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To cite this article: Jane Maria Ussher, Janette Perz, Yasmin Hawkins & Marita Brack (2009) Evaluating the efficacy of psycho-social interventions for informal carers of cancer patients: a systematic review of the research literature, *Health Psychology Review*, 3:1, 85-107, DOI: [10.1080/17437190903033401](https://doi.org/10.1080/17437190903033401)

To link to this article: <https://doi.org/10.1080/17437190903033401>



Published online: 24 Aug 2009.



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Evaluating the efficacy of psycho-social interventions for informal carers of cancer patients: a systematic review of the research literature

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(Received 16 October 2007; final version received 8 May 2009)

Recognition that informal cancer carers experience unmet needs and psychological distress has led to the development of a range of psycho-social interventions. The efficacy of such interventions is examined through a systematic review of the research literature, following National Health and Medical Research Council and Cochrane Collaboration guidelines. Of 13 level II randomised controlled trials (RCTs), only eight showed significant differences across groups, with moderate effect size. This included improvement in caregiver experience or appraisal of caregiving following psycho-education (two studies); improved sexual satisfaction, dyadic coping, relationship quality and communication, or reduced psychological distress, following couple counselling (4); reduced distress following family grief therapy (1); and reduction in distress in bereavement following home palliative care (1). Level III and IV studies were also reviewed, reporting positive effects of psycho-education (5), problem solving (3), an arts intervention (1) and a support group (1). However, methodological concerns limit the generalisability of findings of level III and IV studies. It is concluded that interventions should target those most in need of support; recognise specific needs of carers across cancer type and stage, gender and relationship context; be theory based; and evaluations should utilise RCT designs with outcome measures appropriate to the specific aims of the intervention, rather than global measures of distress.

Keywords: cancer carers; psycho-social interventions; systematic literature review; evaluation of efficacy; well-being; knowledge; dyadic coping

The psycho-social needs of people with cancer have long been recognised, leading to the development of an extensive range of supportive interventions (Newell, Sanson-Fisher, & Savolainen, 2002). However, the needs of informal cancer carers have often been overlooked, to the detriment of the well-being of both the carer, and the person with cancer. There is now consistent evidence that informal cancer carers – the family members and friends who provide both emotional and physical care for a person with cancer – are at risk of experiencing anxiety and depression (Hagedoorn, Buunk, Kuijer, Wobbles, & Sanderman, 2000; Haley, LaMonde, Han, Narramore, & Schonwetter, 2001). Fatigue is also a common symptom reported among cancer carers (Thomas, Morris, & Harman, 2002), as is insufficient rest, time for self-care (Ussher & Sandoval, 2008; Wellisch, Jamison, & Pasnau, 1978), and sleep problems (Carter, 2003). In a number of studies, informal carers have been found to report

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higher levels of cancer-related distress (Matthews, 2003; Matthews, Baker, & Spikers, 2003), or anxiety (Aranda & Hayman-White, 2001; Ferrario, Zotti, Massara, & Nuvolone, 2003; Given, Given, & Kozachik, 2001; Grimm, Zawacki, Mock, Krumm, & Frink, 2000), than people with cancer. It is also now established that women carers are at higher risk of distress than men carers (Hagedoorn, Sanderman, Bolks, Tuinstra, & Coyne, 2008).

The psychological and physical well-being of informal cancer carers is a significant issue, for a number of reasons. Carers are often positioned by health professionals as co-worker, rather than client (Payne, Smith, & Dean, 1999), expected to engage in a wide range of caring and quasi-medical tasks without support (Ussher & Sandoval, 2008) leaving their own needs unmet. Depression, anxiety and fatigue often renders the carer unable to provide the support needed (Christensen, 1999), resulting in greater burden on health and social services. At the same time, the well-being of people with cancer is closely associated with the level of support and care they receive from family and friends (Brown & Stetz, 1999), with good support leading to positive outcomes. As the psychological well-being of people with cancer is also closely associated with the well-being of their primary carer (Hodges, Humphris, & Macfarlane, 2005), caring for informal carers is an essential part of caring for people with cancer.

This growing recognition of the needs of informal cancer carers has resulted in the development of a range of supportive psycho-social interventions, which aim to improve coping and psychological well-being, reduce distress and provide information. Recognising that a single approach will not be acceptable, or meet the broad range of carers' needs across cancer stage and type, these interventions incorporate a variety of modalities and approaches, primarily within a psycho-educational, psychological or practical domain. However, knowing which interventions are effective, and the extent of their impact in meeting carers' needs, is a central question which has not been fully addressed (Harding & Higginson, 2003). This knowledge is crucial to the cost-effective development and allocation of services (Coyne & Lepore, 2006) and the targeting of interventions to meet the needs of specific groups of cancer carers (Carlson, Bultz, Specia, & St-Pierre, 2000). The paucity of rigorous research in this area led Harding and Higginson (2003, p. 63), in a review of the literature prior to 2001, to conclude that 'the current evidence contributes more to feasibility and acceptability than to effectiveness'. However, a substantial amount of research has been published since the Harding and Higginson review, allowing firmer conclusions about effectiveness of certain interventions to now be drawn. The purpose of the present review is thus to systematically examine the efficacy of psycho-social interventions for reducing distress and improving coping in informal cancer carers and to outline the implications of the findings for future research and theory in this field, as well as for the provision of supportive interventions.

