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HOW ARE CANCER TREATMENT DECISIONS MADE? INSIGHTS FROM A QUALITATIVE STUDY CONDUCTED AMONG SELECTED CANCER PATIENTS IN BENGALURU CITY (INDIA)

Sobin George[1], Mohamed Saalim P K[2], Omkar Nadh P[3], Divyashree H V[4]

Abstract

Drawing on qualitative in-depth interviews conducted among cancer patients, their family members and oncologists from Bengaluru city, the paper examines the factors that influence the cancer treatment decision making processes. It examines the pathways of treatment decision making of cancer patients, which are influenced by both biomedical and non-medical factors including the initial coping with the diagnosis, socio-economic and cultural background, type of cancer and availability and accessibility to services. The paper notes that the initial treatment decision making is a combination of practitioner-led, family members/caregivers-led and patient-led pathways wherein factors such as affordability, age, gender, intimacies to the patient, convenience of family members/caregivers, availability of facilities, uncertainty of treatment outcomes and concerns of sufferings alone or jointly played a major role. These factors played a major role during treatment as well. Further, the paper notes that the cancer treatment is mostly practitioner-centric and there is a need to develop a patient-centric approach in cancer care in order to address their unmet needs pertaining to affordability, suffering and uncertainties of treatment outcomes.

Introduction

Cancer treatment decisions are influenced by several medical and non-medical factors and the levels of involvement of practitioners, patients and their significant others. One important set of the non-medical factors relate to the psychologically stressful conditions associated with cancer diagnosis and the dominance of practitioner-centred Treatment Decision Making (TDM) in medical interactions. Studies available from different parts of the world, including India, have shown that since cancer diagnosis often comes as an unexpected shock for patients and their family members/significant others, they tend to be non-active participants in cancer treatment plans (Lam *et al* 2005, Mead 2005, Cancer care 2017, Daniel *et al* 2021). It was also found that even in the contexts of developed countries where doctor-patient interactions were more consultative in nature, patients did not feel that they were offered treatment choices by the practitioners (Stacy *et al* 2010). Pieterse *et al* (2008) noted that most of the patients considered their participation in TDM as "being informed" than choosing what is best suited as per their preferences and values. Available studies from India also showed that the role of patient and family members are limited in cancer treatment decision making (TDM), mainly due to the paternalistic

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[1] Assistant Professor, Centre for Study of Social Change and Development, Institute for Social and Economic Change, Bengaluru, Email: sobing@gmail.com. (corresponding author)

[2] Research Scholar, Institute for Social and Economic Change, Bengaluru.

[3] Research Scholar, Institute for Social and Economic Change, Bengaluru.

[4] Research Assistant, Institute for Social and Economic Change, Bengaluru.

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nature of patient-practitioner interactions and practitioner-centred decision making that exist in India (Malik *et al* 2016, Agarwal *et al* 2012).

Demographic, personal, family and social and cultural contexts are also identified as important non-medical determinants of TDM. Studies have found that the age of the patients influenced the choice of cancer TDM (Bowman *et al* 2002, Hall *et al* 2005). While relatively younger patients actively sought treatment choices from various sources including the internet, older adults tended to accept the interventions suggested by practitioners due to their "trust in oncologist, being sceptical about going online," and testimony of other people (Sattar *et al* 2018). There is not much evidence available on the difference in decision making on the markers of gender of the patient except a few, which highlighted the higher participation of males in decision making (Orom *et al* 2016), greater trust of women in practitioners' decisions (Beaver *et al* 1996, Swainston *et al* 2012) and passive involvement of female patients in TDM due to emotional trauma (Mead, 2005, Lam *et al* 2005). There was no evidence available on how other gender-related reasons such as financial independence of women, agency to take decision and gender roles affect the participation of female patients in their treatment decisions. However, there were studies which analysed the participation of female patients in TDM, especially in breast and ovarian cancer cases without attributing to gender-based differences (Elit *et al* 2003, O'Brien *et al* 2008). Cultural beliefs and background of patients also figured in cancer TDM. A systematic review on cancer TDM by indigenous people found that factors such as "spiritual beliefs, cultural influences, communication and existing healthcare systems and structures" can influence their treatment decisions (Tranberg *et al* 2016).

There is also evidence that systemic reasons such as availability of treatment facilities affect the Cancer TDM that also lead to prolonged waiting time for treatment after the diagnosis especially in countries like India. Studies from India highlighted that lack of infrastructure facilities prolonged the waiting period for treatment, especially for interventions like radiotherapy (Kannan and Bajpai, 2016). Bhattacharjee *et al* (2017) in a study conducted among head and neck cancer patients, found that the waiting time for critical interventions like radiotherapy is linked with the chances of survival of the patients. Menon (2017) and Munshi *et al* (2021) also confirmed the finding that prolonged waiting period for targeted therapeutic interventions are linked with unfavourable treatment outcomes.

Further, studies have shown that lack of participation of patients in treatment decision making can lead to unmet needs pertaining to affordability, suffering, quality of life and longevity (McGuire, 2000, Khan *et al* 2011, Johnson, 2014, Cancercare 2017). Geessink *et al* (2018) in a study conducted among elderly pancreatic cancer patients found that patients' and observers' (caregivers) priorities in TDM communications with the practitioners differed since patients prioritised quality of life and level of satisfaction while observers prioritised more the duration and number of consultations. Studies that examined the involvement of family and caregivers in TDM also highlighted the possible conflicts or differences on decision-making roles and in the priorities of patients and family/caregivers, especially when the patients were older adults (Laidsaar-Powell *et al* 2016, Shin *et al* 2013). Studies also shed light on the disagreements among family members on treatment and care, especially at the advanced stages of cancer, mainly pertaining to "routine treatment decisions, discontinuation of therapeutic treatment, and use of hospice care" (Zhang *et al* 2003).

Literature thus showed that cancer TDM is not merely based on biomedical considerations, but are also affected by social, demographic, economic cultural and systemic factors. These factors could also vary and interplay across the agents and actors of decision making who include medical practitioners, patients, family members and the significant others. Given this, the present study aims to understand the complex pathways of cancer TDM in an Indian setting. It specifically looks at the agents, their roles, concerns and priorities of cancer TDM and how medical and non-medical factors intersect, intertwine and influence treatment decision pathways.

