

Indian patient use of cancer euphemisms: Association with psychological outcomes and health-behaviors

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Abstract

Objective: Euphemisms may be used to reduce the threat associated with the word “cancer”. Cancer may be particularly threatening in Indian culture due to the myths surrounding its cause and prognosis. This study explored the prevalence of euphemism use by Indian patients and the relationship among euphemism use and illness cognitions, affect, health-behavior and spontaneous self-affirmation (a behavior associated with dealing with threat).

Methods: 350 cancer patients in India were recruited to take part in a study exploring patients’ experiences of, and thoughts about, having an illness. They responded to a questionnaire measuring illness-perceptions, coping-strategies, anxiety, depression, health-behaviors, and spontaneous self-affirmation. Patients were asked what words they used to describe their illness; euphemism-users were those who used a euphemism (i.e., non-medical term) as a first word.

Results: 51% of patients used a euphemism as a first word. Those with less education, unskilled employment, a lower income and more children were more likely to be euphemism-users. Euphemism users reported (a) weaker illness-perceptions (less personal-control, greater reporting of symptoms, and less understanding of their condition), (b) less use of 3 of 14 coping-strategies, (c) less likelihood of spontaneously self-affirming, and (d) fewer healthy eating days.

Conclusions: Euphemism use in patients was not related to distress but was related to negative illness-perceptions and use of fewer coping-strategies, suggesting that we need

further study about the extent to which euphemisms signal issues in psychological adaptation to cancer diagnosis.

KEYWORDS: cancer, oncology, coping, euphemism, illness-perceptions, India, self-affirmation

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Patient use of cancer euphemisms: Association with psychological outcomes and health-behaviors

Euphemisms for cancer may be used to reduce the threat associated with the word “cancer”.¹ Cancer may be particularly threatening in India due to the myths surrounding its cause. This study will explore the prevalence of euphemism use by Indian cancer patients and the relationship between euphemism use and illness cognitions, affect, health-behavior and spontaneous self-affirmation (a behavior that is associated with dealing with threat).

In India cancer is particularly threatening as it is stigmatized, indecent (i.e., using the word cancer is seen indecent/aversive/taboo since it is akin to talking about death)²⁻⁴ and its causes are misunderstood^{5,6}. Surveys of cancer patients have found that 97.9% reported they didn't know the cause although with further exploration cancer was attributed to curses from God (85.6%), other supernatural factors (58.9%; spiritual, black magic), environmental factors (98.6%; micro-organisms, pollution), and personal factors (86.9%; hygiene, drug addiction), Other myths include the belief that cancer has no cure (60%),⁷ cancer patients could not lead productive lives (61%),⁵ and cancer is infectious (27.4%).⁵ Furthermore, accurate beliefs about cancer were less common in those who were less educated (in Indian Canadians)⁸ and in older and female patients (residing in India).⁹

Cancer patients in India suffer discrimination due to cancer stigma including in their own families; 87% reported discrimination such as isolation,⁵ asked to use separate clothes, food or utensils⁵ or in-laws disowning them.¹⁰ Until recently, a significant number of families in India did not disclose a diagnosis of cancer to the family member affected.^{11,12} However, there has been a recent shift in medical communication with more patients wanting to

Accepted Article

become involved in their medical decision making but patients and families still finding communicating about cancer difficult owing to a lack of skills in this area and the stigma associated with it.¹³ Euphemism use may present a way of openly talking about the illness without causing offence by eliminating the taboo of the word “cancer”.¹⁴ Therefore, it could be beneficial to the patient as it could reduce stigma and discrimination associated with cancer and allow communication; however, there may also be negative effects.