Method

Database searches were undertaken in September 2006, and updated in October 2008. These were supplemented by hand searches of contents of journals, and reviews of reference lists of identified papers. The search engine used was EBSCOHost, which accesses a range of databases, including Medline, PsychInfo, CancerLit and a range of others from nursing, health and psychology. Keywords

used for the searches were cancer carer(s)/caregiver(s) intervention/support, cancer couple intervention/support. Papers which reported evaluations of supportive psycho-social interventions for informal carers of a person with cancer, or for couples where one person had cancer, were included. Psycho-social interventions under three broad categories were identified: psycho-educational (both general and specific problem solving); psychological (psychotherapeutic, problem solving psychological and support groups); and practical, or a combination of these approaches. Couple or family interventions which only reported on the outcomes for the patient, did not distinguish patient from carer outcomes, only provided data on baseline, or post-intervention satisfaction, or where sample size precluded statistical analysis, were not included in the review.

There are a number of recognised frameworks for making evidence-based treatment recommendations, which propose a hierarchical ranking of evidence (National Health and Medical Research Council [NHMRC], 1999; Ropka & Spencer-Cisek, 2001). In the present review, all studies were rated following the NHMRC guidelines (see Table 1). Most highly valued (level I) are systematic reviews of multiple, high quality, randomised controlled trials (RCTs) – either a qualitative integrative review, or a quantitative meta-analyses. The next level (II) includes at least one well-designed randomised control trial; followed by a well-designed trial without randomisation (level III-1); comparative studies with concurrent controls and allocation not randomised (cohort studies), case-control studies or interrupted time series with a control group are rated level III-2; comparative studies with historical control, two or more single-arm studies, or interrupted time series without a parallel control group are rated level III-3; and case series, either post or pre-test and post-test are rated level IV.

Meta-analysis was considered, but deemed inappropriate (see Mohr, Judd, & Terry, 1998), because of the variable nature and quality of the existing studies including lack of consistency in interventions and outcomes, differences in participant eligibility criteria and length of follow-up periods, and availability of sufficient detailed information in trials results (see also Newell et al., 2002). Instead, a systematic qualitative review of level II studies, high-quality RCTs, was conducted (Hunt & McKibbin, 1998) (Table 1). In order to provide a broad picture of the current research knowledge in relation to psycho-social interventions for informal cancer carers, an evaluation of studies which would be rated as level III and IV using the NHMRC guidelines was also included (Table 2). This follows Barsevick, Sweeney, Haney and Chung (2002, p. 75), who included level III and IV studies in their systematic qualitative analysis of psycho-educational interventions for people with cancer, in order to provide ‘additional support’ for the evaluation of level II studies.

In addition to each study being rated for level of evidence (Tables 1 and 2), the methodological quality of each of the randomised controlled trials was also evaluated, using the guidelines recommended by the Cochrane Collaboration (Mulrow & Oxman, 1997). Following Newell et al. (2002), each trial was awarded three points for fulfilling each of 10 criteria: adequate concealment of allocation; participants randomly selected; participants blinded to treatment group; care-providers blinded to treatment group; except trial intervention, other treatments equivalent; care-providers adherence monitored; detailed loss to follow-up information provided; percentage of participants not in the analysis; and outcomes measured

Table 1. Design and study characteristics, interventions and findings by type of outcome for level II randomised control trial studies.

Study and quality score ^a	Design and study characteristics	Intervention	Psychological constructs	Caregiver efficacy findings ^b
Christensen (1983), 23	Design: T0, T1 I: $n = 10$; C: $n = 10$ % Male: 100 Caregiver mean age: 39.5 years Type: breast Stage: post-mastectomy Eligibility: patient's cancer arrested and non-metastatic; surgery completed not <two months and not >three months prior to study; absence of current mitigating crisis or major emotional disturbance	Counselling: structured couples programme; four weekly sessions. C: unspecified	Psychological disturbance; marital adjustment; sexual satisfaction; depression; self-esteem; helplessness; anxiety	Improved: sexual satisfaction* ($d = 0.51$); emotional discomfort* ($d = 0.87$)
Kissane et al. (2006), 23	Design: T0, T2 (six and 13 months post-bereavement) I: $n = 180$; C: $n = 102$. % Male: I: 47; C: 49 Caregiver mean age: I: 37; C: 36 Type: mixed Stage: advanced Eligibility: patient prognosis of six months age 35 and 70 years; one or more children >12 years	Psychotherapy: family focussed grief therapy; 4–8 sessions. C: usual care	Family functioning; psychological morbidity and distress; depression; social functioning; grief	Improved: psychological distress* at T2 six and 13 months; depression* at T2 six and 13 months for the 'most distressed' caregivers at baseline
Blanchard, Toseland, and McCallion (1996), 23	Design: T2 (six months) to Toseland (see below)	See below	See below	NS

Table 1 (Continued)