Methods

The study aims to understand the cancer TDM in the context of the nature of doctor-patient/family members interactions. It used qualitative methods of in-depth interviews and observation for data collection. Data was collected from cancer patients/family members and practitioners specialised in medical and surgical oncology who worked in public and private hospitals in Bengaluru. We adopted the 'snowball' method to select the participants for the study, initially from our personal contacts and through palliative care centres in Bengaluru. In-depth interviews were conducted with 48 willing patients/family members till data saturation and six practitioners from public, private and charity hospitals that are specialised in cancer treatment. The fieldwork was conducted in two phases. The first phase was between November 2019 and February 2020. The study used the grounded theory approach to analyse the data. All interviews were recorded and the verbatim transcribed and translated to English by bilingual experts. The transcribed data was anonymised in order to preserve the identity of the patients and others who participated in the study.

Results

A profile of the participants is presented in table 1.Out of 48 participants, 30 were females and 18 were males. Most of them were currently married and from the age group of 50-59. The sample had 16 working and 20 non-working participants. There were four students and two retired participants in the sample. Most of the patients did not reveal their monthly income. There were ten participants who were from a relatively lower economic background. There were eight participants who had a monthly income above Rs.10,000 and ten participants who had monthly family income which was above Rs.50,000 but less than Rs.1,00,000. There were no non-literate person in the sample and a good number of them (20) were graduates and above. A majority of the participants were from the Hindu religion. Most of the participants preferred not to reveal their caste identity.

Table 1: Profile of the participants

Characteristics	Number
Gender	
Male	18
Female	30
Age (at the time of diagnosis)	
0-9	2
10-19	0
20-29	4
30-39	6
40-49	10
50-59	16
60-69	10
Marital status	
Currently married	32
Currently unmarried	8
Widowed	6
Separated	2
Occupation	
Student	4
Working in government sector	2
Working in private sector	14
Retired	2
Farmer	6
Own business	4
Not earning	16
Monthly Income	
0-24,999	10
25,000-49,999	2
50,000-74,999	8
75,000- 99,999	2
1 Lakh and above	8
Income not declared	18
Education	
Upto secondary	18
Secondary	10
Graduate	8
Post graduate and above	12
Religion	
Christian	2
Hindu	44
Muslim	2

Source: Primary study

Waiting Period after Diagnosis

The present study found that there were no significant delays in initiating cancer specific treatment for the participants after the diagnosis. The average duration was 21.6 days (see table 2). However, the time period between diagnosis and treatment was found to be more than the sample average for patients who had breast cancer (nearly 37 days), ovarian cancer (33 days) and blood cancer (27 days). Patients with lymphoma melanoma, testicular cancer and liver cancer began treatments within 18 days of diagnosis.Patients in the first stage of cancer took more days (29 days) than the sample average whereas the patients who were diagnosed in the advanced stage were found to have started treatment within a period of 15 days from the diagnosis. Female patients took more days than male patients to start the treatment. Also, patients in the age group of 40-59 had a longer waiting period for commencing the treatment than the sample average. Further, the study has traced the treatment decision-making pathways of cancer patients, which are presented in table 3.

Table 2: Average days of delay from diagnosis to treatment interventions (N=48)

Characteristics	Days taken from diagnosis to first treatment intervention
Gender	
Male	17.7
Female	25.5
Age group	
0-19	15
20-39	16
40-59	33.5
Above 60	22
Type of Cancer	
Breast cancer	36.9
Ovarian cancer	32.6
Lung cancer	18.7
Lymphoma melanoma	16.4
Endometrial cancer	19.5
Glioblastoma (brain cancer)	16.5
Testicular cancer	17.5
Lymphoblastic Lymphoma	18.6
Intestinal cancer	21.6
Liver cancer	17
Pancreatic cancer	19.8
Stomach cancer	18.7
Blood cancer	26.5
Stage of Diagnosis	
1st	28.5
2nd	20.7
3rd	22.6
4th	14.5
All	**21.6**

Source: Primary study

Anticipated stigma and psychological factors increased treatment waiting period

The major theme that emerged commonly from all participants was the sudden shock, psychological distress and time taken for coping with the cancer diagnosis. The study found that most of the respondents were not in an "emotionally balanced" state of mind to begin the treatment due to the shock, distress and disappointment. Distress, for a few participants even led to fatalistic thinking that came from the understanding that cancer means "suffering and death", which prolonged the waiting period for treatment. Further, it was found that patients feared stigmatisation due to taboos associated with cancer that "it will be difficult for finding bridegroom for daughters if the mother is diagnosed with cancer". In such cases, patients tended to hide the diagnosis and secretly undertook AYUSH treatments, which did not have visible side effects as compared to allopathic interventions like chemotherapy, surgery and radiation. They did not want society to 'label' them as a 'living cancer patient' in the family for the fear of social ostracism pertaining to above-mentioned issues like finding a bridegroom for their daughters.

Confused with information on systems of medicine and type and modalities of treatment

Cancer diagnosis also proceeded with collecting information, opinions and suggestions from several formal and informal sources as well as from laymen, experts, and people who have prior exposures to cancer treatments. The most common form of collecting information was internet surfing, which opened up a wide world of information without any evidence on what is authentic or unauthentic and verified and unverified. The virtual world offers cancer treatment information and options through all kinds of online options such as blogs, *vlogs*, Youtube channels, news, testimonies, popular articles, referred articles, advertisements and other propaganda. The present study found that patients and their family members also increasingly seek information from relatives, friends and people who underwent treatment and other significant people who they find knowledgeable such as spiritual leaders and medical professionals in the kin network. The patient and family members thus get flooded with diverse options and information, which most of the time lack any authenticity. While such information helps patients to find out suitable treatment options in some cases, there were instances when they got confused with these. Furthermore, it was found that there were conflicts among family members as well as between patients and family members on deciding on a particular treatment that increased the waiting time of treatment. Similarly, suggestions, recommendations and information from various sources also created confusions and conflicts about selection of system of medicine and selection of hospital (see table 3). Seeking of second opinion from specialists and doctors from other hospitals (other than the hospital where cancer was confirmed) was also a common practice that prolonged the waiting time for commencing the treatment.

