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Do Changes in Illness Perceptions Predict Changes in Psychological Distress among
Oesophageal Cancer Survivors?

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Abstract

This study aimed to examine whether changes in the illness perceptions of oesophageal cancer survivors explain changes in their levels of psychological distress relative to demographic and biomedical variables and coping strategies. Oesophageal cancer survivors completed the Illness Perception Questionnaire-Revised, the Cancer Coping Questionnaire and the Hospital Anxiety and Depression Scale at 2 points in time, 12 months apart. Cluster analysis was used to identify groups of respondents who reported a similar profile of change in their illness perception scores over time. Findings suggested that enhancing control cognitions and encouraging a positive focus coping strategy may be important in improving psychological health.

Keywords:

Cancer; oesophagus; depression; anxiety; illness perceptions

Do Changes in Illness Perceptions Predict Changes in Psychological Distress among Oesophageal Cancer Survivors?

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. Previous research indicates that Leventhal's Self-Regulatory Model (Leventhal, Meyer, & Nerenz, 1980) may be a useful approach to clarifying the interrelationships among these cognitive and emotional constructs (Llewellyn, McGurk, & Weinman, 2007; Miller, Purshotham, McLatchie, George, & Murray, 2005; Rozema, Völlnick, & Lechner, 2009; Scharloo et al., 2005; Traeger et al., 2009).

Leventhal's Self-Regulatory Model (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 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.

There is a growing body of research demonstrating strong relationships between the illness perceptions component of this model and (physical and psychological) health outcomes (Cameron & Moss-Morris, 2004). For example, illness perceptions have been shown to explain a significant proportion of the variance in psychological distress in head and neck cancer (Llewellyn et al. 2007; Scharloo et al., 2005), in breast cancer (Miller et al.,

2005), in prostate cancer (Traeger et al., 2009) and in a range of other chronic illnesses (eg. Cartwright, Endean, & Porter, 2009; Dorrian, Dempster, & Adair, 2009; Evans & Norman, 2009), even after controlling for disease-related variables.

Most of the research conducted in this area has used a cross-sectional design. The information provided in these studies is useful to indicate the types of illness perceptions and coping strategies that are associated with psychological distress, but stronger evidence is required to indicate that an intervention based on illness perceptions would be likely to change levels of psychological distress. Therefore, longitudinal data is required to examine how any changes in illness perceptions are related to any changes in psychological distress.

The production of longitudinal research in the area has mostly been a recent development. Stafford, Berk, & Jackson (2009) demonstrate that beliefs about the consequences of coronary artery disease are related to depressive symptomatology 6 months later but not to changes in depression over the 6 month period; and Skinner et al. (2006) showed that perceptions of coherence, chronicity, control and consequences of Type 2 diabetes were associated with some quality of life outcomes 3 months later. In the area of cancer, Llewellyn et al. (2007) demonstrate that beliefs about the chronicity of head and neck cancer are related to depressive symptoms 6-8 months later, but not to symptoms of anxiety or assessments of quality of life. On the basis of these studies, there is no clear pattern of relationships between illness perceptions and health outcomes over time. The lack of consensus may be a result of the different populations in which the research was conducted and it may be the case that the nature of the longitudinal relationship between illness perceptions and health outcomes is specific to the population under investigation.

In addition, none of these longitudinal studies address the question of whether changes in illness perceptions are likely to lead to changes in health outcomes. Rather, they all focus on the ability of illness perceptions at one point in time to predict health outcomes at

a later point in time. The need for an intervention to improve health outcomes based on illness perceptions would be further strengthened if research demonstrated that these health outcomes changed in line with changes in illness perceptions.

Foster et al. (2008) examined factors that predicted changes (over 6 months) in assessments of disability among people with low back pain and showed that changes in beliefs about consequences, control and emotional representations of low back pain were significant predictors. In a more recent and longer term study, Bijsterbosch et al. (2009) have demonstrated that changes in beliefs about consequences, chronicity, control, coherence and emotional representations of osteoarthritis are related to changes in levels of disability over a 6 year period. The relationship between changes in illness perceptions and changes in other measures of physical functioning among this sample of people with osteoarthritis was confirmed by Kaptein et al. (2010). These are important studies which provide a real impetus for the development of illness perception based interventions to improve physical functioning, at least within these populations.

Nevertheless, there is no published research which has examined the relationship between changes in illness perceptions and changes in psychological health outcomes. The present study aims to address that gap.

