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Illness representations and psychological distress in Indian cancer patients:

Does being aware of one's cancer diagnosis make a difference?

Running head: Illness perceptions in Indian cancer patients

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Illness representations and psychological distress in Indian cancer patients: Does being aware of one's cancer diagnosis make a difference?

Abstract

Objectives. This study applied the Common Sense Model (CSM) of illness representations to understand the psychological reactions of Indian cancer patients who report being aware or unaware of their cancer diagnosis. *Methods.* Adult Indian cancer patients ($N = 329$) were asked about their understanding of their illness (to assess awareness of a cancer diagnosis), and then completed the Brief Illness Perception Questionnaire and the Hospital Anxiety Depression Scale. *Results.* Patients who reported being unaware of their cancer diagnosis (54.1%) experienced higher levels of anxiety and depression. After controlling for awareness, education, income, cancer symptoms and cancer stage, illness perceptions accounted for significant amounts of variance in anxiety ($\Delta R^2 = .42$) and depression ($\Delta R^2 = .33$). Illness coherence mediated the relationship between awareness of a cancer diagnosis and anxiety. Moderated regression analyses indicated that several relationships between illness perceptions and anxiety/depression were stronger among patients who reported being unaware of their cancer diagnosis. *Conclusions.* The CSM provides a useful framework for explaining the psychological reactions of Indian cancer patients to their illness, particularly for those who report being unaware of their cancer diagnosis.

Keywords. Cancer; Oncology, Disclosure; Anxiety; Depression.

Introduction

There are large variations in psychological distress in patients with chronic illnesses, such as cancer, that are not fully explained by clinical factors (e.g., disease severity) alone [1]. Instead, the way in which patients interpret and respond to their illness is more closely associated with levels of psychological distress [2]. The Common Sense Model (CSM) of illness representations [3] provides a comprehensive account of the processes through which individuals respond to health threats. Central to the CSM are individuals' illness representations of the health threat that are based on general "lay" information that the individual has about their illness, information that is provided to them from others (e.g., family members, doctors) and their own experiences of the illness (e.g., symptoms). These representations are based around five core dimensions (i.e., identity, cause, consequences, timeline, cure/control) [4], although more recent work has also considered patients' understanding (i.e., coherence), concern, and emotional representations about their illness [5].

The CSM has been applied extensively to examine associations between patients' illness representations and psychological distress [6], including a small number of studies on cancer. These have found that identity (i.e., attributing symptoms to the illness) and emotional representations (about the emotional impact of the illness) are consistently associated with measures of psychological distress [1, 7-12], although studies have also reported significant associations for timeline (i.e., perceived duration of the illness) [10,13], treatment control (i.e., perceived efficacy of the treatment to control and/or cure the illness) [11] and coherence (i.e., perceived understanding of the illness) [14].

To date, there have been no applications of the CSM to examine psychological distress in cancer patients in Asia. Yet, Asian cultures provide an interesting context in which to test the CSM given that there are strong cultural influences upon medical decision-making and cancer diagnosis disclosure practices [15]. In Western cultures, patient autonomy and

choice are central to medical practice and patients are routinely informed of their cancer diagnosis [16]. In contrast, in Asian cultures, a family-centred model of medical decision-making is followed, typically without the input of the patient [17]. Often, family members decide not to inform the patient of their cancer diagnosis. Cancer non-disclosure rates of between 33-61% have been reported in Asia [18,19] and there is some evidence that patients who report being unaware of their cancer diagnosis have higher levels of psychological distress [20,21].