Financial and logistics constraints

One of the important themes associated with the prolonged waiting time for treatment that came up from participants who were from lower income group was about mobilising financial resources for the treatment. There is already evidence that poor affordability was identified as a major reason for cancer treatment delay in the Indian context (Pati *et al* 2013, Hazarika *et al* 2019) and financial constraints increased the treatment delay for cancer patients (Kumar *et al* 2019). The present study found that the first preference of patients/family members was to go ahead with the treatment plan as suggested by the medical oncologist even though the cost was high. Their immediate priority was to arrange money. While some of the participants from lower economic group were successful in mobilising money through various sources and channels, there were a few others who could not arrange the funds and finally sought treatment from government hospitals or moved to alternative systems of medicine. It was found that these processes increased the waiting time for the commencement of the treatment. Further, issues such as availability of caregivers were factors that led to the prolonged waiting period for treatment for a few participants in the sample.

Table 3: Waiting time from diagnosis to treatment: qualitative illustrations

Themes	Illustrative quotations
Shock, psychological distress and time taken for coping with cancer	She was just 59 years old and it was a sudden shock for all of us. We were scared. We were disappointed and we did not have any clue how to go ahead which place to go (PC02)
Fatalistic thoughts and delaying treatment	I thought it's better to die than treating and suffering more. I thought of suicide and finally after one month we started the treatment (PC31)
Taboo and delay of treatment	Yes, she was worried about money and my marriage. So she delayed for a year or two she tried *ayurveda* for about a year; she tried homeopathy for a couple of months (PC12)
So much of information on treatment; but nothing was certain	So many interventions, so many people, so many suggestions and so many influences that come across and you are not certain about anything. Everything is not easy especially when you are not from a medical background (PC11)
Seeking second opinion and uncertainty in decision making	When you get a second opinion you are always in a dilemma. You again consult family and friends and refer to the family doctor or who have been through it (P41)
Arranging funds	We were worried about arranging money after the doctor explained the cost, which was almost Rs 5 lakh. I have no job, no insurance and finally we decided to go to Kidwai [government] hospital (PC01) We were told that there is specialist treatment available. It was already too late. Since we could not afford it, we dropped that plan (PC08)
Finalising hospital	He was in fourth stage. We were not sure about the treatment available in Bangalore. One of our relatives said to go to …..hospital in Kochi and met Dr….. (PC8)
Finalising system of medicines	His [patient's) condition was very bad. They [doctors] said it was last stage. So we were worried whether surgery or chemotherapy would suit him. We decided to go to Shimoga for naturopathy (PC37)
Arranging caregivers	We were working. Children were studying and we had no clue who would be with her in the hospital (PC26) I had to wait till my leave gets sanctioned to begin her treatment (PC31)

Source: Primary study

Treatment decision-making pathways

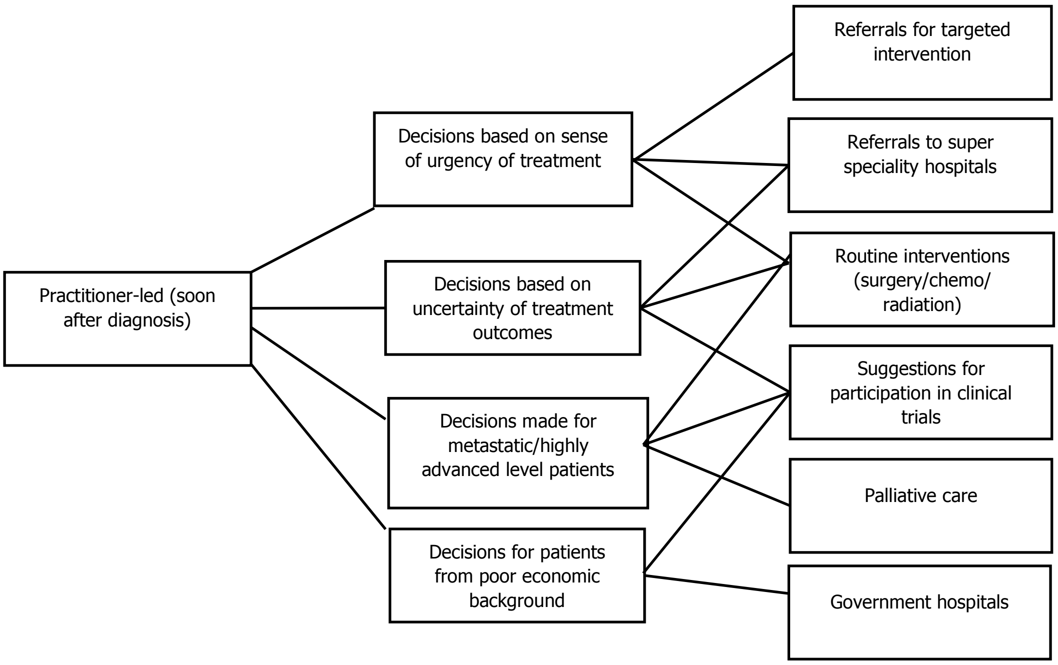
The study further examined the treatment decision-making pathways of patients and families to understand the drivers of treatment decision across various contexts. The study identified the pathways of practitioner-led decision making, family-led and patient-led decision making in all stages of care, which are illustrated below.

Practitioner-led initial treatment making models

Figure 1 represents the pathways of the practitioner-led initial treatment making found in the present study. The practitioner-led initial treatment making model shows that the decision made by the practitioners are entirely based on the biomedical view of the disease conditions of patients and availability of treatment options. It was found that the medical oncologist who confirmed the diagnosis and revealed it to the patient/family members/caregivers played a significant role in the initial decision making regarding type of treatment, place of treatment, line of treatment and course of treatment. This decision was first made based on the sense of urgency that the oncologists assessed and conveyed to the patients/family members. The practitioners, based on the sense of urgency in terms of stage and severity of the disease and interventions available, suggested the routine line of treatment at the same hospital. If such facilities were not available in the hospital where the diagnosis was confirmed the patients were sent to other (mostly super speciality) hospitals where such facilities were available. In certain cases where the interventions required were very specific such as hormone therapy and immune therapy, the patients were referred to such treatment based on the willingness of the patients/family members to undergo such treatments.

