

## Review article

## Interventions to improve the experience of caring for people with severe mental illness: systematic review and meta-analysis

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**Background**

Informal caregiving is an integral part of the care of people with severe mental illness, but the support needs of those providing such care are not often met.

**Aims**

To determine whether interventions provided to people caring for those with severe mental illness improve the experience of caring and reduce caregiver burden.

**Method**

We conducted a systematic review and meta-analyses of randomised controlled trials (RCTs) of interventions delivered by health and social care services to informal carers (i.e. family or friends who provide support to someone with severe mental illness).

**Results**

Twenty-one RCTs with 1589 carers were included in the review. There was evidence suggesting that the carers' experience of care was improved at the end of the intervention by psychoeducation (standardised mean difference  $-1.03$ , 95% CI  $-1.69$  to  $-0.36$ ) and support groups (SMD =  $-1.16$ , 95% CI  $-1.96$  to  $-0.36$ ).

Psychoeducation had a benefit on psychological distress more than 6 months later (SMD =  $-1.79$ , 95% CI  $-3.01$  to  $-0.56$ ) but not immediately post-intervention. Support interventions had a beneficial effect on psychological distress at the end of the intervention (SMD =  $-0.99$ , 95% CI  $-1.48$  to  $-0.49$ ) as did problem-solving bibliotherapy (SMD =  $-1.57$ , 95% CI  $-1.79$  to  $-1.35$ ); these effects were maintained at follow-up. The quality of the evidence was mainly low and very low. Evidence for combining these interventions and for self-help and self-management was inconclusive.

**Conclusions**

Carer-focused interventions appear to improve the experience of caring and quality of life and reduce psychological distress of those caring for people with severe mental illness, and these benefits may be gained in first-episode psychosis. Interventions for carers should be considered as part of integrated services for people with severe mental health problems.

**Declaration of interest**

None.

The deinstitutionalisation of psychiatric care in high-income countries has increased the number of people being cared for in the community.<sup>1,2</sup> People caring for adults with schizophrenia spend an average of 6–9 h per day providing care.<sup>3</sup> In the UK data suggest that 15% of those caring informally for people with schizophrenia spend 9–32 contact hours per week providing care and 43% spend over 32 h per week.<sup>4</sup> Many people are unable to work or have to take time off work to provide care. The informal unpaid care they provide saves the National Health Service (NHS) the cost of providing comparable paid care, which is approximately £34 000 per person with schizophrenia (calculated using a mean of 5–6 h per day).<sup>5</sup> Families who take on the responsibility of caring for a relative with schizophrenia save the public £1.24 billion a year.<sup>6</sup> Caring can be a strongly positive experience,<sup>7</sup> but it is often associated with burdens that are subjective (perceived) and objective (for example, contributing directly to ill health and financial problems or in displacing other daily routines).<sup>8</sup> Other reported negative consequences of caring for those with psychosis include poor satisfaction with services provided, and difficulties in coping.<sup>9</sup> Many interventions for those with serious mental health problems provided by health and social care services are focused on the person using the service. Even when family interventions are offered to people with severe mental illness and their families, the number of sessions that specifically include the carer varies, and clinical staff typically do not see it as 'their job' to offer direct help to carers.<sup>10</sup> However, it is well established that the burden of care and ability of a carer to cope can have an impact on the

recovery of the patient.<sup>11,12</sup> Family interventions for people with severe mental illness may reduce relapse rates and increase cooperation with pharmacotherapy,<sup>13</sup> and the burden of care may be reduced by psychosocial interventions,<sup>14,15</sup> but the specific effects of interventions for carers themselves are not usually reported or are seen as secondary outcomes.

A number of reviews have evaluated published research on interventions for people caring for someone with serious mental illness, such as mutual support and interventions delivered by community mental health nurses. Chien & Norman surmised that although it is recognised that mutual support has a beneficial effect on outcomes both for people with severe mental illness and for their families, further research is required to evaluate the effects of mutual support on the carers themselves.<sup>16</sup> The review by Macleod *et al* of nurse-delivered interventions for carers reported that support and education interventions, community outreach programmes and mutual support all had beneficial effects on carer burden.<sup>17</sup> A recent systematic review assessed the effectiveness of family interventions on relatives of people with psychosis,<sup>18</sup> but did not include a meta-analysis. The aim of our review was to investigate interventions provided by health and social care services for people caring for someone with severe mental illness. This is the first systematic review and meta-analysis of interventions with the primary goal of improving carers' experience and reducing carer burden. The review was not registered.

**Method**

We conducted a systematic review of randomised clinical trials (RCTs) to evaluate interventions delivered by health and social

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care services to the carers of people with severe mental illness (schizophrenia spectrum and bipolar disorders). We therefore excluded studies in which more than a third of the study population cared for a person with major depression or a common mental health disorder. Carers were defined as family or friends who provided informal and regular care and support to someone with severe mental illness. Interventions were included if they were provided to the carer alone (i.e. without the patient present) and if the content of the intervention had the aim of improving the carer's experience of care and reducing carer burden. Studies were included if they evaluated interventions aimed at improving the experience of caregiving. We excluded studies that were limited to the provision of financial and day-to-day practical support (for example personal assistance or direct payments) or to interventions targeted at the patient rather than the carer.

### Outcome measures

The primary outcome of the review was the experience of caregiving, involving positive and negative experiences of caring for someone with severe mental illness. Secondary outcomes were carer quality of life, satisfaction with services and psychological distress. Only data from validated outcome measures were included in the meta-analysis. Outcome data were grouped by the following time points: end of intervention, up to 6-month follow-up and longer than 6-month follow-up. For outcomes measured at several time points within these intervals, we selected the longest follow-up point following randomisation.

### Search strategy

We conducted a search for RCTs published from the inception of databases up to June 2013 with no language restrictions (see online Appendix DS1). The following databases were searched: CENTRAL, CDSR, DARE, HTA, EMBASE, Medline, Medline In-Process, AEI, ASSIA, BEI, CINAHL, ERIC, IBSS, PsycINFO, Sociological Abstracts and SSA. Reference lists from previous reviews and included studies were examined and study authors were contacted. Titles and abstracts were screened based on the review protocol by one author (B.H.) and reviewed by another author (A.Y.-U.). Full texts of studies meeting inclusion criteria were then retrieved and reviewed to further establish inclusion in the review. Any disagreements were discussed with a third author (E.M.-W.) until a consensus was reached.

### Data management

Following Cochrane Collaboration methods, data were extracted independently by two reviewers (A.Y.-U. and B.H.). We extracted data for study characteristics (setting, number randomised and duration), inclusion criteria, carer and patient demographics, characteristics of the interventions (content, frequency and duration, contextual information) and outcomes. Authors were contacted to request missing participant characteristics and outcome data, and to enquire about unpublished studies.

### Assessment of bias

We assessed each study using the Cochrane Collaboration risk of bias tool,<sup>19</sup> and judged whether each study was at low, high or unclear risk of bias for specified domains. Each study was rated for risk of bias due to sequence generation; allocation concealment; masking of participants, assessors and providers; selective outcome reporting; and incomplete data. Studies were independently assessed by two authors (A.Y.-U., B.H.), and disagreements were

discussed with a third author (E.M.-W.). Authors of included studies were contacted to supply any unreported information such as outcomes or study methods. The Grading of Recommendations Assessment, Development and Evaluation (GRADE) approach was used to assess the quality of the evidence for each outcome.<sup>20</sup> This approach uses a structured method of assessing the overall quality of each outcome into one of four GRADE ratings (high, moderate, low and very low) based on an assessment of five factors: limitations, inconsistency, indirectness, imprecision and publication bias ([www.gradeworkinggroup.org](http://www.gradeworkinggroup.org)). Where more than ten trials were included in a meta-analysis, publication bias was assessed using funnel plots.

### Statistical analysis

Where possible data were entered directly into Review Manager (RevMan) version 5.2 for Windows. For dichotomous outcomes we calculated relative risks (RRs) or rate ratios and 95% confidence intervals using Mantel–Haenszel methods. For continuous outcomes, standardised mean differences (SMDs) and 95% CIs were calculated using Hedges' *g* and combined using inverse variance methods. We used random-effect methods for all meta-analyses. When studies reported data in multiple formats we calculated the SMD and its standard error before entering data in RevMan. Effect estimates favour intervention (i.e. carer intervention rather than control) when the relative risk is reduced ( $RR < 1$ ) or the standardised difference is negative ( $SMD < 0$ ). Statistical heterogeneity was assessed by visual inspection of forest plots, by the test (assessing *P* value) and by calculating the  $I^2$  statistic, which describes the percentage of observed heterogeneity that would not be expected by chance.<sup>21</sup> If *P* was less than 0.10 and  $I^2$  exceeded 40%, we considered heterogeneity to be substantial. In these cases we explored the possible reasons for heterogeneity which included sensitivity analysis with and without studies that were causing the heterogeneity. When subgroup analyses were conducted, differences between groups were tested using within RevMan. To assess the possibility of small study bias, random-effects estimates were compared with fixed-effect estimates. Data were analysed and presented first as intervention *v.* control (e.g. treatment as usual, active control, waiting list, no treatment), followed by direct comparisons of carer interventions. We conducted a planned subgroup analysis on the basis of the diagnosis of the patient; these analyses were conducted and reported dependent on data availability.

## Results

From 9220 records 24 studies met inclusion criteria for the review; of these, 20 studies were included in the meta-analysis (Fig. 1). Three studies did not report any eligible outcome and were thus excluded. One study did include relevant outcomes but did not report sufficient data in a format that could be used for meta-analysis. The findings from this study are described narratively. All included studies were published in English. Reasons for excluding 33 studies are summarised in online Table DS1. Two ongoing studies were identified (Table DS1).

### Description of studies

Studies assigned 1589 carers with a median sample size of 63, ranging from 40 to 225 (Table 1).<sup>22–42</sup> The 20 studies included in meta-analyses randomised 1364 carers (86% of people included in the review). Comparisons included treatment as usual/control compared with psychoeducation,<sup>22,35</sup> a support group,<sup>23,36–38</sup> a combined psychoeducation and support group,<sup>35</sup> problem-solving

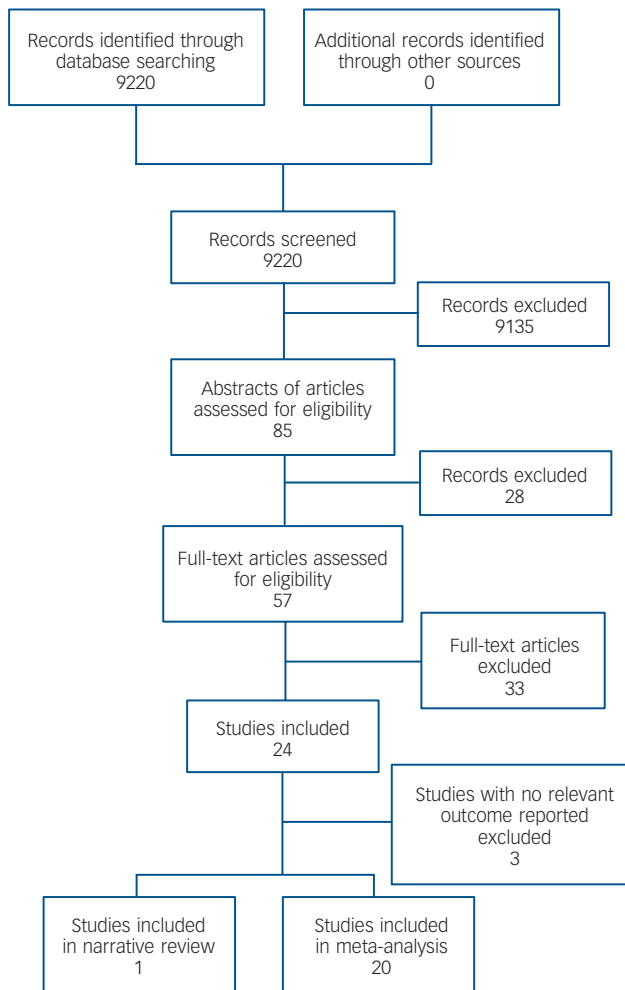


Fig. 1 Study selection.

bibliotherapy,<sup>39</sup> and self-management.<sup>40</sup> One study compared enhanced psychoeducation with standard psychoeducation,<sup>41</sup> and one study compared psychoeducation delivered by post with practitioner-delivered psychoeducation.<sup>42</sup> Two of the included studies were three-arm studies comparing two active interventions with treatment as usual,<sup>23,35</sup> and are therefore included in multiple comparisons. One study included a group evaluating an intervention termed ‘psychotherapy’;<sup>28</sup> however, this arm was not included in our review because it did not meet the eligibility criteria outlined above. Experience of caregiving was measured using the Experience of Caregiving Inventory,<sup>43</sup> the Family Burden Interview Schedule,<sup>44</sup> the Social Behaviour Assessment Schedule,<sup>45</sup> the Family Burden Questionnaire,<sup>46</sup> and the Zarit Caregiver Burden Scale.<sup>47</sup> Carer quality of life was measured using the 12-item and 36-item Short Form Health Surveys (SF-12 and SF-36) and satisfaction with services was measured using the Consumer Satisfaction Questionnaire.<sup>48</sup> Finally, psychological distress was measured using the 12-item and 28-item General Health Questionnaires,<sup>49</sup> the Symptom Rating Test,<sup>50</sup> the Beck Depression Inventory,<sup>51</sup> the Kessler Psychological Distress Scale,<sup>52</sup> and the Clinical Interview Schedule – Revised.<sup>53</sup> For a summary of the components of the interventions provided in the included studies, see online Table DS2.