Study and quality score ^a	Design and study characteristics	Intervention	Psychological constructs	Caregiver efficacy findings ^b
Bultz, Specia, Brasher, Geggie, and Page (2000), 21	Design: T0, T1, T2 (three months) I: <i>n</i> = 15; C: <i>n</i> = 19 % Male: 100 Caregiver mean age: 51 Type: breast Stage: early Eligibility: patient diagnosis within 12 months	Psycho-educational: short-term problem solving; six sessions. C: wait list, usual care	Perceived health status; depression; anxiety; marital adjustment; coping behaviour	NS
Walsh et al. (2007), 21	Design: T0, T2 (4, 9 and 12 weeks) I: <i>n</i> = 137; C: <i>n</i> = 134 % Male: 21 Caregiver mean age: I: 56.4; C: 56.1 Type: mixed Stage: advanced Eligibility: score >5/6 on the GHQ-28	Education/support: advice and support; six weekly sessions. C: usual care	Psychological morbidity and distress; strain; quality of life; grief	NS
Toseland, Blanchard, and McCallion (1995), Level II, 20	Design: T0, T2 (two months) I: <i>n</i> = 40; C: <i>n</i> = 38 % Male: 50 Caregiver mean age: I: 56; C: 51 Type: mixed Stage: varied Eligibility: exclusion if patient diagnosis <three months or terminal phase; received other counselling in <six months	Psycho-social counselling: problem solving and coping; six sessions. C: usual care	Depression; anxiety; marital satisfaction; satisfaction with support; perceived health status; burden; help-seeking behaviour; coping; pressing problems; personal change and pressing problems	NS Improved: physical, role and social functioning* (for highly distressed caregivers only); ability to cope with pressing problems* (for moderately burdened caregivers only)

Table 1 (Continued)

Study and quality score ^a	Design and study characteristics	Intervention	Psychological constructs	Caregiver efficacy findings ^b
Northouse, Kershaw, Mood, and Schafenacker (2005), 19	Design: T0, T2 (three and six months) I: $n=69$; C: $n=65$ % Male: not specified Caregiver mean age: 52 Type: breast Stage: III and IV Eligibility: patient life expectancy at least six months; family members	Education/support: family focussed programme; five sessions and two boosters. C: usual care	Appraisal; uncertainty; hopelessness; coping; quality of life	Improved: negative appraisal* at T2 three months ($d=0.37$); hopelessness** at T2 three months ($d=0.54$)
Scott, Halford, and Ward (2004), 18	Design: T0, T1, T2 (six and 12 months) $N=94$ % Male: 100 Caregiver mean age: 53 Type: breast and gynaecological Stage: early Eligibility: patient about to commence treatment; committed relationship > one year	Psychotherapy: couple-coping training; three sessions. C: medical information (MI) and patient coping training (PC)	Couple communication; coping; psychological distress	Improved: couple coping* and $d=1.23$ between I and MI; withdrawal* at T2 six months; coping effort* at T2 12 months and $d=0.64$ between I and MI
Hudson, Aranda, and Hayman-White (2005), 17	Design: T0, T1, T2 (eight weeks post-bereavement) I: $n=54$; C: $n=52$ % Male: 34.9 Caregiver mean age: 60.78 Type: not specified Stage: advanced Eligibility: residing with patient receiving home-based palliative care services	Psycho-education: information-focussed intervention; two sessions and one follow-up. C: usual care	Preparedness for caregiving; caregiver competence; self-efficacy; rewards; anxiety	Improved: rewards** at T1 ($d=0.68$) and at T2* ($d=0.66$)

Table 1 (*Continued*)

Study and quality score ^a	Design and study characteristics	Intervention	Psychological constructs	Caregiver efficacy findings ^b
Kozachik et al. (2001), 17	Design: T0, T1 (nine weeks post-entry), T2 (24 weeks post-entry) I: $n = 61$; C: $n = 59$ % Male: 50 Caregiver mean age: 52.44 years Type: mixed Stage: varied Eligibility: patient to be newly diagnosed; eligible to receive chemotherapy; <56 days of initiating chemotherapy	Education/support: supportive nursing intervention; nine contacts. C: usual care	Depression	NS
Goldberg and Wool (1985), 13	Design: T0, T1 (six weeks after diagnosis), T2 (3–4 months after diagnosis) I: $n = 27$; C: $n = 21$ % Male: I: 15; C: 19 Caregiver mean age: I: 47; C: 53 Type: lung Stage: newly diagnosed	Psycho-social: social support counselling; 12 sessions. C: usual care	Emotional, social and physical functioning	NS
Kuijter, Buunk, and de Jong (2004), 16	Design: T0, T1, T2 I: $n = 20$; C: $n = 19$ % Male: I: 70; C: 68 Caregiver mean age: I: 49; C: 50 Type: mixed Stage: varied Eligibility: married or cohabitating; patient life expectancy at least six months	Counselling: cognitive behaviourally oriented couple counselling; five sessions. C: wait list, usual care	Perceptions of inequity; relationship quality; psychological distress	Improved: perceptions of overinvestment/underbenefit** at T1 ($d = 0.44$); relationship quality* at T1 ($d = 0.43$)

Table 1 (Continued)

Study and quality score ^a	Design and study characteristics	Intervention	Psychological constructs	Caregiver efficacy findings ^b
Kayser (2005), 12	Design: T0, T1, T2 N: 50 % Male: 98 Caregiver mean age: 49 Type: breast Stage: early Eligibility: patient currently receiving treatment; married or in intimate relationship	Psycho-social: couple intervention; nine sessions. C: usual care	Individual well-being; relationship functioning	Improved: stress communication coping at T2*
McCorkle, Robinson, Nuamah, Lev, and Benoliel (1998), 11	Design: spousal data collected 5 × 6-week intervals, starting at two months after diagnosis N: 46 % Male: I: 10; C: 40 Caregiver mean age: 58 Type: lung Stage: advanced	Support/education: specialised oncology home care. C: standard home care programme (SHC); office care programme (OC)	Psychological distress	Improved: depression*; paranoid ideation*

^aMethodologic quality rating (Newell et al., 2002).

