

Indian Cancer Patients' use of Traditional, Complementary and Alternative Medicine (TCAM) and delays in presentation to Hospital

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Abstract

Objectives: A majority of Indian cancer patients are often presented with incurable diseases at the latest phase of disease progression. The use of traditional, complementary and alternative medicine (TCAM) has been identified by Indian oncologists as a potential factor for the delay in seeking health from medical practitioners but no research has been conducted to verify such claims. The aim of this study is to identify socio-demographic and disease status differences between TCAM and non-TCAM users among cancer patients in India and associated patterns of seeking professional medical help.

Methods: A random survey of 825 cancer patients in one public and one private hospital was conducted in Delhi, India. Using four interviewers, a list sampling technique was used to interview every patient over a four month period, with a response rate of 80%.

Results: The results showed that 34.3% of cancer patients had used TCAM. The results also demonstrated a statistically significant relationship between the use of TCAM and reported delay in seeking help from clinical medicine ($p < 0.001$). On the other hand, 35.2% of TCAM users reported seeking help immediately after onset of symptoms, whereas 50% of non-users immediately

sought help from conventional medicine. Furthermore, 11.5% of TCAM users reported waiting for six months or more after noticing cancer-related symptoms, while only 2.1% of non-users waited this long.

Conclusion: Overall, early diagnosis and intervention is critical for effective treatment of many malignancies. Delays in presentation related to the use of TCAM may be an important factor relating to the high rates of advanced disease on presentation and low survival rates in the care of Indian cancer patients. Further research is needed to explore the reasons for using TCAM and to ensure existing issues of delays in help seeking are addressed.

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Introduction

The Indian subcontinent is home to 16.5% of the world's population and at any one time it is estimated that there are over 2 million people with cancer.¹ Whilst cancer has not been a prominent healthcare issue in India compared with other communicable diseases, with an increasingly ageing population, cancer is emerging as a critical health problem.² India confronts very specific social, cultural and economic issues when it comes to addressing cancer (e.g. geographical diversity, class and caste structure). Low socioeconomic status and illiteracy also contribute to advanced stages of disease on presentation to biomedical clinics, and Traditional, Complementary and Alternative Medicines (TCAM) are often the only therapies available.³ According to the UN Development Programme (2007), India has just 48 doctors per 100,000 people compared to the UK with 230 and the US with 256.⁴ The poor provision of public sector healthcare means many people (even the poor) turn to the private sector. Both conventional medical treatment and TCAM are minimally regulated by the government.⁵

The majority of Indian cancer patients have late stage incurable diseases (75% to 80%) when first diagnosed.^{1,6-8} Earlier presentation could significantly enhance survival rates, making the identification of factors hindering this crucial. It is estimated that approximately 50% of cancer patients in developed countries die from their malignancy, whereas 80% of cancer patients die in developing countries.⁸ Presently in India, out of a million newly diagnosed cancer patients each year, more than 50% die within 12 months of diagnosis and another one million cancer survivors show progressive disease within five years of diagnosis.⁸ Out of the 1.5 million in need of palliative care, less than 0.1 million patients can be covered by the existing facilities.⁸

In 2005, cancer killed approximately 826,000 people in India; 519,000 under the age of 70.⁹ This is predicted to rise disproportionately compared with cardiovascular and communicable diseases by 2030, to nearly 1.5 million deaths annually. Public health advocacy has been largely focused on communicable diseases, nutritional deficiencies, population stabilisation, and

recently on HIV/AIDS. Cancer has thus far been a relatively low priority.¹⁰

This study shows the socio-demographic and disease status patterns of TCAM and non-TCAM users, providing the first statistical analysis of the use of TCAM and help-seeking behaviour among cancer patients in India.

Background

TCAM generally refers to health care practices not offered within hospital facilities (or by clinical practitioners). Traditional medicine (TM) refers to local indigenous practice and belief systems that are used largely in developing countries for health-related purposes.¹¹ Complementary and alternative medicine (CAM) is generally used to refer to a range of non-indigenous, unorthodox practices including homeopathy, naturopathy, herbalism, etc.¹² TM has often been the dominant means of treatment for health problems for centuries, and in some cases, it continues to dominate health care beliefs and practices. India's indigenous systems of medicine, such as Ayurveda, Siddha, and Unani, are more than 5,000 years old, and in rural areas, the Indian population has relied heavily on these practices, particularly Ayurveda. In this study, the TCAMs were combined and analysed whether they are consistent with the World Health Organization (WHO), in order to create a broad distinction between clinical cancer treatment and non-clinical practice.