Seven studies were conducted in China, four in the UK, two in the USA, two in Australia, two in Iran, one in Canada, one in Spain, one in Chile and one in Ireland. The median of the mean age of carers was 49 years, and the median study included 76%

women. The median percentage of carers living with patients was 100% (range 49–100); however, this was not reported in six studies. The diagnoses of the patients varied across studies: 16 studies included people with diagnoses of psychosis or schizophrenia spectrum disorder and 3 included people with bipolar disorder. Of the remaining two mixed population studies, the majority of patients had a diagnosis of psychosis and schizophrenia (Table 1).

### Quality of included studies

Sequence generation was adequately described in 14 studies and unclear in 7 studies (Fig. 2, online Fig. DS1). There was low risk of bias for allocation concealment in 8 studies but this was unclear for 13 studies. Masking of participants and personnel was not possible; all studies were at high risk of bias *per se*. For masking of outcome assessment, 14 studies were at low risk of bias, 1 was at high risk of bias and 6 were unclear. At the study level, 12 studies were at low risk of bias for missing data, 6 studies were at high risk of bias and 3 studies were unclear. We were able to confirm by contacting trial authors and checking review protocols that 2 studies were completely free of selective outcome reporting (i.e. clearly reported all outcomes measured). However, 16 studies were at unclear risk of selective outcome reporting and 3 were at high risk. Overall, the primary outcome was measured in a variety of ways (both within and between studies) and follow-up data beyond the end of the intervention were inconsistent. Therefore, there is a high possibility of selective reporting in this review.

### Effects of interventions

The results of the meta-analysis of prespecified outcomes are summarised in online Table DS3.

#### Psychoeducation v. any control

Eight studies with 428 participants were included in the analysis of the experience of caregiving assessed at the end of the intervention.<sup>22,24–26,30–32,34</sup> There was very low-quality evidence of a large effect of psychoeducation on experience of caregiving. Four studies with 215 participants provided data up to 6-month follow-up.<sup>23,26,31,34</sup> There was very low-quality evidence of a large effect on the experience of caregiving. Three studies including 151 participants reported very low-quality evidence of a large effect of the intervention on the experience of caregiving at greater than 6-month follow-up.<sup>23,24,28</sup> However, despite large effect sizes being reported for the experience of caregiving at all end of treatment and follow-up assessments, heterogeneity was very high ( $I = 89%$ , 79% and 86% respectively) so interpretation of results should be done cautiously. Sensitivity analysis did not explain the possible reason for the high heterogeneity. However, inspection of the forest plots shows that the direction of effect is consistent across studies and the high heterogeneity may have been caused by differences in the magnitude of effects across studies. See online Figs DS2–4 for the corresponding forest plots.

One study including 44 participants found low-quality evidence of no significant difference between psychoeducation and control in quality of life at the end of the intervention.<sup>25</sup> One study with 39 participants found low-quality evidence of no significant difference between the intervention and control in satisfaction with services at either the end of the intervention or up to 6-month follow-up.<sup>29</sup> Two studies with 86 participants were included in the analysis of carer psychological distress;<sup>29,34</sup> there was very low-quality evidence of no difference between the intervention and control at the end of the intervention. Similarly, there was low-quality evidence of no difference between the groups up to 6-month follow-up. However, one study with

**Table 1** Characteristics of included studies, categorised by intervention

Study	Country	Sample size (n)	Mean age (years)	Gender, female (%)	Living with patient (%)	Patient diagnosis
<i>Psychoeducation v. any control</i>						
Cheng & Chan (2005) <sup>22</sup>	China	64	NR	63	NR	SSD
Chien & Wong (2007) <sup>24</sup>	China	84	41	67	100	SSD
Gutierrez-Maldonado & Caqueo-Urizar (2007) <sup>25</sup>	Chile	45	54	76	NR	SSD
Koolaee & Etemadi (2009) <sup>26</sup>	Iran	62	55	100	100	SSD
Leavey <i>et al</i> (2004) <sup>27</sup>	UK	106	NR	NR	54	SMI
Madigan <i>et al</i> (2012) <sup>28</sup>	Ireland	47	52	53	55	BPD
Posnor <i>et al</i> (1992) <sup>29</sup>	Canada	55	NR	NR	58	SSD
Reinares <i>et al</i> (2004) <sup>30</sup>	Spain	45	48	76	100	BPD
Sharif <i>et al</i> (2012) <sup>31</sup>	Iran	70	52	NR	NR	SSD
So <i>et al</i> (2006) <sup>32</sup>	China	45	49	78	100	SSD
Solomon <i>et al</i> (1996) <sup>33,a</sup>	USA	225	56	88	84	SMI
Szmukler <i>et al</i> (1996) <sup>34</sup>	Australia	63	46	NR	68	SSD
Szmukler <i>et al</i> (2003) <sup>35</sup>	UK	61	54	82	49	SMI
<i>Support group v. any control</i>						
Chien <i>et al</i> (2004) <sup>36</sup>	China	48	44	56	100	SSD
Chien & Chan (2004) <sup>23</sup>	China	96	42	31	100	SSD
Chien <i>et al</i> (2008) <sup>37</sup>	China	76	36	55	100	SSD
Chou <i>et al</i> (2002) <sup>38</sup>	China	84	NR	66	NR	SSD
<i>Psychoeducation plus support group v. any control</i>						
Szmukler <i>et al</i> (2003) <sup>35</sup>	UK	61	54	82	49	SMI
<i>Problem-solving bibliotherapy v. any control</i>						
McCann <i>et al</i> (2012) <sup>39</sup>	Australia	124	47	82	82	Psychosis
<i>Self-management v. any control</i>						
Lobban <i>et al</i> (2013) <sup>40</sup>	UK	103	NR	83	73	Psychosis
<i>Enhanced psychoeducation v. standard psychoeducation</i>						
Perlick <i>et al</i> (2010) <sup>41</sup>	USA	46	53	84	65	BPD
<i>Practitioner-delivered v. postal psychoeducation</i>						
Smith & Birchwood (1987) <sup>42</sup>	UK	40	NR	NR	NR	SSD

BPD, bipolar disorder; NR, not reported; SMI, serious mental illness or mood disorder; SSD, schizophrenia spectrum disorder. a. Not included in meta-analysis.

18 participants provided data at over 6-month follow-up showing moderate quality of a large effect of psychoeducation over control on psychological distress.<sup>28</sup>

One study of participants receiving individual psychoeducation found the intervention less helpful than group psychoeducation for understanding of medication ( $= 8.39$ ,  $d.f. = 1$ ,  $P < 0.004$ ).<sup>33</sup> Furthermore, those receiving the group psychoeducation intervention found the sessions less useful than participants in the individual psychoeducation group for learning about the community resources available to them ( $= 8.69$ ,  $d.f. = 1$ ,  $P < 0.004$ ).

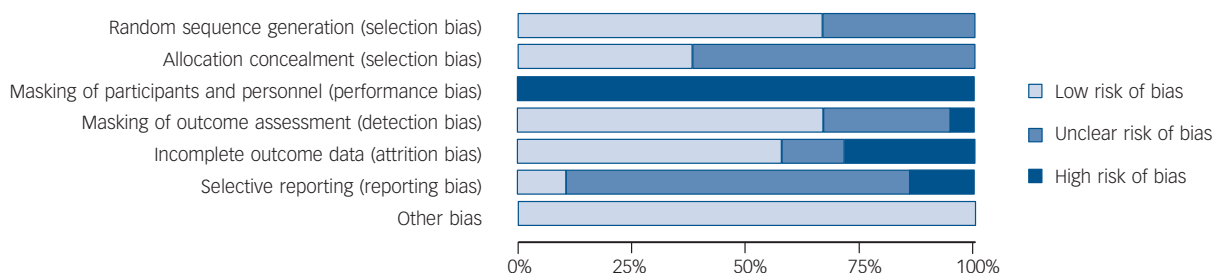
#### Support group v. any control

Three studies including 194 participants provided very low evidence of a large effect on the experience of caregiving at the end of the intervention.<sup>36–38</sup> There was low-quality evidence of a moderate effect at up to 6-month follow-up. However, although a clinically large effect was observed, this effect was no longer

statistically significant at more than 6-month follow-up. However, although the studies included in the analysis at end of intervention and greater than 6-month follow-up showed large effects favouring support groups, heterogeneity was very high ( $I = 85\%$  and  $I = 96\%$  respectively). The direction of the effect consistently favoured the intervention and sensitivity analysis showed that high heterogeneity was possibly caused by difference in the magnitude of effect across included studies. One study with 70 participants provided low-quality evidence of a large effect of support groups on psychological distress at the end of the intervention and up to 6-month follow-up.<sup>38</sup> See online Figs DS5–7 for the corresponding forest plots.

#### Psychoeducation plus support group v. any control

One study contributing 49 participants provided low-quality evidence of no effect of psychoeducation plus support group on the experience of caregiving at over 6-month follow-up;<sup>35</sup> data were only available for a psychosis and schizophrenia spectrum disorder sample (see online Fig. DS8 for the corresponding forest

**Fig. 2** Risk of bias summary.

plot). The same study provided low-quality evidence of no statistically significant difference between the intervention and control groups on psychological distress at over 6-month follow-up.<sup>35</sup>

#### Problem-solving bibliotherapy v. any control

One study including 114 participants provided low-quality evidence of no effect of problem-solving bibliotherapy on the experience of caregiving at the end of the intervention,<sup>39</sup> and of no statistically significant effect at 6-month follow-up. Data were only available for a psychosis and schizophrenia spectrum disorder sample (see online Figs DS9 and DS10 for the corresponding forest plots). This study provided low-quality evidence of no clinically meaningful difference between intervention and control groups in quality of life at the end of the intervention,<sup>39</sup> but moderate benefit was observed up to 6-month follow-up. There was moderate-quality evidence of a large effect of the intervention on psychological distress at the end of the intervention and up to 6 months later.<sup>39</sup>

#### Self-management v. any control

One study with 86 participants provided moderate-quality evidence of no effect on self-management on either the experience of caregiving or psychological distress at the end of the intervention.<sup>40</sup> Data were available only for a mixed severe mental illness sample (see online Fig. DS11 for the corresponding forest plots).

#### Enhanced v. standard psychoeducation

One study, contributing 43 participants to the review, provided moderate-quality evidence that enhanced psychoeducation had a moderate effect on the experience of caregiving when compared with standard psychoeducation at the end of the intervention.<sup>41</sup> Data were available from only a single study including a bipolar disorder sample (see online Fig. DS12 for the corresponding forest plot).

#### Practitioner-delivered v. postal psychoeducation

One study with 40 participants provided low-quality evidence that practitioner-delivered psychoeducation was no more effective than postal psychoeducation for either family distress or psychological distress at the end of the intervention and at up to 6-month follow-up.<sup>42</sup>

### Subgroup analysis

A test for difference based on the diagnosis of the patient could only be conducted for the psychoeducation intervention compared with control. All other comparisons included only carers for people with psychosis or schizophrenia and thus no subanalysis was possible. Subgroup data for psychoeducation compared with control was available only for the outcome of experience of caregiving at the end of the intervention and greater than 6-month follow-up. However, the bipolar disorder subgroup accounted for only 11% of the participant data included in this analysis and thus subanalysis based on diagnosis was unlikely to be meaningful.