^bOnly statistically significant results representing improvements (i.e., caregiver intervention group was statistically better than the caregiver control group).

T0, before/pre-test; T1, post-test; T3, follow-up; I, intervention; C, control; Type, type of cancer; Stage, stage of cancer; *d*, calculated effect size when all relevant statistics were provided (Zimmerman et al., 2007); NS, no significant caregiver outcomes between I and C.

p* < 0.05; *p* < 0.01.

Table 2. Design and study characteristics, interventions and findings by type of outcome for level III and IV studies.

Study and level of evidence ^a	Design and study characteristics	Intervention	Psychological constructs	Caregiver efficacy findings ^b
Heinrich and Schag (1985), III-1	Design: T0, T1, T2 I: $n = 12$; C: $n = 13$ Caregiver mean age: not specified Type: mixed Stage: varied	Psycho-education: group stress and activity management programme; six sessions. C: usual care	Cancer information Psycho-social adjustment to illness; quality of life; daily activities; psychological distress; satisfaction with care received	Improved: information* at T2; recreational activity* at T2; satisfaction with care* at T2
Gagnon et al. (2002), III-2	Design: T0, T1 I: $n = 66$; C: $n = 58$ % Male: 18 Caregiver mean age: I: 54.6; C: 53.3 Type: not specified Stage: advanced	Psycho-education: written information. C: usual care	Delirium knowledge; perceived competence; attitude towards delirium; mood	Improved: knowledge of delirium frequency*; medication* competency in decision making**
Sabo, Brown, and Smith (1986), III-3	Design: T0, T1 I: $n = 6$; C: $n = 17$ % Male: 100 Caregiver mean age: not specified Type: breast Stage: post-mastectomy	Support: facilitated men's support group; multisession. C: non-participants	Gender expectations; self-esteem; depression; sexual compatibility; verbal communication about mastectomy; supportive attitude towards wife; marital happiness	Improved: verbal communication about mastectomy**

Table 2 (Continued)

Study and level of evidence ^a	Design and study characteristics	Intervention	Psychological constructs	Caregiver efficacy findings ^b
Bucher et al. (2001), IV	Design: T0, T2; within subjects. N: 49 % Male: 26 Caregiver mean age: 48 Type: not specified Stage: advanced	Education: individualised problem-solving educational session programme for patients and caregivers. C: none	Confidence in ability to provide care; information about community resources; problem-solving ability	Improved: information about community resources* caregiver problem-solving*
Cameron, Shin, Williams, and Stewart (2004), IV	Design: T0, T1; within subjects N: 34 % Male: 32 Caregiver mean age: 53.6 Type: mixed Stage: advanced	Psychotherapy: brief problem-solving intervention; one session. C: none	Amount of caregiving assistance provided; confidence in caregiving; emotional well-being; problem-solving ability	Improved: emotional tension*
Ferrell, Grant, Chan, Ahn, and Ferrell (1995), IV	Design: T0, T1, T2; within subjects N: 50 % Male: 24 Caregiver mean age: 60.5 Type: mixed Stage: varied	Psycho-education: pain education programme for patients and family caregivers; eight sessions. C: none	Quality of life; knowledge and attitudes about pain; caregiver burden	Improved: quality of life* at T1; knowledge* and experience* regarding pain
Lewis et al. (2008), IV	Design: T0, T1; within subjects N: 20 % Male: 100 Caregiver mean age: 53 Type: breast Stage: varied	Education/counselling: skills and confidence focus; five sessions. C: none	Depression; anxiety; marital adjustment; self-efficacy; communication skills; interpersonal support; interview	Improved: depressed mood**; anxiety**; self-efficacy**; spouse behavioural skills** Interview results reflected strengthening of relationship

Table 2 (Continued)

Study and level of evidence ^a	Design and study characteristics	Intervention	Psychological constructs	Caregiver efficacy findings ^b
Walsh, Martin, and Schmidt (2004), IV	Design: T0, T1; within subjects N: 40 % Male: 25 Caregiver mean age: 51.43 Type: not specified Stage: not specified	Psychotherapy: creative arts intervention; one session. C: none	Stress; anxiety; negative and positive affect	Improved: stress**; anxiety**; positive emotions**
Pasacreta, Barg, Nuamah, and McCorkle (2000), IV	Design: T0, T2; within subjects N: 187 % Male: 17 Caregiver mean age: not specified Type: mixed Stage: varied	Psycho-education: information and support; three sessions. C: none	Reactions to caregiving; caregiver burden	Improved: impact on household finances**; interpersonal relationships*; caregiver responsibility for providing intimate care*; responsibility towards supervision**; physical tasks intensity**

^aLevel of evidence.
^bOnly statistically significant results representing improvements (i.e., caregiver intervention group was statistically better than the caregiver control group or within group difference where no control group).
 III-1, psuedorandomised controlled trial; III-2, comparative study with concurrent controls; III-3, comparative study without concurrent controls; VI, case series; T0, before/pre-test; T1, post-test; T3, follow-up; I, intervention; C, control; Type, type of cancer; Stage, stage of cancer.
 * $p < 0.05$; ** $p < 0.01$.

blind. The quality of a trial was considered good if it had a score of more than 20 points; fair if it had 11–20 points, and poor if it had less than 11 points (Newell et al., 2002). Effect size was also calculated for the RCTs which had a significant positive outcome, and where sufficient statistical detail was provided, in order to provide an assessment of clinical importance of the results.