Illness-representations and coping-strategies

The Common Sense Model (CSM) of Illness-representations refer to lay people’s perspectives of their illness;¹⁵ whereby individuals develop cognitive- and emotional-perceptions of their illness simultaneously. The CSM comprises five dimensions: identity (i.e., symptoms experienced), consequences (i.e., illness effects), cause, timeline (i.e., duration), and control. The dimensions have been revised with control now encompassing personal- (i.e., self-efficacy in dealing with illness) and treatment-control (i.e., response-efficacy of treatment) and the addition of emotional-representation broken down into concern (i.e., cognitive aspects), emotions (i.e., emotional such as fear and anger) and coherence (i.e., understanding of the illness).¹⁶ Illness-representations have direct effects on health outcomes (e.g., anxiety and depression) and functioning and indirect effects through coping-strategies.¹⁷ Coping-strategies are cognitive and affective methods of dealing with illness such as self-blame or planning.¹⁸

Euphemism use and illness-representations and coping-strategies

There is a dearth of research into the extent of euphemism use in patients and the relationship between patient's euphemism use and illness-representations and coping-strategies. There has been similar research of euphemism use by doctors.

Emotional-representation. Euphemism use by doctors was associated with less emotional-representation in non-patients. Participants given a vignette about a doctor giving a diagnosis to a patient reported that a euphemistic term for heart failure would lead to a lower expectation of becoming upset compared to the medical term.¹⁹ Euphemistic terms about minor illnesses (e.g., "sore throat", "stomach upset") were also rated as likely to cause less fear and anxiety than the medical term.²⁰

The research above was conducted on healthy people; research conducted on samples with the target illness found that euphemism use led to increased rather than reduced emotional-representation. Obese patients reported that the euphemistic term "your weight may be damaging your health" would lead to more anxiety and depression than the term "you are obese".²¹ Euphemism use (i.e., referring to "illness" rather than "cancer") on a questionnaire was related to higher reported state-anxiety.²² Euphemism use with patients whose diagnosis had not been disclosed to them (a common practice in India, where diagnoses may be disclosed only to patients' families)¹³ was associated with increased levels of anxiety and depression.¹¹

One of the few studies that looked at patient use of euphemisms interviewed patients undergoing radiotherapy and found that increased use of euphemisms and avoiding use of "cancer" was associated with higher levels of anxiety in Turkish patients (who typically hold myths about causes of illness; and are less likely to emotionally-represent their illness).²³

However, the opposite was true for Belgian patients (who have more accurate perceptions of illness).²³

Consequences. Euphemism use could affect the perceptions in non-patients as euphemism use decreased perceptions that serious medical events have major consequences.¹⁹ Additionally, Pakistani cancer patients, aware of their diagnosis, preferred the doctor to use euphemisms for cancer so they did not automatically assume they would die.²⁴ Additionally, many patients preferred “disguised” or evasive language when doctors gave poor prognoses as it increased hopefulness and ability to cope with the information at their own pace.²⁵

Coherence. Euphemism use affected coherence in non-patients given scenarios which included cancer euphemisms actually used by doctors; almost half demonstrated a low level of understanding of the diagnosis when euphemisms were used.²⁶

Timeline. Euphemism use affected timeline as it increased perceptions that symptoms of serious medical events would be cyclical rather than permanent in non-patients.¹⁹

Identity. Euphemism use by patients may also affect symptom reporting as Turkish patients, were likely to report more euphemism use and positive symptoms of cancer and lesser symptomatic distress than Belgian patients.²³

Coping-strategies. Increased denial and reduced acceptance in patients were linked to patients who preferred doctors to use euphemisms.²⁴

Other cognitions. Euphemism use also influenced cognitions, in non-patients, about minor illnesses including greater acceptance of responsibility, less validation and decreased confidence in the doctor when assessing minor illnesses.²⁰

The above evidence suggests that with non-patients euphemisms use by doctors can reduce anxiety but this may be due to their misunderstanding the severity and consequences of the illnesses and increased feelings of responsibility. With patients the evidence is mixed as there is evidence that euphemisms use by doctors may increase anxiety and some evidence that it may increase hope and ability to cope. Euphemism use by patients in some cultures, where cancer is stigmatized, may be related to increased anxiety, a greater number of positive symptoms and less distress from those symptoms. To our knowledge there is little research of euphemism use in patients in countries where cancer is stigmatized and no research of the effect of euphemism use in Indian patients (when their diagnosis is disclosed).