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, medical history (time since diagnosis and number of comorbidities) and the following questionnaires:

The Hospital Anxiety and Depression Scale (HADS) (Snaith & Zigmond, 1983). This is a 14 item scale which is divided into two dimensions – anxiety (7 items) and depression (7 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 (Smith et al., 2002) and is the most frequently used screening tool for psychological distress in cancer care (Reuter & Härter, 2001). A review of the optimal cut-off values for the HADS indicates that a score of 8 or more should be used to provide an appropriate balance of sensitivity and specificity (approximately 0.8 in each case), when assessed against the structured clinical interview based on the DSM criteria (Bjelland et al., 2002).

The Cancer Coping Questionnaire (CCQ) (Moorey, Frampton, & Greer, 2003). This is a 21 item questionnaire which assesses 5 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 (Moorey et al., 2003).

Illness Perception Questionnaire – Revised (IPQ-R) (Moss-Morris et al., 2002). This questionnaire was used to assess the following illness cognitions: identity, timeline acute/chronic, timeline cyclical, personal control, treatment control, consequences, cause and illness coherence. The identity scale addresses symptoms that describe the condition. Higher scores on the personal control and treatment control scales indicate that the person has a stronger belief in the effectiveness of their ability or the treatment to control the symptoms of oesophageal cancer; higher scores on the consequences scale suggests that the person perceives more severe consequences of oesophageal cancer; higher scores on the illness

coherence scale indicates that the person has a clearer understanding of the condition; higher scores on the timeline acute/chronic and timeline cyclical scales indicate a stronger belief that the condition is chronic (rather than acute) and goes through cycles of getting better and worse rather than remaining stable. The 18 items which measure the perceptions of the causes of oesophageal cancer were factor analysed (in line with the questionnaire authors' suggestion) and were found to load on 3 factors, which were labelled emotional causes (e.g. stress or worry), behavioural causes (e.g. smoking or alcohol) and externalised causes (e.g. hereditary or a virus). Higher scores on the cause scales indicate a stronger belief that this was a cause of the oesophageal cancer. The IPQ-R has sound psychometric properties, with evidence for construct, discriminant and predictive validity and for internal and test-retest reliability (Moss-Morris et al., 2002).

All respondents were mailed the same questionnaires approximately 1 year later.

The research was approved by the University Ethics Committee.

Statistical analysis

Changes in the IPQ-R, CCQ and HADS scales were calculated by subtracting the score at the second time point from the score at the first time point. Consequently, a negative change score represents an increase in scores on the scale over time and a positive change score indicates a decrease in scores on the scale over time.

Following the method suggested by Clatworthy, Hankins, Buick, Weinman, & Horne (2007) and applied to the analysis of change scores by Kaptein et al. (2010), change scores in illness perceptions were subjected to cluster analysis, which provides an indication of people who share a similar illness representation schema. A 2 stage cluster analysis was conducted. Initially, all change scores were converted to Z scores and Ward's clustering method was used to identify the number of clusters. A k-means analysis was then conducted using the number of clusters and the centroids identified by Ward's method. The squared Euclidean

distance was the proximity measure chosen. On the basis of the dendrogram and the agglomeration schedule, 4 clusters was considered to be the optimum solution.

To examine the relationship between changes in illness perceptions and changes in outcomes, we conducted separate hierarchical regression analyses for the change in each outcome variable (anxiety and depression), with demographic and medical details, cluster membership, and changes in coping scores entered as separate blocks. As there were 4 clusters identified, these were included in the regression analyses as 3 dummy variables, with cluster 1 as the reference category.

Results

A total of 189 oesophageal cancer survivors provided complete data on all the questionnaires at both points in time. Respondents were, on average, 64.8 years old ($SD = 8.83$), approximately 74% (140/189) were male and they had been diagnosed with oesophageal cancer for a median time of 48 months prior to completing the questionnaire. All participants had been diagnosed with early stage oesophageal cancer and, consequently, had undergone surgery to remove the cancer from their oesophagus.

Descriptive statistics for change in all scales between the 2 points in time are presented in Table 1. Most notable, in Table 1, is the change on the scores on the HADS scales, with a significant and very large change reported on both the anxiety and depression scales. When we examine these scores using the cut-off point suggested by Bjelland et al. (2002) to classify respondents into probable anxiety or not and probable depression or not, we find that 45% of respondents (85/189) reported no change in anxiety status across time, with the remaining 55% (104/189) moving from the no anxiety to anxiety category over time. In the case of depression scores, 24% (46/189) remained steady over time, whereas 76% (143/189) reported a deterioration. No-one reported an improvement in anxiety or depression over time, in terms of these categories.