## Discussion

This is the first formal systematic review and meta-analysis of carer-focused interventions for people caring for someone with

severe mental illness, and despite shortcomings in the underpinning evidence it suggests that psychosocial interventions specifically aimed at helping carers can lead to both improvements in the experience of caregiving and quality of life, and decreases in burden and psychological distress. The findings of this review are consistent with previous reviews in finding that education and support may be beneficial to those caring for people with severe mental illness.<sup>16–18</sup> Although most evidence in this review comes from studies of psychoeducation and support groups, with most other interventions evaluated in single studies (often with small numbers of participants), it was not possible to identify with certainty which specific intervention was superior. The evidence is derived from studies of those caring for people with severe mental illness, including schizophrenia spectrum disorders, psychosis, schizophrenia and bipolar disorder, and there is growing evidence that providing these interventions early (in the first episode of psychosis) has benefits for carers.

### Strengths and limitations

The limitations of this data-set are substantial. First, the quality of the evidence underpinning critical outcomes in this meta-analysis was very low to moderate. For example, in studies of psychoeducation the experience of caregiving had a large effect size derived from four studies of reasonable size, but the quality was downgraded to 'very low' owing to a high risk of bias, significant heterogeneity and a lack of precision. Data on support groups also showed high levels of heterogeneity. It is possible that for both psychoeducation and support groups for carers, the interventions pooled in the analysis had some important differences leading to heterogeneity. Moreover, we sought to combine outcomes across studies, but there was only evidence from one trial for some outcomes and meta-analysis was not always possible. Given the small number of studies and participants, important effects may be statistically insignificant because the analyses lack power, or they may be overestimated by chance or by small study bias. We have reported all results to maximise the transparency and completeness of the review, but many results are limited by the lack of replication, imprecision and risk of reporting bias. Most measures in this review sought to assess subjective, participant-reported outcomes. Compared with objective outcomes, these measures may be associated with more error and greater risk of bias (e.g. response bias). Despite these limitations and variations in effect sizes, the critical outcomes for both psychoeducation and support groups were consistently positive and provide qualified evidence of benefit.

The range of conditions represented in the study populations may have contributed to heterogeneity, but may also have contributed to the external validity of our results. Studies included those caring for people with schizophrenia and other schizophrenia spectrum disorders, first-episode psychosis and bipolar disorder. It is possible that this variation contributed to statistical heterogeneity in the meta-analyses. Although the majority of the evidence relates to carers of people with psychosis, carers of people with other conditions face similar difficulties and challenges, and this evidence may suggest that interventions for carers could be beneficial for a number of populations. Finally, our review of support groups included studies conducted only in East Asian populations, with healthcare settings and practices likely to be substantially different from those found in other countries, thus limiting generalisability. Nevertheless, a variety of countries were represented in the wider review, suggesting consistently beneficial effects across different countries, and we can surmise that support groups are likely to be better than nothing for carers. Indeed, this finding, and those for psychoeducation,

confirm the results of systematic literature reviews of interventions for carers,<sup>16,17</sup> and of a systematic review of outcomes for carers in studies of interventions for patients.<sup>18</sup>

### Implications for practice

The interventions evaluated in this review are themselves complex, and there is a clear argument that a focus on those in a caring role will be beneficial both for them and for patients. Although this review cannot recommend any specific intervention, it does raise the importance of assessing the experience of caregiving, levels of burden and psychological distress, and the quality of life of people caring for someone with severe mental illness, including psychosis, in routine practice. The sometimes substantial improvements in critical outcomes shown in a number of quite varied studies can (at least in part) be taken as evidence of an underlying need that carers have for help, not just as caregivers but as individuals. This supports the view that those caring for someone with severe mental illness would benefit from help and interventions focused on their own needs as an additional component of healthcare service provision for patients supported by carers in the community.<sup>10</sup> Clearly, if a carer assessment suggests that a carer needs help, whether this is to enhance caregiving or to reduce psychological distress and improve quality of life, carer-focused interventions should be considered. The National Institute for Health and Care Excellence (NICE) guideline on psychosis and schizophrenia recommends that all people with psychosis or schizophrenia, including people with first-episode psychosis, should be routinely offered family interventions to promote better outcomes for patients, especially to reduce relapse.<sup>54</sup> The evidence from this review suggests we should also consider carer-focused interventions.

### Implications for research

Over the past 40 or more years studies have repeatedly shown that relapse rates for people with psychosis can be substantially reduced through family interventions. The positive role that carers can play is clear: at the end of treatment relapse rates are nearly halved, an effect that diminishes over time but may still be clinically significant several years later.<sup>54</sup> This important role stands in stark contrast to carers' often negative experience of services.<sup>55,56</sup> Our review suggests that carer-focused interventions are likely to be helpful to carers. What is less clear is which intervention is likely to benefit carers most, although psychoeducation and support groups are probably the best candidates. In addition, it is not possible to say from the evidence whether carer-focused interventions should be offered alongside traditional patient-focused family interventions for severe mental illness or offered separately. Combining patient-focused family interventions with interventions that focus on carers' needs may offer advantages. Perhaps a next step could be to develop and evaluate, through a randomised controlled trial, a patient-focused and carer-focused family intervention, comparing it with a traditional patient-focused family intervention, using both patient and carer outcomes, to examine their possible interdependence in the context of first-episode psychosis. Future studies should be registered in advance, be reported in full to avoid reporting biases, be rigorously designed and clearly report information about the carer and patient participants, the interventions, comparison group and the primary outcomes of interest, and should take into consideration previous research regarding the most beneficial components of carer-focused interventions. Better methodology might well require better funding for this largely ignored group of carers.

In our view it is no longer sustainable, nor economically supportable, to ignore the central role that many carers have in the care and support, and effectiveness of therapy, of people with severe mental illness. With the newly emerging consensus on parity of esteem between mental and physical health, now is the time for concerted action to help those caring for people with some of the most impairing of mental health problems.

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**Online data supplement**

**Interventions to improve the experience of caring for people with severe mental illness: systematic review and meta-analysis**

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## Appendix DS1 Electronic searches

Embase, Medline, Medline In-Process, PsycINFO - OVID SP

1	((car\$ adj for\$1) or caregiv\$ or care giv\$ or carer\$).ti,ab,hw.
2	exp child parent relation/ or family assessment/ or exp family attitude/ or family coping/ or family functioning/ or family health/ or family interaction/ or exp family life/ or family nursing/ or exp family relation/ or family therapy/ or family/ or friend/ or *home care/ or exp nuclear family/ or stepfamily/
3	2 use emez
4	community networks/ or family characteristics/ or family conflict/ or family health/ or family nursing/ or family relations/ or family therapy/ or family/ or home nursing/ or intergenerational relations/ or marriage/ or exp nuclear family/ or exp parents/ or exp *parent-child relations/ or sibling relations/ or siblings/ or spouses/ or visitors to patients/
5	4 use mesz, prem
6	family/ or exp family conflict/ or exp family members/ or exp family relations/ or exp family therapy/ or friendship/ or exp marital relations/ or home care/ or intergenerational relations/ or marriage attitudes/ or nuclear family/ or exp parent child relations/ or exp parental attitudes/ or parental role/ or sibling relations/ or significant others/ or spouses/ or stepfamily/
7	6 use psych
8	((home adj2 (care or caring)) or ((informal or non professional) adj5 (care or nursing)) or care giv\$ or caregiv\$ or carer\$ or community based or couples or home nursing or daughter\$ or famil\$ or father\$ or friend\$ or home based or husband\$ or marital\$ or mother\$ or multifam\$ or neighbo?r\$ or next of kin or niece or nephew\$ or parent\$1 or partner\$1 or relative or relatives or sibling\$ or significant other\$ or spous\$ or step relationship\$ or wife\$1 or wives).ti,ab.
9	or/3,5,7-8
10	*education/ or education program/ or educational model/ or educational technology/ or health education/ or health literacy/ or health promotion/ or learning environment/ or patient education/ or problem based learning/ or psychoeducation/ or teaching/ or training support/
11	10 use emez
12	exp consumer health information/ or health education/ or health knowledge, attitudes, practice/ or health promotion/ or models, educational/ or "patient education as topic"/ or problem based learning/ or exp "programmed instruction as topic"/ or teaching/ or exp teaching materials/ or training/
13	12 use mesz, prem
14	adult learning/ or client education/ or collaborative learning/ or consumer

	education/ or cooperative learning/ or educational programs/ or health education/ or health knowledge/ or health literacy/ or health promotion/ or learning/ or learning strategies/ or literacy programs/ or problem based learning/ or psychoeducation/ or self instructional training/ or exp skill learning/ or exp teaching/ or training/
15	14 use psych
16	(booklet\$ or brochure\$ or educat\$ or empower\$ or leaflet\$ or multimedia or multi media or pamphlet\$ or poster\$ or psychoeducat\$ or psycho educat\$ or ((oral or printed or written) adj3 (inform\$ or material\$)) or workbook\$ or work book\$).ti,ab.
17	((didactic or systemic) adj3 (coach\$ or communicat\$ or educat\$ or instruct\$ or interven\$ or knowledge\$ or learn\$ or program\$ or taught\$ or teach\$ or therap\$ or train\$ or treat\$)).ti,ab.
18	or/11,13,15-17
19	problem solving/ use emez,mesz,psych
20	(problem\$ adj3 (skill\$ or solv\$)).ti,ab.
21	or/19-20
22	exp coping behavior/ use emez
23	*adaptation, psychological/ use mesz, prem
24	coping behavior/ or stress management/
25	24 use psych
26	((cope or copes or coping or stress\$) adj3 (assertive\$ or awareness\$ or coach\$ or communicat\$ or didactic\$ or educat\$ or empower\$ or engag\$ or focus\$ or goal set\$ or information\$ or instruct\$ or interven\$ or knowledge or learn\$ or liaison\$ or literac\$ or manag\$ or program\$ or promot\$ or services\$ or session\$ or skill\$ or strateg\$ or support\$ or taught or teach\$ or technique\$ or therap\$ or train\$ or treat\$)) or psychoed\$ or psycho ed\$ or strateg\$ or stress\$).ti,ab.
27	or/22,23,25-26
28	family therapy/ use emez,mesz
29	family intervention/ or exp family therapy/
30	29 use psych
31	(famil\$ adj2 consultation\$).ti,ab.
32	or/28,30-31
33	exp self care/ or self evaluation/
34	33 use emez
35	self administration/ or self care/ or self-help groups/ or self medication/
36	35 use mesz, prem
37	self care skills/ or self evaluation/ or exp self help techniques/ or self monitoring/ or self regulation/ or self reinforcement/

38	37 use psych
39	(expert patient\$ or (hearing voices adj2 (group\$ or network\$ or support\$)) or (minimal adj (contact or guidance)) or helpseek\$ or (help\$ adj2 seek\$) or (mutual adj (aid\$ or help or support\$)) or recovery model\$ or smart recovery or (self adj (administer\$ or assess\$ or attribut\$ or care or change or directed or efficacy or help\$ or guide\$ or instruct\$ or manag\$ or medicat\$ or monitor\$ or regulat\$ or reinforc\$ or re inforc\$ or support\$ or technique\$ or therap\$ or train\$ or treat\$)) or selfadminister\$ or selfassess\$ or selfattribut\$ or selfcare or selfchange or selfdirected or selfefficacy or selfhelp\$ or selfguide\$ or selfinstruct\$ or selfmanag\$ or selfmedicat\$ or selfmonitor\$ or selfregulat\$ or selfreinforc\$ or self re inforc\$ or selfsupport\$ or selftechnique\$ or selftherap\$ or selftrain\$ or selftreat\$).ti,ab.
40	bibliotherapy/
41	40 use mesz, prem
42	bibliotherapy/
43	42 use psych
44	(bibliotherap\$ or biblio therap\$ or manual\$1).ti,ab.
45	(booklet\$ or brochure\$ or leaflet\$ or pamphlet\$ or poster\$ or psychoeducat\$ or psycho educat\$ or workbook\$ or work book\$ or ((adult\$ or client\$ or consumer\$ or health or inpatient\$ or outpatient\$ or participant\$ or patient\$ or service user\$) adj2 (educat\$ or focus\$ or information\$ or knowledge or learn\$ or literac\$ or promot\$ or taught or teach\$)) or empower\$ or ((oral or printed or written) adj3 (material\$ or inform\$))).ti,ab.
46	adaptive behavior/
47	46 use emez
48	exp adaptation, psychological/
49	48 use mesz, prem
50	adaptive behavior/
51	50 use psych
52	((behav\$ or psychologic\$) adj3 (adapt\$ or adjust\$)) or cope or copes or coping).ti,ab.
53	patient participation/
54	53 use emez
55	exp consumer participation/
56	55 use mesz, prem
57	client participation/
58	57 use psych
59	((adult\$ or client\$ or consumer\$ or inpatient\$ or outpatient\$ or participant\$ or patient\$ or service user\$) adj2 (involv\$ or participat\$)).ti,ab.
60	or/34,36,38-39,41,43-45,47,49,51-52,54,56,58-59

