

Illness perceptions among carer–survivor dyads are related to psychological distress among Oesophageal cancer survivors

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Abstract

Objective: To examine the extent to which the illness perceptions of Oesophageal cancer survivors and the illness perceptions of their carers explain the survivors' levels of psychological distress (in terms of anxiety and depression symptoms) relative to demographic and biomedical variables and patients' coping strategies. **Method:** Everyone registered with the Oesophageal Patients' Association in the UK was mailed a questionnaire booklet containing questions about medical and demographic variables, the Illness Perception Questionnaire-Revised, the Cancer Coping Questionnaire, and the Hospital Anxiety and Depression Scale. Patients were asked to pass a modified version of the Illness Perception Questionnaire-Revised to someone they identified as a carer. Complete responses were received from 317 dyads. **Results:** Regression models indicated that the variables measured could explain 56% of the variance in

anxiety and 54% of the variance in depression. Patients' illness perceptions explained the majority of this variance. Positive focus coping strategies were also found to be important in explaining psychological well-being. Some of the carers' illness perceptions made a significant contribution to the explanation of the patients' levels of psychological distress, and in some instances, carer perceptions were found to moderate the relationship between patients' perceptions and psychological distress. **Conclusion:** The findings suggest that cognition-based interventions could potentially be most effective in minimizing emotional distress among survivors of Oesophageal cancer. This study also shows that these interventions could usefully be delivered at the level of the patient–carer dyad.

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Introduction

In order to develop effective interventions to address psychological distress among people diagnosed with cancer, it is important that we understand the types of cognitions that are associated with higher levels of distress among this population. Research (particularly focused on women with breast cancer) indicates that anxiety and depression is

associated with the type of coping strategies adopted and the person's perceptions of their cancer [1–4]. Consequently, Leventhal's Self-Regulatory Model (SRM) [5] may be a useful approach to clarifying the interrelationships among these cognitive and emotional constructs.

Leventhal's SRM suggests that when an individual is confronted with an illness or condition, they will attempt to assign meaning to this illness by accessing their perceptions about the illness. These illness perceptions will be influenced by the individual's emotional state and their emotional state will be influenced by their perceptions of the illness. The SRM proposes that, in an effort to restore normal functioning, individuals will develop coping

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strategies (based on their illness perceptions and emotional state), which will then be evaluated in terms of their success in restoring equilibrium. The result of this evaluation may be a change in coping strategy and/or a change in perceptions about the illness. In summary, the model suggests that a person's perceptions about an illness and their coping strategies can have an impact on their psychological well-being.

Research using quantitative methodologies has tended to focus on the illness perceptions component of the model and there is a growing body of research demonstrating strong relationships between illness perceptions and (physical and psychological) health outcomes [6]. Illness perceptions, as assessed by the Illness Perception Questionnaire-Revised [7], are mental representations of illness by the individual within various domains: time line (acute/chronic), time line (cyclical), personal control, treatment control, consequences, cause, and illness coherence.

Illness perceptions have been shown to explain a significant proportion of the variance in psychological distress in head and neck cancer [8,9] and in breast cancer [10], even after controlling for disease-related variables. However, the nature of the relationships between illness perceptions and psychological distress differ between the different types of cancer. This clearly suggests that the factors which may impact on psychological health are specific to the type of cancer of interest. However, no published research has examined the relationship between illness perceptions and psychological health among survivors of Oesophageal cancer. The present study will address this gap.

Furthermore, previous research suggests that the levels of psychological distress experienced by people with chronic illness can also be affected by the illness perceptions of family carers [11–13]. This previous research indicates that in some situations, incongruence in couples' perceptions is detrimental to psychological health. For example, the mood of women with breast cancer is affected detrimentally when their assessment of their adjustment to breast cancer is incongruent with their husband's assessment [13] and the incongruence of perceptions of controllability over infertility between a woman and her partner has been shown to be related to distress [11]. Yet, in other situations, incongruence appears to be a positive outcome. For example, people with eating disorder who did not agree with the illness perceptions expressed by their relatives were less distressed than those who agreed with their relative's perceptions of eating disorder [12]. Again, therefore, the effect of the illness perceptions held by the carer on the distress experienced by the patient may be condition-specific.

In summary, previous research indicates that illness perceptions are useful in explaining the levels of psychological distress experienced by people with chronic illness and that the illness perceptions held by their carers might also impact on these levels of distress. However, given the condition-specific nature of these relationships, it is

important to investigate the nature and extent of these relationships within the Oesophageal cancer population. Therefore, the specific research questions which will be addressed are:

1. To what extent do the illness perceptions of Oesophageal cancer survivors and the illness perceptions of their carers explain psychological distress (in terms of anxiety and depression symptoms), relative to demographic and biomedical variables, among these survivors of Oesophageal cancer?
2. To what extent do the survivors' coping strategies influence or mediate these relationship between illness perceptions and psychological distress?

Method

Participants were recruited via the Oesophageal Patients' Association (OPA) UK database. The OPA is a support group formed to help patients and their families cope with the difficulties arising from the treatment associated with Oesophageal cancer. Cancer survivors on the database were mailed a questionnaire booklet containing items relating to demographic information (sex, age and whether there was someone in their life who they would label a "carer"), medical history (time since diagnosis, number of comorbidities, number of symptoms experienced during the previous month that were considered to be related to Oesophageal cancer) and the following questionnaires:

The Hospital Anxiety and Depression Scale (HADS) [14]. This is a 14 item scale which is divided into two dimensions—*anxiety* (seven items) and *depression* (seven items). Respondents choose one from four responses to each item. Their responses are then summed within dimensions and a total score for each dimension is obtained, with higher scores representing higher levels of anxiety and depression. Scores for the anxiety dimension and the depression dimension can be categorised as follows: 0–7, normal; 8–10, mild; 11–14, moderate; 15–21, severe. The HADS has been validated among a population of people with cancer [15] and is the most frequently used screening tool for psychological distress in cancer care [16].

The Cancer Coping Questionnaire (CCQ) [17]. This is a 21-item questionnaire which assesses five dimensions: reflection/relaxation coping, positive focus, diversion, planning and use of interpersonal support. Higher scores on each scale indicate that this coping strategy is used more often. Psychometric properties are sound [17].

Illness Perception Questionnaire-Revised (IPQ-R) [7]. This questionnaire was used to assess the following illness cognitions: time line acute/chronic, time line cyclical, personal control, treatment control, consequences, cause, and illness coherence. Higher scores on the personal control and treatment control scales indicate that the person has a stronger belief in the effectiveness of their

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