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Treatment trajectory of tobacco-related cancer patients: A study in Assam, India

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ABSTRACT

Background: In India, more than half of the total cancer cases are diagnosed at an advanced stage resulting in a high mortality rate. Early diagnosis and proper treatment may result in reduced mortality. Understanding the treatment trajectory followed by a patient is important for reducing diagnostic delay which may result in improved prognosis and treatment. With this background, the current study attempts to understand the treatment-seeking processes of Tobacco-related Cancer (TRC) patients in the state of Assam.

Methods: Explanatory Sequential Mixed design was adopted for the study. In the first phase of the study, 100 participants were interviewed using an interview schedule and then 11 in-depth interviews were conducted in the later phase to understand the subject matter in more depth.

Results: The study revealed that the initial point of contact for seeking help for most of the participants was their family, which was followed by an alternative system of medicine including faith healers and quacks. Participants with a lower level of literacy and economic instability were seen to have approached family members, faith healers and quacks more as compared to the people with a higher level of literacy and economic stability who approached health professionals, friends, and others for initial help-seeking. Also, an association between causal health beliefs and treatment choices of the patients were discovered.

Conclusions: The study suggests addressing the beliefs and practices associated with cancer care (both modern and traditional) by engaging mass awareness. Need for designing cancer-education programmes for the general population was also advocated.

1. Introduction

Cancer, one of the major NCDs, with increasing morbidity and very high mortality results in a heavy burden of disease [1,2]. Globally around ten million people are diagnosed with cancer each year and more than half of the patients eventually die from the disease [2]. It is among the top five leading causes of global death [1,3]. GLOBOCAN estimates that there were 18.1 million incidence cases of cancer worldwide with 9.6 million mortalities in 2018 [4]. In India, in the same year, around 1.15 million cancer incidence and 7.84 lakh mortalities were reported [4]. Cancer is the second most common disease responsible for maximum mortality in India [5], and about 40% of the cancers reported in the country are due to tobacco. The North-eastern states comprise more than 50% of the TRCs compared to all cancer cases. The North-Eastern region shows a marked increase in cancer incidence and mortality, with a very different pattern compared to the rest of India [6]. TRCs like lung, oesophagus, oral cavity etc. are very common [6,7]. According to the Indian Council of Medical Research (ICMR) Report (2009-11), the leading sites of cancer in Assam are oesophagus, hypopharynx, lung, oral cavity, larynx etc. which are tobacco-related sites.

The mortality rate in India due to cancer is as high as 68% and the survival rate is very low, below 30% [8,9]. Cancer causes more than 10% of the annual deaths in India [9]. Incidence and mortality cases due to the disease are higher in more affluent states and also in the rural areas mortality is high where availability and accessibility of cancer treatment is a matter of concern [9]. On the other hand, countries like North America and Western Europe have a survival rate of around 60% for cancer patients [9]. So, delayed diagnosis, poor prognosis and inadequate or suboptimum treatment along with the indictment in the availability, accessibility, affordability, and inequality in the cancer care delivery are the factors which result in reduced survival of cancer patients [10]. In the less developed and geographically sparse regions of the nation including the north-eastern states, diagnostic and treatment delay for cancer patients are also connected with the availability, accessibility and awareness about specialized treatment facilities along with their unique socio-cultural practices [11]. The state of Assam is not an exception in that case.

The awareness about cancer disease and its treatment alternatives are low among the people suffering from it and also among those people who surround the patient. Seeking and receiving proper timely

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treatment among cancer patients is very rare [11]. Further, lack of awareness regarding the signs, symptoms and treatment settings of cancer was identified by WHO (2009) as one of the major contributors to treatment delay [12]. This is the reason why cancer patients usually report it at an advanced stage of the disease. As the statistics also reveal in India more than 50% of the cancers are reported at an advanced stage. The study by Pati et al. (2013) also notes that most of the preventable delays in seeking cancer treatment are because of the lack of awareness about the signs and symptoms, risks factors for cancer and appropriate prevention and treatment facilities [12].

It is evident from studies that cancer patient's pathways to the presentation and initial management of their illness in the healthcare setting are key determinants of the patient's treatment outcomes [13]. The study by Walter et al. (2012) tried to understand patient's pathways to present to health care in accessing cancer diagnosis and treatment and found factors associated with patients, system, psychological, social and behavioural etc. to be responsible for the delay in treatment. Also, other studies revealed that in every phase of delay in diagnosis and treatment, the decision-making process is involved at individual, family and the institutional level [11]. Every step towards seeking treatment involves the decision-making process from the patient, their family members, and physicians which is a complex interplay of several factors [12]. Many of these factors are linked to the beliefs and understanding of the patients and at the broader level connected with the socio-cultural milieu and the interplay of these varied factors show various treatment-seeking pathways [11,12]. Usually, cancer treatments are prolonged and misleading due to misbeliefs surrounding the disease and varied misinformation prevailing in the socio-cultural ambit. Furthermore, the literature reveals that early diagnosis of cancer and proper treatment may improve the outcome by reducing the mortality [9,12,13]. It is also observed that most of the studies on the treatment-seeking process were on cancers of the reproductive tract [11]. So, understanding the treatment trajectory followed by a patient to access cancer-specific treatment is important for reducing diagnostic delay which may result in improved prognosis and treatment. Considering the significance of the research concern, the current paper aims to understand the treatment-seeking behaviour of TRC patients. It also seeks to understand the decision-making processes involved in choosing and continuing a particular treatment, as the delay in different phases of decision-making affects the treatment and the treatment-seeking behaviour of a patient.

