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Review

The psychological impact of cancer on patients' partners and other key relatives: a review

C. Pitceathly[a,*], P. Maguire[a]

[a]*CRUK Psychological Medicine Group, Stanley House, Christie Hospital, Manchester M20 4BX, UK*

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Abstract

Partners and other family members are key supports for cancer patients. Most cope well with the caregiving role, but an important minority become highly distressed or develop an affective disorder. Female carers and those with a history of psychiatric morbidity are more vulnerable, as are those who take a more negative view of the patient's illness and its impact on their lives. Carers are likely to become more distressed and develop psychiatric morbidity as the illness advances and treatment is palliative. Carers are also more at risk when they lack a support network of their own and when there are relationship difficulties with the patient. The review discusses why, given this evidence, carers fail to take advantage of interventions designed to help them and those who participate derive only limited psychological benefits.

Keywords: Cancer; Caregivers; Psychological adjustment; Affective disorders

1. Introduction

Patients' preferences and economic considerations mean that most cancer patients receive their medical care as outpatients or within their own homes. The increasing reliance on informal carers to provide practical and emotional support has generated research into the demands and impact of the carer's role. This review considers the prevalence of psychological distress and psychiatric morbidity among carers, the factors related to distress and morbidity, and interventions designed to support carers.

2. Prevalence of psychiatric morbidity amongst carers—is there a problem?

Most cancer patients' carers adjust, but some report high levels of emotional distress or psychiatric morbidity (major depressive illness, anxiety or adjustment disorders) [1–5].

Studies using self-report questionnaires have found that between 20 and 30% of carers are probable cases of psychiatric morbidity [2,5–9]. Studies of patients with advanced disease or receiving palliative care report probable caseness rates amongst carers of between 30 and 50% [10–12].

The few studies that have used trained interviewers to administer standardised psychiatric interviews have found lower levels of morbidity. These range from 10% amongst carers of newly diagnosed patients [1,13] to 33% when patients are terminally ill [14].

Unfortunately, there are no period prevalence rates for affective disorders among carers that cover the lifetime of the patient's illness. Studies have usually assessed psychological adjustment at a single time point or only over a short time period.

3. How chronic are carers' psychological problems?

Some studies suggest that carers' distress reduces over time after diagnosis [15], but others show it increases [16,17]. There is evidence that, for some carers, psychological difficulties are prolonged [4,13,16]. In a longitudinal study of breast patients and their

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[*] Corresponding author. Tel.: +44-161-446-3688; fax: +44-161-446-8103.

E-mail address: carolyn.pitceathly@man.ac.uk (C. Pitceathly).

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husbands, Northouse and colleagues [18] found that the husbands' emotional distress after diagnosis predicted their distress a year later. Haddad [13] found that in 40% of partners who developed an affective disorder, the episode lasted over 6 months. Psychological difficulties may become prolonged because carers disregard their own problems in order to focus exclusively on patients' needs [19]. Carers are less likely than patients to disclose their concerns and worries [20] and only half of those with serious psychological problems will seek help [8,13,14].

3.1. Summary

A minority of cancer patients' carers develop psychiatric disorders and a greater number develop high levels of emotional distress. These problems may become chronic, but carers are unlikely to seek help.

4. What factors are associated with psychological distress amongst carers?

Individual and systemic models have been investigated. The way carers appraise cancer-related events and the demands placed upon them, and how they cope with these issues have been considered important mediators of their subsequent psychological adjustment [2,7,18,21]. In systemic models, the marital dyad or family has been the focus for investigation [12,22–26].

5. Vulnerability factors

5.1. Demographic factors

Female gender, young age and lower social class have been associated with depression in the general population [27]. The same associations have been found in carers of cancer patients [28], but findings have not been so consistent.

Female carers are more likely to be emotionally distressed and develop affective disorders than males [5,13,29–31]. Hagedoorn and colleagues [5] found that 35% of female partners compared with 12% of male partners scored over the cut-off for depression on the Center for Epidemiologic Studies Depression Scale (CES-D). In Haddad's [13] study, 23% of female carers developed affective disorders over the 2 years after the patients' cancer diagnoses compared with 7% of male carers.

