

A meta-analytic investigation of the relationship between the psychological distress of cancer patients and their carers

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Abstract

The identification of factors that might affect the relationship between patients' and carers' psychological distress has received insufficient attention to date. A meta-analysis was conducted with 21 independent samples of cancer patients and their carers, to quantify the relationship and difference between respective measures of psychological distress. Correlation coefficients and standard differences were extracted from 21 studies that met pre-defined inclusion criteria. Random effects models were used. Variables that modified this relationship were examined with potential causes of heterogeneity explored. Analysis confirmed the positive association between patient and carer psychological distress ($r = 0.35$, $P < 0.0001$), and indicated that patients and carers did not experience significantly more or less psychological distress than one another ($P = 0.64$). Subgroup analysis was performed to explore potential sources of heterogeneity, and initial findings indicated a relationship between time since diagnosis and the strength of correlation between patient and carer psychological distress. The meta-analysis was limited by the large clinical and methodological variability between studies, and further systematic prospective research is required. This preliminary evidence suggests that early intervention with the patient and their carer could prevent later development of psychological distress in both members. © 2004 Elsevier Ltd. All rights reserved.

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Introduction

Cancer is increasingly recognised and conceptualised as a disease that affects all the family (Manne, 1998). A growing body of research has focused on the experience of both the individual cancer patient and their family network. The cancer diagnosis can have a ripple effect (Maughan, Heyman, & Matthews, 2002), and it has been claimed that psychological distress reverberates substantially throughout the nuclear family (Kissane, Bloch, Burns, McKenzie, & Posterino, 1994).

The crisis of cancer draws attention to the patient's needs, yet the spouse can receive little or no attention

(Hoskins, 1995). Family members have been described as co-sufferers in the battle against cancer (Bowman, Deimling, Smeglia, Sage, & Kahana, 2003). Carers have an essential role in both cancer treatment and longer-term adaptation to the disease, and hold the dual responsibility of caring for and caring about the patient (Grant, Ramcharan, McGrath, Nolan, & Keady, 1998). Carers may actively engage in emotion work with the patient, shaping their illness experience, whilst also attempting to manage their own feeling states (Thomas, Morris, & Harman, 2002).

Previous literature has reported on the prevalence of emotional distress and psychiatric morbidity experienced by both cancer patients and their carers (see Pitceathly & Maguire, 2003 for recent review). Despite the large number of studies reporting a significant

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positive relationship between carer and patient distress, some researchers have failed to replicate this effect or have found negative correlations. Similarly, example papers can be found to show that patients experience significantly higher psychological distress than their carers, the reverse phenomenon or no reliable effect in either direction.

The identification of factors that might affect the level of, and relationship between, psychological distress experienced by patients and their carers have received insufficient attention to date.

The majority of research studies have failed to demonstrate an association between the psychological distress of both cancer patients and their carers and a number of demographic variables, including age and employment status (Baider & Denour, 1999; Cassileth et al., 1985; Glasdam, Bonde-Jensen, Lindegaard-Madsen, & Rose, 1996; Northouse, 1989). Researchers have consistently argued that illness or patient variables have little influence in terms of the level of reported psychological distress—and that it is more likely the actual diagnosis of cancer than the illness severity or treatment type, that is the important factor (Ell, Nishimoto, Mantell, & Hamovitch, 1988; Glasdam et al., 1996). Goldberg, Wool, Glicksman, and Tull (1985) argued that psychological factors were more important in determining the level of a spouse's depression than the patient's physical condition. However, Cassileth et al. (1985) found the treatment status of the patient was a relevant determinant, with carers of patients undergoing palliative care reporting more distress than those undergoing active treatment or follow-up care.

There appears to be less consistency in the exploration of gender and role effects on the development of psychological distress following a cancer diagnosis. A great number of studies have found that women, regardless of role, experience greater distress than their male counterparts. It has been suggested there may be an additive effect for risk of experiencing elevated levels of psychological distress, in being both the spouse of a cancer patient and of female gender (Northouse, Mood, Templin, Mellon, & George, 2000). Yet other researchers have demonstrated female patients as being the most distressed group (Leiber, Plumb, Gerstenzang, & Holland, 1976) and that male patients tend to fair worse in comparison with male carers (Hagedoorn, Buunk, Kuijer, Wobbes, & Sanderman, 2000). The relationship between patient–carer psychological distress may be stronger amongst patient–partner pairings in comparison with patient–non-partner carers (Ell et al., 1988), and partners are often acknowledged as providing the most extensive and comprehensive care (Oberst & James, 1985).

Baider and Denour (2000) report an “unanimous agreement that the time factor with regard to the

diagnosis of cancer to the psychological assessment is not highly relevant”. However, their interpretation appeared to be based upon a limited and inconsistent set of results. Some studies have suggested that distress experienced by the carer decreases with time since diagnosis (Hoskins, 1995), whilst others have reported an increase (Ell et al., 1988). Researchers tend to report changes in distress levels in individuals over time, with less attention directed on the nature of the relationship or difference between distress levels over time.

Hence, the current study was conducted to systematically review reports of distress experienced by both cancer patients and their carers. A meta-analysis is a quantitative equivalent of a narrative literature review (Clark-Carter, 1997). This is the first meta-analysis linking patient and carer levels of psychological distress. A meta-analysis may contribute to the field by drawing together the available evidence and providing a statistical average of the strength of the relationships in question. In addition, this approach would allow a preliminary examination of variables that could modify this relationship, perhaps shedding light on potential underlying mechanisms, whilst also making suggestions for the direction of future research.

The aims of this study were to determine the correspondence between the psychological distress of cancer patients and their carers, and ascertain the nature of this relationship. The following specific questions were raised.

Research Question 1: Is there a significant positive correlation between cancer patient and carer psychological distress?

Research Question 2: Are there significant group differences in the psychological distress experienced by cancer patients and their respective carers?

Method

Selection of studies

All available published research articles on the relationship between cancer patients' and carers' psychological distress were sought after. Studies were traced by literature databases available through the John Rylands Library, University of Manchester. These databases included PSYCINFO (1974–April 2003), MEDLINE (1966–April 2003) and CANCER LIT (1975–October 2002).

The search strategy included the keywords: ‘cancer’ AND ‘psychological distress’ AND ‘patient’, plus a broad definition of carer, e.g. ‘carer’ OR ‘caregiver’ OR ‘partner’ OR ‘spouse’ OR ‘family’.

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