Spontaneous self-affirmation

An effective way of reducing threat whilst retaining accurate cognitions is through self-affirmation. Self-affirmation occurs when a person reflects on their positive characteristics, relationships or values. Self-affirming when threatened leads to less use of defensive-strategies, such as denying risk, and thus allows more appropriate actions to deal with the threat. For example, performing a self-affirmation task (e.g., writing an essay about their values) before reading health-risk information led to a reduction in risky health-behaviors.²⁷ The tendency to self-affirm in real life, i.e., spontaneous self-affirmation, has been linked to greater positive-affect, optimism, health-efficacy, subjective health²⁸ and intentions to quit smoking.²⁹ Spontaneous self-affirmation has also been linked to greater information-seeking about genetic susceptibility to unpreventable/untreatable diseases in those who experience anticipated-regret.³⁰ In cancer survivors, higher spontaneous self-affirmation was linked to greater happiness, hopefulness, and efficacy for obtaining health

information.³¹ This would suggest a reduced need for euphemism use in those patients who spontaneously self-affirm.

There is little research that explores the extent of euphemism use, in India, and in patients generally and the relationship between patient euphemism use and (a) illness-perceptions, (b) coping, (c) anxiety and depression, (d) spontaneous self-affirmation, (e) health-behaviors (i.e., physical-activity, diet, alcohol use and smoking) and (f) demographic factors. In this study cancer patients will complete a questionnaire to assess the above.

The hypotheses are that euphemism use will be associated with (a) increased emotional-representations, (b) decreased perceptions of consequences, (c) decreased coherence, (d) decreased timeline, (e) increased identity, (f) increased use of denial-coping, (g) decreased use of venting-coping, (h) decreased acceptance-coping, (i) higher anxiety, (j) and less likelihood of spontaneous self-affirming. The study will also explore the association between euphemism use and health-behaviors and demographic factors.

Method

Procedure

Adult patients, attending cancer treatment at hospitals in Hyderabad, India, were asked to participate in a study to explore patients' experiences of and thoughts about having an illness, by an Indian research assistant. The researcher did not use "cancer" throughout the interaction with the patient and interviewed in private (to reduce chances of collusion). After providing written informed consent the participants completed the questionnaire orally in Telugu.

Ethical approval

Approval was received from the Institutional Ethics Committee, IIT Hyderabad and the Institutional Review Boards of the hospitals (reference IEC/2016/34.2).

Questionnaire

For full details of the questionnaires used including reliability see online supplemental-materials Table 1. All questionnaires were translated, back-translated and piloted to ensure their internal consistency and closeness to the English versions.

Patients were asked demographic questions, illness characteristics and “what words do you use to describe your illness?”. Most patients listed both medical terms and euphemisms; however, we operationalized euphemism users as those who used a euphemism first as according to models of information processing (i.e., recent and frequently used words are more accessible thus likely to be used first).³² See online supplemental-materials Table 1 for full description of operationalization.

Other questionnaires measured illness-perceptions (Brief Illness Perception Questionnaire, BIPQ),¹⁶ coping-strategies (Brief COPE),¹⁷ anxiety and depression (Hospital Anxiety & Depression Scale, HADS),³³ health-behavior (an adapted version of the relevant items from the Diabetes Self-Care Activities Measure),³⁴ and spontaneous self-affirmation.^{30,35}

Analysis Plan

Due to deviations from normality in much of the data non-parametric tests were used to determine differences between groups that did and did not use euphemisms as the first word.

Results

Participants

The patients (*mean age*=50.62; *SD*=13.77; 48% female) were 350 patients (*N*=346 analyzed). See online supplemental-materials Table 2 for a description of the sample.

