samples (in total n = 141) of different illness durations, Onwumere, Kuipers, et al. (2011) found that distress was associated with avoidant coping in caregivers (r = .51, p < .01). There were no associations between caregivers’ coping strategies and demographic variables (caregiver’s sex, age and cohabitation with the patient), and avoidant coping remained associated with distress after controlling for illness length (partial r = .51, p < .01). An association between caregiver burden and avoidant coping was also found by Hinrichsen and Lieberman (1999) even though the participants had a reasonably good emotional adjustment, with an average burden score between ‘mild to moderate’. Multivariate analyses found avoidant coping to be associated with all three indices used by Hinrichsen et al. to measure emotional adjustment in caregivers – patient rejection (β = .37, p < .001), burden (β = .39, p < .001) and SCL-90 (β = .45, p < .001) – while neither family nor patient characteristics were related to caregiver burden. Moreover, Cotton et al. (2013) found avoidant coping to be associated with psychological distress (β = .58, p < .001), EOI (β = .51, p < .001), CC (β = .29, p < .001) and burden (β = .41, p < .001). In their study, tension reduction, cognitive escape and optimistic coping together explained 50% of the variance in caregiver distress. In one of the few prospective studies, Möller-Leimkühler and Obermeier (2008) and Möller-Leimkühler (2005, 2006) found that emotion-focused coping predicted, caregiver burden as measured by SCL-90 in a logistic regression (Wald χ² = 7.39, p = .007) and that general negative stress response predicted burden as measured by BF-S (Wald χ² = 16.52, p ≤ .001), SCL-90 (Wald χ² = 7.53, p = .006) and LQ (Wald χ² =
18.96, p ≤ .001) at two years follow-up. Of particular note, severity of illness, the type of symptoms, and psychosocial functioning at first admission were not associated with caregivers’ ratings of objective burden or other stress indicators. Möller-Leimkühler (2005) concluded that both EE and burden were “significantly associated with several psychosocial resources and dispositions of the relatives” (p. 223).

In summary, avoidance coping has consistently been shown to be associated with distress and burden even in the early stages of the illness, a finding that is consistent with studies of more long-term or chronic patients (Fadden et al., 2000; Kuipers, Onwumere, & Bebbington, 2010; Kuipers et al., 2006) and qualitative studies (Gerson et al., 2011; Huang et al., 2008). There are few prospective studies and therefore it is difficult to assess the direction of these effects. Other studies have found a number of factors associated with avoidant coping, including internalised stigma (Yanos, Roe, Markus, & Lysaker, 2008), insight (Cooke et al., 2007), shorter duration of untreated psychosis (Skeate, Jackson, Birchwood, & Jones, 2002) and high EE (Kuipers et al., 2006).

To the best of our knowledge, no study has examined whether interventions aimed at reducing avoidant, or emotional coping, influence the level of caregiver distress. Coping based on acceptance, e.g., through mindfulness-based approaches, has also been examined. However, this has been shown to reduce distress in a number of other studies, including anxiety (Völlestad, Nielsen, & Nielsen, 2012), depression (Hofmann, Sawyer, Witt, & Oh, 2010) and psychosis (Khoury, Lecomte, Gaudiano, & Paquin, 2013).

3.4.2. Appraisal and attribution

Seven studies (Addington et al., 2003; Barrowclough et al., 2014; Gleeson et al., 2010; Hinrichsen & Lieberman, 1999; McNab et al., 2007; Patterson et al., 2005; Raune et al., 2004) explored how caregiver distress was related to one of the following: the way caregivers appraised the impact of illness, the extent to which they attributed control of illness to the patients, or the views they held regarding the effectiveness of their EE behaviour. Addington et al. (2003) found that caregivers’ appraisal of the impact and consequences of the illness, as measured by the ECI negative subscale, had the greatest association with their psychological well-being (β = .52, p < .05) and that appraisal together with the patient’s age and age of onset explained 36% of the variance in caregivers’ psychological well-being. The authors also concluded that, while “the difficult experiences of being a caregiver are associated with patient variables such as negative and positive symptoms and poor social functioning … at this early stage of the illness, specific patient characteristics seem to play a minor role in families’ appraisal of their situation” (p. 288). In a prospective study assessing the contribution of illness perceptions to caregiver distress, Barrowclough et al. (2014) found that caregivers’ perception of future negative consequences (β = .04, p < .001) and a more pessimistic appraisal of prognosis (β = .03, p < .05) at baseline were significant predictors of distress at six months follow-up. Moreover, caregivers’ appraisals of poor ability to cope (β = .20, p < .05), higher age in caregivers (β = 4.63, p < .001) and higher PANSS scores predicted less reduction in distress at follow-up.