61	consumer advocacy/ or friend/ or friendship/ or group therapy/ or group process/ or home care/ or home rehabilitation/ or peer counseling/ or peer group/ or psychosocial care/ or social care/ or social network/ or social support/ or social work/ or social worker/ or support group/ or vocational rehabilitation/ or voluntary worker/ or volunteer/
62	61 use emez
63	community networks/ or consumer advocacy/ or education, nonprofessional/ or friends/ or group processes/ or home care services/ or hotlines/ or peer group/ or psychotherapy, group/ or rehabilitation, vocational/ or self-help groups/ or social support/ or social work/ or social work, psychiatric/ or voluntary workers/
64	63 use mesz, prem
65	advocacy/ or friendship/ or group counseling/ or group discussion/ or group instruction/ or exp group psychotherapy/ or home care/ or home visiting programs/ or hot line services/ or network therapy/ or outreach programs/ or peer counseling/ or peer relations/ or peer tutoring/ or peers/ or exp psychosocial rehabilitation/ or social casework/ or social group work/ or exp social networks/ or social programs/ or social services/ or social support/ or social workers/ or exp support groups/ or vocational counselors/ or volunteers/
66	65 use psyh
67	(advocac\$ or advocate\$ or befriend\$ or be\$1 friend\$ or buddy or buddies or ((community or lay or paid or support) adj (person or worker\$)) or ((community\$ or home) adj (based or visit\$)) or ((consumer\$ or friend\$ or lay or mutual\$ or peer\$ or social\$ or volunteer\$) adj3 (help\$ or network\$ or support\$ or visit\$)) or ((consumer\$ or peer\$ or social\$ or support\$ or volunteer\$) adj2 (group\$ or network\$)) or ((consumer\$ or friend\$ or lay\$ or peer\$ or user\$ or volunteer\$) adj (based or counsel\$ or deliver\$ or interact\$ or led or mediat\$ or operated or provides or provider\$ or run\$)) or ((consumer\$ or friend\$ or lay\$ or peer\$ or relation\$ or support\$) adj3 trust\$) or (coping adj3 (behavio?r\$ or skills\$)) or (emotion\$ adj (focus\$ or friend\$ or relation\$)) or ((dyadic or loneliness) adj2 (intervention\$ or program\$ or therap\$ or treat\$)) or ((emotion\$ or one to\$1 one or transition\$) adj support\$) or (lay adj (led or run)) or ((lay or peer) adj5 (advisor\$ or consultant or educator\$ or expert\$ or facilitator\$ or instructor\$ or leader\$ or person\$ or tutor\$ or worker\$)) or expert patient\$ or mutual aid or (peer\$ adj3 (advic\$ or advis\$ or counsel\$ or educat\$ or mentor\$)) or (social adj (adapt\$ or support\$)) or supportive relationship\$ or social interaction program\$ or support\$ listening or recover inc or schizophrenics anonymous or visit\$ service\$ or (voluntary adj3 worker\$) or (volunteer\$ adj5 (trained or aide))).ti,ab.
68	(helpline or help line or ((phone\$ or telephone\$) adj3 (help\$ or instruct\$ or interact\$ or interven\$ or mediat\$ or program\$ or rehab\$ or strateg\$ or support\$ or teach\$ or therap\$ or train\$ or treat\$ or workshop\$ or work

	shop\$) or ((phone or telephone\$) adj2 (assist\$ or based or driven or led or mediat\$)).ti,ab.
69	((emotional\$ or practical\$ or group\$) adj2 support) or (support\$ adj5 (interven\$ or program\$ or therap\$ or treat\$)).ti,ab.
70	(psychosocial\$ or psycho social\$).ti,ab,hw.
71	or/62,64,66-70
72	case management/ use emez
73	exp continuity of patient care/ or exp managed care programs/ or patient-centered care/
74	73 use mesz, prem
75	case management/ use psych
76	((assertive adj1 community adj1 treatment) or ((care or case) and management) or (care adj1 programme adj1 approach) or (madison adj4 model\$) or (training adj2 (community adj1 living)) or cpa or pact or tcl).ti,ab.
77	or/72,74,75-76
78	(((((home or communit\$) adj5 care) or ((informal or non professional) adj5 (care or nursing)) or community based or couples or home nursing or daughter\$ or famil\$ or father\$ or friend\$ or home-based or husband\$ or marital\$ or mother\$ or multifam\$ or neighbo?r\$ or next of kin or niece or nephew\$ or parent\$1 or partner\$1 or relative\$1 or sibling\$ or significant other\$ or spous\$ or step relationship\$ or wife\$1 or wives) adj (based or counsel\$ or deliver\$ or interact\$ or led or mediat\$ or operated or provides or provider\$ or run\$)).ti,ab.
79	(((((home or communit\$) adj5 care) or ((informal or non professional) adj5 (care or nursing)) or community based or couples or home nursing or daughter\$ or famil\$ or father\$ or friend\$ or home-based or husband\$ or marital\$ or mother\$ or multifam\$ or neighbo?r\$ or next of kin or niece or nephew\$ or parent\$1 or partner\$1 or relative\$1 or sibling\$ or significant other\$ or spous\$ or step relationship\$ or wife\$1 or wives) adj4 (assertive\$ or awareness\$ or coach\$ or communicat\$ or didactic\$ or educat\$ or empower\$ or engag\$ or focus\$ or goal set\$ or information\$ or instruct\$ or interven\$ or knowledge or learn\$ or liaison\$ or literac\$ or manag\$ or program\$ or promot\$ or service\$ or session\$ or skill\$ or strateg\$ or support\$ or taught or teach\$ or technique\$ or therap\$ or train\$ or treat\$ or workshop\$)) or psychoed\$ or psycho ed\$ or strateg\$).ti,ab.
80	((rebuilding or re building) adj2 life adj2 (families or friends)) or (journey adj2 hope) or (strategy adj2 enhance working partnerships adj2 (carers or families)) or (therap\$ adj2 (wellbeing or recover\$)) or (triangle adj2 care) or wellness recovery action planning or carers trustfamily liaison service\$ or family sensitive practice or meriden project\$ or recovery college\$ or sympra or ward champion\$ or young diverse minds).ti,ab.
81	or/78-80

82	attitude to computers/ or audiovisual aid/ or audiovisual equipment/ or communication software/ or computer assisted therapy/ or computer program/ or computer system/ or computer/ or decision support system/ or e-mail/ or human computer interaction/ or information technology/ or internet/ or mobile phone/ or multimedia/ or exp optical disk/ or personal digital assistant/ or social media/ or telecommunication/ or teleconsultation/ or telehealth/ or telemonitoring/ or telephone/ or telepsychiatry/ or teletherapy/ or text messaging/ or video disk/ or videorecording/ or videotape/
83	82 use emez
84	attitude to computers/ or audiovisual aids/ or exp cellular phone/ or communications media/ or computer literacy/ or computer user training/ or computing methodologies/ or exp computer systems/ or decision making, computer assisted/ or decision support systems, clinical/ or electronic mail/ or hotlines/ or multimedia/ or exp optical storage devices/ or exp programmed instruction as topic/ or social networking/ or exp software/ or telecommunications/ or telemedicine/ or exp telemetry/ or telephone/ or text messaging/ or therapy, computer assisted/
85	84 use mesz, prem
86	audiotapes/ or audiovisual communications media/ or communications media/ or computer applications/ or exp computer assisted instruction/ or computer assisted therapy/ or computer attitudes/ or computer literacy/ or computer mediated communication/ or computer software/ or computer training/ or computers/ or decision support systems/ or digital video/ or educational audiovisual aids/ or electronic communication/ or exp human computer interaction/ or hot line services/ or human computer interaction/ or hypermedia/ or information technology/ or instructional media/ or internet/ or exp mobile devices/ or exp multimedia/ or online therapy/ or programmed instruction/ or exp social media/ or exp social networks/ or telecommunications media/ or telemedicine/ or telemetry/ or exp telephone systems/ or videotapes/
87	86 use psych
88	((((audio\$ or cd or cd rom or cdrom or communication or computer\$ or cyber\$ or (digital adj (assistant\$ or divide)) or dvd or (e\$1 adj (communicat\$ or consult\$ or mail\$ or portal\$ or tablet\$ or visit\$)) or electronic\$ or email\$ or ecommunicat\$ or econsult\$ or eportal\$ or etablet\$ or evisit\$ or facebook\$ or floppy or handheld or hand held or information technolog\$ or instant messag\$ or interactiv\$ or internet or iphone\$ or laptop\$ or multimedia or multi media or myspace\$ or my space\$ or online or palmtop or palm top or pc\$1 or pda or personal digital or phone\$ or portal\$1 or reminder system\$ or remote consultation\$ or short messag\$ or skype or sms or (social adj (media or network\$)) or tablet\$1 or technolog\$ or telephone\$ or texts or texting or video\$ or virtual or web or website or wireless communication or www) adj3 (aid\$ or assist\$ or based or deliver\$ or diary or diaries)) or (video\$ adj3

	(feedback or information\$ or model\$)) or (virtual adj2 (environment\$ or reality))).ti,ab.
89	((audio\$ or cd rom or cdrom or communication aid\$ or computer\$ or cyber\$ or (discussion adj (board\$ or group\$)) or (digital adj (assistant\$ or divide)) or dvd or email\$ or ecommunicat\$ or econsult\$ or etablet\$ or evisit\$ or (e\$1 adj (communicat\$ or consult\$ or mail\$ or tablet\$ or visit\$)) or facebook\$ or floppy or handheld or hand held or information technolog\$ or instant messag\$ or interactiv\$ or internet or iphone\$ or laptop\$ or mobile or multimedia or multi media or myspace\$ or my space\$ or online or palmtop or palm top or pc\$1 or pda or personal digital or phone\$ or portal\$1 or reminder system\$ or remote consultation\$ or short messag\$ or skype or sms or (social adj (media or network\$)) or tablet\$1 or telephone\$ or texts or texting or video\$ or virtual or web or website or wireless communication) adj7 (advocacy or application\$ or approach\$ or coach\$ or educat\$ or exchang\$ or guide\$1 or help\$ or instruct\$ or interact\$ or interven\$ or learn\$ or manag\$ or meeting\$ or module\$ or network\$ or package\$ or participat\$ or prevent\$ or program\$ or psychoanaly\$ or psychotherap\$ or rehab\$ or retrain\$ or re train\$ or self guide\$ or self help or selfguide\$ or selfhelp or session\$ or skill\$ or strateg\$ or support\$ or teach\$ or technique\$ or therap\$ or train\$ or treat\$ or work shop\$ or workshop\$)).ti,ab.
90	(call in or (caller\$1 adj3 (interven\$ or program\$ or therap\$ or treat\$)) or callline\$ or call line\$ or ediar\$ or ehealth or elearn\$ or etherap\$ or (e adj (diar\$ or learn or health or therap\$)) or telecare or telecommunication or teleconsult\$ or telehealth or telemedicine or telepsychology or telepsychiatry of teletherap\$ or (tele adj (care or communication or consult\$ or health or medicine or psychology or psychiatry or therap\$))).ti,ab.
91	or/83,85,87-90
92	counselling.hw. or religion/ or spiritual care/ or spiritual healing/
93	92 use emez
94	exp religion/ or exp spiritual therapies/
95	94 use mesz, prem
96	pastoral counseling/ or religion/ or exp religious beliefs/ or religious education/ or exp religious literature/ or exp religious personnel/ or exp religious practices/ or spirituality/
97	96 use psych
98	(church or cleric or clergyman or deity or divinity or divine or faith\$ or god or ((higher or supreme) adj being) or inner peace or meditat\$ or (pastoral adj3 (care or caring)) or priest or preacher or pray or prayer\$ or praying or religious or religiosity or religion\$ or spiritual\$).ti,ab.
99	(buddhism or buddist\$ or christian\$ or catholic\$ or eastern orthodoxy or jehovah\$ witness or protestant\$ or hindu* or islam\$ or judaism or taoism or sikk or rastafari).ti,ab.
100	or/93,95,97-99

101	counsel?ing.ti,ab,hw.
101	1 or (9 and 18,21,27,32,60,71,77,81,91,100,101)