2. Methodology

This paper reports the findings of a study conducted in the Barak Valley region of Assam. Assam is a northeastern state of India and Barak Valley is located in the southern part of the State. The Valley consists of three districts with the overall health status including the Human Development Index and Infant Mortality Index below the State average [14]. The participants of the study were drawn from two main hospitals which provide cancer-specific treatment and services in the Valley namely, Silchar Medical College & Hospital, Silchar (SMCH) and Cachar Cancer Hospital & Research Centre, Silchar, Assam (CCHRC). CCHRC is a charitable hospital that provides comprehensive cancer care, and SMCH is the only state-funded referral hospital in the Barak Valley having various treatment facilities including cancer. The Population-Based Cancer Registry of Cachar district is situated in SMCH and the Hospital-Based Registry is placed in CCHRC.

Explanatory Sequential Mixed design was adopted for the study which followed two separate stages of data collection and analysis. At the first phase of the study, quantitative data was collected and analyzed followed by the collection and analysis of qualitative data in the second phase of the research. In the first phase, 100 participants were randomly selected (35 from SMCH and 65 from CCHRC) and Microsoft Excel was used to draw the participants of the study on a random basis. Then in the second phase, 11 participants with diverse treatment-seeking experiences were purposively selected (5 from SMCH and 6 from CCHRC) for in-depth understanding about their experiences in seeking treatment. The different criteria namely age, site of cancer, nature of the treatment, different experiences etc. were considered for inclusion of samples.

Standardized interviews using interview schedules were conducted for the 100 participants in the first phase of the study and then interview guides were used in the later phase. Tools were validated after doing a pilot study prior to the data collection. Furthermore, analysis of the quantitative data was done using the package of SPSS (version 20) and then the descriptive statistical approach was used to present the findings. For qualitative data, thematic analysis procedure was used to analyze the data. Emphasis was given in pinpointing and recording patterns across the data sets that are important to the description of the phenomena under study and associated with the research questions.

3. Findings

3.1. Socio-demographic profile of the participants

Three-fourth of the study participants (75%) was male and the remaining (25%) were female. The higher representation of men in the sample is in reflection with the higher prevalence of TRCs among the male population than their female counterparts in the study area. The majority of the participants (51%) were in the age group of 50–70 years, followed by those in the age group of 30–50 years (41%), with 5% below 30 years and 3% above 70 years of age.

One-fourth of the total participants had not received any formal education. Of those who were illiterate, 56% were male and the remaining (44%) were female. The majority of the participants (28%) had middle school level education followed by 20% with only primary education and 13% in the higher secondary level. Also, of those participants qualified up to higher secondary level, 90% were male-only. Of the total participants who were graduates or above, 75% were male. The literacy rate was relatively lower among the female participants.

A major section of the participants (27%) were unable to work and were dependent on their family members for the livelihood. Of those dependent participants, about 67% were male and the remaining (33%) were female. Around half of the females (48%) were housewife; they had not been engaged in major wage-earning activities. Almost an equal number of the participants (16%) were engaged in semi-skilled work, wage-earning and business (Table 1).

Table 1
Socio-demographic Profile of the Participants.

Variable	Gender of the Participants		Total (N = 100)
Age Group	Men	Women	
< 30 years	2 (2%)	3 (3%)	5 (5%)
30–50 years	27 (27%)	14 (14%)	41 (41%)
50–70 years	43 (43%)	8 (8%)	51 (51%)
> 70 years	3 (3%)	0	3 (3%)
Educational Qualification			
Illiterate	14 (14%)	11 (11%)	25 (25%)
Primary Education	15 (15%)	5 (5%)	20 (20%)
Middle School	21 (21%)	7 (7%)	28 (28%)
Secondary	13 (13%)	0	13 (13%)
Higher Secondary	9 (9%)	1 (1%)	10 (10%)
Graduate & Above	3 (3%)	1 (1%)	4 (4%)
Occupation			
House Wife	0	12 (12%)	12 (12%)
Wage Earner	16 (16%)	0	16 (16%)
Semi-skilled worker/ Farmer	14 (14%)	2 (2%)	16 (16%)
Business	17 (17%)	0	17 (17%)
Govt. Employee	4 (4%)	2 (2%)	6 (6%)
Retd. Employee	5 (5%)	0	5 (5%)
Student	1 (1%)	0	1 (1%)
Dependent	18 (18%)	9 (9%)	27 (27%)
Total	75 (75%)	25 (25%)	**100** (100%)

Table 2
Initial Approach for Seeking Help.