In the only randomised controlled study on caregiver intervention in early psychosis to be included, Gleeson et al. (2010) examined the effect of an intervention based on psychoeducation and relapse prevention strategies on caregiver appraisal. Their intervention showed a specific advantage in caregiver appraisals in relation to greater positive personal experiences of caring (F(1, 62.17) = 4.19, p = .045) and greater overall positive scores (F(1, 63.58) = 4.39, p = .040). However, this did not influence caregivers’ level of distress as measured by GHQ-28. There were no significant association on the overall negative subscale. This finding casts doubt on whether the manipulation of positive appraisals alone is sufficient to improve distress, and suggests that negative appraisals instead need to be addressed. Another interpretation might be that distress is an unavoidable aspect of being close to someone with a psychotic disorder in the early phase of illness, and that other measures such as quality of life, social functioning and meaningfulness might be equally important to overall well-being. However, this obviously does not mean that reducing prolonged and unnecessarily high levels of distress is not a significant objective of family intervention.

In a prospective study, Patterson et al. (2005) found that caregivers’ appraisal of loss was related to their level of distress as measured by depression (r = .44, p < .01) and burden (r = .43, p < .01). Moreover, their appraisal of loss was associated with EOI but not CC at baseline. Interestingly, the appraisal of loss was reduced at nine months follow-up in those changing from high EOI to either high CC or low EE, suggesting that EOI might evolve into criticism as a way of easing the unresolved loss. Hinrichsen and Lieberman (1999) found poorer emotional adjustment as measured by the Burden Interview in caregivers who attributed patients’ psychiatric problems to moral failings (β = .32, p < .05) or to psychological problems from earlier life (β = .28, p < .05). With the Burden Interview as outcome measure, attribution was found to explain 45% of the variance in caregiver distress. Finally, in an attempt to understand reasons for engaging in EE behaviour, McNab et al. (2007) assessed caregivers’ ‘utility beliefs’, i.e. their beliefs in the utility of criticism and self-sacrifice when interacting with the person with psychosis. They found that some caregivers often thought self-sacrifice or coercive behaviour would be helpful in changing patients’ behaviour for the better. As hypothesised, they found that caregiver distress was associated with the endorsement of utility beliefs concerning person-focused criticism (r = .24, p < .05) and self-sacrifice (r = .27, p < .05).

In summary, there is some consistency across findings that caregivers’ appraisal of various illness related factors – ranging from control, symptoms, loss, interpersonal functioning and utility of EE behaviour – are predictive of the level of distress and burden that caregivers experience. The findings correspond with those of studies of more chronic forms of psychosis (Barrowclough et al., 2001; Szmukler et al., 1996). They are also in agreement with the stress-appraisal-coping model (Lazarus & Folkman, 1984) of distress and with a cognitive model of caregiving (Kuipers et al., 2010). From this perspective, the appraisals and related behaviour are seen as understandable responses made by caregivers to the demands of caring for their psychiatrically impaired relative. However, while these appraisals are often unhelpful and based on fear and lack of knowledge about psychosis, they are open for modification in a supportive collaborative relationship (Barrowclough, Tarrier, & Johnston, 1996). With regard to our understanding of appraisal and attribution, prospective studies with measures of distress as outcome variables are needed in order to determine direction of effects and potential moderators and mediators. As mentioned earlier, there are some inconsistencies in the research literature as to how service user characteristics such as demographic variables and illness severity relate to distress and only a few studies have considered these (Addington et al., 2003; Barrowclough et al., 2014; Hinrichsen & Lieberman, 1999; Möller-Leimkühler, 2005). One reason why these variables may not have been considered when modelling the effects of appraisal on distress may have been that sample sizes have rarely enabled these kinds of analyses. Furthermore, the question of why some caregivers engage in more negative and less positive appraisals and attributions remains largely unanswered, as well as the question as to whether interventions aimed at reducing these appraisals are effective.