Illness representations may help explain levels of psychological distress in cancer patients who report being aware versus unaware of their cancer diagnosis. In an earlier paper based on the current dataset [20], patients in India who reported being unaware of their cancer diagnosis had more negative illness perceptions and higher levels of anxiety and depression than those who were aware of their cancer diagnosis. However, the study did not examine associations between illness representations and psychological distress. In addition, illness representations may mediate associations between reported awareness of a cancer diagnosis and psychological distress, as patients' knowledge of their diagnosis may be an important source of information when forming representations of their illness which, in turn, may be related to psychological distress. Moreover, awareness of a cancer diagnosis may moderate relationships between illness representations and psychological distress given that patients who are aware of their cancer diagnosis have a clear health threat to respond to, whereas patients who are unaware of their cancer diagnosis may have been given a less severe explanation for their symptoms (e.g., lump, fever) [22] that may not fit with their illness experience.

The present study examined associations between illness representations and psychological distress (i.e., anxiety, depression) in a sample of Indian cancer patients who report being aware or unaware of their cancer diagnosis. The study also examined whether

patients' illness representations mediate associations between awareness of a cancer diagnosis and psychological distress, and whether awareness of a cancer diagnosis moderates associations between illness representations and psychological distress.

Method

Participants and Procedure

Potential participants were adult cancer patients at the Indo-American Cancer Hospital and Research Centre (IACH&RC) in Hyderabad, India, who were recruited using opportunity sampling. Patients were excluded if they were over 75 years, unable to speak English, Hindi or Telugu, or had a psychiatric condition (as indicated by hospital staff). Potential participants were first approached by hospital staff during a hospital appointment and were then introduced to the researcher if they expressed an interest in participating. After obtaining informed consent (orally, if participants were illiterate (n = 182)), the researcher administered the questionnaires orally in English, Hindi or Telugu in a private setting, using response cards as necessary. All measures underwent forward and back translations. Ethical approval was obtained from the Research Ethics Committee at the University of Sheffield. Approval for the study was also granted by IACH&RC. The study employed a cross-sectional design.

Measures

Awareness of a cancer diagnosis. Participants were asked a range of questions to assess their awareness of a cancer diagnosis, similar to those used in previous studies [12-14]. Thus, participants were asked about their physical problem, their illness, why they had been admitted to hospital, their treatment, and what their family and doctor had told them about their illness. Patients who used the word "cancer" in response to any of these questions were classified as being aware of their cancer diagnosis, whereas those who did not were classified as being unaware of their cancer diagnosis.

Brief Illness Perception Questionnaire (BIPQ) [24]. Illness perceptions were assessed using the BIPQ, a brief version of the Illness Perception Questionnaire-Revised [5], which comprises 8 items, rated on 0-10 response scales, assessing perceptions of illness identity, consequences, timeline, personal control, treatment control, concern, emotional representation, and coherence. The items were scored so that high scores reflected high values on the variable of interest. An open-ended question also asks participants to list possible causes of their illness. Responses to this question were coded 0 if respondents failed to cite a cause and 1 if a cause was cited. All items were asked in relation to “your illness”. The BIPQ has been reported to correlate strongly with the IPQ-R, have good test-retest reliability, and good construct, discriminant and predictive validity [24]. The BIPQ has been used with a range of patient samples in Asia [25,26].

Hospital Anxiety and Depression Scale (HADS) [27]. Anxiety and depression were assessed using the 14-item HADS. Responses are made on 4-point response scales ranging from 0 to 3, and summed to provide two sub-scale scores for anxiety and depression. The HADS has been used in previous studies of Indian cancer patients [28,29]. The anxiety ($\alpha = .91$) and depression ($\alpha = .90$) sub-scales had excellent internal reliability in the present study.

Demographic and medical information. The questionnaire contained questions on participants’ age, gender, marital status, number of children, religious affiliation, level of education, and household income. Participants also completed the Modified Rotterdam Symptom Checklist (RSCL-M) [30] which comprises 28 cancer-related symptoms rated on 4-point response scales that are summed. The RSCL-M had satisfactory internal reliability in the present study ($\alpha = .79$). Information on cancer site, cancer stage, and treatment were obtained from patients’ medical records.