Variables	Initial Approach by Patients for Seeking Help					Total (N = 100)
Gender	Family Members	Friends	Health Professionals	Faith Healers	Others[1]	
Male	44 (44%)	9 (9%)	9 (9%)	6 (6%)	7 (7%)	75 (75%)
Female	21 (21%)	0	1 (1%)	2 (2%)	1 (1%)	25 (25%)
Total	65 (65%)	9 (9%)	10 (10%)	8 (8%)	8 (8%)	**100** (100%)
Educational Qualification						
Illiterate	20 (20%)	1 (1%)	1 (1%)	3 (3%)	0	25 (25%)
Primary Education	10 (10%)	0	1 (1%)	2 (2%)	3 (3%)	20 (20%)
Middle School	19 (19%)	1 (1%)	2 (2%)	2 (2%)	4 (4%)	28 (28%)
Secondary	9 (9%)	1 (1%)	1 (1%)	1 (1%)	1 (1%)	13 (13%)
Higher Secondary	5 (5%)	2 (2%)	3 (3%)	0	0	10 (10%)
Graduate & Above	2 (2%)	0	2 (2%)	0	0	4 (4%)
Total	65 (65%)	9 (9%)	10 (10%)	8 (8%)	8 (8%)	**100** (100%)
Occupation						
House Wife	9 (9%)	0	1 (1%)	2 (2%)	0	12 (12%)
Wage Earner	9 (9%)	1 (1%)	2 (2%)	2 (2%)	2 (2%)	16 (16%)
Semi-skilled worker/Farmer	12 (12%)	2 (2%)	1 (1%)	0	1 (1%)	16 (16%)
Business	6 (6%)	4 (4%)	3 (3%)	1 (1%)	3 (3%)	17 (17%)
Govt. Employee	4 (4%)	1 (1%)	1 (1%)	0	0	6 (6%)
Retd. Employee	4 (4%)	0	1 (1%)	0	0	5 (5%)
Student	0	0	1 (1%)	0	0	1 (1%)
Dependent	21 (21%)	1 (1%)	0	3 (3%)	2 (2%)	27 (27%)
Total	65 (65%)	9 (9%)	10 (10%)	8 (8%)	8 (8%)	**100** (100%)

[1] **Other** sources for seeking initial help were Chemist and Quacks including different tradtional healers.

3.2. Patients' initial approach for seeking help

The different nature of health complications, other associated problems and the kind of exposures available made a participant approach it in a different way. On being faced by difficulties, the concerned person first discusses with his/her family members and then approaches others as per the necessity. Likewise, for a majority of the participants (65%) the initial point of contact for seeking help was the family, followed by health professionals (10%) such as medical professionals (medicine, surgery, and ENT), friends (9%), faith healers and others. Around 8% of the total participants had approached some other sources like - Chemist, Quacks for seeking help. It was also seen that 84% of the female participants sought the help of family members which was relatively higher than the male participants. On the other hand, the initial approaches to health professionals, friends, and others for seeking help were relatively higher among male participants (Table 2).

Participants with a low level of literacy were seen to have approached family members & faith healers more as compared to the people with a higher level of literacy. Again, the participants with a higher level of literacy had approached health professionals more after the appearance of the primary symptoms as a point of initial contact for seeking help in comparison with the less educated participants who reached faith healers (including shrine, sages to take charms and amulets) more. Furthermore, the participants who were dependent on others for their livelihood had approached the family more for initial help-seeking. Also, people engaged in skilled employment (such as government employee, businessman, retired. employee) had sought the help of health professionals more than those with unskilled or semi-skilled work.

Table 3 provides an understanding of the patient's initial approach for help-seeking in the light of their perceived cause of illness. By and large, most of the participants with diverse health beliefs towards the causality of cancer approached their family members first for seeking help. Among the other points of contact for help-seeking, health professionals were approached by participants who attributed factors associated with lifestyle & food habits, biological and other factors to be the cause of their illness. Participants who attributed the cause of their illness to supernatural factors (God's will or bad luck) were found to be highest among the participants who approached faith healers in the beginning for seeking help.

3.3. Initial treatment trajectory of cancer patients

Consultation with other health professionals along with other sources of support & services before visiting Cancer Care Professionals (CCPs) prolonged the treatment trajectory. The health beliefs and understanding of the patients and their family members played a significant role in choosing and approaching a particular source to seek help.