3.4.3. Interpersonal response in caregivers

Six studies (Alvarez-Jiménez et al., 2010; Jansen et al., 2014; Möller-Leimkühler, 2005, 2006; Möller-Leimkühler & Obermeier, 2008; Patterson et al., 2005; Raune et al., 2004; Tomlinson et al., 2013) examined the association between EE and distress. In cross-sectional studies, Jansen et al. (2014) found EOI to be associated with distress (r = .67, p < .01), which corresponds to McNab et al.’s (2007) findings (high vs. low EOI: r(47) = 2.22, p < .05). In a prospective study, Alvarez-Jiménez et al. (2010) found that baseline EOI predicted
caregiver distress \( (F(1) = 5.76, p < .05) \) and burden \( (F(1) = 8.53, p < .01) \) at seven months follow-up. In another prospective study, Möller-Leimkühler (2006) found EE to predict caregiver burden as measured by SCL-90 \( (b = -.34, p < .001) \) as well as in interaction with other variables for other measures of distress at one year follow-up. They also found EE to predict distress at two-year follow-up when measured by FBQ in a logistic regression \( (\text{Wald } \chi^2 = 28.01, p < .001) \), FBO \( (\text{Wald } \chi^2 = 28.21, p < .001) \) and SCL-90 \( (\text{Wald } \chi^2: 20.04, p < .001) \). Finally, Raune et al. (2004) found higher burden in caregivers high in EE \( (r = .44) = -2.4, p = .02 \) and Tomlinson et al. (2013) found distress to be associated with high EE \( (r = .65, p < .01) \). Patterson et al. (2005) on the other hand, did not find a significant association between burden and EE, although high EOI relatives reported higher burden scores \( (M = 84.5, SD = 28) \) than low EOI \( (M = 66.4, SD = 17.9) \), \( p < .01 \).

While interpersonal skills, including emotional regulation and psychological problem solving are central and inter-related to family functioning (Lysaker et al., 2011), only two studies have examined caregivers’ abilities to reflect upon and make sense of other peoples’ cognitive and emotional states. Janssen et al. (2014) studied caregivers’ capacity for metacognition, which is defined as the understanding of one’s own- and others’ thoughts and emotions, as well as the ability to solve emotional problems. They found that, while higher levels of metacognition in caregivers were not associated with less negative caregiver experiences, they were associated with reports of more positive caregiver experiences \( (r = .52, p < .01) \). One possibility is that greater capacity to form complex ideas about one self and others does not necessarily reduce distress and burden, which is a natural and understandable reaction when faced with psychosis. However, it seems to allow for a broader perspective on caregiving, allowing for both positive and negative experiences.

In a related study on social cognition, Tomlinson et al. (2013) found that performance on social cognition tasks was impaired in both caregivers and patients compared with the expected means for the measure \( (t(40) = 4.75, p < .001) \). This is in line with previous studies that have shown reduced social cognition capabilities in first-degree relatives of individuals with psychosis (Janssen, Krabbendam, Jolles, & van Os, 2003). However, in Tomlinson et al.’s study, social cognition did not significantly predict their level of distress or burden. Finally, in the only study investigating personality dimensions included, (Möller-Leimkühler, 2005, 2006; Möller-Leimkühler & Obermeier, 2008) found that neuroticism was predictive of caregiver distress measured by FBQ in a logistic regression \( (\text{Wald } \chi^2 = 18.51, p < .001) \), FBO \( (\text{Wald } \chi^2 = 28.48, p = .001) \) and LQLP \( (\text{Wald } \chi^2 = 7.80, p = .005) \) both at one- and two-year follow-ups. Möller-Leimkühler and Obermeier (2008) argue that, neuroticism may operate as a vulnerability factor in caregivers, rendering them more susceptible to critical events such as mental illness in the family. Referring to a meta-analysis by Connor-Smith and Flachsbart (2007), showing that neuroticism strongly relates to engaging in more avoidant or emotional coping styles, Möller-Leimkühler and Obermeier (2008) argue for including this as a vulnerability factor within the stress-appraisal-coping framework of caregiver distress.