Results

Descriptive findings

Of the 356 patients approached, 19 declined to participate and eight were excluded. The final sample comprised 329 patients, of whom 151 (45.9%) reported that they were aware of their cancer diagnosis and 178 (54.1%) gave responses that suggested that they were unaware. The majority of the sample was female ($n = 204$, 62.0%), married ($n = 264$, 80.2%), and Hindu ($n = 289$, 87.8%). Just over half the sample had been educated to at least 10th grade ($n = 178$, 54.1%) and the mean monthly income was 16,820 Rupees ($SD = 42,379$), approximately \$300. The most common cancers in the sample were breast ($n = 84$, 25.5%), ovarian ($n = 28$, 8.5%), and stomach ($n = 25$, 7.6%). The sample consisted of 49 (14.9%) patients with stage 1 cancer, 146 (44.4%) with stage 2 cancer, 94 (28.6%) with stage 3 cancer, and 40 (12.2%) with stage 4 cancer. Patients had been in treatment for a mean of 8.94 months ($SD = 17.18$). Their mean score on the Rotterdam Symptom Checklist was 42.02 ($SD = 9.56$).

Bivariate analyses

With the exception of perceived cause, all of the illness representation dimensions were associated with both anxiety and depression (see Table I). Awareness of a cancer diagnosis was associated with anxiety, $t(327) = 3.47$, $p = .001$, and depression, $t(327) = 2.81$, $p = .005$, such that those who reported that they were unaware of their cancer diagnosis had higher levels of anxiety ($M_s = 6.47$ vs 4.26) and depression ($M_s = 6.84$ vs 5.05) than those who reported being aware of their cancer diagnosis. Patients who had been educated to at least 10th grade had lower levels of anxiety ($M_s = 4.44$ vs 6.65), $t(327) = 3.47$, $p = .001$, and depression ($M_s = 5.30$ vs 6.87), $t(327) = 2.45$, $p = .02$, than those educated to a lower level; monthly income was inversely associated with anxiety, $r(327) = -.13$, $p = .02$, and depression, $r(327) = -.11$, $p = .04$; scores on the Modified Rotterdam Symptom Checklist were positively associated with anxiety, $r(327) = .40$, $p < .001$, and depression, $r(327) = .50$, $p < .001$; and cancer stage was positively associated with depression, $r(327) = .16$, $p = .004$. The socio-

demographic and medical variables that had significant associations with anxiety and/or depression were controlled for in subsequent regression analyses.

Regression analyses

Two hierarchical regression analyses were conducted to examine the amount of variance in anxiety and depression explained by illness representations (see Table II). For each analysis, the independent variables were entered in three blocks: (i) awareness of a cancer diagnosis, (ii) socio-demographic and medical variables (i.e., education, income, symptoms, cancer stage), and (iii) illness representation dimensions. Prior to the regression analyses, three multivariate outliers were identified and removed.

Awareness of a cancer diagnosis explained 3% of the variance in anxiety, $R^2 = .03$, $F(1,324) = 11.05$, $p < .001$. The addition of the socio-demographic and medical variables at step 2 increased the amount of variance explained, $\Delta R^2 = .19$, $F(4,320) = 19.05$, $p < .001$. Awareness of a cancer diagnosis was significant along with scores on the Rotterdam Symptom Checklist. The addition of the illness representation dimensions at step 3 further increased the amount of variance explained, $\Delta R^2 = .42$, $F(9,311) = 40.56$, $p < .001$. The effect of awareness of a cancer diagnosis became non-significant at this step. Rotterdam Symptom Checklist scores, personal control, treatment control, concern, emotional representation, and coherence were significant in the final regression equation which explained 64% of the variance in anxiety, $R^2 = .64$, $F(14,311) = 39.61$, $p < .001$. However, the significant positive beta for personal control may be a suppressor effect given that the corresponding correlation was negative. As a result, this effect is not interpreted further [31].