The treatment trajectory followed by the study participants were alternative systems of medicine such as Homeopathic Medicine, and Ayurvedic Medicine along with faith healers, Quacks & Naturopaths (e.g., *jodi-boti*, *kabiraj*[1], sages to take charms and amulets), other Allopathic physicians (like- doctors of medicine, surgery, ENT). Before visiting the CCPs, 26% of the participants consulted other Allopathic physicians which were followed by Homeopathic treatment (23%), others (18%) (viz. Ayurvedic medicine & faith healing, Homeopathic treatment & Chemist, Homeopathic & Ayurvedic), and Quacks (10%). Around 9% had undergone Ayurvedic treatment, and also the same percentage of the participants had visited faith healers too. Only five participants directly visited the cancer hospital for treatment.

Concerning the participant's educational qualification and their perceived cause of the illness, it was observed that there was variation across the participants in respect of the choice of the treatment. The participants without any formal education and those with a lower level of education (such as primary education, middle school) had consulted alternative systems of medicine (Homeopathic, Ayurvedic), and Quacks more as compared to those with a higher level of literacy (viz. secondary, higher secondary, graduation and above). Participants with a higher level of literacy had consulted Allopathic physicians relatively more.

People with diverse socio-cultural backgrounds make diverse health attributions influencing health beliefs and subsequent health behaviour, practices and treatment choices [15]. Several studies have confirmed the significant association between health beliefs, health practices, and treatment-seeking processes. Table 4 presents the treatment trajectory of cancer patients in the light of the participant's perceived cause of their illness. Concerning the participant's health beliefs

[1] **Kabiraj** is a person who traditionally practices Ayurveda in India.

Table 3
Perceived Cause of Cancer & Initial Approach by Patient for Seeking Help.

Perceived Cause of Cancer	Initial Approach by Patient for Seeking Help					Total (N = 100)
	Family Members	Friends	Health Professionals	Faith Healers	Others	
Life style & food habits	13 (13%)	4 (4%)	4 (4%)	0	1 (1%)	22 (22%)
Biological (aging, genetics)	1 (1%)	0	1 (1%)	0	0	2 (2%)
Family history	3 (3%)	0	0	0	0	3 (3%)
God's will or Bad luck	22 (22%)	4 (4%)	2 (2%)	5 (5%)	4 (4%)	37 (37%)
Others	14 (14%)	0	2 (2%)	2 (2%)	3 (3%)	21 (21%)
God's will & also food habits	12 (12%)	1 (1%)	1 (1%)	1 (1%)	0	15 (15%)
Total	65 (65%)	9 (9%)	10 (10%)	8 (8%)	8 (8%)	**100** (100%)

Table 4
Initial Treatment Trajectory of Patients & Its Interface with Perceived Cause of Cancer and Education.

Variables	Treatment Trajectory of Patients							Total (N = 100)
Educational Qualification	Homoeopathic	Ayurvedic	Faith Healers	Other Allopathic Physicians	Directly visited CCPs	Quacks	Others[1]	
Illiterate	6 (6%)	2 (2%)	6 (6%)	2 (2%)	1 (1%)	2 (2%)	6 (6%)	25 (25%)
Primary Education	6 (6%)	3 (3%)	2 (2%)	6 (6%)	0	1 (1%)	2 (2%)	20 (20%)
Middle School	9 (9%)	3 (3%)	0	6 (6%)	2 (2%)	3 (3%)	5 (5%)	28 (28%)
Secondary	0	0	1 (1%)	5 (5%)	0	4 (4%)	3 (3%)	13 (13%)
Higher Secondary	2 (2%)	0	0	4 (4%)	2 (2%)	0	2 (2%)	10 (10%)
Graduate & Above	0	1 (1%)	0	3 (3%)	0	0	0	4 (4%)
Total	23 (23%)	9 (9%)	9 (9%)	26 (26%)	5 (5%)	10 (10%)	18 (18%)	**100** (100%)
Perceived Cause of Cancer								
Life style & food habits	4 (4%)	1 (1%)	2 (2%)	6 (6%)	3 (3%)	2 (2%)	4 (4%)	22 (22%)
Biological (aging, genetics)	0	0	0	1 (1%)	1 (1%)	0	0	2 (2%)
Family history	1 (1%)	0	0	0	0	0	2 (2%)	3 (3%)
God's will or Bad luck	10 (10%)	4 (4%)	6 (6%)	7 (7%)	0	4 (4%)	6 (6%)	37 (37%)
Others	4 (4%)	2 (2%)	1 (1%)	9 (9%)	0	3 (3%)	2 (2%)	21 (21%)
God's will & also food habits	4 (4%)	2 (2%)	0	3 (3%)	1 (1%)	1 (1%)	4 (4%)	15 (15%)
Total	23 (23%)	9 (9%)	9 (9%)	26 (26%)	5 (5%)	10 (10%)	18 (18%)	**100** (100%)