Another criterion based on which the practitioner suggested treatment was the uncertainty of treatment outcomes for patients who were in advanced stages and patients who were with co-morbidities. The practitioners in such cases started with suggestions for the routine line of treatment of chemotherapy, surgery or radiation based on the type and location of cancer. If these initial interventions did not turn out to be effective, practitioners referred the patients to targeted treatments based on the willingness of patients/family members/caregivers or suggested that the patients take medicines which were on clinical trials. Third was based on the severity of the disease. It was found that in metastatic cases, the practitioners started with the initial line of interventions of chemotherapy and radiation. They suggested palliative care if the condition of the patient was very critical. In some cases, metastatic cancer patients in advanced stages were also administered chemotherapy trial drugs. Finally, practitioners from private hospitals referred the patients who could not afford to undergo treatment, to government cancer treatment either at the beginning or during the course of the treatment that was initiated at the private hospital.

Figure 1: Practitioner-led initial treatment decisions making (biomedical model)



Source: Researchers' representation from primary data

Over-emphasis of practitioner's knowledge in TDM

Associated factors of the practitioner-led decision making model are further substantiated with the qualitative illustrations in table 4. While the decisions of practitioners were based on their assessment of the sense of urgency, the patients/family members were not always in a position to understand the benefits and burdens of these interventions. They tended to accept/succumb to the authority of practitioners and followed the treatment decisions taken by the practitioners. In some cases, the patient/family members/caregivers got overwhelmed by the shock and the sense of urgency of interventions suggested by the practitioners. In other words, there was no room available for the discussions on treatment options since the practitioners "decisively communicated" and "immediately planned" the line of treatment and course of treatment which the patient had to undergo. In such case, patient and caregivers did not undertake a second opinion or other possible treatment options. The interviews with practitioners further confirmed that in most of the cancer cases, decisions were taken immediately by the practitioners. Practitioners tended to further normalise this practice with their knowledge and authority on medical profession and its promises of disease management or cure by noting that "doctors take decisions in the best interest of the patients". What is important to note is that cancer is such a disease which in most of the cases can only be managed and cured based on the natural history of the stage of diagnosis of most forms. Values and preferences of patients/caregivers assume importance since they are always at the receiving end and the outcomes of interventions are mostly uncertain.

Interviews with practitioners also revealed that it is mostly the biomedical perspective that dominates over the socio-cultural, demographic or economic background of the patient or their values while making the treatment decisions. For instance, stage of cancer, general conditions of the patient and associated morbidities were the most important factors based on which practitioners decide treatment.

Lack of clarity on the benefits and burden in practitioner-led TDM

It was also found that the balancing of benefits, burdens and risks were not always maintained in the communications of practitioners with patients or their family members/caregivers. It is always the benefits of a particular intervention that assumes prominence in the communication of doctors. For example, the side effects of chemotherapy and radiations are so much generalised and did not find much place in the communication of the patient although it could vary from patient to patient based on their general conditions of health, age and co-morbidities. However, practitioners tended to communicate the possible risk of mortality in interventions like surgery to patients; although benefits of surgical interventions were emphasised mostly in the discussions. Interviews with patients further confirmed the biomedical standpoint of practitioners in treatment decisions. For instance, it was found that a patient with metastatic cancer in advanced stage (PC47) was recommended chemotherapy although the health condition of the patient was deteriorating and the patient refused to undergo chemotherapy.

Dominance of biomedical concerns in practitioner-led TDM

However, in some cases practitioners considered the age and economic conditions of the patients while deciding the treatment. Age, especially old age was a factor for decisions pertaining to surgical interventions. Practitioners, as they noted, have to "balance between the [vital] performance of the patient and treatment protocol" when interventions were to be performed on older adults. Practitioners also used expressions such as "we cannot be aggressive on them [elderly] as on others" referring to the normal line of treatment such as chemotherapy, surgery and radiation administered to a cancer patient. Economic conditions of the patients did not alter the treatment decisions, especially the routine line of treatment. However, patients/families who could not afford more targeted interventions such as hormone therapy, chemotherapy with new expensive drugs and immune therapy were not referred to undergo the same. Patients who could not afford any treatment package offered by the private hospitals were suggested to go to public hospitals. Also, patients who had affordability problem during the course of the treatment were also referred to government hospitals for interim diagnostic and treatment interventions like PET scan and chemotherapy.