Awareness of a cancer diagnosis explained 2% of the variance in depression, $R^2 = .02$, $F(1,324) = 7.39$, $p = .007$. The addition of the socio-demographic and medical variables at step 2 increased the amount of variance explained, $\Delta R^2 = .27$, $F(4,320) = 29.90$, $p < .001$. Awareness of a cancer diagnosis was significant along with the Rotterdam Symptom

Checklist. The addition of the illness representation dimensions at step 3 further increased the amount of variance explained, $\Delta R^2 = .33$, $F(9,311) = 30.54$, $p < .001$. The effect of awareness of a cancer diagnosis became non-significant at this step. Rotterdam Symptom Checklist scores, perceived consequences, timeline, treatment control, concern, and emotional representation were significant in the final regression equation which explained 62% of the variance in depression, $R^2 = .62$, $F(14,311) = 36.58$, $p < .001$.

Mediation analyses

Further analyses were conducted to test whether illness representations mediated associations between awareness of a cancer diagnosis and anxiety and depression [32]. Awareness of a cancer diagnosis was entered with the illness representation dimensions as potential mediators along with the socio-demographic and medical variables as covariates.

The direct path from awareness to anxiety, $B = 1.55$, $SE = 0.61$, $p = .01$, was reduced to non-significance when illness representations were controlled for, $B = 0.75$, $SE = 0.44$, $p = .09$. Using bootstrapping procedures with 5,000 samples, the total indirect effect was non-significant, $B = 0.80$, $SE = 0.48$, $CI = -0.15$ to 1.74 . However, inspection of the individual mediator variables revealed a significant indirect effect through coherence, $B = 0.26$, $SE = 0.13$, $CI = 0.05$ to 0.58 , such that (lack of) awareness of a cancer diagnosis was associated with (reduced) coherence, $B = -1.63$, $SE = 0.35$, $p < .001$, which in turn was associated with (increased) anxiety, $B = -0.16$, $SE = 0.07$, $p = .02$.

The direct path from awareness to depression, $B = 1.30$, $SE = 0.58$, $p = .03$, was reduced to non-significance when illness representations were controlled for, $B = 0.51$, $SE = 0.45$, $p = .26$. However, bootstrapping procedures (5,000 samples) revealed that the total indirect effect was non-significant, $B = 0.78$, $SE = 0.48$, $CI = -0.09$ to 1.65 , as were the indirect effects for each of the individual mediator variables.

Moderation analyses

To assess whether awareness of a cancer diagnosis moderated any relationships between illness representations and anxiety and depression, interaction terms were computed between each illness representation dimension (after mean-centering) and awareness. The interaction terms were then added (individually) to the previous regression analyses at a fourth step.

Three interaction terms were significant. First, awareness of a cancer diagnosis moderated the relationship between concern and anxiety, $B = 0.27$, $SE(B) = 0.11$, $\beta = .13$, $p = .01$. Simple slopes analysis revealed that the relationship was stronger among patients who reported being unaware, $B = 2.43$, $SE(B) = 0.35$, $\beta = .41$, $p < .001$, versus aware, $B = 1.38$, $SE(B) = 0.38$, $\beta = .24$, $p < .001$, of their cancer diagnosis. Second, awareness of a cancer diagnosis moderated the relationship between emotional representation and anxiety, $B = 0.45$, $SE(B) = 0.11$, $\beta = .20$, $p < .001$, such that the relationship was stronger among patients who reported being unaware, $B = 2.79$, $SE(B) = 0.38$, $\beta = .47$, $p < .001$, versus aware, $B = 1.78$, $SE(B) = 0.37$, $\beta = .20$, $p = .002$, of their cancer diagnosis. Third, awareness of a cancer diagnosis moderated the relationship between timeline and depression, $B = 0.42$, $SE(B) = 0.16$, $\beta = .14$, $p = .007$, such that the relationship was stronger among patients who reported being unaware, $B = 1.19$, $SE(B) = 0.32$, $\beta = .20$, $p < .001$, versus aware, $B = 0.08$, $SE(B) = 0.34$, $\beta = .01$, $p = .81$, of their cancer diagnosis.