[1] **Other** Treatment trajectory followed by participants before visiting oncologist are- Ayurvedic & faith healing, Homeopathic & Chemist, Homeopathic & Ayurvedic.

towards the causality of cancer, among the participants who accessed Homeopathic treatment, the majority of them attributed the cause of their illness to supernatural power (God's wishes). Among the participants who consulted other Allopathic Physicians before visiting oncologist, about 35% attributed the cause of their illness to factors like-side effects from other medicine, infection from previous health complications/ earlier diseases. Among the participants who visited faith healers, more than 65% were those who attributed the cause of their illness to some supernatural factors (God's wishes or bad luck). Of those two participants who attributed the cause of their illness to biological factors, one consulted an Allopathic physician and the other participant directly visited CCPs for treatment. Thus, the results are in conformity with the findings of other studies which have confirmed the association between causal health beliefs, practices and treatment choices of the patients.

The trajectory of cancer treatment is a prolonged and lengthy journey. The findings reveal that most of the participants were diagnosed recently. Important to note that before starting off the proper treatment, the participants had to travel an unknown path to access care and treatment. Most of the participants reported that they had visited either the alternative system of medicine or some indigenous forms of treatment in the beginning and mostly those treatments were accessed at the onset of initial symptoms. At that time they were not aware that those were the symptoms of cancer. Several forms of alternative treatment accessed by participants were Homeopathic & Ayurvedic treatment, faith-healing (*tantra-mantra*,[2] incantation, sorcery, visiting shrine, sages to take charms and amulets), Quacks (*jodi-boti*, *kabiraji dawai*).[3]

The findings of the study reveal that more than two months' time was spent by the participants in taking alternative medicine or other indigenous forms of treatment. Thus, participants spent substantial time in taking alternative medicine along with other indigenous forms of treatment. It was also observed that the prolonged practice and dependence on alternative medicine delayed the overall cancer-specific treatment. The findings of the study show that the average time spent by participants in visiting a CCPs or cancer hospital after the appearance of the primary symptoms was 5.5 months. Thus, the study found that the practice & dependence on alternative medicine delays the cancer-specific treatment and prolongs the patient's visit to CCPs. That was also reported in other studies including Pati et al. (2013) which stated that in a traditional faith-based society like India, the belief and practice of an alternative system of medicine delay the seeking of cancer-specific treatment [12].

Along with the beliefs of the participants, there were several other reasons behind the practice of alternative medicine. These were associated with the availability, affordability, and accessibility and acceptability of Cancer care and the structure of the healthcare system. Giving an understanding about the reasons for seeking alternative medicine, a 50-year-old Oropharynx cancer patient said,

[2] ***Tantra-mantra*** is a ritual practice based on a particular idea or belief system. It is a form of community healing and can be considered as a part of

(*footnote continued*)
faith-healing practices. Here the healers are shadus or mullahs or gurus who try to draw on the spiritual energy to treat the patient.

[3] ***Kabiraji dawai*** is a form of Ayurvedic medicine which is locally prepared in the hilly areas. The medicine for *kabiraji treatment* is prepared with grass, shrub, etc.

"We are the inhabitant of hilly areas, and generally people don't know about these modern forms of medicine. My family members and I were completely ignorant about these. Allopathic doctors including the laboratory for doing various investigations are not reachable to us quickly. Instead, kabiraji treatment [Quacks]*, and other traditional treating practices are very much available in our locality. Also, sir, the kabiraji dawai is cheaper as compared to Allopathic treatments, and we can afford the expenditure easily. We were confused at the beginning of the health problems that what to do, where to go and also we had belief in the particular traditional faith-healing that it may cure my illness. It is because of these reasons we had continued this kabiraji dawai for such a long time."*

Stating her fear for the cancer-specific treatment along with the aforesaid reasons, another 37-year-old cervical cancer patient said,

"My family and I were very much fearful of undergoing chemotherapy and radiation. When the doctor advised the need for radiation, we left the hospital due to the fear of treatment only & then started Homeopathic treatment. There is no business of radiation and chemotherapy in the Homeopathy and also Homeopathy is cheaper as compared to Allopathic treatment."

So, the influence of the health care system can be a significant approach to understand the treatment-seeking behaviour of a cancer patient. In addition, the decision-making process for treatment plays an important role in the prolongation of the treatment-seeking process.

3.4. Decision-making process for cancer treatment

Along with the participants, the beliefs and understanding of other people surrounding the patient were also involved in the decision-making process for cancer treatment. It was found that the participants seek assistance from different people such as family members, friends, physicians, faith-healers and others. On the basis of advice received from multiple stakeholders, patients were observed to visit alternative systems of medicine or modern health care. The decision-making process plays a significant role in prolonging the treatment trajectory of the patient. To understand this treatment-seeking processes, it is very imperative to understand the decision-making process.