Some studies have not shown such a gender difference [2,32,33] and some have found male carers to be more distressed [10]. Differences in the measures used and sample characteristics may explain these variable findings.

5.2. Personality/previous history of affective disorders

Neuroticism and past episodes of depressive illness predict the development of affective disorders after major life events in community studies and studies of psychological adjustment in cancer patients [34,35]. There is now evidence they may also influence carers' psychological adjustment. Nijboer and colleagues [36] studied newly diagnosed colorectal patients and their partners and followed-up caregivers for 6 months after patients were discharged from hospital. They found a continuing relationship between neuroticism and depression among the caregivers. Ybema and colleagues [26] found a relationship between neuroticism and symptoms of depression amongst a sample of predominantly male cancer patients and their partners. A previous history of depression was strongly related to the development of affective disorders among partners in Haddad's [13] study.

5.3. Partners vs. non-partner carers

Adult children or parents are often the key carers for adult cancer patients without partners. However, there has been little study of the prevalence of psychological problems amongst non-partners. What evidence there is suggests that they can also develop high levels of emotional distress or affective disorders, whatever the stage of the patients' illnesses [11,37]. Kissane and colleagues [11] examining families of patients receiving palliative care found that 35% of spouses and 28% of children were probable cases of depression. In a study of carers over 2 years following patients' cancer diagnoses, Pitceathly and colleagues [37] found that 24% of female partners and 22% of female non-partner carers developed affective disorders.

5.4. Illness stage and symptoms

Psychological problems and morbidity increase in frequency amongst carers as the illness progresses [17,30,38–39], particularly when patients are suffering from advanced or terminal disease [10–12,14]. A patient in the later stages of illness is likely to need more physical care and provoke more concerns for the carer. Kurtz and colleagues [39] found that as the illness progressed, caregivers experienced more depression, a greater adverse impact on their own health and daily lives and spent more time helping patients cope with daily living activities.

Carers' distress increases as patients experience more physical symptoms like pain and as their functional status deteriorates [3,33,40]. Partners also seem to be more distressed when they have health problems of their own [3,20].

5.5. Impact on lifestyle and role changes

Lifestyle and role disruptions after cancer have been related to the development of depression among carers [9,41,42]. Nijboer [9] found that disruptions to daily life predicted depression amongst carers of newly diagnosed cancer patients. Keller and colleagues [20] found that daily life changes after cancer diagnosis only predicted distress amongst female spouses. In Pitceathly's [42] study, female partners were more likely to take a negative view of role and lifestyle changes and develop depression. So there may be gender differences in the way carers respond to role adjustments.

6. Intrapersonal factors

6.1. Coping style

Avoidance has been related to poor psychological adjustment in carers [6,7,30,43]. Caregivers who avoided issues related to the patients' medical condition or treatment or were passively resigned to their situation in Rodrigue and Hoffman's [6] study were more highly distressed. Morse and Fife [30] studied partners after patients' diagnoses, at first remission, after recurrence and when patients had advanced disease. They found that avoidance by, for example, keeping others from knowing how bad they felt or using alcohol or medication, was related to poorer adaptation among partners, while denial (minimising the impact of the illness on their lives) was related to positive adjustment.

The way patients cope has been related to carers' distress. Ey and colleagues [7] found that male patients' use of avoidance was related to increased anxiety and depression amongst their wives. Ptacek and colleagues [43] found that husbands reported fewer mental health problems when patients used more problem-focused coping and less avoidance.

6.2. Appraisal

Carers' adjustment has been related to their appraisals of the patients' illness [30,33,44]. Caregivers who are optimistic are less depressed and better adjusted psychologically [33]. Negative appraisals have been associated with a poorer adjustment [2,3,21,42,45]. Carers who perceive the cancer as more serious [2], consider treatments as more stressful [45], feel more uncertain or hopeless [3,18], or report more illness-related demands and concerns [22,46] are much more likely to be emotionally distressed or clinically anxious or depressed.