Table 4: Practitioner-led treatment decision making: qualitative illustrations

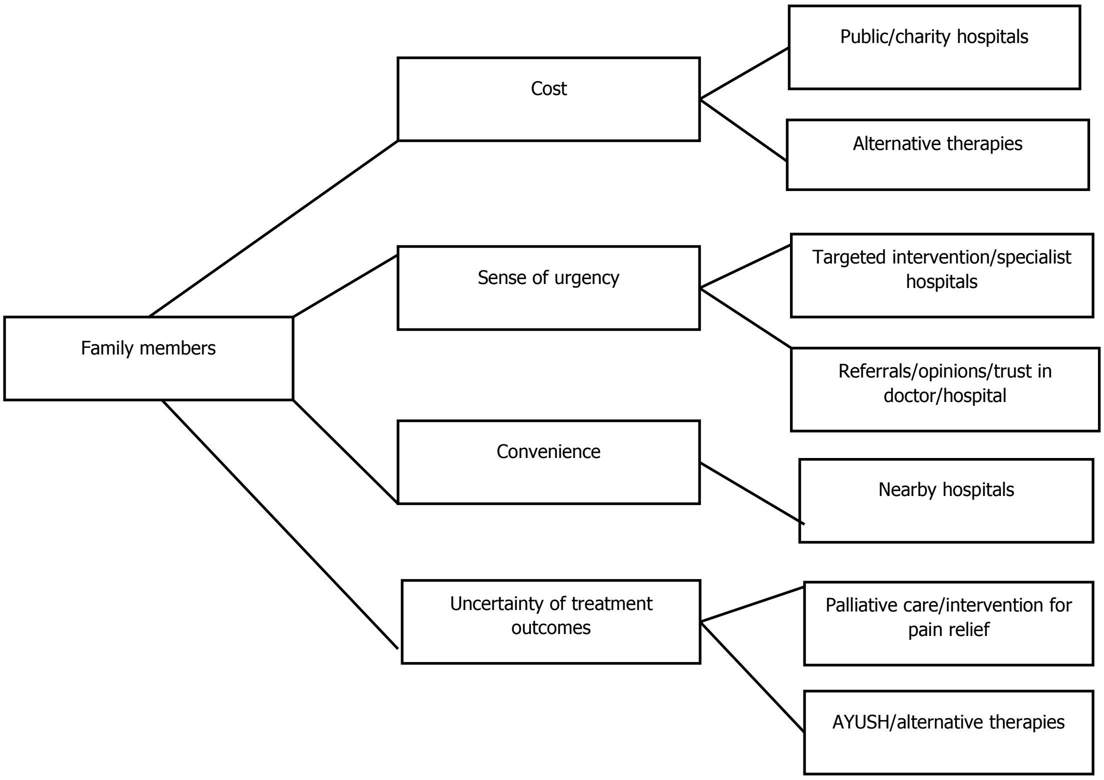
Themes	Illustrative quotations
Patients wanted practitioners to take treatment decisions on behalf of them	See, they know everything after seeing the reports. They know what is good for us. What will work and not work (PC09) I completely trusted the decisions taken by the doctor (PC18)
Urgency as communicated by the practitioner/doctors take decision in the best interest of patients	He [doctor] just asked to get a complete PET, CT scanning and we just got it done and he just told that it is cancer and it is in stage 2 and it has to be operated as it will not clear with the medicines. The breast has to be removed and because the cancerous cells had spread across the armpits (PC15) Best protocol we give to them. If they don't want surgery or something else, we try to convince, because the decision is taken in best interest of patients; long term survival or cure (PR2)
Stage of cancer	Doctor in advance told me what things will happen [symptoms and bodily changes] I got a picture of what will happen after operation and radiation (CP01) The treatment would be purely based on the stage, general condition of the patient and associated medical co-morbidity. Nothing more than that (PR4)
Uncertainty of treatment outcomes	Our surgeries are even invariably major undertaking; things can go wrong at any time and patient has to be very well informed of what can happen; we will give a realistic opinion that there is a chance of 5% you may not survive the operation which is not the case with appendectomy stakes or other surgeries. Stakes involved in our specialty are high so well informed consent is very important (PR4)
Decisions for metastatic cancer cases	My father was suffering and he said he does not want any treatment, but some relief from pain. It spread everywhere and in a very advanced stage. The doctors insisted on more chemotherapy (PC47)
Age and general health of the patients	We cannot do major surgeries among the elderly. We have to balance between their performance status and our treatment protocol. We will not be too aggressive when their performance status is low. Age and performance is very important (PR2).
Economic conditions of the patient	We will not change our treatment plan because of the economic condition of the patient. There are so many hospitals and institutions where according to their economic status treatment can be given. We can definitely offer a space where they can take treatment (PR2).

Source: Primary study

Family members-led initial treatment making models

As the extant literature showed, family played a considerable role in cancer treatment decision making (Laidsaar-Powell *et al* 2016, Sattar *et al* 2018).The present study found that the role of family members/caregivers was important in the decisions pertaining to initial place of treatment and system of treatment. The family members-led initial decision-making model that emerged from the qualitative interviews is represented in figure 2. The major factor in treatment decision making was the perceived sense of urgency as communicated by the practitioners based on their assessment of the stage and severity of the disease. As it is clear from the model, factors including cost of the treatment, convenience and uncertainty of treatment outcomes alone or together or in different combinations led to the place and choice of treatment. For instance, while the cost was a main concern for most of the family members/caregivers, factors such as age of the patient, severity of illness and intimacies with the patient also played a role to decide the treatment. It was found that the family members prioritised the quality and efficacy of treatment interventions over affordability when the patient was younger, earning member and being an 'intimate' person to the decision maker. Similarly, in some instances, uncertainty of treatment outcomes and convenience of care giving together decided the place and type of treatment for patients who were diagnosed at the advanced stage of cancer. There were also cases wherein cost, convenience and uncertainty of treatment outcomes together decided the treatment options. In short, caregivers perceived the sense of urgency of treatment not only merely based on the biomedical reasons as communicated at the stage of diagnosis, but also based on a combination of social, economic, cultural and personal factors.

Figure 2: Family members-led initial treatment decision making model



Source: Researcher's representation from primary data

Practitioners make the best decisions

Although the initial reaction of participants to cancer diagnosis was shock and psychological distress, they immediately responded to the sense of urgency of treatment as communicated by the practitioner (table 5). The caregivers, without delay, were briefed to the line of treatment and exposed to specialists so that they felt a sudden sense of urgency for treatment. Caregivers did not seek second opinions in this case and agreed for the line of treatment as suggested by the medical oncologist, chemotherapist, radiologist or surgical oncologist. Other factors such as cost, convenience and concerns of patients were not considered in such instantaneous decision making in most of the cases.

Economic concerns conflicted with the best options suggested by practitioners

However, such sudden response to the suggestions of practitioners to treatment was not possible for all, especially for patient with relatively poor economic background. Although they were alerted by the sense of urgency built up by the practitioners for treatment, concerns of cost of care were at the centre of their decisions. They found out hospitals that offered the same treatment at lower cost, mostly at charity hospitals; waited for appointment and treatment at government hospital; resorted to alternative therapies or avoided the expensive targeted interventions suggested and confined to the routine treatment protocols suggested by the doctors. In some cases, cost and convenience of care giving of family members together decided the place and type of treatment. Factor such as proximity to the hospital, familiarity of place and place of work or residence of significant others of the patients decided the place and type of treatment along with choices of lower cost of treatment available. A few family members who tended to collect more information chose places which offered all available specialist treatments. Factors such as reputation of hospitals and oncologists were also important in such cases.