Conclusions

The present study sought to apply the Common Sense Model (CSM) of illness representations [3] to explain the psychological reactions of Indian cancer patients who report being aware or unaware of their cancer diagnosis. Illness perceptions explained significant proportions of variance in anxiety and depression after controlling for various demographic (i.e., education, income) and clinical (i.e., awareness of a cancer diagnosis, cancer symptoms,

cancer stage) variables. In particular, the perception of serious consequences, weak perceptions of treatment control, increased concerns about the illness and a strong emotional representation regarding the impact of the illness on one's emotions were associated with elevated levels of anxiety and depression. In addition, a poor self-reported understanding of one's illness (i.e., coherence) was associated with increased anxiety, and the perception of a chronic timeline was associated with increased depression. These findings are broadly in line with studies that have applied the CSM to cancer patients in Western cultures [1, 7-14] and confirm the important role of both cognitive and emotional representations in the CSM. However, there are two discrepancies with previous findings. First, identity (i.e., the extent to which patients attribute symptoms to their illness) was not significant in the regression analyses. However, this may have been due to the inclusion of the Modified Rotterdam Symptom Checklist [30] which assesses the experience of cancer-related symptoms. Second, consequences was significant for both anxiety and depression, which may reflect the increased impact of cancer in low-income countries [33]. The present findings are also broadly in line with other studies that have examined illness perceptions in cancer patients in Asian cultures (although none have focused on relationships with psychological distress). These studies have shown weaker perceptions of treatment control, increased concerns, stronger emotional representations and weaker coherence to be associated with lower satisfaction with the provision of information [25], and more negative (overall) illness representations to be associated with poorer health-related quality of life [26].

There was some evidence that illness perceptions mediated associations between awareness of a cancer diagnosis and psychological distress. In particular, illness coherence mediated the association between awareness of a cancer diagnosis and anxiety, such that being unaware of one's cancer diagnosis was associated with a poorer self-reported understanding of one's illness that, in turn, was associated with increased levels of anxiety.

Such a finding is consistent with the idea that information provided by others (e.g., family members, doctors) about one's illness can shape patients' illness representations and impact upon psychological well-being. Awareness of a cancer diagnosis was found to moderate a number of relationships between illness representations and psychological distress. In particular, the relationships between concern and emotional representation and anxiety and between timeline and depression were stronger among those who reported being unaware of their cancer diagnosis. Patients who are not informed of their cancer diagnosis are often given an alternative, less severe, explanation for their symptoms (e.g., lump, fever) [22] that may not fit with their experiences of their illness. This may lead to increased concern and psychological distress. Future qualitative research is needed to explore the illness representations of patients who are unaware of their cancer diagnosis in more detail and, in particular, how they reconcile (or not) a potential mismatch between the illness label they have been given and the severity of the symptoms they are experiencing.

There are some study limitations and, as a result, the above conclusions are made with some caution. First, the study employed a cross-sectional design; therefore, it is not possible to infer causality or make strong statements regarding the likely direction of relationships. Second, the present study represents only a partial application of the CSM as patients' coping efforts, which are hypothesised to mediate relationships between illness representations and psychological outcomes, were not assessed. However, previous applications of the CSM to cancer have found little evidence for the proposed mediational role of coping [e.g., 9,11]. Third, awareness of a cancer diagnosis was assessed with questions designed to indirectly assess patients' awareness of their diagnosis. However, it is also possible that some patients may have chosen not to tell the researcher in order to collude with family members' perceived wishes or due to feelings of embarrassment, shame or denial [34]. This may have led to an

underestimation of awareness and more conservative tests of the effect of awareness on psychological distress.

These current findings have a number of clinical implications. First, health professionals caring for patients with cancer should be aware of, and strive to address, the psychological impact of the illness (to reduce emotional concerns) while treating the physical symptoms of cancer. Second, patients may benefit from clear information on the efficacy of the treatments they are receiving (to increase perceptions of treatment control), especially as in many Asian countries there is a strong belief that a cancer diagnosis is tantamount to a death sentence [35]. Third, health professionals need to be aware of the broader impact of cancer on the patient (to reduce perceptions of serious consequences) which may include the stigma often attached to a cancer diagnosis in Asian countries [35] as well as the financial difficulties that many families in low-income countries face when making decisions about cancer treatment [33].