Table 5 reveals that the majority (56%) of the participants were dependent on their family members and 17% on physicians for making decisions regarding treatment. Moreover, only one-fifth of the total participants took their own decision regarding treatment and they were male only. No female participant reported taking her own decision. It was also seen that the participants with a higher level of literacy were found to involve themselves more in decision-making in comparison to the patients with a lower level of literacy. Moreover, participants from all levels of education were found to be dependent on their physicians & family members to decide on several steps associated with cancer treatment. Unlike the participants with a relatively higher level of literacy, people without any formal education and those literate up to primary education were found to seek faith-healers assistance in deciding for their treatment. It was seen that the self-decision making among the dependent participants was very less and they were relying on their family members for the decision-making processes (23% of the participants). Self-decision making was also low among the participants who were wage earners, semi-skilled worker, in comparison with employees and businessman. For the participants with differentials like gender, age, caste, class along with occupation, the participant's dependence on the physician and the physician's role & influence on the different aspects associated with cancer treatment was very high.

Mostly the decision-making processes for cancer treatment were found to be influenced by the physician either directly or indirectly. Among the family members also, a certain pattern was followed while deciding on starting off or continuation of treatment. In most of the cases, the earning male member of the family made the decision regarding the treatment based on the advice of the physician. Only in a few families, collective decisions were taken for the treatment. The Guardian (male) or head of the family or husband or son in case of a widow were seen to be the key decision-maker in the family for the treatment. The narratives of the participants made those dynamics clear.

A 50-year-old widow with oropharynx cancer said,

"Mainly my son decides the treatment based on the advice of the doctor."

Another 37-year-old married woman with cervical cancer said,

"Since my husband is the guardian, so he takes all the decision in regards to my treatment."

Talking about the decision-making process at home, a 26-year-old unmarried girl diagnosed with Ca tonsil said,

Table 5
Decision-making Process for Cancer Treatment and Gender, Education & Occupation.

Variables	Decision-making Process for Cancer Treatment						Total (N = 100)
Gender	Patient (self)	Family members	Friends	Physicians	Faith healers	Others	
Male	21 (21%)	37 (37%)	2 (2%)	13 (13%)	2 (2%)	0	75 (75%)
Female	0	19 (19%)	0	4 (4%)	1 (1%)	1 (1%)	25 (25%)
Total	21 (21%)	56 (56%)	2 (2%)	17 (17%)	3 (3%)	1 (1%)	**100** (100%)
Educational Qualification							
Illiterate	3 (3%)	15 (15%)	0	5 (5%)	2 (2%)	0	25 (25%)
Primary Education	4 (4%)	12 (12%)	1 (1%)	2 (2%)	1 (1%)	0	20 (20%)
Middle School	4 (4%)	18 (18%)	0	5 (5%)	0	1 (1%)	28 (28%)
Secondary	4 (4%)	5 (5%)	0	4 (4%)	0	0	13 (13%)
Higher Secondary	4 (4%)	5 (5%)	1 (1%)	0	0	0	10 (10%)
Graduate & Above	2 (2%)	1 (1%)	0	1 (1%)	0	0	4 (4%)
Total	21 (21%)	56 (56%)	2 (2%)	17 (17%)	3 (3%)	1 (1%)	**100** (100%)
Occupation							
House Wife	0	10 (10%)	0	1 (1%)	0	1 (1%)	12 (12%)
Wage Earner	3 (3%)	9 (9%)	0	2 (2%)	2 (2%)	0	16 (16%)
Semi-skilled worker/Farmer	3 (3%)	5 (5%)	1 (%)	6 (6%)	1 (1%)	0	16 (16%)
Business	8 (8%)	4 (4%)	1 (1%)	4 (4%)	0	0	17 (17%)
Govt. Employee	2 (2%)	4 (4%)	0	0	0	0	6 (6%)
Retd. Employee	4 (4%)	0	0	1 (1%)	0	0	5 (5%)
Student	0	1 (1%)	0	0	0	0	1 (1%)
Dependent	1 (1%)	23 (23%)	0	3 (3%)	0	0	27 (27%)
Total	21 (21%)	56 (56%)	2 (2%)	17 (17%)	3 (3%)	1 (1%)	**100** (100%)

"My elder brother decides for my treatment. He always accompanies me to the hospital and while hospital stay. He is concern about the health of mine."

Furthermore, in the collective decision-making process also, the head of the family or the earning member of the family had a strong voice. It was reflected in the narrative of a 35-year-old patient,

"…all the decision in our family is taken collectively. Here since the decision regarding cancer is a critical matter, so we all family members mainly my father and brothers sat together and took the decision. Financially also, they helped me tremendously along with other kinds of support like- assistance in taking care of my family in my absence and marketing and others."