Disease conditions and uncertainty of treatment outcomes affected the family-led TDM

In some cases, family members took decisions of treatment based on the conditions of patients and possible treatment outcomes, especially when the patient was diagnosed at an advanced stage. Although doctors communicated the urgency to initiate treatment immediately, family members tended to avoid "aggressive" interventions that have considerable side effects and can increase the suffering of the patients such as chemotherapy and surgery. The family members either did not decide to undertake these interventions suggested by the practitioner from the very beginning of the treatment or stopped these interventions in between witnessing the suffering of the patient.

Table 5: Family members/caregiver-led treatment decision making: qualitative illustrations

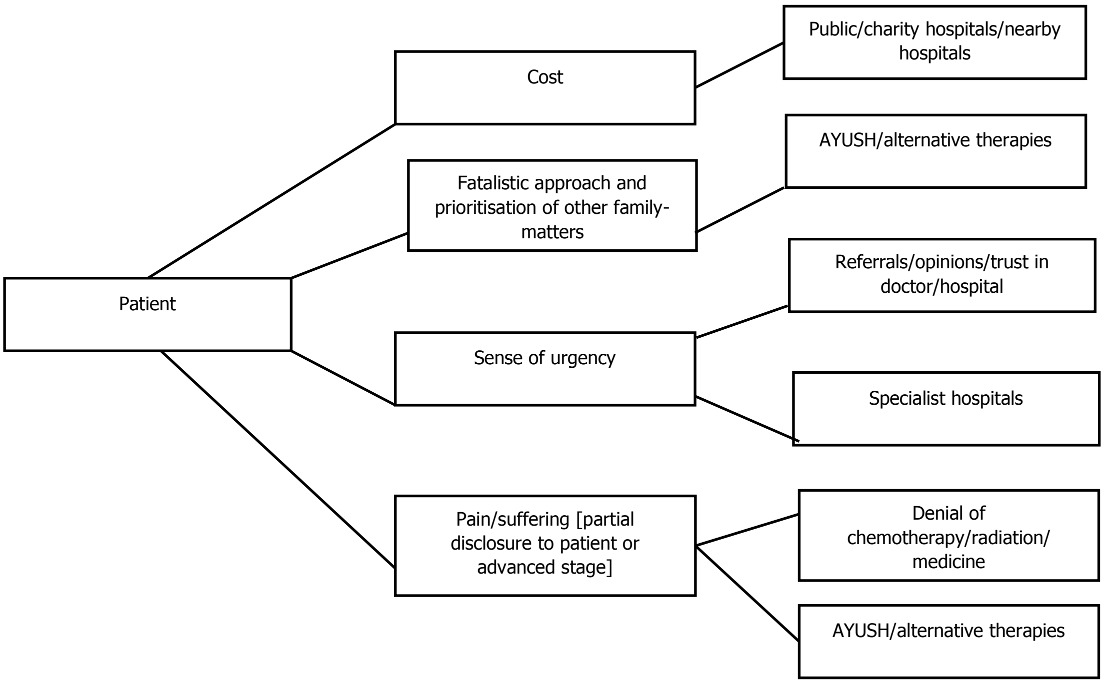
Themes	Illustrative quotations
Perceived sense of urgency	She [doctor] said, at least 27 chemos have to be done, weekly once. I told, OK (PC03)
Cost	We chose government hospital because in private and all one injection will cost 14to 15 thousand. It also depends on the medicines they would have written there is 9, 14, 18, 20 [thousands] like that and all it will go (PC01)
Convenience and cost	I have decided the place of treatment because I had my job here so I thought that I have to work. I cannot take long leave so I thought that if I bring her here I can manage my job and at the same time I can take care of her (PC02)
Availability of treatment, reputation of doctor/hospital	We asked a few people about the reputation of hospital; affordability is one of the issues but we cannot compromise with the health so we had to keep in mind the two things - the quality of the treatment and financial affordability. So then we have taken a decision here we could manage both the things (PC02).

Source: Primary study

Patient-led initial treatment decision-making models

In some cases, patients themselves made the initial treatment decisions. As it was found in the family/caregiver-led decision-making models, patients' treatment making decisions were influenced by cost, sense of urgency, sufferings and uncertainty of treatment outcomes. What was found additionally was the initial period of patients' coping with the diagnosis that led them to think that "they were dying" irrespective of the treatments available (see figure 3). While concerns of cost and affordability led them to opt for government or charity hospital, factors such as fear of suffering, taboo associated with the visible side effects of allopathic cancer treatments, fatalistic thinking and uncertainty of outcomes led the patients to opt for AYUSH and alternative therapies. However, those who perceived a higher sense of urgency opted for routine line of allopathic treatment or other specialised interventions based on the suggestions of oncologists.

Figure 3: Patient-led initial treatment decision making model



Source: Researcher’s representation from primary data

Patient's felt sense of urgency

Patients who felt a sense of urgency took immediate decisions regarding to place and type of treatment primarily based on the initial communication with the practitioners. Among this group of patients, all underwent immediate treatment interventions as suggested by the oncologists. It was also found that their sense of urgency of treatment came out of the economic reasons of joining back work as early as possible since the entire family financially depended on the patient. Some of the patients actively participated in the discussions with the oncologists on their treatment decisions while a few of them wanted to go ahead with the options suggested by the doctors although there were conflicting views and concerns raised by family members on these suggestions.

Economic constraints affected patient-led TDM

Affordability has come up as another important factor that influenced the patients to take the treatment decisions. This was found among patients who were the sole earners of the family and those who were economically dependent, especially married women and older adults. There were instances that the patients tended to hesitate to start the treatment, delay it or stop in between. They also opted for treatments and system of medicines that were more affordable and convenient. In a few cases, patients tended to be fatalistic and hesitated to begin the treatment, which they thought would be “a waste of money for the family”.