While urban areas are increasingly utilising orthodox practice, around 80% of the Indian population still rely on non-biomedical practice.^{13,14} A study conducted by the Indian Council of Medical Research (2007) of 45,000 people found that 33% used TCAM for 'common ailments', while only 18% preferred to use this system for serious ailments.¹⁵ Around 38% of households reported visiting TCAM practitioners; 40% in rural and about 30% in urban areas. The reasons for preferring TCAM were mainly the perceived lack of side effects and low costs. Slow progress was the main reason for not preferring TCAM.^{15,16}

In terms of cancer, until now there has been little data available regarding patient usage of TCAM, although estimates have

suggested usage may be around 38%.^{3,17} Chaturvedi et al. (2002) surveyed 550 cancer patients in a Delhi hospital and found that 38% had visited practitioners who offered alternative treatments before going to the hospital.¹⁸ This study found that women were much more likely to use alternative medicines than men (83% of women) and recorded varying delays in seeking biomedical treatment.^{3,18} However, the results were descriptive and there was no statistical testing of the relationship between variables.

Method

Data collection

This article is based on data collected in a structured survey of cancer patients in a private and a public hospital in Delhi, India. After ethical approval was obtained, interviewers were trained in the administration of the survey and the aims of the study. The survey was conducted over the course of four months (November 2007 to February 2008) and all patients presented at the hospitals were interviewed over this period. Discussions with practitioners ensured that the particular period did not introduce any systematic bias. Over this period, the response rate for the survey was 80% resulting in a sample of 825 patients. Patients were approached in the waiting rooms, the study was explained, and informed consent sought. 90% of the interviews were conducted in Hindi and 10% in English.

Sample

The sample included 825 cancer patients. As shown in Table 1, the sample contained a good distribution of patients in terms of gender (53.2% Male; 46.8% Female) and age (mean of 41.39). 61.2% were from the private hospital and 38.8% from the public hospital. The majority were Hindu (87.7%), upper caste (78.3%) and married (82.2%). The sample included a broad mix of disease types and stages (38.3% localised; 16.9% advanced; 29.8% metastatic; 15% unknown). The sample probably represents a relatively wealthier cohort of the Indian population than would be seen in rural and remote areas, or if the study had just focused on public hospitals in Delhi.

Table 1: Socio-demographic characteristics of study participants and health-related variables for users and non-users of TCAM

Characteristics	TCAM user	Non user	p-value
Age (year)			0.020
Mean ± SD	48.38±15.88	43.53±17.52	
Sex (% and count)			0.046
Male	48.4 (137)	55.7 (302)	
Female	51.6 (146)	44.3 (240)	
Marital status (% and count)			0.015

Table 1: Socio-demographic characteristics of study participants and health-related variables for users and non-users of TCAM -continued

Characteristics	TCAM user	Non user	p-value
Single	11.4 (32)	18.8 (101)	0.001
Married	86.4 (242)	80.0 (429)	
Others (Widowed, Divorced)	2.2 (6)	1.2 (6)	
Religion (% and count)			0.001
Hindu	90.8 (246)	86.5 (463)	0.723
Muslim	3.0 (8)	10.3 (55)	
Others	6.2 (17)	3.2 (17)	
Caste (% and count)			0.723
Upper caste	79.1 (178)	77.9 (385)	0.054
Non-upper caste	20.9 (47)	22.1 (109)	
Location (% and count)			
Delhi	45.4 (128)	43.7 (235)	0.054
Surrounds	40.1 (113)	35.1 (189)	
Others	14.5 (41)	21.2 (114)	
MEDICAL VARIABLES			
Hospital (% and count)			0.0001
Public	10.6 (30)	53.4 (290)	0.001
Private	89.4 (253)	46.6 (252)	
Cancer type (% and count)			0.001
Haematological	18.6 (52)	29.4 (155)	0.0001
Solid tumour	81.4 (227)	70.6 (372)	
Disease stage (% and count)			0.0001
Localised	29.0 (82)	43.2 (234)	0.0001
Metastatic	29.3 (83)	30.1 (163)	
Advanced	25.8 (73)	12.2 (66)	
Unknown	15.9 (45)	11.8 (79)	
Delays in seeking help (% and count)			0.0001
Immediately	35.2 (80)	50.0 (117)	0.0001
One week	9.7 (22)	6.8 (16)	
One month	30.8 (70)	36.8 (86)	
Three months	12.8 (29)	4.3 (10)	
More than 3 months	11.5 (11.5)	2.1 (5)	

SD: Standard Deviation; TCAM: Traditional, Complementary and Alternative Medicines

Statistical analysis

Bivariate analysis was carried out to examine the differences, if any, between TCAM users and non-TCAM users. Chi-square tests were used to examine categorical variables (e.g. gender, caste, religion, cancer type), while the t-test was used to examine continuous variables such as age (see table 1). The assumptions of minimum frequency threshold and mutual exclusiveness of the categories were met. This analysis identified a set of background

characteristics of the study participants and their diseases that were significantly different between persons who are and those who are not seeking TCAM treatment. Those who are not seeking TCAM received clinical cancer treatment.