- Table 1 here -

Table 2 provides the centroids for the 4 clusters identified in the cluster analysis for change in illness perception variables. The centroids suggest that respondents in cluster 1 have more positive cognitions over time and respondents in cluster 2 have a stronger belief in personal control but less belief in treatment control over time. The people in cluster 2 also demonstrated an increase in the strength of their belief that their condition was chronic rather than acute, and express a slightly stronger belief in emotional or externalised causes for their oesophageal cancer. Cluster 3 is characterised by generally more negative cognitions over time, and cluster 4 appears to group respondents together who have increased their belief that their condition is cyclical, they have less understanding of their condition and report experiencing more symptoms over time.

- Table 2 here -

The covariates in the regression model specified in Table 3 explained a total of 12% of the variance in change in anxiety ($F(12,176) = 2.056, p = .022$). The 12% of the variance in change in anxiety explained by the model is allocated among the separate blocks of variables as follows. The block containing the medical and demographic variables explained 5% of the variance in change in anxiety; the illness cognitions clusters explained an additional 3% of the variance in change in anxiety; and the coping variables explained an additional 4% of the variance in change in anxiety scores.

- Table 3 here -

The regression model specified in Table 4 explained a total of 11% of the variance in change in depression ($F(12,176) = 1.776, p = .055$). The medical and demographic variables explained 1% of the variance in change in depression scores; the illness cognitions clusters explained an additional 4% of the variance in change in depression scores; and the coping variables explained a further 6% of the variance in change in depression scores.

- Table 4 here -

Tables 3 and 4 indicate that the anxiety and depression levels of those in cluster 3 increase significantly more over time than those in cluster 1. Furthermore, an increase in the use of interpersonal interaction as a coping strategy is significantly associated with an increase in anxiety levels and an increase in the use of reflection/relaxation as a coping strategy is significantly associated with an increase in depression levels. Depression levels decrease significantly over time when a positive focus coping strategy is adopted.

Discussion

The research presented here indicates that oesophageal cancer survivors experience levels of symptoms of anxiety and depression similar to that reported for people with other head and neck cancers (Hodges & Humphris, 2009; Llewellyn et al., 2007) but higher than rates reported for other breast, prostate, bronchial and gastrointestinal cancers (Frick, Tyroller, & Panzer, 2007; Nordin & Glimelius, 1999). It is possible that the higher rates of psychological distress can be explained by the consequences of oesophageal and head and neck cancer, which have a potential impact on appearance and social functioning (McCorry, Dempster, Clarke, & Doyle, 2009).

Disconcertingly, symptoms of anxiety and depression increased significantly within the sample over the 12 month period of the study, with the majority of the sample becoming anxious or depressed during this time. Regression analyses were conducted in an attempt to explain why this deterioration in psychological health occurred. The regression models were guided by Leventhal's Self-Regulatory Model, which suggests that illness perceptions and coping would help to explain health-related outcomes. We found that changes in the illness perceptions and coping variables explained 10% of the variance in the change in symptoms of depression and 7% of the variance in the change in symptoms of anxiety, after accounting for sex, age, number of other medical conditions and number of months since diagnosis of

oesophageal cancer. Although the change in the illness perception and coping variables explained more of the variance in change in psychological well-being than the demographic and medical variables, a considerable proportion of the variance in the change in anxiety and depression scores remains unexplained.

Nevertheless, the illness perception clusters provided one of the few statistically significant contributions to the regression models. Four distinct patterns of change in illness perceptions were identified. Cluster 1 appears to describe a group of survivors who develop more positive cognitions over time and tend to have decreased scores on the personal control scale. Cluster 2 groups together survivors who increasingly engage in self-blame for the cause of the oesophageal cancer and who increasingly believe that treatment provided by health professionals is unlikely to cure or control their condition. However, this group also have a reduced belief in the likelihood of severe consequences from their condition and have an increased belief in their own ability to control their condition. The third cluster represents a group of survivors who report reduced belief in the ability of the treatment or in their own ability to control the condition and report an increase in the likelihood of severe consequences from their condition. Finally, respondents in cluster 4 tend to believe more strongly that their condition is cyclical and report poorer understanding of their condition over time. Yet, their perception of treatment control and personal control strengthens over time. In summary, we might label these clusters as follows: cluster 1 represents a group with an increasing external locus of control and a positive perception of the consequences of their condition; cluster 2 represents a group with an increasing internal locus of control and a positive perception of the consequences of their condition; cluster 3 represents an increasingly helpless/hopeless group; and cluster 4 represents a group of survivors who increasingly find their condition confusing but are hopeful that it can be controlled.

