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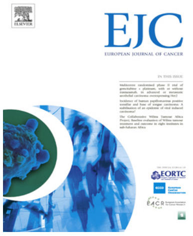

Unmet needs and depression among carers of people newly diagnosed with cancer

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Abstract ***Aims:*** The aims of this analysis were to examine levels of unmet needs and depression among carers of people newly diagnosed with cancer and to identify groups who may be at higher risk, by examining relationships with demographic characteristics.
Methods: One hundred and fifty dyads of people newly diagnosed with cancer and their carers, aged 18 years and older, were recruited from four Australian hospitals. People with cancer receiving adjuvant cancer treatment with curative intent, were eligible to participate. Carers completed the Supportive Care Needs Survey-Partners & Caregivers (SCNS-P&C45), and both carers and patients completed the Centre of Epidemiologic-Depression Scale (CES-D).
Results: Overall, 57% of carers reported at least one, 37% at least three, 31% at least five, and 15% at least 10 unmet needs; the most commonly endorsed unmet needs were in the domains of information and health care service needs. Thirty percent of carers and 36% of patients were at risk of clinical depression. A weak to moderate positive relationship was observed between unmet needs and carer depression ($r = 0.30$, $p < 0.001$). Carer levels of unmet needs were significantly associated with carer age, hospital type, treatment type, cancer type, living situation, relationship status (in both uni- and multi-factor analysis); person with cancer age and carer level of education (in unifactor analysis only); but not with carer gender or patient gender (in both uni- and multi-factor analyses).

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Conclusion: Findings highlight the importance of developing tailored programmes to systematically assist carers who are supporting patients through the early stages of cancer treatment.

1. Introduction

With an increasing incidence of cancer in western society, family members and friends have assumed responsibility for the role of informal carers providing practical and emotional support to the person with cancer [1]. Prevalence of depression among carers is significant with up to 70% experiencing depressed mood [2,3]. Previous research has focused on the assessment of unmet needs experienced by carers during the cancer survivorship phase [4–9] and at end-of-life stage [10–14]. Findings suggest higher prevalence of unmet needs in carers of palliative care patients than among those caring for patients who are in the survivorship phase [15] and a decrease in carer unmet needs throughout the survivorship phase [16].

Limited information is available on the prevalence of unmet needs in carers of persons newly diagnosed with cancer receiving treatment with curative intent. Soothill et al. [17] assessed the universal, situational, and personal needs of persons diagnosed with one of four tumour types and their carers at four different time points: early post-diagnosis, early survivorship phase, first recurrence, and at early palliative care stage. While the authors identified carer and patient specific support needs, no analysis was undertaken as to the time point during the cancer trajectory these needs occurred. Ream et al. [18] examined unmet needs in carers of persons newly diagnosed with colorectal cancer and lymphoma receiving chemotherapy. Overall, nearly 70% of carers reported one or no unmet needs and nearly one-quarter reported 5–10 unmet needs, most commonly in the information domain. This study included carers of palliative care as well as curative patients, thus it is unclear whether differences in unmet needs existed between these two carer groups. Kim et al. [19] conducted a cross-sectional study assessing unmet needs in carers of colorectal cancer patients at two months and at two and five years post-diagnosis. Results indicated that 68% of carers experienced at least one unmet need two months post-diagnosis and a decrease in unmet needs over time was observed. Finally, Nikoletti et al. [20] assessed unmet needs in carers of newly diagnosed early stage breast cancer patients receiving adjuvant chemo- or radiotherapy at two different time points post-surgery (one week, two to three weeks later). The highest ranked needs reported were health care service and communication needs and again, a decrease in unmet needs between the two assessment points was observed. Since this study focused solely on breast cancer patients and the majority of carers were male (70%), generalisation of findings to other carer groups is compromised. Similar results were found by Kilpatrick et al. [21] who examined unmet needs in 84 male carers of newly diagnosed breast cancer patients.

The literature highlights the existence of unmet needs in carers throughout the cancer trajectory, with a particular focus on end-of-life stage, survivorship phase, specific tumour sites and carer groups. Limited research has been carried out to assess unmet needs in carers of newly diagnosed persons with cancer of various types, receiving treatment with curative intent. Therefore, this study aimed to examine levels and types of unmet needs in this less well-understood group of carers and the relationship between unmet needs and depression.

2. Methods

2.1. Design

This analysis forms part of a multi-centre, randomised, controlled trial to test the efficacy and cost-effectiveness of a telephone intervention to reduce carer burden and depression in carers of persons with cancer [PROTECT study]. The PROTECT study design is described in detail elsewhere [22]. Briefly, patients and their caregivers were recruited at three Victorian health services and one South Australian health service. These hospitals are public or private with a socially diverse patient population. The sites are metropolitan and regional with large catchment areas stretching as far as the border of New South Wales and the Northern Territory. Persons with cancer attending cycles’ 2–5 of adjuvant chemotherapy or fraction 2–10 for radiotherapy [approx. 2-months post-diagnosis, determined in pilot work to be the optimal time to approach prospective participants] and receiving treatment with curative intent, together with their carers, were recruited into the study. Each dyad was given a brief introduction to the study and initial consent was sought from both individuals for a researcher to contact them. Consenting dyads were asked to complete the consent form and baseline questionnaires and post them back to the researchers. Ethics approval was obtained from Deakin University Human Research Ethics Committee: 2012-083. The PROTECT study is registered with the Australian New Zealand Clinical Trial Registry: ACTRN12613000731796.