Carers' negative perceptions of how patients' illnesses impact on their lives seem more closely associated to carers' adjustment than objective measures of how burdensome the illness is for them [2,44]. Carey and colleagues [21] found that while low mood among caregivers was associated with reports of more demands and difficulties in their caregiving role, most of their mood disturbance was accounted for by negative appraisal rather than burden. In Pitceathly's [42] study, partners who had developed a depressive illness were likely to view changes in relationships and lifestyle as problematic.

7. Interpersonal factors

7.1. Informal support

Positive adjustment to the cancer predicament has been associated with the availability of support and confidants [16,47,48]. However, a stronger association has been found between a lack of support and high levels of emotional distress or affective disorders [6,9,49]. The mental health of carers has been found to improve in the year after diagnosis when carers felt the adequacy of support they received had improved [16]. Schumacher and colleagues [29] found that social support mediated between patients' functional status and caregivers' depression. Carers were more likely to be depressed when patients' function was poor, but the strength of that relationship was weaker when carers felt they were well supported.

Some studies have failed to find a strong relationship between carers' depression and their perception of support [31,50]. The inconsistency of findings reflects the complexities of trying to measure different aspects of support. Gender differences may also play a part. Ptacek and colleagues [43] found that breast cancer patients and their husbands who sought more support had better mental health. In a further study, they found [51] there was a relationship between spousal support and better adjustment for husbands. However, there was a slightly negative correlation between support and adjustment for wives. Baider and De-Nour [48] also found a relationship between family support and better psychological adjustment for husbands, but not wives, of cancer patients.

A possible reason for these mixed findings is that whilst carers are less likely to become distressed after a cancer diagnosis and treatment if they are well supported, support may only be forthcoming for some carers once friends and relatives can see evidence of their distress [52].

Studies of couples have found that partners are less distressed when they perceive that patients are supportive of them [47] and mutual patient/partner support appears to offer the best protection [53] against high levels of distress.

7.2. Communication

The relationship between confiding concerns and worries about the illness and carers' psychological adjustment is unclear. There is some evidence that open communication is helpful to carers. Vess and colleagues [54] found that couples who talked together adapted more effectively to illness-related changes in their roles. Glasdam and colleagues [8] found that spouses who were most anxious were less likely to have confided their problems.

Some studies have failed to find a direct relationship between confiding and psychological distress, or the development of affective disorders amongst carers [20,42,46,47]. Fear of recurrence amongst spouses in Lee Walker's [47] study was related to more communication and Pitceathly [42] found that partners who talked about role and relationship changes after the cancer were those with a more negative view of those changes. So, whilst confiding about concerns may be protective and helpful to partners' psychological adjustment, carers may also confide more when they become anxious or distressed.

Gender may influence what type of confiding is helpful. While husbands in Keller's [20] study were less distressed if they communicated within the family, wives were less distressed when support came from outside.

7.3. *Marital dissatisfaction/difficulties*

Many couples are drawn closer together by the experience of cancer, but a minority report increased strain and difficulties within their relationship. This is more likely when there were problems prior to the diagnosis of cancer [55].

The nature of the patient/carer relationship prior to the cancer also predicts psychological problems amongst carers afterwards. Williamson and Schulz [12] studied patients receiving palliative radiotherapy and their relative caregivers (mostly spouses). They found that those who had been in close relationships (each partner responsive to and concerned about the others needs) felt less burdened by the caregiving role and reported fewer symptoms of depression than those who had not been in such mutually supportive relationships.

Equity theory has also been applied to the relationship between depression among cancer patients and their partners [26]. Equity theory predicts that individuals in inequitable relationships will become distressed. In a study of 106 patients and their partners, Ybema and colleagues [26] found that patients were more likely to become depressed when they felt they were underinvesting in the relationship. Partners were more likely to be depressed if they felt they were underbenefiting from the relationship, a situation that follows the traditional patient-caregiver division of roles. In studies of families' adaptation to breast cancer, Lewis and colleagues [23,24] found that depression had a negative effect on the quality of the marriage. So, while marital difficulties may be associated with the development of high levels of psychological distress, a partner's psychological distress may also negatively impact on the marital relationship.