Overview of findings and discussion

Of 13 level II RCTs reviewed, five showed no significant difference across treatment groups and eight showed significant effects, with moderate effect size. However, if we accept the contention that only high-quality RCTs be considered in assessments of efficacy of psycho-social interventions in oncology (Manne & Andrykowski, 2006), the present review would base its conclusions on the five RCTs which received a good quality rating (21 and over) using the Cochrane criteria. This would result in the conclusion that there is very little evidence for the efficacy of psycho-social interventions in reducing distress and improving coping in informal cancer carers. Three studies showed no significant difference across treatment groups, following problem solving (Blanchard, Toseland, & McCallion, 1996), or supportive psycho-education interventions (Bultz, Specia, Brasher, Geggie, & Page, 2000; Walsh et al., 2007). Two studies showed minimal impact, reporting increases in sexual satisfaction following couple counselling (Christensen, 1983) and reductions in general distress following family focussed grief therapy (Kissane et al., 2006). Of the eight other studies which would also be classified level II in the NHMRC ranking, and which received a fair quality rating (11–20), two showed no significant effect following supportive counselling (Goldberg & Wool, 1985; Kozachik et al., 2001). Modest positive effects were reported from three couple-focussed interventions, in relation to improvements in dyadic coping (Kayser, 2005), ratings of relationship quality (Kuijter, Ybema, Buunk, de Jong, Thijs-Boer, & Sanderman, 2000), and supportive communication, sexual adjustment, coping effort and psychological distress (Scott, Halford, & Ward, 2004). Supportive psycho-education interventions were reported to result in a more positive caregiver experience (Hudson, Aranda, & Hayman-White, 2005), and less negative appraisal of caregiving (Northouse, Kershaw, Mood, & Schafenacker, 2005), and home nursing palliative care was found to reduce psychological distress in bereavement (McCorkle, Robinson, Nuamah, Lev, & Benoliel, 1998).

The present review also considered 12 non-RCT level III and IV studies, which did report positive results, across a range of domains. Psycho-education was reported to result in increased knowledge (Ferrell, Grant, Chan, Ahn, & Ferrell, 1995; Gagnon et al., 2002; Heinrich & Schag, 1985), improved self-efficacy in relation to coping (Lewis et al., 2008) or decision making (Gagnon et al., 2002), improved psychological well-being (Ferrell et al., 1995; Lewis et al., 2008) and reduction in caregiver burden (Pasacreta, Barg, Nuamah, & McCorkle, 2000). Problem solving interventions were reported to increase knowledge and problem solving ability (Bucher et al., 2001), and to reduce emotional tension (Cameron, Shin, Williams, & Stewart, 2004). An arts intervention was reported to improve psychological well-being (Walsh, Martin, & Schmidt, 2004), and a support group improved marital communication (Sabo, Brown, & Smith, 1986).

Positive results from level III and IV studies cannot be accepted without caution, however, as few of these studies demonstrate methodological rigour. Limitations

include the absence of standardised measures, no pre-post outcome measures or absence of follow-up, no comparison or control groups, no information about attrition rates and absence of information about participant eligibility. However, RCTs are also not immune from methodological criticism. Small sample size is the norm in all studies, level II–IV, increasing the likelihood of type II errors. The Kissane et al. (2006) and Walsh et al. (2007). RCTs are the only studies which met the recommended benchmark for evidence evaluation of over 100 participants per group (Hardorn, Baker, Hodges, & Hicks, 1996). Whilst 100 participants per group may be unrealistic in many research contexts, power calculations can be conducted, allowing estimates of the number of participants needed to have a 0.70 likelihood of detecting a moderate effect size. Few of the studies achieved this. The majority of the reviewed studies also employed a relatively short follow-up period, which prevents assessment of the long-term effectiveness of interventions, and in some studies participants in the control condition accessed psychological support as part of usual care (e.g., Toseland, Blanchard, & McCallion, 1995), compromising the rigour of the controlled trial design. The emphasis on positive results recorded on a single outcome measure, in studies that used a range of measures, must also be viewed with caution, as this precludes standard interpretation of significance levels and increases the likelihood of a Type I error occurring.

There are a number of explanations for the paucity of significant findings in relation to psycho-social interventions reducing distress and improving coping in informal cancer carers. Whilst a number of informal carers experience elevated levels of distress associated with the presence of cancer, many participants in cancer carer interventions are described as highly functioning, and do not show elevated levels of depression, stress or burden (e.g., Christensen, 1983; Goldberg & Wool, 1985). This confirms the suggestion that carers are not under stress when they access interventions, rather that they are doing so to collect information in order to prevent future problems (Toseland & Rossiter, 1989). This can result in a ceiling effect in relation to changes in psychological well-being. It has been suggested that those who decline participation may be those most in need of support (Goldberg & Wool, 1985). This appears to be borne out by the findings of Kissane et al. (2006, p. 1216), who reported that the 66% of eligible families who declined to take part in their family focussed grief therapy could be described as predominantly ‘chaotic/alientated’.