Fear of stigmatisation of female patients affected choice of treatment

It is also important to note that although not very common, a few participants, especially female patients, tended to opt for treatment options that helped them to hide their disease conditions for the fear of stigmatisation when facing events such as marriages in the family, especially their daughters. Patients in such situations did not want the family of the bridegroom to know their disease conditions since they feared that the disease conditions of the mother could be seen as a possible risk of future cancer affliction for the daughter. In such cases, patients either postponed treatment till the marriage or underwent AYUSH or alternative treatment that did not have many side effects so that the disease was not apparent. As studies have already highlighted (Dwivedi *et al* 2012, Rath *et al* 2018) a few female participants were worried about the possible side effects that could alter their bodily appearance that delayed/suspended the treatment.

Table 6: Patient-led treatment decision making: qualitative illustrations

Themes	Illustrative quotations
Perceived sense of urgency and immediate treatment	It was in 3rd stage so I immediately got ready for the operation. I got operated upon in Ambedkar hospital and after that they told me to take chemotherapy and radiation (PC01). I did not go back home. I got directly admitted after that I did not go later when I got operated. I went back home (PC06)
Collection of information and choosing the suitable place and type of treatment	You actually try to reach out to friends and family that you might know other people who went through the same condition so I got in touch with a friend of mine whose sister-in-law had breast cancer and another friend's aunt so you know you try and gather some different pieces of information from similar experiences that other women have been through and at the same time you are also trying to approach the right doctor get the right test, see if you got the correct diagnosis etc. On the one hand I was talking to people the other of course I was *googling* (PC18).
Convenience and cost	Bagalkote was near so I took treatment from there. For me this was near and comfortable and my son goes to college and my husband goes to work. It was the only cancer hospital which was near to my village so I took treatment there. Not every village will have cancer hospitals. (PC23).
Fatalistic approach and hesitancy to treatment (*It's better to die than treating and suffering more)*	No matter how educated you are whatever you have studied or read we will become dumb sometimes (*yeshtupeddaragthiwi*) when we hear cancer. We will think like there is no treatment; they cannot give any treatment; we will die so anyhow I will die let me die; showing it to doctor and getting it diagnosed. Why should I suffer (PC05).
Anticipated side effects, body perceptions and hesitancy to treatment	The cancerous cells had spread across the armpits and the breast had to be removed; he just suggested it to us and my mother was totally not ready for that because for a women it is not easy to lose any organ just like that because the organ which is seen outside and 50% of the women's beauty is with her breast (PC15)

Source: Primary study

TDM across social, demographic and economic categories: economic dependency, intimacies and suffering

Table 7 presents how sub-categories such as age, disease conditions, and economic dependency and independency of female patients influenced the treatment decision making. As it is already discussed the decision by practitioners were mostly based on the disease conditions of female patients from all these categories. However, it was found that for patients who were not economically dependent on the family, the decisions by family members/caregivers and patients were mostly based on the sense of urgency of intervention. In some cases, patients who were the sole income earners of the family tended to take treatment decisions immediately and as suggested by the practitioners.

While cost of care was not a major factor that family members and patients considered for the treatment of financially independent female patients, cost played a major role in the case of financially dependent female patients who were uninsured and not from “rich” families. Family members attempted to find treatments that balance the concerns of cost and quality of care, although cost assumed prominence most of the time in such cases. However, it should be highlighted that strong family ties and intimacies made the family members to take decisions beyond the concerns of affordability in some cases. Other factors that intersected the decision making were related to patients’ apprehensions and concerns on adverse outcomes and morbidities. For instance, as it was already discussed, female patients who were economically dependent tended to refuse treatment to prevent the family from falling into financial crisis as they did not perceive a recovery. Also, fear of treatment outcomes and anticipated side effects led to refusal or delay of treatment by female patients. Treatment decisions of elderly and financially dependent female patients were taken mostly after considering the possible treatment outcomes since the diagnosis among this group of patients were done at a later stage of cancer. Their age and stage of cancer in most of the cases came up as concerns of going ahead with interventions such as surgery or chemotherapy even though oncologists suggested these interventions.

Table 7: Decision making for female patients

Who is the patient	Who made the decision	Why	Illustrative quotation
Married independent (economically) female	Practitioners	Urgency based on stage of disease	Actually it was entering 4th stage. I could not delay even one day as treatment was also important when I came to know it was cancer. After that the tumor started growing big (PC22)
	Family members	Sense of urgency	She was diagnosed at an advanced stage and the doctor said it was some stage 3 C and treatment is to be started soon to avoid further spread (PC31)
	Patients	Sense of urgency to get cured since she was the only earning member	At any cost, I had to be alive, I had to survive and I had to do my work and my health was not supporting me immediately, and (I knew) we can get treated by English medicine only (PC23)
		Stigma and taboo	She wanted me to get married; she delayed the whole treatment quite late (PC12)
Married dependent female	Practitioners	Urgency based on stage of disease	He [doctor] just asked us to get a complete PET, CT scanning and we got it done and he told us that it is cancer and it is in stage 2 and it has to be operated upon as it will not clear up with the medicines. The breast had to be removed because the cancerous cells had spread across the armpits (PC15)
	Family members	Cost, convenience and quality of care	We asked a few people about the reputation of hospital as affordability is one of the issues but we cannot compromise on health so we had to keep in mind two things: the quality of the treatment and financial affordability. So then we have taken a decision how we could manage both the things (PC02)
		Intimacies	We were ready to go to any extent, spend as much as we can for her treatment (CP03)
	Patients	Fatalistic approach and concerns of cost	I will die. Let me die, showing it to doctor getting it diagnosed; why should I suffer and die (PC05)
		Fear, perception of body and sexuality	50% of the women's beauty is only with her breast. I can say so nobody obviously wants to lose their organ (PC15)
Elderly dependent female	Practitioners	Urgency based on stage of disease	Her health conditions were deteriorating and the doctor asked to chart the surgery soon (PC33)
		Uncertain outcome	Age definitely is very important for us because it’s an indicator of the performance status of the patient; so if it’s a 70-year-old then we wouldn't be too aggressive with treatment unlike when the same patient is younger (PR3)
	Family members	Uncertain outcome	It was already advanced to stage 4. We were not sure whether surgery was to be done (PC41)