7.4. *Patients' adjustment*

The psychological adjustment of couples appears to be correlated, regardless of cancer type or illness stage [2,3,7,16,18,20,48], although sometimes this correlation has been low [11] or absent [26]. Northouse and colleagues [3] studied breast patients with recurrent cancer and their husbands. Although couples' adjustment was correlated, they found no evidence that patients' adjustment affected their partners. It was husbands' distress that impacted on patients' adjustment.

There are suggestions that correspondence in couple's adjustment is less likely when the patient is male [20,49].

Studies with a mix of relative carers in their samples (spouses and non-spouses) have found a relationship between patients' and carers' adjustment [38] and depression [33]. Few studies have investigated the correspondence in adjustment between patients and non-spouse carers and findings from those studies have not been consistent. Ell and colleagues [16] and Pitceathly and colleagues [37] found no correspondence in the adjustment of patients and non-spouse carers, although both studies found that patients' and spouses' psychological adjustment was correlated. However, Gilbar and Refaeli [56] did find a correlation in the adjustment of newly diagnosed adult cancer patients and their parents.

7.5. *Formal supports*

Investigations have shown that carers are more distressed when their needs for medical information are not met. Haddad [13] found that dissatisfaction with medical information was related to affective disorders among partners of newly diagnosed cancer patients. Derdiarian and colleagues [57] showed that patients and partners who received an information package tailored to their requirements rather than a standardised package were better adjusted and more satisfied. This accords with the findings of Keller and colleagues [20]. They studied spouses of patients with chronic advanced disease who were receiving outpatient chemotherapy. They found no relationship between the amount of information that spouses had received and their levels of distress. Involvement in medical decision-making was felt to be burdensome by a substantial minority of spouses. The authors concluded that levels of information and participation in decision-making should be tailored to meet the needs and wishes of individual spouses and patients. A view confirmed by studies of the impact of illness-related information on patients' psychological adjustment [58].

7.6. Summary

Carers who will develop high levels of emotional distress or psychiatric morbidity are more negative about the patients' illness and illness-related events, regardless of a patient's objective health status. The use of avoidance as a way of coping is related to carers' psychological problems. Deterioration in the couple relationship may also adversely affect partners' adjustment. Some risk factors like gender, age, personality and marital difficulties predate the cancer. It seems that the support or confiding opportunities that carers find helpful differ for male and female carers. Lifestyle changes have a bigger impact on female carers.

8. Interventions

Over the last 20 years, a wide range of interventions for carers has been reported. Some have been designed for families [59,60] or couples [57,61–63]. Some interventions have focused on carers in groups [64–69] or as individuals [46,62,70–74]. Whilst most interventions have been offered face-to-face, some have been conducted over the telephone [63] or reinforced by computer-driven sources of information and support [74].

The basis, aims and designs of interventions have varied considerably. Some interventions have been based on knowledge about factors related to adjustment difficulties. Hence, Walsh-Burke [59] and Sabo and colleagues [64] focused on the importance of support, provision of information and sought to improve open communication within families and couples, respectively.

Other investigators offered standardised interventions based on explicit psychotherapeutic models. Goldberg and Wool [70] designed a 12-session intervention for spouses of lung cancer patients. Donnelly and colleagues [63] gave interpersonal psychotherapy by telephone to patients with metastatic breast cancer who were receiving chemotherapy and their partners. Peteet and Greenberg [75] described a Circumplex Model for the assessment of intervention with couples in crisis, while Carter and Carter [62] sought to provide psychotherapeutic intervention to breast cancer patients and their husbands, individually or together. Bloch and Kissane [60] developed a model of family grief therapy for families of terminally ill patients who were considered to be at risk of maladaptive bereavement.