In summary, there seems to be a robust association between EE, especially EOI, and distress in caregivers of persons with early psychosis, a finding that corresponds with those from studies of more chronic forms of psychosis (Boye et al., 1998; Breitborde, López, Chang, Kopelowicz, & Zarate, 2009). Only a few studies have examined caregivers’ capacity to understand their own and others’ thoughts and feelings, which taps into a range of inter-related concepts such as mindfulness (Baer, 2006), metacognition (Lysaker et al., 2008), mentalisation (Fonagy, Bateman, & Bateman, 2011), social cognition (Penn, Sanna, & Roberts, 2008) and theory of mind (Brüne, 2005). However, while metacognitive and social cognitive abilities were found to be compromised in caregivers of persons with early psychosis in the included studies, the findings are preliminary and the correlational designs preclude any firm conclusions with regard to whether they are a reaction to a difficult situation (state) or some characteristics inherent in the caregivers (trait). In general, studies on caregivers’ capacities and personality characteristics and their relation to distress are sparse. An exception however, was the studies of Möller-Leimkühler and Obermeier (2008) and Möller-Leimkühler (2006) who found neuroticism in caregivers to be predictive of distress, which is in line with findings from studies on more long-term or chronic patients (Möller-Leimkühler & Wiesheu, 2012).

4. Discussion

We sought to identify empirical studies that have investigated psychological factors accounting for caregiver distress in early psychosis, with the aim of summarising key findings and critically evaluating the methodologies used.

4.1. Psychological factors in caregiver distress

Within a stress-appraisal-coping framework, psychological factors seem to account for a great deal of variation in caregiver distress although there are still a limited number of studies on early psychosis samples. For the purpose of overview and synthesis, we organised the encountered psychological variables into the three non-mutually exclusive groups of coping, appraisal/attribute and interpersonal response. There were considerable data to support the link between distress and coping as well as distress and appraisal of various illness related factors — ranging across control, symptoms, loss, interpersonal functioning and utility of EE behaviour. Moreover, there was a strong association between EE, especially EOI, and caregiver distress. EE has received much attention in the published research on psychotic disorders, although not so much as a predictor of caregiver distress as a risk factor for relapse (Butzlaff & Hooley, 1998; Hooley, 2007; Kavanagh, 1992).

Finally, there seems to be less knowledge as to whether some caregivers are more vulnerable to appraising the caregiving experience as more negative and to having more negative interpersonal responses faced with a difficult caregiving situation. One way of understanding this might be in terms of caregivers’ abilities to form complex accounts of their own and other people’s mental states and utilising this knowledge to regulate emotions and to solve interpersonal problems with the person with a psychotic disorder. In the included studies, these abilities were examined in terms of social cognition, metacognition and neuroticism, which might operate as vulnerability factors within the stress-appraisal-coping model. However, while studies on individual characteristics are promising, more studies are needed before firm clinical implications can be drawn.

4.2. Methodological limitations and future research

We identified a number of important methodological issues in the literature. First, the overwhelming majority of the studies were cross-sectional and the consideration of potential confounding factors such as time of assessment, length of illness or duration of untreated psychosis was limited. Second, only one of the studies made an explicit definition of distress and an extensive list of overlapping terms and measures for distress were used across and within studies. This makes comparison between studies difficult. A related challenge is the potential conceptual and item overlap on key measures of distress across the studies in this review. As an example, the display of distressing emotions such as crying yields high EE ratings on some measures, thus participants may score high on both EE and distress measures. Another example is ECI, which in some studies is used as a predictor of distress and in other studies used as an outcome. Third, only half of the studies had caregiver distress as a main variable of interest, which might be a reflection of the fact that caregiver distress has, until recently, been primarily studied as a predictor of EE and relapse. An interesting observation was also that none of the studies reported on physical indicators of distress, such as physical illness or visits to a general practitioner, which are otherwise
important indicators of general well-being. Finally, there was a predominance of observational studies as opposed to trials, which further limits the ability to test the direction of effects.