In recent reviews of the efficacy of psycho-social interventions for people with cancer (Andrykowski & Manne, 2006; Barsevick et al., 2002), it was concluded that when interventions are delivered to those with elevated levels of distress, the positive effect of such interventions is more evident. Two studies contained in the present review reported similar findings, suggesting that this may also be the case for informal cancer carers. Kissane et al. (2006) reported that only families with high baseline depression scores reported significant reductions in depression following their family focussed grief intervention. Similarly, Toseland et al. (1995) only found significant effects of their problem solving intervention for those who scored one standard deviation below the mean on the Dyadic Adjustment Scale. This leads to the conclusion that psycho-social interventions which aim to reduce psychological distress should be targeted at those carers who have the most difficulty coping (Carlson et al., 2000).

The importance of establishing exactly what interventions can be expected to accomplish, and tailoring outcome measures accordingly, is also paramount. It has been argued that outcome measures currently used in cancer carer intervention research are measuring more global indices of burden, stress or depression (Harding & Higginson, 2003; Toseland & Rossiter, 1989), or measuring trait rather than state characteristics (Kissane et al., 2006), both of which would not be expected to change over short periods of time. In many instances, caregiving demands increase over the course of the cancer journey (Pasacrete et al., 2000), particularly for individuals providing end of life care (Walsh & Schmidt, 2003), which could also confound any prospective evaluation of psychological distress pre–post intervention. Rather than focussing on global indices of distress, it may be more applicable to adopt a range of measures appropriate to the specific aims of the intervention under investigation, such as increased knowledge or appraisal of caregiving following psycho-education, or relationship communication and satisfaction following a couple intervention. These were the constructs which showed significant positive change in the present review, with moderate effect size, in contrast to measures of psychological distress which largely showed no change. It has also been suggested that that psycho-social interventions with informal cancer carers should focus on maintaining quality of life (Northouse et al., 2005), on increasing positive emotions which can act as a buffer against stress (Hudson et al., 2005), or on developing skills for managing and dealing with specific illness-related concerns in concrete gender-sensitive ways (Cochrane & Lewis, 2005), rather than on reducing psychological distress.

One factor which needs to be considered in evaluating psycho-social interventions for cancer carers is the way in which participants are recruited for studies. It has been suggested that ‘gate keeping’ of cancer carer access to interventions occurs via organisations, patients and health professionals (Hudson et al., 2005), resulting in the exclusion of those who might benefit the most. Participants are primarily made up of those contacted through the person with cancer, who may decline involvement (Cochrane & Lewis, 2005), or those who volunteer to take part in response to a direct approach, with low uptake reported, 20–30% on average (e.g., Blanchard et al., 1996; Bultz et al., 2000; Goldberg & Wool, 1985; Goldstein, Alter, & Axelrod, 1996; Keefe et al., 2005; Ostroff, Ross, Steinglas, Ronis-Tobin, & Singh, 2004; Sabo et al., 1986). One reason for low participation may be the use of the term ‘care giver’, or ‘carer’ in recruitment for studies, as many partners of a person with cancer, or those primarily providing emotional rather than physical support, may not identify with the term ‘carer’ (Hagedoorn et al., 2008). The corollary to this is that participants who take part in interventions on the basis of being the partner or first degree relative of a person with cancer may not be a ‘carer’ (Hagedoorn et al., 2008), and thus may have different concerns and needs to those who are in a caring role.

Reasons for non-participation in psycho-social interventions include carers feeling that they do not need support, belief that they are coping well with managing the illness, only wanting the intervention focus to be on the needs of the patient, and concerns about leaving the patient alone (Harding & Higginson, 2003). This parallel findings of research on cancer support group non-attendance more broadly (Bui et al., 2002; Ussher, Kirsten, Butow, & Sandoval, 2008; Winefield, Coventry, Lewis, & Harvey, 2003), and suggests that it should not be assumed that cancer carers will want to avail themselves of interventions that are offered, and that this should be respected. Many carers adapt well to the illness and the caring role without having

undertaken any psychological intervention (Goldberg & Wool, 1985; Weisman & Worden, 1977). Equally, cancer carers consistently report that self-reliance and independence are important values (Grande, Todd, & Barclay, 1997), and the reports of negative effects of interventions in a proportion of studies (Jepson, McCorkle, Adler, Nuamah, & Lusk, 1999; Skilbeck et al., 2005) suggest that interventions are not for everyone.

However, many informal cancer carers position their own needs or concerns as irrelevant or insignificant in comparison to those of the person with cancer (Ussher & Sandoval, 2008). Their perception of the severity of their own distress may be underestimated, leading to low motivation to attend to their own needs or to seek help, as predicted by the Health Belief Model (Janz & Becker, 1984). The provision of information about the emotional and physical costs of caring, and about the buffering effects of engaging in self-care or social support, may increase carer engagement with interventions. Equally, the high expectations placed on carers by health professionals and other family members (Soothill et al., 2003), may serve to create both a subjective and group norm which delegitimises carers articulating their own needs, seeking help or engaging in self-care. Reducing the costs of engagement with interventions, and greater social acknowledgement of carers needs, may overcome such barriers.

