A Cross-Sectional Study to Assess the Prevalent Myths and Misconceptions Among the Caregivers of Patients With Cancer

Pallvi Kaul  
Shri Guru Ram Rai Institute of Medical and Health Sciences

Ajeet Ramamani Tiwari  
Shri Guru Ram Rai Institute of Medical and Health Sciences

Deepti Choudhary  
Shri Guru Ram Rai University

Rhythm Walia  
Shri Guru Ram Rai Institute of Medical and Health Sciences

Pankaj Kumar Garg (✉️ dr.pankajgarg@gmail.com)  
Shri Guru Ram Rai Institute of Medical and Health Sciences

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Abstract

INTRODUCTION

Certain popular ideas about how cancer starts and spreads—though scientifically wrong—can seem to make sense, especially when those ideas are rooted in old theories. The present study was conducted to assess the prevalence of myths and misconceptions among the caregivers of patients with cancer.

MATERIAL AND METHOD

A hospital-based survey in a tertiary teaching hospital was conducted where caregivers (aged 18–70 years) were administered questionaries containing 10 close-ended questions. The study was conducted in small batches of 20-25 participants per week. The questionnaire was analysed, and a health care worker discussed the questionnaire with the participants and clarified their myths.

RESULTS

A total of four hundred participants were included in the study. The median age of the participants was 45 years (IQR 35-59). The majority of the participants were males (85%, n=340). Table 1 displays the common myths and misconceptions prevalent in the caregivers of patients with cancer.

CONCLUSION

The present study highlights the widespread cancer myths and misconceptions among the caregivers of patients with cancer. Therefore, the need of the hour is to eliminate them to avoid any unnecessary treatment delays and strengthen the emotional and social support system for patients with cancer.

Introduction

The new global cancer data extracted from the GLOBOCAN 2020 database suggest that the global cancer burden has risen to 19.3 million cases and almost 10 million cancer deaths. The global cancer burden is expected to rise to about 28.4 million cases by 2040, a 47% rise from 2020, with a larger increase in transitioning (64–95%) versus transitioned (32–56%) countries due to demographic changes (1). The increasing prevalence of cancer in the developing world can be attributed to the increase in life expectancy, increased urbanization, and the adoption of western lifestyles. There is heterogeneity in cancer incidence and patterns across India and a lower proportion (< 33%) of early-stage presentation for common cancers. The traditional image of cancer is one of fear and pain. Many cancers are curable, provided detected early by screening, and treated effectively. Cancer is a disease where myth can prematurely end a life. The social, emotional, and financial devastation that all too often accompanies a diagnosis of cancer is, in large part, due to the cultural myths and taboos surrounding the disease. Certain popular ideas about how cancer starts and spreads—though scientifically wrong—can seem to make sense, especially when those ideas are rooted in old theories. But wrong ideas about cancer can lead to needless worry and even hinder good prevention and treatment decisions.
Undoubtedly, cancer is still a dreadful challenge for oncologists and researchers but that does not stop us from combating this killer disease. Diagnosis of cancer does not indicate that the person is suffering from an incurable disease where death is inevitable. Therefore, the need of the hour is to emphasize debunking innumerable myths and misconceptions associated with cancer. The present study was conducted to assess the prevalence of myths and misconceptions among the caregivers of patients with cancer.

**Methods**

**Study Design** - Cross-sectional questionnaire-based survey.

**Setting** - Hospital-based survey in a tertiary teaching hospital in north India.

**Sample Size** - The sample size was calculated using the following formula. Considering the 50% prevalence of cancer myths and misconceptions among the caregivers of patients with cancer ($p = 0.5$), the sample size ($n$) was calculated to be 384 with a 95% confidence level and 5% precision of estimate ($d = 0.05$) using the formula $n = \frac{z^2(p)(1-p)}{d^2}$.

**Participants** – Caregivers (aged 18–70 years) of the patients with cancer admitted to a tertiary teaching hospital in North India. Informed consent was obtained from all the participants before they participated in the study. The participants were informed that their participation was completely voluntary and would not affect the treatment of their patients in any way.