CINAHL, Ebsco Host

s87	s1 or (s22 and (s23 or s24 or s25 or s26 or s27 or s28 or s29 or s30 or s31 or s32 or s33 or s34 or s35 or s36 or s37 or s38 or s39 or s40 or s41 or s42 or s43 or s44 or s45 or s46 or s47 or s48 or s49 or s50 or s51 or s52 or s53 or s54 or s55 or s56 or s57 or s58 or s59 or s60 or s61 or s62 or s63 or s64 or s65 or s66 or s67 or s68 or s69 or s70 or s71 or s72 or s73 or s74 or s75 or s76 or s77 or s78 or s79 or s80 or s81 or s82 or s83 or s84 or s85 or s86))
s86	ti ((counsel?ing) or ab ( counsel?ing) or mw (counsel?ing))
s85	ti ( (buddhism or buddist* or christian* or catholic* or "eastern orthodoxy" or "jehovah* witness" or protestant* or hindu* or islam* or judaism or taoism or sikk or rastafari ) or ab ( (buddhism or buddist* or christian* or catholic* or "eastern orthodoxy" or "jehovah* witness" or protestant* or hindu* or islam* or judaism or taoism or sikk or rastafari ) )
s84	ti ( (church or cleric or clergyman or deity or divinity or divine or faith* or god or ((higher or supreme) n1 being) or "inner peace" or meditat* or (pastoral n3 (care or caring)) or priest or preacher or pray or prayer* or praying or religious or religiousity or religion* or spiritual* ) ) or ab ( (church or cleric or clergyman or deity or divinity or divine or faith* or god or ((higher or supreme) n1 being) or "inner peace" or meditat* or (pastoral n3 (care or caring)) or priest or preacher or pray or prayer* or praying or religious or religiousity or religion* or spiritual* ) )
s83	(mh "religion and religions+")
s82	ti ( ("call in" or (caller * n3 (interven* or program* or therap* or treat*)) or callline* or "call line*" or ediar* or ehealth or elearn* or etherap* or (e n1 (diar* or learn or health or therap*)) or telecare or telecommunication or teleconsult* or telehealth or telemedicine or telepsychology or telepsychiatry of teletherap* or (tele n1 (care or communication or consult* or health or medicine or psychology or psychiatry or therap*))) ) or ab ( ("call in" or (caller * n3 (interven* or program* or therap* or treat*)) or callline* or "call line*" or ediar* or ehealth or elearn* or etherap* or (e n1 (diar* or learn or health or therap*)) or telecare or telecommunication or teleconsult* or telehealth or telemedicine or telepsychology or telepsychiatry of teletherap* or (tele n1 (care or communication or consult* or health or medicine or psychology or psychiatry or therap*))) )
s81	ti ( ((audio* or "cd rom" or cdrom or "communication aid*" or computer* or cyber* or (discussion n1 (board* or group*)) or (digital n1 (assistant* or divide)) or dvd or email* or ecommunicat* or econsult* or etablet* or evisit* or (e * n1 (communicat* or consult* or mail* or tablet* or visit*)) or facebook* or floppy or



	<p>handheld or "hand held" or "information technolog*" or "instant messag*" or interactiv* or internet or iphone* or laptop* or mobile or multimedia or "multi media" or myspace* or "my space*" or online or palmtop or "palm top" or pc or pda or "personal digital" or phone* or portal * or "reminder system*" or "remote consultation*" or "short messag*" or skype or sms or (social n1 (media or network*)) or tablet or telephone* or texts or texting or video* or virtual or web or website or "wireless communication") n7 (advocacy or application* or approach* or coach* or educat* or exchang* or guide * or help* or instruct* or interact* or interven* or learn* or manag* or meeting* or module* or network* or package* or participat* or prevent* or program* or psychoanaly* or psychotherap* or rehab* or retrain* or "re train*" or "self guide*" or "self help" or selfguide* or selfhelp or session* or skill* or strateg* or support* or teach* or technique* or therap* or train* or treat* or "work shop*" or workshop*)) ) or ab ( ((audio* or "cd rom" or cdrom or "communication aid*" or computer* or cyber* or (discussion n1 (board* or group*)) or (digital n1 (assistant* or divide)) or dvd or email* or ecommunicat* or econsult* or etablet* or evisit* or (e * n1 (communicat* or consult* or mail* or tablet* or visit*)) or facebook* or floppy or handheld or "hand held" or "information technolog*" or "instant messag*" or interactiv* or internet or iphone* or laptop* or mobile or multimedia or "multi media" or myspace* or "my space*" or online or palmtop or "palm top" or pc or pda or "personal digital" or phone* or portal * or "reminder system*" or "remote consultation*" or "short messag*" or skype or sms or (social n1 (media or network*)) or tablet or telephone* or texts or texting or video* or virtual or web or website or "wireless communication") n7 (advocacy or application* or approach* or coach* or educat* or exchang* or guide * or help* or instruct* or interact* or interven* or learn* or manag* or meeting* or module* or network* or package* or participat* or prevent* or program* or psychoanaly* or psychotherap* or rehab* or retrain* or "re train*" or "self guide*" or "self help" or selfguide* or selfhelp or session* or skill* or strateg* or support* or teach* or technique* or therap* or train* or treat* or "work shop*" or workshop*)) )</p>
s80	<p>ti ( (((audio* or cd or "cd rom" or cdrom or communication or computer* or cyber* or (digital n1 (assistant* or divide)) or dvd or (e n1 (communicat* or consult* or mail* or portal* or tablet* or visit*)) or electronic* or email* or ecommunicat* or econsult* or eportal* or etablet* or evisit* or facebook* or floppy or handheld or "hand held" or "information technolog*" or "instant messag*" or interactiv* or internet or iphone* or laptop* or multimedia or "multi media" or myspace* or "my space*" or online or palmtop or "palm top" or pc or pda or "personal digital" or phone* or portal * or "reminder system*" or "remote consultation*" or "short messag*" or skype or sms or (social n1 (media or network*)) or tablet or technolog* or telephone* or texts or texting or video* or virtual or web or website or "wireless communication "or www) n3 (aid* or assist* or based or deliver* or diary or diaries)) or (video* n3 (feedback or information* or model*)) or (virtual n2 (environment* or reality))) ) or ab ( (((audio* or cd or "cd rom" or cdrom or communication or computer* or cyber* or (digital n1 (assistant* or divide)) or dvd or (e n1 (communicat* or consult* or</p>

	mail* or portal* or tablet* or visit*)) or electronic* or email* or ecommunicat* or econsult* or eportal* or etablet* or evisit* or facebook* or floppy or handheld or "hand held" or "information technolog*" or "instant messag*" or interactiv* or internet or iphone* or laptop* or multimedia or "multi media" or myspace* or "my space*" or online or palmtop or "palm top" or pc or pda or "personal digital" or phone* or portal * or "reminder system*" or "remote consultation*" or "short messag*" or skype or sms or (social n1 (media or network*)) or tablet or technolog* or telephone* or texts or texting or video* or virtual or web or website or "wireless communication" or www) n3 (aid* or assist* or based or deliver* or diary or diaries)) or (video* n3 (feedback or information* or model*)) or (virtual n2 (environment* or reality))) )
s79	(mh "therapy, computer assisted")
s78	(mh "text messaging")
s77	(mh "telemetry")
s76	(mh "telemedicine+")
s75	(mh "telecommunications")
s74	(mh "software+")
s73	(mh "social networking")
s72	(mh "programmed instruction")
s71	(mh "optical disks+")
s70	(mh "multimedia")
s69	(mh "telephone information services")
s68	(mh "electronic mail")
s67	(mh "decision support systems, clinical")
s66	(mh "decision making, computer assisted")
s65	(mh "computer systems+")
s64	(mh "computing methodologies")
s63	(mh "computer user training")
s62	(mh "computer literacy") or (mh "computers, portable") or (mh "computers and computerization")
s61	(mh "communications media")
s60	(mh "computer assisted instruction") or (mh "computers, hand-held") or (mh "therapy, computer assisted")
s59	(mh "wireless communications") or (mh "telephone")
s58	(mh "audiovisuals")
s57	(mh "attitude to computers")
s56	ti ( (((rebuilding or "re building") n2 life n2 (families or friends)) or (journey n2

	<p>hope) or (strategy n2 “enhance working partnerships” n2 (carers or families)) or (therap* n2 (wellbeing or recover*)) or (triangle n2 care) or “wellness recovery action planning” or “carers trust family liaison service*” or “family sensitive practice” or “meriden project*” or “recovery college*” or sympra or “ward champion*” or “young diverse minds”) ) or ab ( (((rebuilding or “re building”) n2 life n2 (families or friends)) or (journey n2 hope) or (strategy n2 “enhance working partnerships” n2 (carers or families)) or (therap* n2 (wellbeing or recover*)) or (triangle n2 care) or “wellness recovery action planning” or “carers trust family liaison service*” or “family sensitive practice” or “meriden project*” or “recovery college*” or sympra or “ward champion*” or “young diverse minds”) )</p>
s55	<p>ti ( (((((home or communit*) n5 care) or ((informal or “non professional”) n5 (care or nursing)) or “community based” or couples or “home nursing” or daughter* or famil* or father* or friend* or “home-based” or husband* or marital* or mother* or multifam* or neighbo?r* or “next of kin” or niece or nephew* or parent * or partner * or relative * or sibling* or “significant other*” or spous* or “step relationship*” or wife * or wives) n4 (assertive* or awareness* or coach* or communicat* or didactic* or educat* or empower* or engag* or focus* or “goal set*” or information* or instruct* or interven* or knowledge or learn* or liaison* or literac* or manag* or program* or promot* or service* or session* or skill* or strateg* or support* or taught or teach* or technique* or therap* or train* or treat* or workshop* or “work shop*”) ) or psychoed* or “psycho ed*” or strateg*) ) or ab ( (((((home or communit*) n5 care) or ((informal or “non professional”) n5 (care or nursing)) or “community based” or couples or “home nursing” or daughter* or famil* or father* or friend* or “home-based” or husband* or marital* or mother* or multifam* or neighbo?r* or “next of kin” or niece or nephew* or parent * or partner * or relative * or sibling* or “significant other*” or spous* or “step relationship*” or wife * or wives) n4 (assertive* or awareness* or coach* or communicat* or didactic* or educat* or empower* or engag* or focus* or “goal set*” or information* or instruct* or interven* or knowledge or learn* or liaison* or literac* or manag* or program* or promot* or service* or session* or skill* or strateg* or support* or taught or teach* or technique* or therap* or train* or treat* or workshop* or “work shop*”) ) or psychoed* or “psycho ed*” or strateg*) )</p>
s54	<p>ti ( (((((home or communit*) n5 care) or ((informal or “non professional”) n5 (care or nursing)) or “community based” or couples or “home nursing” or daughter* or famil* or father* or friend* or “home-based” or husband* or marital* or mother* or multifam* or neighbo?r* or “next of kin” or niece or nephew* or parent * or partner * or relative * or sibling* or “significant other*” or spous* or “step relationship*” or wife * or wives) n1 (based or counsel* or deliver* or interact* or led or mediat* or operated or provides or provider* or run*)) ) or ab ( (((((home or communit*) n5 care) or ((informal or “non professional”) n5 (care or nursing)) or “community based” or couples or “home nursing” or daughter* or famil* or father* or friend* or “home-based” or husband* or marital* or mother* or multifam* or neighbo?r* or “next of kin” or niece or nephew* or parent * or</p>

	partner * or relative * or sibling* or “significant other*” or spous* or “step relationship*” or wife * or wives) n1 (based or counsel* or deliver* or interact* or led or mediat* or operated or provides or provider* or run*)) )
s53	ti ((assertive n1 community n1 treatment) or ((care or case) and management) or (care n1 programme n1 approach) or (madison n4 model\$) or (training n2 (community n1 living)) or cpa or pact or tcl) or ab ((assertive n1 community n1 treatment) or ((care or case) and management) or (care n1 programme n1 approach) or (madison n4 model\$) or (training n2 (community n1 living)) or cpa or pact or tcl)
s52	(mh "patient centered care") or (mh "case management (omaha)") or (mh "case management")
s51	(mh "managed care programs+")
s50	(mh "continuity of patient care+")
s49	ti ( ( psychosocial* or “psycho social*”) ) or ab ( ( psychosocial* or “psycho social*”) ) or mw ( ( psychosocial* or “psycho social*”) )
s48	ti ( ((emotional* or practical* or group*) n2 support) or (support* n5 (interven* or program* or therap* or treat*))) or ab ( ((emotional* or practical* or group*) n2 support) or (support* n5 (interven* or program* or therap* or treat*)))
s47	ti ( (helpline or “help line” or ((phone* or telephone*) n3 (help* or instruct* or interact* or interven* or mediat* or program* or rehab* or strateg* or support* or teach* or therap* or train* or treat* or workshop* or “work shop*”)) or ((phone or telephone*) n2 (assist* or based or driven or led or mediat*))) ) or ab ( (helpline or “help line” or ((phone* or telephone*) n3 (help* or instruct* or interact* or interven* or mediat* or program* or rehab* or strateg* or support* or teach* or therap* or train* or treat* or workshop* or “work shop*”)) or ((phone or telephone*) n2 (assist* or based or driven or led or mediat*))) )
s46	ti ( (advocac* or advocate* or befriend* or “be * friend*” or buddy or buddies or ((community or lay or paid or support) n1 (person or worker*)) or ((community* or home) n1 (based or visit*)) or ((consumer* or friend* or lay or mutual* or peer* or social* or volunteer*) n3 (help* or network* or support* or visit*)) or ((consumer* or peer* or social* or support* or volunteer*) n2 (group* or network*)) or ((consumer* or friend* or lay* or peer* or user* or volunteer*) n1 (based or counsel* or deliver* or interact* or led or mediat* or operated or provides or provider* or run*)) or ((consumer* or friend* or lay* or peer* or relation* or support*) n3 trust*) or (coping n3 (behavio?r* or skill*)) or (emotion* n1 (focus* or friend* or relation*)) or ((dyadic or loneliness) n2 (intervention* or program* or therap* or treat*)) or ((emotion* or “one to one” or transition*) n1 support*) or (lay n1 (led or run)) or ((lay or peer) n5 (advisor* or consultant or educator* or expert* or facilitator* or instructor* or leader* or person* or tutor* or worker*)) or “expert patient*” or “mutual aid” or (peer* n3 (advic* or advis* or counsel* or educat* or mentor*)) or (social n1 (adapt* or support*)) or “supportive relationship*” or “social interaction program*” or “support listening” or “recover inc” or “schizophrenics anonymous” or “visit* service*”