The patients reported their illness was low threat on the BIPQ (*mean*=29.16, *SD*=16.25). The majority were not depressed (86%) or anxious (86%) as reported with the HADS. The most used coping-strategies were Emotional-support (*mean*=5.48, *SD*=1.97) and Religion (*mean*=4.68, *SD*=2.45) and the least used were Substance Use (*mean*=2.04, *SD*=.40) and Humor (*mean*=2.10, *SD*=.52).

Regarding health-behaviors, few patients smoked (*n*=4) or used alcohol (*n*=5); therefore, these two behaviors were not analyzed. Exercise (*mean*=2.67; *SD*=2.37) and healthy diet days were moderate (*mean*=4.41; *SD*=2.10).

Correlations between variables

These are shown in online supplemental-materials Tables 3 and 4 (correlations between variables by euphemism used as first word).

Extent and type of euphemism

Two hundred and thirty-eight participants used at least one euphemism (68.79%) and 171 used over 50% euphemisms (49.42%)¹. Fifty-one percent of the sample used a euphemism as their first word to describe their illness. 46% used the word “gadda” (i.e.,

¹ See online supplemental-materials - Tables 5 and 6 for analysis comparing (a) those who used >50% euphemisms vs. those who used ≤50% and (b) those who used ≥ one euphemism vs those who didn't use euphemisms.

hardened mass), 38% used words describing their symptoms, treatment or the cause of their illness, other words used to a lesser extent included “kanthi” (i.e., tumor), “noppi” (i.e., pain), and ulcer (see online supplemental-materials - Table 2 for full list).

Those who used a euphemism as a first word listed more euphemisms, *Mann-WhitneyU*=4967.50, $p<.001$, and fewer medical terms, *Mann-WhitneyU*=3780.00, $p<.001$.

Association between demographics and euphemism use

For first word used, there were differences associated with education, $\chi^2(N=345)=39.16$, $p<.001$, employment, $\chi^2(N=346)=20.77$, $p<.001$, number of children, *Mann-WhitneyU*=12674.00, $p=.006$, and income, *Mann-WhitneyU*=2449.50, $p<.001$. Those with high-school education, degrees, post-graduate education, in skilled employment or retired were less likely to use a euphemism first and those with “other” education, more children or a lower income were more likely to use a euphemism first.

For first word used, there were no differences due to gender, marital status (married vs. other marital status), age, or distance lived from hospital.

Association between cancer and treatment characteristics and euphemism use

For first word use there were associations with cancer type, $\chi^2(N=288)=12.28$, $p=.031$; patients with gynecological cancers were more likely to use a euphemism and those with head/neck cancers and leukemia were less likely to use a euphemism first. For first word use there were no associations with stage, time since diagnosis, duration of treatment, or treatment type (chemotherapy and multiple only).

How is euphemism use related to illness-perceptions, coping and psychological outcomes?

Illness-perceptions. Those who used euphemisms as the first word had lower perceptions of personal-control, $Mann-WhitneyU=10334.50, p=.040$, perceived a greater illness-identity, $Mann-WhitneyU=12418.50, p=.003$ and reported less coherence (i.e., understanding of their illness), $Mann-WhitneyU=10532.50, p<.001$. There were no differences on the overall illness-perceptions scale. There were a variety of causes listed by the participants (see online supplemental-materials - Table 2). After adjusting for multiple comparisons only illness-identity and coherence were significant (adjusted alpha $.05/8 = .006$)

Coping. Euphemism as a first word was related to lower use of self-distancing coping, $Mann-WhitneyU=12964.00, p=.010$, emotional-support, $Mann-WhitneyU=13049.50, p=.002$, positive-reframing, $Mann-WhitneyU=12904.00, p=.010$, planning, $Mann-WhitneyU=13697.50, p=.020$, acceptance, $Mann-WhitneyU=13224.00, p=.003$, religious-coping, $Mann-WhitneyU=11975.50, p<.001$ and blame, $Mann-WhitneyU=13877.50, p=.031$. After adjusting for multiple comparisons only emotional-support, acceptance and religious-coping were significant (adjusted alpha $.05/14 = .004$).