**Questionnaire** – It consisted of 10 close-ended questions, available in two of the most common languages read and spoken in the country- Hindi, and English. To facilitate the participation of respondents willing to participate but lacking sufficient skills to read and/or write, a language translator was provided to aid comprehension and filling of the questionnaires. To maintain the absolute confidentiality of the participants, no information apart from the age and gender of the participants was asked to inspire confidence and ensure that they could answer the questions with absolute honesty. The study was conducted in small batches of 20–25 participants per week. After the participants completed the questionnaire, a health care worker discussed the questionnaire and clarified all the myths.

**Result**

A total of 400 participants were included in the study. The median age of the participants was 45 years (IQR 35–59). The majority of the participants were males (85%, $n = 340$). The majority of the patients opted for questionnaires in the Hindi language (94%) followed by the English language (supplementary file). A language translator was needed for 8 (2%) participants. The discussion rounds were attended by 378 (94.5%) of the participants. At the end of the discussion rounds, a survey was conducted to assess the effectiveness of the intervention i.e discussion rounds. About 91.7% of participants reported that the discussion rounds were “effective” while 6% found them to be “somewhat effective”. Table 1 displays the demographic details and an overview of the responses of the participants.
Table 1 Demographic details and responses of the participants.

<table>
<thead>
<tr>
<th>PARAMETER ASSESSED</th>
<th>NO. OF PATIENTS (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender of respondents (n= 400)</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>340 (85%)</td>
</tr>
<tr>
<td>Female</td>
<td>60 (15%)</td>
</tr>
<tr>
<td>Age (in years)</td>
<td></td>
</tr>
<tr>
<td>Range</td>
<td>19-68</td>
</tr>
<tr>
<td>Median (IQR)</td>
<td>45 (35-59)</td>
</tr>
<tr>
<td>Preferred language (n= 400)</td>
<td></td>
</tr>
<tr>
<td>Hindi</td>
<td>377 (94%)</td>
</tr>
<tr>
<td>English</td>
<td>15 (3.75%)</td>
</tr>
<tr>
<td>Translator</td>
<td>8 (2%)</td>
</tr>
<tr>
<td>Discussion rounds (n= 400)</td>
<td></td>
</tr>
<tr>
<td>Attended</td>
<td>378 (94.5%)</td>
</tr>
<tr>
<td>Missed</td>
<td>22 (5.5%)</td>
</tr>
<tr>
<td>Post-intervention survey (n=378)</td>
<td></td>
</tr>
<tr>
<td>Effective</td>
<td>347 (91.7%)</td>
</tr>
<tr>
<td>Somewhat effective</td>
<td>23 (6%)</td>
</tr>
<tr>
<td>Not effective</td>
<td>0 (0%)</td>
</tr>
<tr>
<td>Can’t say</td>
<td>8 (2.1%)</td>
</tr>
</tbody>
</table>

Table 2 displays the common myths and misconceptions prevalent among the caregivers of patients with cancer.
Table 2
Responses of the participants for various cancer myths.

<table>
<thead>
<tr>
<th>Serial number</th>
<th>Myths</th>
<th>Agree</th>
<th>Disagree</th>
<th>Not sure</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Number (n)</td>
<td>Percentage (%)</td>
<td>Number (n)</td>
</tr>
<tr>
<td>1</td>
<td>Cancer spreads from one person to another.</td>
<td>83</td>
<td>20.8%</td>
<td>198</td>
</tr>
<tr>
<td>2</td>
<td>Cancer is most commonly an inherited disease and so it runs in families.</td>
<td>22</td>
<td>5.5%</td>
<td>298</td>
</tr>
<tr>
<td>3</td>
<td>Cancer affects elderly people only</td>
<td>44</td>
<td>11.0%</td>
<td>336</td>
</tr>
<tr>
<td>4</td>
<td>Cancer occurs in individuals who have done harm to others</td>
<td>104</td>
<td>26.0%</td>
<td>276</td>
</tr>
<tr>
<td>5</td>
<td>Injuries such as falls cause cancer</td>
<td>91</td>
<td>22.8%</td>
<td>221</td>
</tr>
<tr>
<td>6</td>
<td>Cancer is always very painful</td>
<td>182</td>
<td>45.5%</td>
<td>120</td>
</tr>
<tr>
<td>7</td>
<td>Diagnostic needle biopsy contribute to the spread of cancer</td>
<td>63</td>
<td>15.8%</td>
<td>60</td>
</tr>
<tr>
<td>8</td>
<td>Cancer treatment should not be administered to elderly patients</td>
<td>3</td>
<td>0.8%</td>
<td>377</td>
</tr>
</tbody>
</table>
The most prevalent myth amongst the caregivers was that cancer is painful 45.5%. Other common myths reported include: cancers occurring due to some sin/harm done to others, cancer resulting from some form of injuries, and cancer spreading from one person to another reported in 26%, 22.8%, and 20.8% of the respondents respectively. Diagnostic needle biopsy contributes to the spread of cancer reported in as high as about 15.8% of the respondents. The caregivers were also very concerned about the chances of inheriting the disease from the patients especially if they were blood relatives. Figure 1 shows the pictorial representation of the responses to the prevalent myths.