	<p>or (voluntary n3 worker*) or (volunteer* n5 (trained or aide))) ) or ab ( (advocac* or advocate* or befriend* or be * friend* or buddy or buddies or ((community or lay or paid or support) n1 (person or worker*)) or ((community* or home) n1 (based or visit*)) or ((consumer* or friend* or lay or mutual* or peer* or social* or volunteer*) n3 (help* or network* or support* or visit*)) or ((consumer* or peer* or social* or support* or volunteer*) n2 (group* or network*)) or ((consumer* or friend* or lay* or peer* or user* or volunteer*) n1 (based or counsel* or deliver* or interact* or led or mediat* or operated or provides or provider* or run*)) or ((consumer* or friend* or lay* or peer* or relation* or support*) n3 trust*) or (coping n3 (behavio?r* or skill*)) or (emotion* n1 (focus* or friend* or relation*)) or ((dyadic or loneliness) n2 (intervention* or program* or therap* or treat*)) or ((emotion* or "one to one" or transition*) n1 support*) or (lay n1 (led or run)) or ((lay or peer) n5 (advisor* or consultant or educator* or expert* or facilitator* or instructor* or leader* or person* or tutor* or worker*)) or "expert patient*" or "mutual aid" or (peer* n3 (advic* or advis* or counsel* or educat* or mentor*)) or (social n1 (adapt* or support*)) or "supportive relationship*" or "social interaction program*" or "support* listening" or "recover inc" or "schizophrenics anonymous" or "visit* service*" or (voluntary n3 worker*) or (volunteer* n5 (trained or aide))) )</p>
s45	<p>(mh "community networks") or (mh "consumer advocacy") or (mh "education, nonprofessional") or (mh "group processes") or (mh "health information networks") or (mh "home health aide service (saba ccc)") or (mh "home health aides") or (mh "home health care") or (mh "home rehabilitation") or (mh "home visits") or (mh "ineffective family coping, compromised (nanda)") or (mh "peer counseling") or (mh "peer group") or (mh "psychotherapy, group") or (mh "rehabilitation, vocational") or (mh "social network analysis (saba ccc)") or (mh "social networks") or (mh "social support (iowa noc)") or (mh "social work") or (mh "social work practice") or (mh "social work, psychiatric") or (mh "social work service") or (mh "social workers") or (mh "support group (iowa nic)") or (mh "support groups") or (mh "support, psychosocial+") or (mh "support system enhancement (iowa nic)") or (mh "telephone information services") or (mh "trust") or (mh "volunteer workers") or (mh "voluntary health agencies")</p>
s44	<p>ti ( ((adult* or client* or consumer* or inpatient* or outpatient* or participant* or patient* or "service user*") n2 (involv* or participat*)) or ((behav* or psychologic*) n3 (adapt* or adjust*)) or cope or copes or coping ) or ab ( ((adult* or client* or consumer* or inpatient* or outpatient* or participant* or patient* or "service user*") n2 (involv* or participat*)) or ((behav* or psychologic*) n3 (adapt* or adjust*)) or cope or copes or coping )</p>
s43	<p>ti ( (booklet* or brochure* or leaflet* or pamphlet* or poster* or psychoeducat* or "psycho educat*" or workbook* or "work book*" or ((adult* or client* or consumer* or health or inpatient* or outpatient* or participant* or patient* or "service user*") n2 (educat* or focus* or information* or knowledge or learn* or literac* or promot* or taught or teach*)) or empower* or ((oral or printed or written) n3 (material* or inform*)) ) or ab ( (booklet* or brochure* or leaflet* or pamphlet* or poster* or psychoeducat* or "psycho educat*" or workbook* or</p>

	“work book*” or ((adult* or client* or consumer* or health or inpatient* or outpatient* or participant* or patient* or “service user*”) n2 (educat* or focus* or information* or knowledge or learn* or literac* or promot* or taught or teach*)) or empower* or ((oral or printed or written) n3 (material* or inform*)) )
s42	(mh "adaptation, psychological") or (mh "consumer participation")
s41	ti ( (“expert patient*” or (“hearing voices” n2 (group* or network* or support*)) or (minimal n1 (contact or guidance)) or helpseek* or (help* n2 seek*) or (mutual n1 (aid* or help or support*)) or “recovery model*” or “smart recovery”) ) or ab ( (“expert patient*” or (“hearing voices” n2 (group* or network* or support*)) or (minimal n1 (contact or guidance)) or helpseek* or (help* n2 seek*) or (mutual n1 (aid* or help or support*)) or “recovery model*” or “smart recovery”) )
s40	ti ( ((self n1 (administer* or assess* or attribut* or care or change or directed or efficacy or help* or guide* or instruct* or manag* or medicat* or monitor* or regulat* or reinforc* or “re inforc*” or support* or technique* or therap* or train* or treat*)) or selfadminister* or selfassess* or selfattribut* or selfcare or selfchange or selfdirected or selfefficacy or selfhelp* or selfguide* or selfinstruct* or selfmanag* or selfmedicat* or selfmonitor* or selfregulat* or selfreinforc* or “self re inforc*” or selfsupport* or selftechnique* or selftherap* or selftrain* or selftreat*) ) or ab ( ((self n1 (administer* or assess* or attribut* or care or change or directed or efficacy or help* or guide* or instruct* or manag* or medicat* or monitor* or regulat* or reinforc* or “re inforc*” or support* or technique* or therap* or train* or treat*)) or selfadminister* or selfassess* or selfattribut* or selfcare or selfchange or selfdirected or selfefficacy or selfhelp* or selfguide* or selfinstruct* or selfmanag* or selfmedicat* or selfmonitor* or selfregulat* or selfreinforc* or “self re inforc*” or selfsupport* or selftechnique* or selftherap* or selftrain* or selftreat*) )
s39	(mh "self administration") or (mh "self care") or (mh "self care agency") or (mh "self medication")
s38	ti (famil* n2 consultation*) or ab (famil* n2 consultation*)
s37	(mh "family therapy (iowa nic)")
s36	ti ( (problem* n3 (skill* or solv*)) ) or ab ( (problem* n3 (skill* or solv*)) )
s35	(mh "problem solving") or (mh "family problem solving communication")
s34	ti ( ((didactic or systemic) n3 (coach* or communicat* or educat* or instruct* or interven* or knowledge* or learn* or program* or taught* or teach* or therap* or train* or treat*)) ) or ab ( ((didactic or systemic) n3 (coach* or communicat* or educat* or instruct* or interven* or knowledge* or learn* or program* or taught* or teach* or therap* or train* or treat*)) )
s33	ti ( (booklet* or brochure* or educat* or empower* or leaflet* or multimedia or “multi media” or pamphlet* or poster* or psychoeducat* or “psycho educat*” or ((oral or printed or written) n3 (inform* or material*)) or workbook* or “work book*”) ) or ab ( (booklet* or brochure* or educat* or empower* or leaflet* or multimedia or “multi media” or pamphlet* or poster* or psychoeducat* or

	"psycho educat*" or ((oral or printed or written) n3 (inform* or material*)) or workbook* or "work book*") )
s32	(mh "teaching") or (mh "teaching materials+") or (mh "communication skills training")
s31	(mh "programmed instruction")
s30	(mh "problem-based learning")
s29	(mh "patient education") or (mh "patient education (iowa nic) (non-cinahl)")
s28	(mh "models, educational")
s27	(mh "health promotion") or (mh "health promotion (saba ccc)") or (mh "mental health promotion (saba ccc)") or (mh "health promoting behavior (iowa noc)")
s26	(mh "knowledge: health behaviors (iowa noc)") or (mh "knowledge: health resources (iowa noc)")
s25	(mh "health information management") or (mh "health knowledge (iowa noc) (non-cinahl)") or (mh "health knowledge and behavior (iowa noc) (non-cinahl)") or (mh "health knowledge")
s24	(mh "health education")
s23	(mh "consumer health information")
s22	s2 or s3 or s4 or s5 or s6 or s7 or s8 or s9 or s10 or s11 or s12 or s13 or s14 or s15 or s16 or s17 or s18 or s19 or s20 or s21
s21	ti ( ((home n2 (care or caring)) or ((informal or "non professional") n5 (care or nursing)) or "care giv*" or caregiv* or carer* or "community based" or couples or "home nursing" or daughter* or famil* or father* or friend* or "home based" or husband* or marital* or mother* or multifam* or neighbo?r* or "next of kin" or niece or nephew* or parent * or partner * or relative or relatives or sibling* or "significant other*" or spous* or "step relationship*" or wife * or wives) ) or ab ( ((home n2 (care or caring)) or ((informal or "non professional") n5 (care or nursing)) or "care giv*" or caregiv* or carer* or "community based" or couples or "home nursing" or daughter* or famil* or father* or friend* or "home based" or husband* or marital* or mother* or multifam* or neighbo?r* or "next of kin" or niece or nephew* or parent * or partner * or relative or relatives or sibling* or "significant other*" or spous* or "step relationship*" or wife * or wives) )
s20	(mh "family services")
s19	(mh "visitors to patients")
s18	(mh "spouses")
s17	(mh "siblings") or (mh "sibling support (iowa nic)") or (mh "sibling relations")
s16	(mh "sibling relations")
s15	(mh "parent-child relations+")
s14	(mh "parents+")

s13	(mh "nuclear family+")
s12	(mh "marriage")
s11	(mh "intergenerational relations")
s10	(mh "home nursing")
s9	(mh "family")
s8	(mh "family therapy") or (mh "family therapy (iowa nic)")
s7	(mh "family relations")
s6	(mh "family nursing")
s5	(mh "family health") or (mh "family health (iowa noc) (non-cinahl)") or (mh "family member health status (iowa noc) (non-cinahl)")
s4	(mh "family conflict")
s3	(mh "family characteristics")
s2	(mh "community networks")
s1	ti ( caregiv* or carer or "care giv*" ) or ab ( caregiv* or carer or "care giv*" ) or mw ( caregiv* or carer or "care giv*" )