The regression analyses suggest that oesophageal cancer survivors in cluster 3 are more likely to become anxious and depressed than the other cancer survivors. The key difference between those in cluster 3 and those in other clusters is that the respondents in cluster 3 report a decrease in their belief that either they can control their condition or that the treatment from health professionals can control their condition. For some clusters, the locus of control changes over time and this does not appear to be particularly detrimental to psychological health but increasingly believing that the condition cannot be controlled has an adverse effect. Intuitively this makes sense and lends support to the clustering approach. Indeed, control cognitions were highlighted as the important element in the relationship between illness perception clusters and functional status among people with osteoarthritis, in the only other published longitudinal research which has used the clustering approach (Kaptein et al., 2010).

In addition, it appears that changes in coping strategies are also associated with changes in psychological well-being. Specifically, survivors who increasingly engaged in interpersonal interaction as a coping strategy experienced an increase in their level of anxiety over time and increases in reflection/relaxation as a coping strategy were associated with increases in depression over time. However, increasing the use of positive focus as a coping strategy was the strongest predictor (within the model examined) of a decrease in depression over time.

In summary, enhancing control beliefs among oesophageal cancer survivors and encouraging a more positive focus type of coping strategy could be important elements of an intervention to improve psychological well-being. Nevertheless, caution is warranted in the interpretation of these findings, given the low proportion of variance in changes in psychological well-being which was explained by the models. On the basis of these results, it could be argued that illness perceptions contribute little to our explanation of psychological

well-being among oesophageal cancer survivors and, therefore, would not be a sound basis for an intervention. A counter argument is that this study demonstrates only a weak relationship between illness perceptions and deterioration in psychological health and this has been achieved even though there is relatively little variation in the illness perceptions over time. This does not obviate the possibility that changes in illness perceptions in a desired direction may result in positive changes in psychological health, as this relationship has not been tested in the current study. Furthermore, previous research which has evaluated interventions designed to modify illness perceptions has shown improvements in health-related outcomes among people who have experienced a myocardial infarction (Broadbent, Ellis, Thomas, Gamble, & Petrie, 2009) and among those with Type 2 diabetes (Skinner et al., 2006). However, the effectiveness of illness perception based interventions in the improvement of psychological well-being among cancer survivors has not yet been demonstrated. Given that the majority of oesophageal cancer survivors in our sample experienced a deterioration in their psychological health over time, this evidence is required urgently.

It should also be noted that the findings of the present study are limited because they are based on oesophageal cancer survivors who had registered with a patient support group (the Oesophageal Patients' Association). It is possible that patients involved with a support group may differ from other patients in terms of the psychological constructs assessed. However, the sample in the present study had similar scores on an assessment of psychological health when compared with survivors of other head and neck cancers (Hodges & Humphris, 2009; Llewellyn et al., 2007).

In conclusion, the present study has shown that changes in illness perceptions are related to changes in psychological well-being over time. From this limited evidence, it appears that increasing control beliefs could be an important element of an illness perception

based intervention which aims to improve the psychological health of oesophageal cancer survivors.

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Table 1: Change Over Time

	Potential Midpoint	Time 1 Mean (SD)	Time 2 Mean (SD)	t	p
HADS Anxiety	10.5	6.17 (4.62)	13.40 (4.70)	32.783	<.001
HADS Depression	10.5	4.50 (3.66)	11.64 (3.65)	41.455	<.001
CCQ Reflection/relaxation	12.5	9.18 (3.12)	9.21 (3.01)	0.154	.878
CCQ Positive focus	7.5	7.94 (2.19)	7.84 (2.15)	0.667	.506
CCQ Diversion	7.5	6.41 (2.13)	6.43 (2.12)	0.118	.906
CCQ Planning	7.5	7.39 (2.45)	7.25 (2.43)	0.870	.385
CCQ Interpersonal	17.5	14.05 (5.46)	13.58 (5.07)	1.493	.137
IPQ Acute/chronic timeline	18	23.25 (4.33)	23.81 (4.23)	1.937	.054
IPQ Cyclical timeline	14	12.09 (3.61)	12.36 (3.65)	1.031	.304
IPQ Treatment control	15	17.03 (3.54)	16.26 (3.43)	2.800	.006
IPQ Emotional cause	15	11.77 (3.71)	12.06 (3.34)	1.336	.183
IPQ Behavioural cause	12	10.25 (3.69)	10.21 (3.61)	0.218	.828
IPQ Externalised cause	12	14.86 (3.46)	14.79 (3.15)	0.293	.770
IPQ Consequences	18	20.72 (4.60)	20.12 (4.78)	2.151	.033
IPQ Personal control	18	20.14 (4.78)	19.75 (4.63)	1.122	.263
IPQ Illness coherence	15	19.40 (3.89)	19.24 (3.58)	0.617	.538
IPQ Identity	7.5	7.39 (3.09)	5.57 (3.28)	7.900	<.001