It is important to note that regardless of the mode of intervention, participants in psycho-social interventions report a high level of satisfaction (Bucher, Houts, Nezu, & Nezu, 1999; Gilbar, 1997; Ostroff et al., 2004; Walsh et al., 2007), rating interventions positively in terms of their usefulness (Bultz et al., 2000; Feldman, 1993; Goldstein et al., 1996), their impact on experience of the rewards of caring (Hudson et al., 2005; Manne, Babb, Pinover, Horowitz, & Ebbert, 2004a) and on improvements in communication and subjective well-being (Plant et al., 1987). The inclusion of qualitative evaluations of subjective experience of intervention efficacy and process, alongside standardised instruments, would be a valuable addition to future research, as qualitative research can identify both mechanisms of change, and previously neglected variables for consideration in quantitative studies (Hagedoorn et al., 2008). It is notable that two studies which adopted a qualitative methodology reported improvements in psychological well-being (Grahm & Danielson, 1996; McLane, Jones, Lydiatt, Lydiatt, & Richards, 2003), suggesting that there may be a disparity between subjective evaluation of intervention efficacy, and changes recorded on standardised instruments.

A number of further recommendations can be made for future research in this field. The importance of targeting interventions to the needs of cancer carers has been emphasised by many researchers (Goldberg & Wool, 1985; Harding & Higginson, 2003; Hudson et al., 2005; Kissane et al., 2006). However, many research studies include both carers and people with cancer, with no attempt to tailor support to their different needs, and in some instances, little or no differentiation between them (e.g., Bucher et al., 1999; Feldman, 1993; Ussher, Kirsten, Butow, & Sandoval, 2006; Wells, Hepworth, Murphy, Wujcik, & Johnson, 2003), or an overt focus on the needs of the patient (e.g., Keefe et al., 2005). There has been little attempt to recognise the range of relationship types present in the informal cancer carer population – which include spousal, friendship, parental, sibling and other family relationships. The gender balance of carers participating in interventions has also received little attention. It is now well established that women cancer carers report

higher rates of depression and anxiety, and lower life satisfaction and quality of life ratings, compared to men carers (Hagedoorn et al., 2008). Women have also been found to construct and experience the caring experience differently from men, leading to different patterns of coping (Ussher & Sandoval, 2008). However, no interventions, to date, have targeted gender specific needs, and none have examined gender differences in the experience or efficacy of interventions. Such research is long overdue.

Equally, few studies include participants from a variety of cultural groups, those with poor literacy skills, or English as a second language, limiting generalisability of findings to such groups (Hudson et al., 2005). The intervention needs and barriers to participation of carers in rural and remote areas has also been overlooked, despite the evidence that rural family caregivers experience greater burden, due to isolation and limited resources (Conley & Burman, 1997). There are many areas of cancer carer needs not incorporated in current interventions studies. One example is sexuality and intimacy issues, which are frequently identified as problematic for cancer carers (Hawkins, Ussher, Gilbert, Perz, & Sandoval, 2009), with negotiation of sexual matters within the couple relationship often reported to be difficult (De Groot et al., 2005). This can have a significant impact on the well-being of the carer and the person with cancer (Schober, 2004). Yet, to date, there has been no systematic evaluation of interventions to address cancer carer psycho-sexual needs, and there is a general neglect of relationship issues in the majority of cancer carer interventions (Cochrane & Lewis, 2005). Another issue that needs consideration is the absence of research into the caregiving experience for partners in same sex relationships, as health care practices may not be attuned to the specific dynamics of gay and lesbian relationships, or to other social issues which may impact upon care (Kayser, 2005). Only one study reviewed in the present paper reported attempting to include same sex couples in their sample (Bultz et al., 2000), but they were not successful in doing so.

The relative efficacy of interventions for carers across different stages and types of cancer, or the merits of focussing on single types of cancer versus mixed types, has also been neglected. The needs and concerns of cancer carers will vary depending on the stage of cancer and prognosis, ranging from dealing with the shock of diagnosis in early stages, to anticipatory grieving in palliative care. However, many carer intervention studies do not specify cancer stage, and interventions are rarely targeted to meet the needs of carers at particular stages. Stage of cancer may also be a factor in recruitment, with some studies reporting higher take-up in carers of a person with newly diagnosed or early stage cancer, in comparison to those at later stages or remission (Carlson & Strang, 1996). Equally, whilst many of the studies fail to describe the breakdown of cancer types of the participants, those which do have predominantly focussed on breast, lung and prostate cancer. For people with cancer, interventions which focus on a single type of cancer (breast cancer) have been found to be more effective than those that include a range of cancer types, and the training of the health professionals offering the intervention has also been found to influence effectiveness (Zimmerman, Heinrichs, & Baucom, 2007). Future research should systematically compare the experience of carer interventions across cancer type and stage, and the mediators and moderators of effectiveness, including the professional background of the service deliverer, in order to inform health professionals as to the most effective time, modality and content of delivery for these difference groups. Examination of the influence of other potential moderating factors, such as level of

carer burden (Lutsky & Knight, 1994), activity restriction (Matthews et al., 2003) and unmet needs (Allen, 1994), could also provide useful insight into the reasons why interventions may be effective for some carers, but not for others.