**Table DS1** Studies not included in the review

Study	Reason for exclusion
<i>Excluded studies</i>	
Anderson 1986 <sup>57</sup>	Sample not relevant
Barrowclough 1999 <sup>58</sup>	Intervention not aimed at improving carer experience or reducing carer burden
Barton 2008 <sup>59</sup>	Intervention not aimed at improving carer experience or reducing carer burden
Bazzoni 2003 <sup>60</sup>	Non-English
Berkowitz 1984 <sup>61</sup>	Non-RCT
Birchwood 1992 <sup>62</sup>	Non-RCT
Brooker 1992 <sup>63</sup>	Non-RCT
Carra 2007 <sup>64</sup>	No relevant outcome
Chien 2010 <sup>65</sup>	Intervention not carer-focused (no carer-only sessions)
Cozolino 1988 <sup>66</sup>	No relevant outcome
Das 2006 <sup>67</sup>	Intervention not carer-focused (no carer-only sessions)
Fiorillo2011 <sup>68</sup>	Intervention not carer-focused (no carer-only sessions)
Fraser 2008 <sup>69</sup>	Non-RCT
Kageyama 2007 <sup>70</sup>	Intervention not carer-focused (no carer-only sessions)
Kane 1990 <sup>71</sup>	Non-RCT
Kulhara 2008 <sup>72</sup>	Intervention not carer-focused (no carer-only sessions)
Lacruz 1999 <sup>73</sup>	Intervention not carer-focused (no carer-only sessions)
Leff 2001 <sup>74</sup>	Intervention not carer-focused (no carer-only sessions)
Levy- Frank 2011 <sup>75</sup>	Intervention not carer-focused (no carer-only sessions)
MacCarthy 1989 <sup>76</sup>	Non-RCT
Merinder 1999 <sup>77</sup>	Intervention not carer-focused (no carer-only sessions)
Michielin 2007 <sup>78</sup>	Outside the scope
Moxon 2008 <sup>79</sup>	Intervention not carer-focused (no carer-only sessions)
Murray 1997 <sup>80</sup>	Sample not relevant (included families and not just carers)
Nasr 2009 <sup>81</sup>	Intervention not carer-focused (no carer-only sessions)
Pitschel-Walz 2006 <sup>82</sup>	Intervention not carer-focused (no carer-only sessions)
Schulze-Monking 1994 <sup>83</sup>	Non-RCT
Sellwood 2001 <sup>84</sup>	Intervention not carer-focused (no carer-only sessions)
Shimazu 2011 <sup>85</sup>	Intervention not carer-focused (no carer-only sessions)
Stengard 2003 <sup>86</sup>	Non-RCT
Van Gent 1991 <sup>87</sup>	No relevant outcomes
Xiong 1994 <sup>88</sup>	Intervention not carer-focused (no carer-only sessions)
<i>Current studies</i>	

Sensky 2000 <sup>89</sup>	Ongoing
Sin 2013 <sup>90</sup>	Ongoing
RCT, randomised controlled trial.	

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**NOTES** TAU = Treatment as usual



Fig. DS1 Detailed risk of bias

	Random sequence generation (selection bias)	Allocation concealment (selection bias)	Blinding of participants and personnel (performance bias)	Blinding of outcome assessment (detection bias)	Incomplete outcome data (attrition bias)	Selective reporting (reporting bias)	Other bias
Cheng 2005	+	?	-	+	?	?	+
Chien 2004A	+	?	-	?	+	?	+
Chien 2004B	?	?	-	+	+	?	+
Chien 2007	?	?	-	+	+	?	+
Chien 2008	+	+	-	?	+	?	+
Chou 2002	+	?	-	?	-	?	+
Gutierrez-Maldonado 2007	+	?	-	+	-	?	+
Koolae 2009	?	?	-	?	-	?	+
Leavey 2004	+	+	-	+	+	-	+
Lobban 2013	+	+	-	+	+	+	+
Madigan 2012	+	+	-	+	+	?	+
McCann 2012	+	+	-	+	+	-	+
Perlick 2010	+	+	-	+	+	?	+
Posnor 1992	?	?	-	+	-	?	+
Reinares 2004	+	?	-	+	+	?	+
Sharif 2012	?	+	-	+	+	+	+
Smith 1987	?	?	-	+	?	?	+
So 2006	+	?	-	+	?	?	+
Solomon 1996	+	?	-	?	-	-	+
Szmukler 1996	?	?	-	?	-	?	+
Szmukler 2003	+	+	-	-	+	?	+

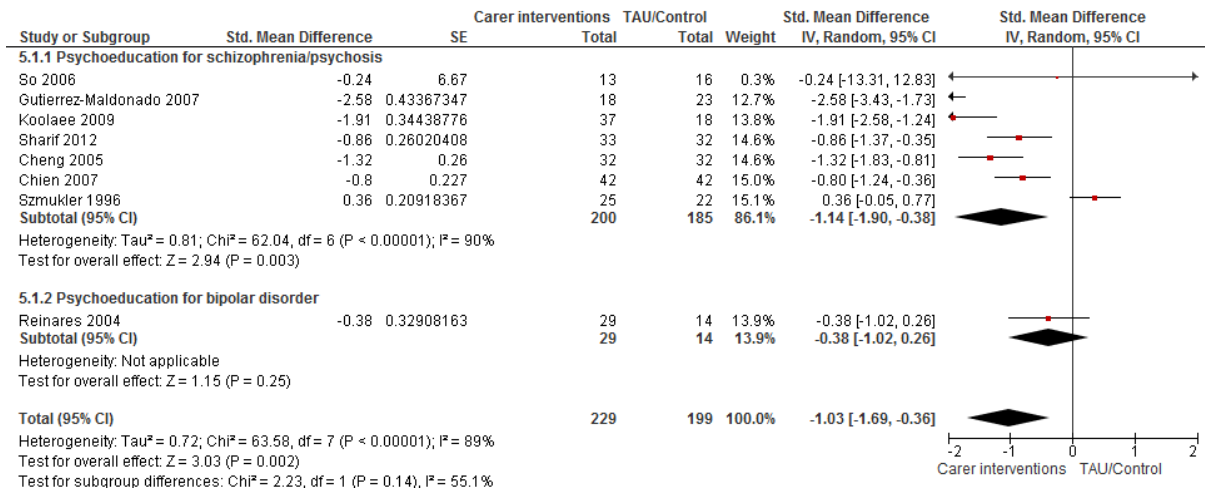
**Table DS3** Summary of pooled effects

	Studies	Participants (n)	Effect size SMD (95% CI)	Heterogeneity $I^2$ ; $X^2$ (P)	Quality (GRADE)
<i>Psychoeducation v. any control</i>					
Experience of caregiving					
End of intervention	8	428	-1.03 (-1.69, -0.36)	89%; 63.58 ( $P < 0.00001$ )	Very low <sup>a,b</sup>
Up to 6 month follow-up	4	215	-0.92 (-1.51 to -0.32)	79%; 14.42 ( $P = 0.003$ )	Very low <sup>a,b</sup>
>6 month follow-up	3	151	-1.29 (-2.4 to -0.18)	86%; 13.99 ( $P = 0.0009$ )	Very low <sup>a,b</sup>
Quality of life					
End of intervention	1	41	-0.31 (-0.93 to 0.31)	NA	Low <sup>a,d</sup>
Satisfaction with services					
End of intervention	1	39	-0.42 (-1.06 to 0.22)	NA	Low <sup>a,d</sup>
Up to 6 month follow-up	1	39	-0.41 (-1.04 to 0.23)	NA	Low <sup>a,d</sup>
Psychological distress					
End of intervention	2	86	-0.30 (-0.84 to 0.24)	38%; 1.62 ( $P = 0.20$ )	Very low <sup>a,b,d</sup>
Up to 6 month follow-up	2	86	-0.34 (-0.76 to 0.08)	0%; 0.95 ( $P = 0.33$ )	Low <sup>a,d</sup>
>6 month follow-up	1	18	-1.79 (-3.01 to -0.56)	NA	High
<i>Support group v. any control</i>					
Experience of caregiving					
End of intervention	3	194	-1.16 (-1.96 to -0.36)	85%; 13.07 ( $P = 0.001$ )	Very low <sup>a,b,c</sup>
Up to 6 month follow-up	3	166	-0.67 (-0.99 to -0.35)	0%; 2.01 ( $P = 0.37$ )	Low <sup>a,c</sup>
>6 month follow-up	2	123	-1.95 (-4.22 to 0.31)	96%; 23.77 ( $P < 0.00001$ )	Very low <sup>a-d</sup>
Psychological distress					
End of intervention	1	70	-0.99 (-1.48 to -0.49)	NA	Low <sup>a,c</sup>
Up to 6 month follow-up	1	70	-0.99 (-1.48 to -0.49)	NA	Low <sup>a,c</sup>
<i>Psychoeducation plus support group v. any control</i>					
Experience of caregiving					
>6 month follow-up	1	49	-0.05 (-0.61 to 0.51)	NA	Low <sup>a,d</sup>
Psychological distress					
>6 month follow-up	1	49	-0.28 (-0.84, 0.29)	NA	Low <sup>a,d</sup>
<i>Problem-solving bibliotherapy v.</i>					

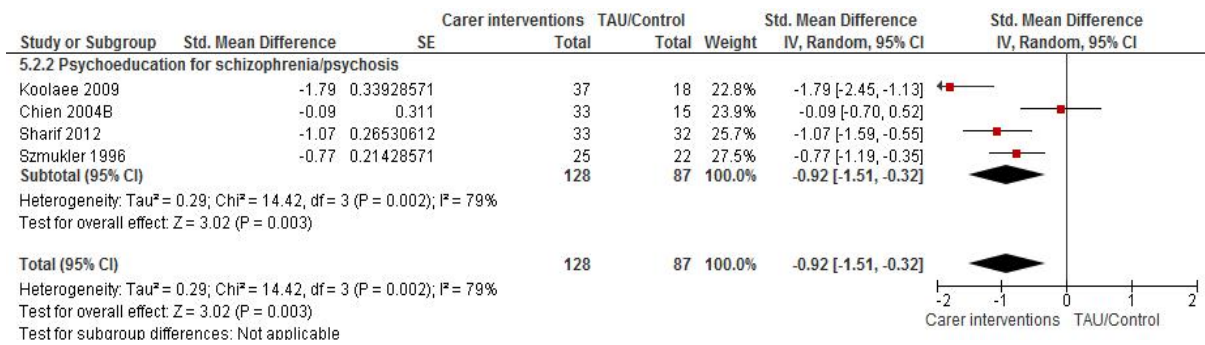
<b>Table DS3</b> Summary of pooled effects					
	Studies	Participants (n)	Effect size SMD (95% CI)	Heterogeneity $I^2$ ; $X^2$ (P)	Quality (GRADE)
<i>any control</i>					
Experience of caregiving					
End of intervention	1	114	-0.17 (-2.45 to 2.11)	NA	Low <sup>a,d</sup>
Up to 6 month	1	114	-1.09 (-2.52 to 0.34)	NA	Low <sup>a,d</sup>
follow-up					
Quality of life					
End of intervention	1	114	-0.14 (-0.5 to 0.23)	NA	Low <sup>a,d</sup>
Up to 6 month	1	114	-0.5 (-0.87 to -0.12)	NA	Low <sup>a,d</sup>
follow-up					
Psychological distress					
End of intervention	1	114	-1.57 (-1.79 to -1.35)	NA	Moderate <sup>a</sup>
Up to 6 month	1	111	-1.54 (-1.95 to -1.13)	NA	Moderate <sup>a</sup>
follow-up					
<i>Self-management v. any control</i>					
Experience of caregiving					
End of intervention	1	86	-0.19 (-0.58 to 0.2)	NA	Moderate <sup>d</sup>
Psychological distress					
End of intervention	1	86	-0.32 (-0.73 to 0.09)	NA	Moderate <sup>d</sup>
<i>Enhanced psychoeducation v. standard psychoeducation</i>					
Experience of caregiving					
End of intervention	1	43	-0.64 (-1.25 to -0.03)	NA	Moderate <sup>d</sup>
<i>Practitioner-delivered v. postal psychoeducation</i>					
Family burden					
End of intervention	1	40	-0.41 (-1.04 to 0.21)	NA	Low <sup>a,d</sup>
Up to 6 month	1	40	-0.41 (-1.03 to 0.22)	NA	Low <sup>a,d</sup>
follow-up					
Psychological distress					
End of intervention	1	40	-0.38 (-1.0 to 0.25)	NA	Low <sup>a,d</sup>
Up to 6 month	1	40	0 (-0.62 to 0.61)	NA	Low <sup>a,d</sup>
follow-up					
GRADE, Grading of Recommendations Assessment, Development and Evaluation; NA, not applicable; SMD, standardised mean difference.					
a. Risk of bias.					
b. Inconsistency.					
c. Indirectness.					

Table DS3 Summary of pooled effects				
Studies	Participants ( <i>n</i> )	Effect size SMD (95% CI)	Heterogeneity <i>I</i> <sup>2</sup> ; <i>X</i> <sup>2</sup> ( <i>P</i> )	Quality (GRADE)
d. Imprecision.				
e. Publication or reporting bias.				