Psychological Outcomes. There were no differences in depression, $\chi^2(N=284)=132.83, p=1.00$, or anxiety, $\chi^2(N=284)=153.92, p=1.00$, between people who used a euphemism as a first word and those who did not.

How is euphemism use related to spontaneous self-affirmation?

Those who used a euphemism as a first word were less likely to spontaneously self-affirm, $Mann-WhitneyU=13250.50, p=.032$.

How is euphemism use related to health-behavior?

A healthy diet, *Mann-Whitney* $U=11569.00$, $p<.001$, was performed on fewer days by those who used a euphemism as their first word. There were no differences in those who did and did not use a euphemism as their first word for days exercised.

Discussion

Euphemism use in cancer patients was common with 69% of patients listing at least one euphemism. Around half used over 50% euphemisms when describing their illness and just over half of those used a euphemism as their first word. Using a euphemism as the first word to describe the illness was most common among those with lower levels of education, in unskilled employment or retired, on lower income or with more children. Regarding cancer characteristics, those with gynecological cancer were more likely, and those with head/neck cancers and leukemia were less likely, to use a euphemism as the first word. For coping, euphemism use as first word was related to less likelihood of using three of the fourteen coping-strategies: emotional-support, acceptance and religious-coping. For illness-perceptions, using a euphemism as the first word was related to less personal-control, lower coherence (i.e., less understanding), and stronger illness-identity (i.e., more symptoms). Euphemism use as a first word was also related to less use of spontaneous self-affirmations and fewer healthy eating days.

Some of these findings are likely to be generalizable; e.g., using euphemisms for gynecological cancer may be due to embarrassment, which might be common across cultures.³⁶ Also, the effect of spontaneous self-affirmation may be generalizable across cultures, given that those who were most likely to feel threatened by the illness in this sample (i.e., those who reported lower tendency to spontaneously self-affirmation in response to

threats) were most likely to use euphemisms. This is consistent with the possibility that patients use euphemisms to protect themselves from self-threats, such as stigma associated with cancer or feelings of responsibility for contracting cancer, thus downplaying their illness.

However, some of the findings may be specific to Indian culture. In contrast to many Western countries, in India (a) cancer is subject to myths about the causes/prognosis, and subsequent stigma⁶ (b) talking about cancer openly is regarded as indecent/aversive/taboo since it is akin to talking about death,²⁻⁴ and (c) medical decision-making is often associated with low personal-control due to family involvement.³⁷ Euphemisms use may allow patients to downplay the illness, avoid stigma, preserve the decency of self and others, and also allow some personal-control.

There is evidence from this study to suggest that euphemisms are used to avoid stigma, as those most likely to use euphemisms are those who are more likely to believe in cancer myths and thus be more subject to stigma;⁹ e.g., in this sample, those with lower levels of education (and relatedly with lower income and non-skilled employment). Additionally, those who may most need to protect their families from stigma may be more likely to use euphemisms: for example, in this sample, people with more children were more likely to use euphemisms.⁸ Euphemism use would also allow a way of communicating about the illness whilst protecting the family from the emotional impact of the word “cancer” in a society whose members may consider it indelicate to mention.³⁸

Downplaying one’s illness by using euphemisms could also remove the need to use acceptance and invalidate emotional-support and religious-coping as strategies to deal with

the illness. If using euphemisms downplays illness severity, then this removes the need to “accept the fact it happened” and “learn to live” (i.e., measures of acceptance used in the Brief COPE)¹⁸ with the disease as these are associated with severe/ life changing illnesses. Downplaying the illness could lead to external (i.e., social norms) and internal influences (i.e., cognitive dissonance³⁹ – whereby the patient starts to regard the illness as less severe too and behaves accordingly) to avoid particular coping-strategies. For example, patients may not ask for emotional-support as others would not see this as necessary if the patient does not convey to them that the disease is severe. Similarly, religious practices such as relying on God to help them through (e.g., going to the temple, praying more than usual), would be out of place as this is only reserved for the most serious of illnesses. This may also be the reason for euphemism users to engage in fewer days of a healthy diet, i.e., these patients tended to prefer downplaying their illness and, thereby, did not pay any particular attention to maintaining a healthy diet.