Thus, in most of the cases, participants were not involved in the decision-making process, rather someone else be it a physician or the family members were taking decisions on behalf of the participant.

4. Discussion

Understanding the treatment-seeking processes for cancer patients and the way they walk through the healthcare system is important to facilitate early diagnosis, proper prognosis and prompt treatment especially in countries like India where cancer mortality is very high. The treatment trajectory of cancer is a prolonged and complicated journey. Most of the participants were found to discuss with their family members after the appearance of the initial symptoms. It is because, in a collectivist society like India, the family is the backbone of all sorts of support during the time of illness or any form of crisis. Also, in relation to the developed nations, in India, the tertiary support is very limited to the privileged section of society [16] and in the Barak Valley, there is no formal institution which offers extensive psychosocial support. Therefore, most caregiving to the patient is offered by families and friends. Then, the treatment trajectory followed by the patients were alternative systems of medicine such as Homeopathic medicine, Ayurvedic medicine, along with faith healing (*tantra-mantra*, incantation, sorcery, visiting shrine, sages to take charms and amulets), Quacks (e.g., *jodi-boti*, *kabiraji dawai*), other Allopathic physicians (like-doctors of medicine, surgery, ENT). The analysis of the findings has resulted in the following framework for treatment-seeking pathways of cancer patients (Fig. 1).

The study found that around two year time was spent by a participant in taking alternative medicine. The initial delay and prolongation in approaching a CCP were mainly because the participants were mostly ignorant and were unable to relate their symptoms to cancer. Considering many symptoms of cancer similar to other non-malignant health complications, a study by McCaffery, Wardle & Waller (2003) stated that with a low level of knowledge, it might not have been possible for the patients to relate their symptoms to cancer [17]. Studies also considered the perceived severity of the illness and low levels of knowledge to be the leading causes of delay in cancer treatment [12]. Moreover, it was found that the participants were less aware of the cancer disease and its treatment alternatives, which made them highly dependent on others primarily physicians for their decision-making regarding treatment. Similarly, the study by Pati et al. (2013) noted that most of the preventable delays in seeking cancer treatment are because of the lack of awareness about the signs and symptoms, risks factors for cancer and appropriate prevention and treatment facilities [12].

Causal health attributions of the participants were found to be associated with the health behaviour and practices of the patients. By and large, most of the participants with diverse health beliefs approached their family members first for seeking help. Health professionals were approached in the initial approach by participants who attributed factors associated with lifestyle & food habits, biological and other factors to be the cause of their illness. Again, the participants who approached faith healers in the initial phase of their illness were mostly those who attributed the cause of their illness to supernatural factors. The practice of faith-healing had stronghold where the patients and the people surrounding them had misbeliefs about cancer diagnosis and its consequences. Most of those participants were the native of remote areas (both pain and hilly area) without access to proper healthcare facilities. These findings were in the same line with other studies which indicate that patients' own beliefs and understanding of health and treatment regulate their health-seeking behaviour [18]. Also, Vaughn, Jacquez & Baker (2009) found that causal health attribution has an essential role in the formation of beliefs and behaviour concerning health, illness and treatment choices [15]. Moreover, the several aspects impacting the treatment trajectory of the participants were their level of education and awareness of the participant and their family members, their health believes and practices, economic condition, and the availability, accessibility and acceptability of the cancer-specific treatment etc. The absence of those factors was found to affect the smooth treatment-seeking process of the participant. Considering these factors Pati et al. stated that timely recognition of cancer signs and symptoms is very critical for early diagnosis and treatment initiation but it is challenging to meet [12]. Barbhuiya (2018) also reported that seeking and receiving proper treatment is challenging and is unusual for cancer patients [11].

The critical decision-making process was involved at each and every step of treatment-seeking and it was a complex interplay of several factors. Family members were found to play an important role in the shared decision-making processes along with the patient and physician by sharing information, expressing preferences and agreeing to implement a proposed treatment. Family member's presence was there when decisions were made reading cancer care. Several studies have reported the crucial role played by the family in decision-making processes and the preference of cancer patients for family-centred decision-making [19–21]. Among the family members also, the voice of the female was very low. In the current study, No female participant reported taking her own decision regarding treatment. The restricted involvement of female cancer patients in the decision-making process might be because of several reasons such as less awareness and acquaintance about cancer disease and its treatment, no space to decide in a male-headed family together with male-dominated society. Further, irrespective of the level of education and other socio-demographic differentials, most of the participants and their family members were dependent on the physicians to take a decision regarding the choice and continuation of treatment. Thus, almost all the decision-making processes for cancer treatment were influenced by the physician either directly or indirectly. Due to the low level of awareness of the study participants and their family members, momentous medical information to take medical decision was primarily extended by the physician that adds to the social power of the physician.