Results

Of the entire sample, 34.3% of patients used TCAM, representing a significant proportion of the population. The most common type

of practice used in this cohort of patients was Ayurveda. 22.8% had used local TM practices (e.g. Ayurveda, Siddha) and 25.5% CAM (e.g. Homeopathy, Meditation, Acupuncture and Reiki). Of the 34.3% of TCAM users, 13.9% used both local TM and non-indigenous CAM.

The results indicate that there are clear differences in the socio-demographic profiles of the two groups as well as their disease status. TCAM users are more likely to be relatively older private patients, they tended to be married upper caste Hindu, generally residing in Delhi or its surrounding states.

Whereas, non-users were more likely to be single, male, non-Hindu public patients in comparison to TCAM users. Non-users also tend to travel longer distances for their treatment (14.8% for TCAM users as compared to 21.6% for non-users). 61.9% of TCAM users reported being influenced in their decision making by information found on the Internet.

When the tumour types were categorized into solid and haematological malignancies, the solid tumour patients were statistically more likely to be TCAM users compared to those with haematological malignancies ($p < 0.001$). TCAM users were statistically more likely to have metastatic or advanced disease compared with non-users ($p < 0.001$).

The study hypothesized that delay in seeking help from orthodox healthcare facilities may be related to being a TCAM user or non-user. In order to test this, all patients were asked about the duration of time between noticing symptoms of cancer, and seeking help from an orthodox practitioner/hospital. The results showed a statistically significant relationship between the use of TCAM and delay in seeking help from orthodox medicine ($p < 0.001$). 35.2% of respondents using TCAM sought help immediately after onset of symptoms whereas 50% of non-users immediately sought help from orthodox medicine. 12.8% of TCAM users waited three months or more after noticing symptoms whereas only 4.3% of non-users waited this long.

Discussion

The WHO has recently been promoting the use of TCAM in developing countries.¹⁹ However, it is important to be aware of the implications of patient use of non-orthodox treatments, particularly in the context of cancer. This study reported on a structured random survey examining Indian cancer patients' use of TCAM, including important socio-demographic factors related to the use of TCAM, and the relationship between TCAM use and timing of presentation to orthodox healthcare facilities. This study of 825 cancer patients illustrated the relative importance of gender, age and hospital type in shaping the use of TCAM.

The study also found that women were marginally more likely to use TCAM than men.¹⁸ Furthermore, it seemed that patients with solid tumours were more likely to use TCAM than patients with hematological malignancies, potentially due to the slower progression of disease in some solid tumours. In acute hematological malignancies the symptomatology is in all likelihood too rapidly developing for patients to start and maintain the use of TCAM

Hitherto no research has been done to examine the statistical relationship between delay in help seeking and TCAM usage. The data presented in this study showed a significant statistical relationship between the use of TCAM and the delay in seeking help from orthodox practitioners and facilities, consistent with anecdotal observations by Indian oncologists. The fact that 12.8% of TCAM users waited three months or longer after noticing symptoms of cancer suggests a need to examine more carefully the role of TCAM in the high rates of advanced disease recorded in patients on initial presentation to orthodox cancer facilities in India.^{1, 3, 8, 20}

Conclusion

While the reasons underlying this delay warrant further examination, there is an urgent need to understand the implications of TCAM usage on patient behaviour, choice and survival. All the patients involved in this study had access (at least eventually) to clinical cancer facilities that many Indians do not have. Given the high rates of TCAM usage in rural and remote areas, it is possible that the trends documented here may in fact be greatly enhanced in more remote locations. The issues of costs associated with TCAM versus orthodox care are critical to such patterns. So too are the potential interactions between TCAM and clinical care, including high levels of heavy metals in certain TCAM remedies.

However, there are also ideological issues that need to be addressed whereby TCAM practitioners view illness and disease differently from orthodox practitioners and seek to treat cancer from a different and even erroneous perspective. The results have significant implications for cancer care in India and potentially in other developing countries. Further research is needed to examine the roles and implications of TCAM usage in different disease stages given the reported high use of TCAM in palliative and end-of-life care.

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