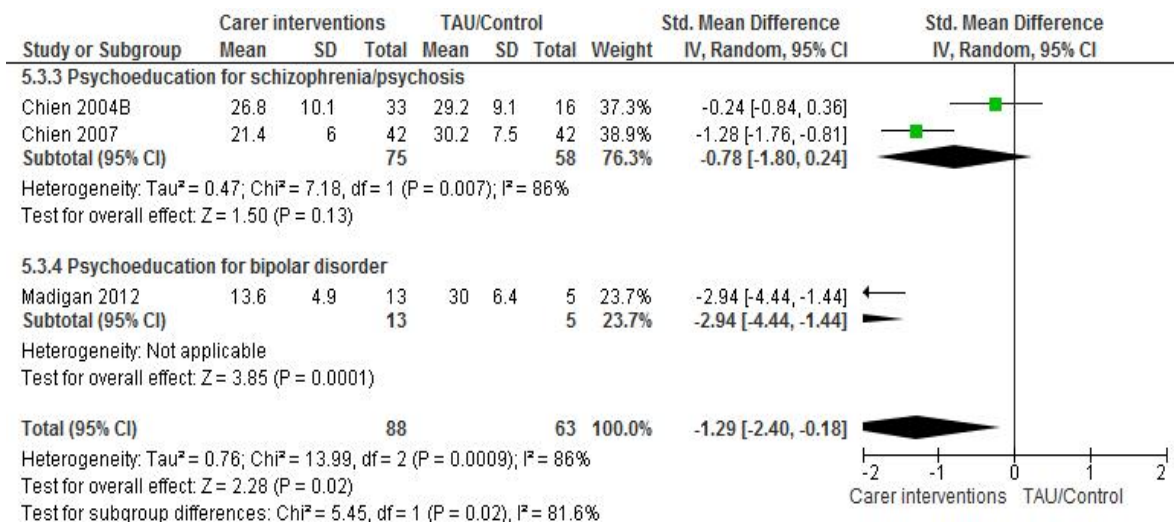
**Fig. DS2 Psychoeducation v. any control, experience of caregiving, end of intervention**



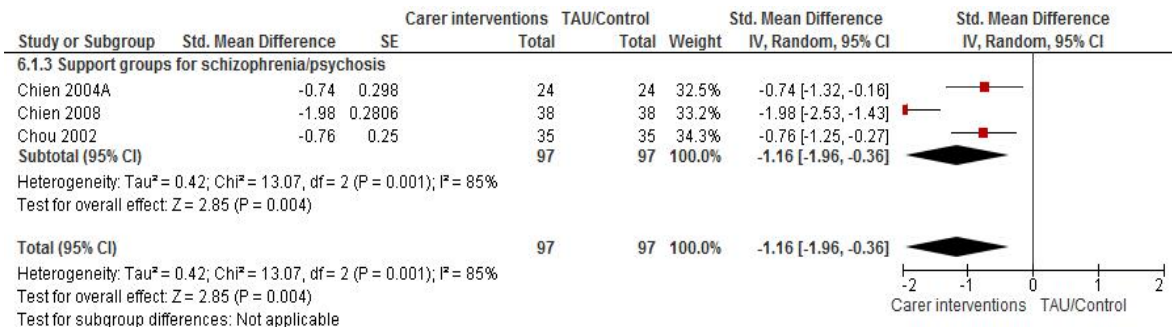
**Fig. DS3 Psychoeducation v. any control, experience of caregiving, up to 6 month follow-up**



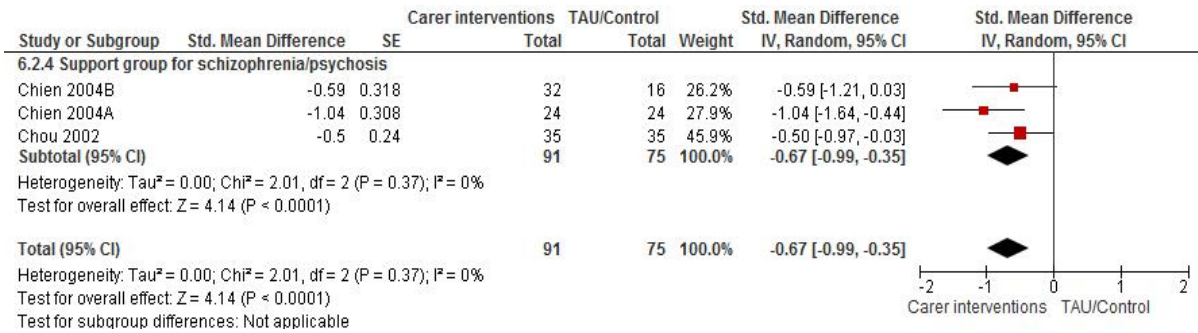
**Fig. DS4 Psychoeducation v. any control, experience of caregiving, > 6 month follow-up**



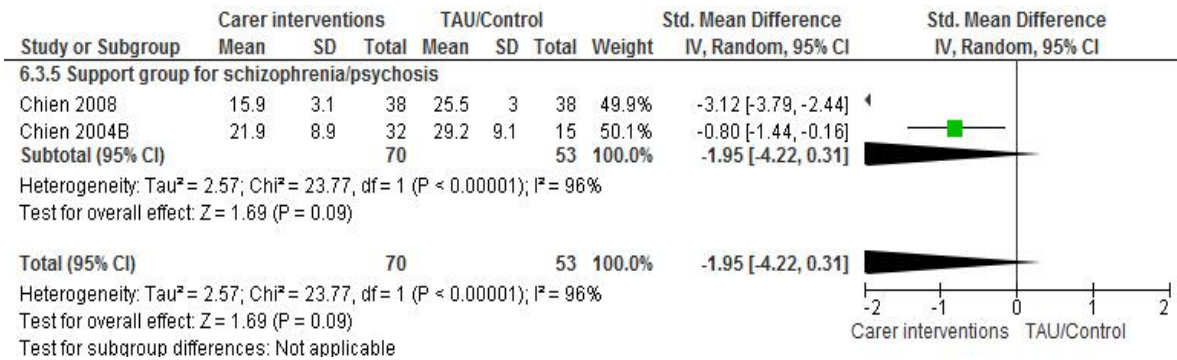
**Fig. DS5 Support groups v. any control, experience of caregiving, end of intervention**



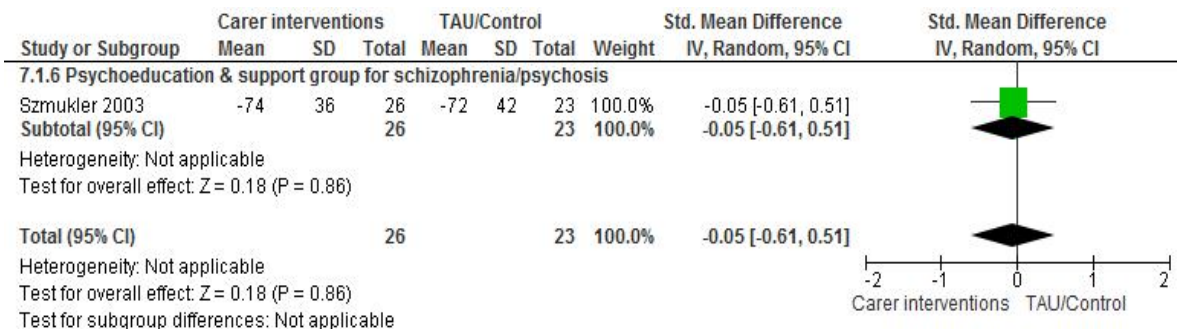
**Fig. DS6 Support groups v. any control, experience of caregiving, up to 6 month follow-up**



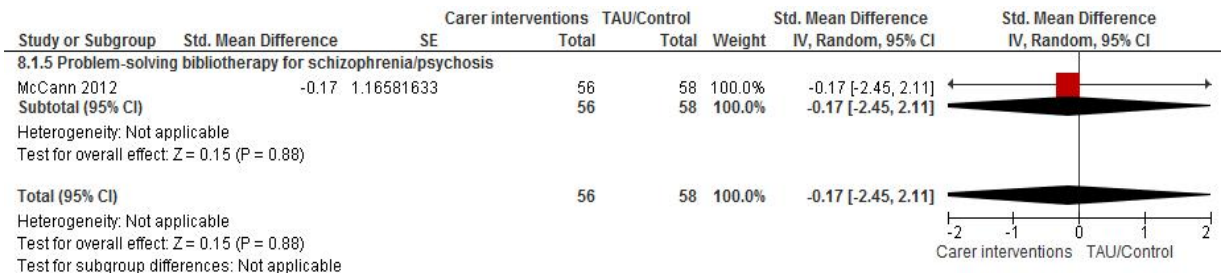
**Fig. DS7 Support groups v. any control, experience of caregiving, > 6 month follow-up**



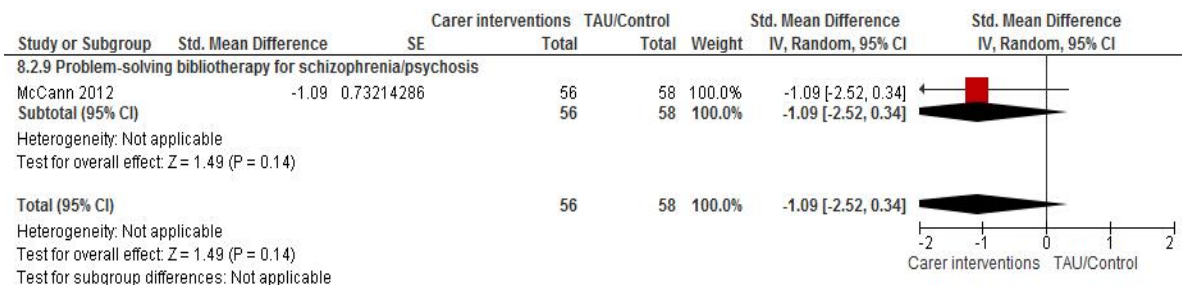
**Fig. DS8 Psychoeducation + support group v. any control, experience of caregiving - >6 month follow-up**



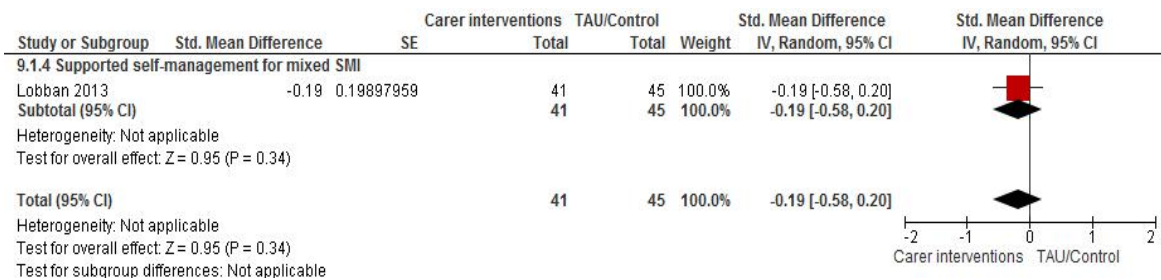
**Fig. DS9 Problem-solving bibliotherapy *v.* any control, experience of caregiving, end of intervention**



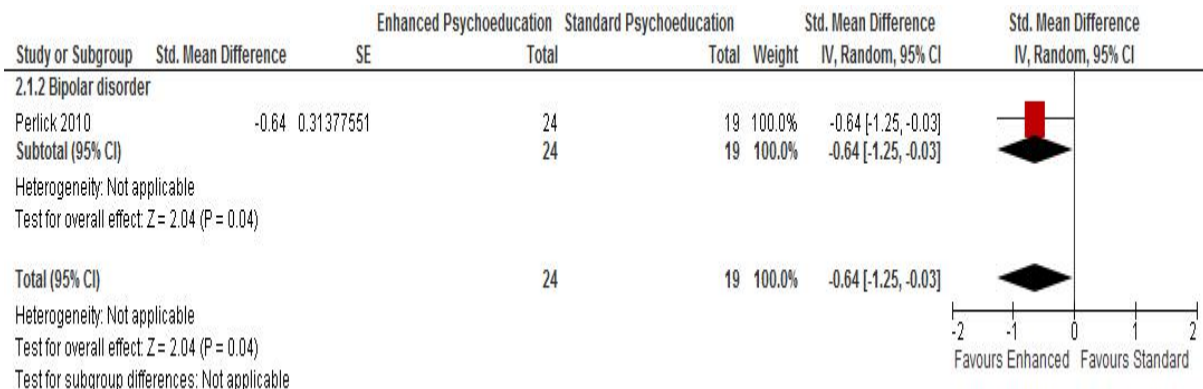
**Fig. DS10 Problem-solving bibliotherapy *v.* any control, experience of caregiving - up to 6 month follow-up**



**Fig. DS11 Self-management *v.* any control, experience of caregiving, end of intervention**



**Fig. DS12 Enhanced psychoeducation *v.* standard psychoeducation, experience of caregiving, end of intervention**



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