**Discussion**

Culture is defined as a set of shared and socially transmitted ideas about the world that are passed down from generation to generation (2, 3). Culture as a socially transmitted phenomenon carries with it the idea that people who interact regularly know the same unwritten rules and criteria for social life that confer status as a member of the group (3). When applied to illness, the beliefs and values from a cultural model of disease influence perceptions about the meaning of an illness, the useful types of treatment, and the likely outcome of health behaviours related to the prevention and control of disease (4). At the same time, previous research has demonstrated that world views, as well as their subsequent attitudes, beliefs, and values related to health, differ among ethnically diverse groups (5). That is why, concerning cancer, cultural beliefs and values are increasingly being recognized as important determinants of not only cancer prevention and control behaviours but also of psychological and behavioural outcomes following cancer diagnosis and treatment.

Cancer-related myths and stigma about cancer are important problems that must be addressed (6, 7). Cancer remains taboo and people with cancer are even subjected to stigma and discrimination that may stop them from admitting that they have cancer. There are several reasons that cancer is stigmatized. Many people perceive cancer to be a fatal disease. Cancer symptoms or body parts affected by the disease can cultivate stigma. Fears about treatment can also fuel stigma. There was evidence of myths associated with cancer, such as the belief that cancer is contagious, or cancer may be seen as a punishment. Cancer symptoms or body parts affected by the disease can cultivate stigma.
Gynaecological or breast cancers may present symptoms that women are reluctant to disclose to their doctors, and they may be even less willing to undergo the necessary physical exams to investigate the cause of such symptoms.

In the present study, the most prevalent myth amongst the caregivers was that cancer is always very painful reported by about 45.5% of the respondents. The majority of the cancers in the early stage are usually painless and early presenting symptoms are usually ignored by the patients resulting in a delay in seeking treatment or presentation at a relatively advanced stage compromising the overall outcome of the treatment (8). Diagnostic needle biopsy contributes to the spread of cancer reported in about 20% of the respondents. This myth was dispelled by the landmark study of more than 2,000 patients by Wallace et.al. (9) which showed that patients receiving EUS-FNA were marginally associated with improved overall survival without any impact on the cancer-specific survival as compared to the Non-EUS-FNA group. This study reinforced that the physicians and the patients should feel reassured that biopsy in a setting of cancer is a safe procedure. Another common misconception about cancer in our study group was the fear of cancer being contagious, which was reported by about 20.8% of the respondents. These figures represent the tip of the iceberg and the estimated prevalence of this myth far exceeds of what is reported especially in the rural areas. The patients with cancers are often isolated by their family members or some form of isolation like avoiding sharing of utensils, clothes or touching the patients is practiced. Unfortunately, several incidents of such practices are even reported by well-educated patients and their families (10). This undermines the efforts of improving the quality of life of patients with cancer which is challenged by the discrimination, often based on unscientific and baseless assumptions. At the same time, it is important to create awareness regarding certain cancers associated with viruses that are transmitted by blood transfusion, shared needles or unprotected sex (11). The use of vaccination in the prevention of virus-associated tumours has evolved as an effective cancer preventive strategy. The results of various studies on vaccination programmes directed against hepatitis B virus (HBV) and the human papillomavirus (HPV) have shown a very high vaccine efficacy with cancer prevention rates of up to 100% (12). Hence, health care policymakers must emphasize proactive vaccination strategies for the widespread adoption of vaccination programmes.