Table 2: Cluster Centroids for Changes in Illness Perceptions Clusters

	Cluster 1 (n=57)	Cluster 2 (n=53)	Cluster 3 (n=44)	Cluster 4 (n=35)
	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)
IPQ Acute/chronic timeline	2.16 (3.70)	-1.26 (2.60)	-3.52 (4.16)	-0.20 (2.86)
IPQ Cyclical timeline	1.16 (2.96)	1.38 (2.63)	-0.91 (3.31)	-4.29 (2.82)
IPQ Treatment control	-1.21 (3.22)	2.07 (2.87)	3.12 (3.91)	-0.94 (3.17)
IPQ Emotional cause	0.53 (3.16)	-0.64 (2.86)	0.25 (2.63)	1.77 (2.81)
IPQ Behavioural cause	0.98 (2.52)	0.06 (2.13)	-0.09 (1.64)	-1.37 (2.41)
IPQ Externalised cause	1.77 (2.68)	-0.47 (2.22)	0.23 (2.79)	-2.11 (3.08)
IPQ Consequences	2.05 (3.26)	2.11 (2.93)	-2.05 (3.18)	-0.71 (4.56)
IPQ Personal control	1.81 (3.53)	-2.17 (2.53)	4.50 (4.54)	-3.20 (4.53)
IPQ Illness coherence	-1.30 (3.21)	-0.57 (2.89)	1.39 (4.22)	2.11 (3.38)
IPQ Identity	2.25 (3.18)	3.19 (2.97)	1.18 (2.69)	-0.14 (2.90)

Table 3: Regression Analysis with Change in Symptoms of Anxiety as the Outcome Variable

	Unstandardised Regression Coefficient	t	p	Standardised Regression Coefficient
Sex	.767	1.476	.142	.111
Age	-.044	-1.684	.094	-.128
Number of other conditions	.596	1.333	.184	.098
Number of months since diagnosis	.008	1.768	.079	.135
IPQ-R Cluster 2 vs IPQ-R Cluster 1	-.988	-1.729	.086	-.147
IPQ-R Cluster 3 vs IPQ-R Cluster 1	-1.312	-2.133	.034	-.183
IPQ-R Cluster 4 vs IPQ-R Cluster 1	-.822	-1.268	.206	-.106
CCQ Change in Reflection/Relaxation	.064	.666	.507	.058
CCQ Change in Positive Focus	-.154	-1.448	.149	-.113
CCQ Change in Diversion	.034	.276	.783	.024
CCQ Change in Planning	-.006	-.080	.936	-.006
CCQ Change in Interpersonal	.115	2.081	.039	.171
Constant	-4.694	-2.884	.004	

Table 4: Regression Analysis with Change in Symptoms of Depression as the Outcome

Variable	Unstandardised Regression Coefficient	t	p	Standardised Regression Coefficient
Sex	-.067	-.164	.870	-.012
Age	-.014	-.681	.497	-.052
Number of other conditions	.253	.718	.474	.053
Number of months since diagnosis	.003	.781	.436	.060
IPQ-R Cluster 2 vs IPQ-R Cluster 1	-.212	-.471	.638	-.040
IPQ-R Cluster 3 vs IPQ-R Cluster 1	-1.070	-2.208	.029	-.191
IPQ-R Cluster 4 vs IPQ-R Cluster 1	-.286	-.561	.576	-.047
CCQ Change in Reflection/Relaxation	.154	2.046	.042	.179
CCQ Change in Positive Focus	-.253	-3.023	.003	-.238
CCQ Change in Diversion	-.016	-.163	.871	-.014
CCQ Change in Planning	.071	1.232	.220	.094
CCQ Change in Interpersonal	.003	.076	.939	.006
Constant	-6.156	-4.801	<.001	