Interventions should also be based on a clear theoretical framework and a prior needs analysis; this is not the case for the majority at present (Cochrane & Lewis, 2005). Hagedoorn et al. (2008), in their recent meta-analysis of distress in couples coping with cancer, suggest that research on stress in marital relations, on mutuality of relationships, and on gender differences in coping in relationships, can be usefully applied to understand distress in couples coping with cancer. The positive effects of couple interventions on relationship and sexual satisfaction, as well as on couple communication and coping (Christensen, 1983; Kayser, 2005; Kuijer et al., 2000; Scott et al., 2004) suggests that this is an area deserved of further investigation. Conceptualising cancer as a relational experience, using a model of dyadic coping (Kayser, Watson, & Andrade, 2007), provides explanation for the finding that interventions targeting couples appear to be more effective than interventions focussing solely on the carer. This model draws on systemic-transactional theory (Bodenmann, 2005), to conceptualise coping as an interaction between the stress signals and communication style of one partner and the coping responses of the other. Supporting this model, couples who are mutually responsive, attend to each others needs, and talk openly about their stress, have been reported to be able to engage in effective emotion and problem focussed coping in relation to cancer (Zunkel, 2002). This allows them to find benefits in the cancer experience, such as personal growth and relationship closeness (Kayser et al., 2007; Manne et al., 2004b). This pattern of mutual communication has also been found to be associated with lower levels of distress for people with cancer and their partners, and higher levels of marital satisfaction (Badr, Acitelli, & Carmack Taylor, 2008; Manne et al., 2006; Ptacek, Ptacek, & Dodge, 1994). Conversely, many partners are overprotective towards the person with cancer, engaging in 'protective buffering' in an attempt to prevent distress (Badr & Carmack Taylor, 2006; Kuijer et al., 2000), or 'disengaged avoidance' (Kayser et al., 2007, p. 412), involving complete denial of cancer or its effects. This is associated with higher levels of distress and lower marital satisfaction (Badr et al., 2008; Kuijer et al., 2000; Manne et al., 2006; Ptacek et al., 1994; Skerrett, 1998; Zunkel, 2002), as well as less supportive behaviour within the couple (Manne, Ostroff, Winkel, Grana, & Fox, 2005). Longer-term follow-up of participants in couple interventions may thus produce findings of reduced distress, associated with improved communication, coping and marital satisfaction.

However, not all informal carers are spouses. More broadly, Wuest's (1997, 2000, 2001) work on patterns of carer coping, and how these shift and develop across the course of the caring relationship, could provide a theoretical framework for tailored interventions across different stages of the cancer journey. Wuest (1997) argues that the initial caring stages are characterised by 'fraying connections', involving daily struggles, altered prospects and ambivalent feelings. For those carers who develop adaptive methods of coping, this is followed by a stage of 'precarious ordering', involving setting boundaries, negotiating, and 're-patterning' care – including strategies such as anticipating, setting ground rules, juggling time, relinquishing and replenishing (Wuest, 2000, 2001). In a recent qualitative study of men and women cancer carers, the majority of women gave accounts which could be characterised as 'fraying connections', regardless of cancer stage, in contrast to the

men carers who gave accounts of strategies of 're-patterned care', and reported higher levels of psychological well-being and coping (Ussher & Sandoval, 2008). There is also evidence that women are more affected than men by the emotional well-being of others (Hagedoorn et al., 2001), or by life events, such as cancer, which affect others (Kessler & Mcleod, 1984; Taylor, 2006). This is because a woman's sense of self is conceptualised as 'being in relation' (Jordan, Kaplan, Miller, Stiver, & Surrey, 1991; Miller, 1986), with mutual connectedness and the well-being of significant others being central to identity. This reinforces the need for interventions to be tailored to the specific needs of men and women carers, across stage of the caring experience, as well as being based on a clear theoretical framework.

In conclusion, this absence of consistent positive findings, accompanied by methodological problems, and moderate clinical impact, does not provide the body of evidence to make reliable clinical recommendations to guide practice (NHMRC, 2000) in relation to the provision of psycho-social interventions to reduce distress and improve coping for informal cancer carers. This parallels the conclusions of recent reviews of psycho-social interventions for people with cancer (Coyne, Lepore, & Palmer, 2006; Newell et al., 2002), or partners of a woman with breast cancer (Cochrane & Lewis, 2005). Isolated studies which appear to reduce distress do not provide sufficient evidence for the overall efficacy of this type of intervention, and consideration needs to be given to possible adverse effects and the other costs of such interventions (Coyne & Lepore, 2006). However, there is evidence that targeted psycho-social interventions can be effective in facilitating change in areas such as increased knowledge, relationship satisfaction or communication, appraisal of caregiver experience and distress following bereavement. Equally, carers subjectively report benefit from engagement in interventions. Further rigorous research using a RCT design with adequate sample size is needed to evaluate which interventions are likely to work for which carers, across types of cancer, stage of illness, gender, cultural group, level of distress and relationship with the person with cancer. Interventions need to be based on a clear theoretical framework, with outcome measures tailored specifically to the mode of intervention, rather than global measures of distress. Without this research evidence, there is not a strong case to be made for the development of specialised interventions which differ from the information and support that characterises 'usual care'.

Acknowledgements

This research was funded by a Linkage Grant from the Australian Research Council, LP0560448, in partnership with Cancer Council New South Wales, Westmead Hospital, and Sydney University. Thanks are offered to Angela Pearce, who assisted with the collection of the literature, and to two anonymous reviewers, who suggested revisions to this paper.

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