In 2008, the Union for International Cancer Control published the famous World Cancer Declaration. The fifth target of this Declaration stated that ‘in 2020 public attitudes towards Cancer will improve and damaging myths and misconceptions about the disease will be dispelled’ about the importance of this issue.

Stigmas about cancer present significant challenges to cancer control: stigma can have a silencing effect, whereby efforts to increase cancer awareness are negatively affected.

A negative public concept of cancer can perpetuate a cycle of fear and misinformation that hinders raising awareness about cancer prevention and the importance of early detection. Good practice requires an understanding of cultural and social aspects of life and death to enable care professionals to best
meet the needs of patients and their families. Workforce education is important in the provision of culturally appropriate palliative and end-of-life care.

In a pilot survey conducted by Ray et al. (13) at the Chittaranjan National Cancer Institute, Kolkata, India, 900 people were assessed for their level of cancer awareness. The authors found that only 8 per cent had prior exposure to any cancer awareness programme, 37% on All India Radio, 36% on Doordarshan / private television channels, 34% via articles and only 13% had seen cancer awareness posters and hoardings (unpublished findings). The results envisaged a great lacuna in cancer awareness prevailing within the common mass. Lack of awareness can be attributed as the root cause of the oncologic misconceptions. Cancer awareness programmes can be a foremost initiative and an effective tool to debunk these myths.

**Limitations**

We feel that our results may underestimate the percentage of the population having some common myth associated with cancer as it represents the population motivated enough to seek medical intervention contrary to the cohort of cancer patients who never seeks an expert opinion or opts for alternative treatment options and succumbs to the disease before reaching the oncologist. To keep the questionnaire crisp yet comprehensive we may have underscored many other prevalent myths which might be more pertinent in some other geographic region.

**Strengths**

We believe that the simplicity of the study design and the requirement of minimal manpower to conduct the same permits easy replicability across various centres. An audit of our post-counselling sessions showed a positive trend and provided an insight for incorporating this strategy as a transformative action for reformed attitudes to revolutionize the mindset to bring forth behavioural and systemic changes. Multicentric prospective cohort studies using validated questions specific and of more concern in a particular geographical area will give a better estimate of the prevailing burden of the pre-existing myths related to cancer and aid in devising an effective strategy to combat and debunk them.

The most important benefit that we derived from this study was that it provided us with a brief overview of some of the most prevalent myths in our geographic area. The information derived is being used by the oncologists at our centre to prospectively address these myths during the patient counselling and inpatient visit sessions. This helps to ensure treatment compliance, decrease the chances of treatment abandonment and seeking alternative treatment strategies which are not backed by concrete evidence and improving the oncological outcomes of our patients.

**Conclusion**
The current study highlights that in the current era of digital health aiming at more efficient and sustainable health systems, health care professionals still need to tackle the lacuna of cancer awareness and widely prevalent myths and misconceptions associated with cancer which are not only confined to LMIC but is a global healthcare concern. These popular ideas about how cancer starts and spreads—though baseless and scientifically incorrect—yet can seem to make sense amongst the common masses especially when these ideas are rooted in old theories. Appropriate communication via the health workers is a concept that needs urgent implementation to create a liaison between the health care providers and the community resulting in early diagnosis, apt treatment and ultimately improved outcomes.

Declarations

**Ethical Approval**: The ethical approval was obtained from the institutional ethics committee of SGRRIMHS & SMIH.

**Competing interests**: not applicable

**Authors' contributions**: PK and PKG conceptualized the design of the study, drafted the manuscript. All authors (PK, PKG, AT, DC, RW) approved the manuscript.

**Funding**: not applicable

**Availability of data and materials**: not applicable

**References**


**Figures**

![Cancer Myths & Their Distribution](image)

**Figure 1**
Histogram showing various responses of the participants to the cancer myths assessed in the questionnaire

**Supplementary Files**

This is a list of supplementary files associated with this preprint. Click to download.

- questionnaires.docx