Source: Primary study

Table 8 illustrates how sub-categories such as age, disease conditions, and economic dependency and independency of male patients influenced the treatment decision making. It was found that the sense of urgency communicated by the practitioners and perceived by the family members/caregivers and patients was the major factor of decision making for the young male patients irrespective of their economic dependency on the family. The stage of the disease was the major interlocking factor for such decision making. However, it was found that other factors such as uncertainty of treatment outcomes, convenience of family members and sufferings that the patient underwent intersected while treatment decisions for elderly male patients who were economically independent were made. It is important to highlight that the decisions of practitioners were also influenced by the uncertainty of treatment outcomes for elderly patients who were in metastatic conditions. They tended to suggest palliative care in such instances after a round of first line treatment intervention of chemotherapy. Cost of treatment and affordability were major intersecting factors for family members/caregivers for the treatment decision of elderly patients who were financially dependent along with uncertainty of treatment outcomes. Family members in such cases sought treatment in government hospitals or alternative therapy centres. Elderly patient who were financially dependent and suffered from advanced stage cancer preferred not to undergo/continue with treatment such as surgery and chemotherapy since they considered it would further increase their sufferings.

Table 8: Decision making for male patients

Who is the patient	Who made the decision	Why	Illustrative quotation
Young dependent male	Practitioners	Sense of urgency based on biomedical conditions	He was in 3C and the doctor said chemotherapy should start soon and we agreed (PC38)
	Family members	Perceived sense of urgency	We started giving him treatment; otherwise, it will grow very fast in1st and 2nd stages. 3rd-4th one treatment chemo will be more as the stages increase (PC10).
	Patients	Perceived sense of urgency	I just wanted to get cured at any cost and immediately started the treatments suggested by the doctor (PC37)
Independent (economically) male (including elderly)	Practitioners	Sense of urgency based on biomedical conditions	The doctor at ....hospital charted the line of treatment and we followed it (PC08)
	Family members & friends	Perceived sense of urgency	My brother-in-law and I went to Kidwai where we had to go from place to place for treatment. We felt bad. His boss intervened and said HCG is our recognized attached hospital of government (PC06)
		Uncertain outcome	The way to probably take out that cancerous part near the stomach and intestine area, but while they checked it further they realized that it had spread throughout; they could have done the surgery but it would not be a complete cure. We could have gone for the surgery also but we did not go; we started with chemo (PC11)
		Convenience	Our family was in Mysore and we thought it would be easy to give care if he was shifted to Mysore (PC40)
		Sufferings and pain	We were looking for a completely alternative treatment like ayurveda and homeopathy because we had heard from a lot of people that there would be a lot of suffering if we went in for chemotherapy (PC17)

Contd...

Elderly dependent male	Practitioners	Sense of urgency based on biomedical conditions	The doctors ruled out surgery and asked us to start chemotherapy immediately. We followed it (PC44)
		Uncertain outcome	The doctors were not sure about the results of surgery and also they said there was a chance of you know…[referring to death] (PC44)
	Family members	Cost and convenience	We went for English medicine/ Allopathy because Ayurvedic is a late process we selected Kidwai hospital because experienced doctors are available and cost-wise also it is low compared to other hospitals (PC13)
		Uncertain outcomes	It is almost like a gamble; there is nothing concrete, there is nobody who can tell us this is what is going to happen if you do this (PC11)
	Patients	Suffering and pain	My father was suffering and he said he does not want any treatment, but some relief from pain. It spread everywhere and was in a very advanced stage. The doctors insisted on more chemotherapy (PC47)

Source: Primary study

Conclusion

The present study examined the factors that lead to cancer decision making and their intertwined pathways. It is found that although the practitioners have a major role in treatment decision making, it is not always a linear process since other non-medical factors often intersected, intertwined and influenced the decision making. Treatment delay was not a major problem identified in the study except for patients who had breast, lung and ovarian cancers and patients who were diagnosed in the first stage wherein the average period between diagnosis and treatment was more than the sample average. Further, it was found that sudden shock and psychological distress (coping with cancer diagnosis), affordability and uncertainty of treatment outcomes led to increased waiting period of treatment for the patients. Besides these, factors such as collection of information from various sources, seeking of multiple expert opinions, taboos, fatalistic thinking, resource mobilisation, arranging caregivers and finalising hospital and system of medicines alone or jointly prolonged the waiting period for treatment.

The study notes that there are several medical and non-medical factors that intersected when the treatment decisions are made, although the final decisions were centred on practitioners, family members/caregivers or patients themselves. While practitioner-led decisions were made based on the biomedical conditions, decisions of patients and family members on treatment were influenced by a combination of biomedical as well as social, demographic, economic and cultural reasons. Further, initial treatment decisions taken by practitioners, family members and patients varied considerably across male and female patients, financially dependent and independent, young and old as well as across all possible permutations and combinations of these categories. The study argues that initial treatment making was a combination of practitioner-led, family members/caregivers-led and patient-led pathways wherein factors such as age, gender, financial dependency, relationship with the patient, convenience of family members/caregivers, availability of facilities, uncertainty of treatment outcomes and concerns of sufferings alone or jointly play a role. These factors not only played a role in initial treatment making in terms of place, system and line of treatment but during the course of treatment as well. For instance, it was found that factors such as affordability, uncertainty in the outcomes of current treatment and patients' concerns of suffering over treatment led to abandonment of treatment, non-compliance with treatment, shifting to affordable care options in government hospitals and resorting to alternative methods. Hence the paper suggests that there is a need to develop a patient-centric approach in cancer care in order to address their unmet needs pertaining to affordability, suffering and uncertainties related to treatment outcomes.

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Dr V K R V Rao Road, Nagarabhavi P.O., Bangalore - 560 072, India
Phone: 0091-80-23215468, 23215519, 23215592; Fax: 0091-80-23217008
E-mail: balasubramanian@isec.ac.in; Web: www.isec.ac.in