Encouragingly, interventions that have targeted negative illness perceptions have produced positive behavioural and psychological outcomes for a number of medical conditions [36] including cancer [37]. However, the application of such interventions in situations where patients are unaware of their true diagnosis raises important practical, ethical and cultural issues.

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Illness perceptions in Indian cancer patients

Table I

Means, Standard Deviations and Correlations between Illness Perceptions and Anxiety and Depression (N = 329)

Variable	<i>M</i>	<i>(SD)</i>	Anxiety	Depression
			<i>r</i>	<i>r</i>
Identity	3.29	(3.39)	.40***	.46***
Consequences	5.34	(3.77)	.52***	.68***
Timeline	4.03	(2.63)	.34***	.49***
Personal Control	6.31	(3.49)	-.39***	-.47***
Treatment Control	8.66	(2.06)	-.37***	-.40***
Concern	3.98	(3.83)	.68***	.51***
Emotional Representation	4.00	(3.60)	.69***	.57***
Coherence	6.01	(3.45)	-.27***	-.24***
Cause ^a	109	(33.1)	-.06	-.04
<i>M</i>			5.45	6.01
<i>(SD)</i>			(5.85)	(5.84)

Note. ^a n and (%) citing a cause. *** $p < .001$.

Table II

Summary of Hierarchical Regression Analyses for Anxiety and Depression (N = 326)

Variable	Anxiety			Depression		
	<i>B</i>	<i>SE B</i>	β	<i>B</i>	<i>SE B</i>	β
Step 1						
Awareness of Cancer Diagnosis	2.14	0.64	.18***	1.76	0.65	.15**
Step 2						
Awareness of Cancer Diagnosis	1.55	0.61	.13*	1.30	0.58	.11*
Education Level	-1.17	0.63	-.10	-0.64	0.60	-.05
Monthly Income	0.00	0.00	-.07	0.00	0.00	-.09
Symptoms (RSC)	0.26	0.03	.42***	0.30	0.03	.49***
Cancer Stage	-0.39	0.34	-.06	0.31	0.33	.05
Step 3						
Awareness of Cancer Diagnosis	0.75	0.44	.06	0.51	0.45	.04
Education Level	-0.38	0.46	-.03	0.33	0.47	.03
Monthly Income	0.00	0.00	-.06	0.00	0.00	-.05
Symptoms (RSC)	0.06	0.03	.10*	0.09	0.03	.14**
Cancer Stage	-0.07	0.25	-.01	0.14	0.25	.02

Identity	0.10	0.08	.06	0.06	0.08	.03
Consequences	0.17	0.07	.11*	0.58	0.07	.37***
Timeline	0.00	0.10	.00	0.26	0.10	.12**
Personal Control	0.16	0.08	.10*	-0.13	0.08	-.08
Treatment Control	-0.32	0.12	-.11**	-0.25	0.12	-.09*
Concern	0.52	0.08	.34***	0.18	0.08	.12*
Emotional Representation	0.54	0.09	.33***	0.19	0.09	.12*
Coherence	-0.16	0.07	-.09*	-0.11	0.07	-.06
Cause	-0.51	0.45	-.04	-0.47	0.46	-.04

Note. Anxiety: Step 1 $\Delta R^2 = .03^{***}$; Step 2 $\Delta R^2 = .19^{***}$; Step 3 $\Delta R^2 = .42^{***}$.

Depression: Step 1 $\Delta R^2 = .02^{**}$; Step 2 $\Delta R^2 = .27^{***}$; Step 3 $\Delta R^2 = .33^{***}$.

* $p < .05$. ** $p < .01$. *** $p < .001$.