5. Conclusion and future implications

To conclude, it can be said that the treatment trajectory for cancer is a prolonged journey and the decision-making process involved in each and every step for seeking treatment may result in treatment delay. There is an appreciable delay in recognizing and relating the patient's initial symptoms to the sign of a fatal disease like cancer. There is also a delay in the initiation of proper treatment. This could have implications on the survival of the patient as delayed diagnosis leads to improper prognosis and untimely and inadequate treatment at an advanced stage of the disease. All these factors result in a high mortality rate. The current study reveals that most preventable delays and redundant prolongation in seeking treatment among cancer patients were due to the lack of awareness about the signs and symptoms of cancer and its treatment alternatives, misbeliefs about the disease, and non-availability of appropriate treatment facilities. Proper mass sensitization about cancer disease and its treatment alternatives along with quick referral of the patient to CCPs would be a positive step. In this course,

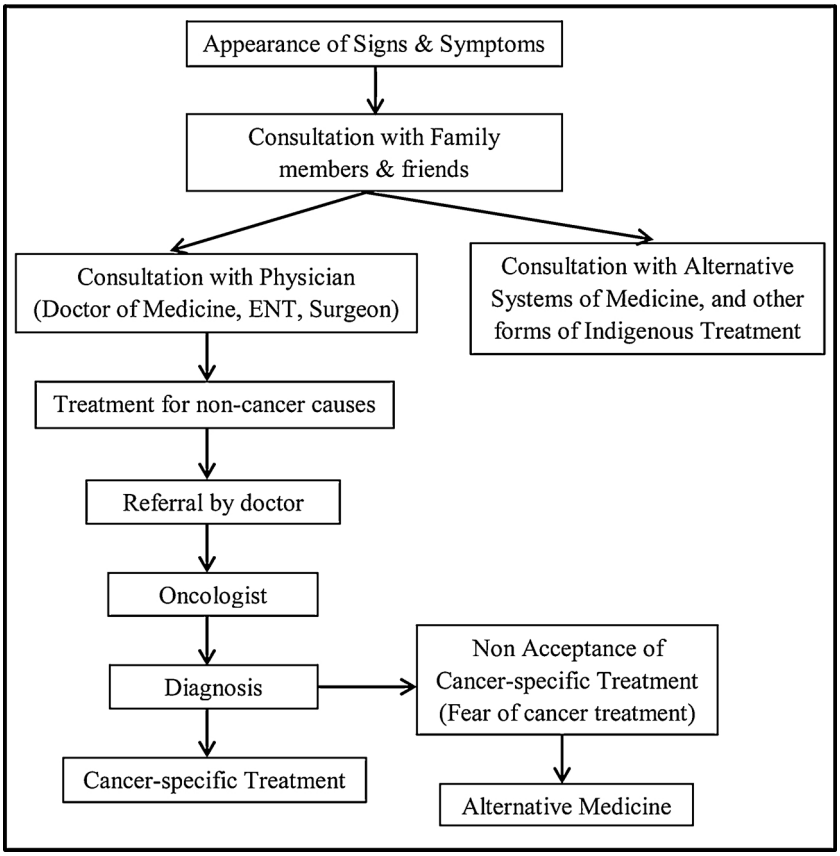

Fig. 1. Treatment-seeking Pathways of Cancer Patient.

there is a need to engage and sensitize the practitioners of alternative medicine and faith healers. In this entire process on mass sensitization, local NGOs should be approached and given key roles to play along with government machinery. Also, the personal and ecological understanding of illness, its social and medical diagnosis and treatment need to be dealt with. Besides, further research is needed in this area to explore the influence of different demographic factors including availability of health infrastructure, intrapersonal and interpersonal communication on health beliefs and practices.

Authorship contribution statement

I, Firdous Barbhuiya, am the sole author for this manuscript entitled "Treatment Trajectory of Tobacco-related Cancer Patients: A Study in Assam, India". I have worked for conceptualizing the content, including the concepts, designing the study, data collection, data analysis and interpretation, writing and other related aspects of this paper. I also certify that this material or similar material has not been submitted to or published in any other publication before its appearance in this Journal 'Cancer Epidemiology'.

The author has no conflicts of interest associated either directly or indirectly with the study and its participants. There are no financial and personal relationships with any person or groups or organizations that could inappropriately influence (bias) the work. The subject matter or materials discussed in this manuscript entitled "Treatment Trajectory of Tobacco-related Cancer Patients: A Study in Assam, India" are purely for academic purpose.

Declaration of Competing Interest

The author has no conflicts of interest associated either directly or indirectly with the study and its participants. There are no financial and personal relationships with any person or groups or organizations that could inappropriately influence (bias) the work. The subject matter or materials discussed in this manuscript entitled "Treatment Trajectory of Tobacco-related Cancer Patients: A Study in Assam, India" are purely for academic purpose.

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