Future studies would benefit from using prospective designs and larger samples to model and capture changes in trajectories of caregiver distress. In addition, controlled studies, including the use of comparison groups, and controlling for confounding variables, would further the field. Moreover, statistical analyses incorporating mediation and moderation effects of variables such as social support, fear of stigma, self-efficacy and expectancy of recovery should be employed (Breitborde, Srijari, Pollard, Addington, & Woods, 2010). While there are some prospective studies included in this review, only one statistically controls for baseline scores on the outcome variable (Barrowclough et al., 2014). Finally, interventions for psychological factors mentioned in this review, including avoidance coping and subjective appraisal, should be further developed and then tested in randomised controlled trials

4.3. Strengths and limitations of the review

The strengths of the current review include the systematic research strategy based on the PRISMA guidelines, the exclusion of non-empirical papers and the focus on psychological hypotheses and models behind the studies. All of the potentially eligible studies were first assessed for inclusion and then assessed for methodological quality by two independent raters. There were also some limitations of the review. First, potential papers written in languages other than English were excluded, which may have resulted in language- or cultural bias by omitting relevant studies. Second, while based on validated measures and standards (Bellier et al., 2013; Cochrane Collaboration, 2011; Von Elm et al., 2007), the templates for data extraction and methodology assessment was developed for this review and validity has not been established. Finally, there might have been a publication bias favouring reports of significant findings and working against failures to replicate.

4.4. Clinical implications

The overall findings of this review have a number of therapeutic implications for supporting caregivers, mostly in terms of a broadening of the repertoire of interventions. First, it might be important to focus more on other aspects than solely reducing EE in early psychosis. Clinicians would benefit from adopting the view of EOI as an understandable reaction to a crisis and also a sign of care and willingness to be engaged in treatment and support (Van Os et al., 2001). In addition, having someone ‘taking over responsibilities’ might actually be of benefit to the person with psychosis in the early phase of illness. Moreover, caregivers’ coping style such as emotional or avoidant coping and their appraisal of the impact of the illness seem to be associated with distress already in the early phase of illness and need to be addressed. Second, in addition to psychoeducation and problem-solving caregivers may benefit from having a better opportunity to tell their story. Good rapport with a therapist may also constitute a setting in which caregivers’ metacognitive abilities are expanded and developed (Lysaker et al., 2011). In addition to the non-specific therapeutic factors such as being heard and understood, a more comprehensive and rich narrative of illness can be developed, encompassing caregivers’ grief and loss, as well as coping efforts, appraisal and understanding of illness. Third, interventions would benefit from targeting caregivers’ negative appraisals of the caregiving situation. This could involve helping caregivers to more accurately perceive the situation they are in, including increasing knowledge about the patient’s illness and the possibility of recovery, as well as assisting in handling difficult thoughts, appraisals and emotions. This, of course, is more than just thinking differently or positively, but rather helping ‘being with’, ‘making room for’ and ‘accepting’ difficult and understandable emotions (Hayes, Villatte, Levin, & Hildebrandt, 2011; Morris, Johns, & Oliver, 2013).

5. Conclusion

In conclusion, this review has considered how psychological factors within caregivers of persons with early psychosis have been investigated empirically to explain variations in caregiver distress. We organised the psychological variables found through the search into the three non-mutually exclusive groups of coping, appraisal/attribute and interpersonal response. A number of methodological issues were noted in the studies included and caution must be taken when generalising to clinical practice. Within the limitations of the studies, the reviewed evidence shows there is considerable data supporting the continued focus on psychological factors such as avoidant coping, negative appraisal and EOI when working with caregivers early in the course of illness. Future studies should aim at: 1) replicating findings with larger, prospective samples which controls for confounders such as time of assessment and duration of illness; 2) expanding the intervention repertoire within family work for psychosis, beyond EE-based interventions; and finally 3) testing these psychological factors in controlled clinical trials.

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None.

References