Many interventions have been based on models of stress and coping [76], but the interventions have varied considerably. They include, a 6-session concerns-focused, cognitive-behavioural intervention offered to partners where the patient has been diagnosed as suffering from an affective disorder as well as cancer [46]; a problem-solving intervention offered to individual spouses of newly diagnosed patients [71,72]; an education programme teaching the principles of problem-solving to groups of caregivers in 3×2 hour sessions or a one day workshop [68]; an information package, individually tailored to meet couples' needs [57], and a single training session in problem-solving techniques and a telephone follow-up for female relatives of women recently diagnosed with breast cancer [67].

Bultz and colleagues [69] acknowledged that their psycho-educational group was not based on a theoretical framework. Psychologists experienced in counselling couples developed the intervention. They identified themes and processes from the literature. Partners of breast cancer patients attended 6-weekly sessions that focused on education and support.

Some studies have targeted carers of patients with a particular cancer, treatment or disease status. Goldberg and Wool [70] offered psychotherapy to spouses of lung cancer patients, Sabo and colleagues [64] provided support groups for husbands of breast cancer patients, Feldman [61] recruited patients with prostate cancer and their families, while Horowitz and colleagues [65] focused on spouses of patients with brain tumours. Bloch and Kissane [60] intervened with families of patients receiving palliative care, while Donnelly and colleagues [63] were concerned with helping couples where the patients were receiving chemotherapy.

Many of the studies mentioned have been before and after studies in clinical settings designed to assess the effectiveness of the intervention [59,61–63,75]. They sought to demonstrate that the intervention was feasible in particular settings and acceptable to the target groups.

Some of the interventions described have still to be evaluated scientifically [46,60,68].

In studies that have used a randomised control design, psychological benefits have been modest. For example, Toseland and colleagues [71,72] offered a six-session problem-solving intervention aimed at helping spouses cope with distress. They found no benefit for the intervention group compared with the controls. Bultz and colleagues [69] ran a 6-session psycho-educational support group and no significant differences were found between the intervention and control groups. Schwartz and colleagues [67] offered two-sessions of problem-solving training to female relatives of recently diagnosed breast cancer patients. A control group received general health counselling. There was no difference in overall distress between the two groups.

Many carers involved in these trials, except in Schwartz's [67] study, were well adjusted before the intervention so there was little likelihood of showing significant psychological benefits. This may also explain high refusal and dropout rates. Distressed carers or those 'at risk' respond more positively when intervention is offered to them [46]. Even so, participation can be jeopardised when the demands of the illness or treatment make the intervention seem too demanding for carers, either physically or emotionally [46,63].

8.1. Summary

While some interventions reported have been based on sound theory, there have been difficulties with recruitment and compliance. Carers who do not feel in need of help or support tend to refuse when it is offered. Interventions designed to produce psychological benefits should target carers at high risk of high levels of distress or affective disorders and be tailored to their specific needs.

9. Conclusions

An important minority of carers of cancer patients become highly distressed, clinically depressed and anxious. There is a need, therefore, to determine how best to try to prevent these problems. The existing literature affords some useful markers for identifying carers likely to be at risk. So, carers in conflicted relationships, who have a negative view of illness-related events or the impact of the caring role on their lives are more likely to have problems, especially if they receive little support or the patient is depressed. Women and those with a history of psychological problems before the cancer are more vulnerable, as are carers of patients who are dying.

Although some important investigations have been carried out in prospective studies, correlational designs are still common and limit progress towards a clear predictive model of carers' psychological adjustment. What is still needed in the cancer literature is a model of adjustment that incorporates both intrapersonal and interpersonal risk factors and identifies the different pathways that lead to psychological problems amongst carers.

A range of interventions have been designed and evaluated, but they have commonly been offered to carers on the basis of broad commonalities without assessment of individual need, interest or circumstance. If we identify carers at risk and offer individual assessment and referral to interventions that are likely to meet their needs, carers are more likely to be interested and those who take up the offer of help are more likely to benefit.

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