Regarding illness perceptions, euphemisms users, by downplaying their illness and maintaining cognitive consistency, could be less likely to research or seek information about their illness (and may not have the resources to do this if they have low income) and thus exhibit less understanding of illness (i.e., *coherence*), and perceive more symptoms (*identity*) to be related to their illness. This could be particularly the case in India where cancer literacy is low.⁹ The low personal-control in those who used euphemisms was not predicted, as there was no previous literature to inform this. However, patients in India may feel particularly low control over their illness due to family involvement in medical decision-making.^{13,37} One of

the few ways to exhibit agency and remove control from the family, for those low in personal-control, may be choosing which word they use to describe their illness.

In this study, there were no differences in anxiety or depression between those who used euphemisms as the first word and those who did not. This could be because those patients who experience high anxiety and depression are those most likely to use euphemisms, which in turn acts as a buffer, thus reducing anxiety and depression to the levels of those who did need to use euphemisms. Furthermore, exercising the choice over words to use may also reduce anxiety and depression. The levels of anxiety and depression may be particularly high in some Indian cancer patients due to the stigma attached to cancer.¹⁰

It is beyond the scope of this study to explore the relationships outlined above. Further research is needed to explore the potential mediating and moderating effects described above.

Clinical Implications

Euphemism use seems to have both potentially positive and negative correlates in Indian cancer patients. It may protect against the effects of stigma, reduce the experience of anxiety and depression, allow those who do not use spontaneous self-affirmation to deal with the threat of cancer, and allow those with low personal-control to have some agency over their disease. However, it may also lead to less understanding of the illness, the perception of more symptoms and a downplaying of the illness that prevents patients from using all available coping strategies. However, it is important to note that the data are correlational, so any such causal interpretations must be treated with caution.

Euphemisms users may benefit from a psycho-education intervention focusing on increasing illness knowledge and how they might be able to manage specific aspects of their illness such as the disease symptoms, treatment side-effects and so on thereby increasing their awareness and sense of control over their illness. Existing research examining the impact of psychoeducation within the context of cancer in India reported that a psychoeducation intervention helped improve quality of life and mood among cancer patients,⁴⁰ and helped caregivers of patients better understand the disease, reduced feelings of stigma, decreased anxieties related to caregiving, and improved their overall patient care behaviors.⁴⁰

Study Limitations

The study limitations are that the sample may not be representative as the patients were recruited within one city in India. The data was not normally distributed, that is most patients reported low anxiety, depression and use of many of the coping-strategies, which prevented parametric analysis. Although many of the scales have been validated for use in Indian samples these had not previously been translated into Telugu. **Additionally, as noted previously, the data are correlational, so it is not possible to infer causation about patient euphemism use.**

Conclusions

This study suggests that Indian cancer patients use of euphemisms for cancer is common with 51% choosing to use a euphemism as the first word to describe their illness and 69% of the sample using at least one euphemism. Those with lower levels of education, not in skilled employment, lower income and having more children were most likely to use

euphemisms. There was no association with patient's euphemism use with anxiety and depression despite the association with (a) less personal-control, greater reporting of symptoms and less understanding of their condition and (b) use of fewer coping-strategies that are related to poorer psychological outcomes. This suggests that euphemism use in patients, although not related to distress, is related to negative illness-perceptions and use of fewer coping-strategies.

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Conflicts of Interest

The authors have no conflicts of interest

Data Availability Statement

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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- Accepted Article
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