

**Summer Training at
Ethnographic Medical Research Group (EMeRG), Bangalore**

**Study on Behavioral Assessment of Patients Suffering from Cancer at
Bangalore Hospitals**

**By
Anil Kumar Airedy**

**Under the guidance of
Dr. Ranjan Kumar Prusty**

**MBA Hospital & Health Management
2017-2019**

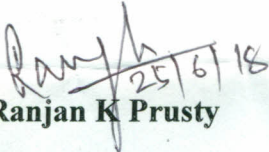
The logo for IIHMR University, featuring the letters 'IIHMR' in a large, bold, serif font, with 'UNIVERSITY' in a smaller, bold, sans-serif font to its right. The letters are white and set against a dark red rectangular background.
Institute of Health Management Research
The IIHMR University, Jaipur
2018

CERTIFICATE

This is to certify that **Mr. A. Anil Kumar** has undergone summer training in **Ethnographic Medical Research Group (EMeRG), Bangalore** from 2nd April 2018 to 2nd June 2018.

The candidate himself completed the project assigned to him during the tenure of his summer training. His approach to the project was sincere and proactive. This summer training is in partial fulfillment of the course requirement recommended for the award of MBA in Hospital and Health Management.

I wish him success in all his future endeavors.


Dr. Ranjan K Prusty

Assistant Professor

IIHMR University, Jaipur


(Col (Dr) Ashok Kumar)
Col.(Dr.) Ashok Kaushik 25.6.18.
for
Dean (Academic & Student Affairs)

IIHMR University, Jaipur

EMeRG

Certificate of Internship

This is to certify that ANIL KUMAR AIREDDY
has successfully completed internship as Trainee Research Associate at

ETHNOGRAPHIC MEDICAL RESEARCH PVT. LTD.

From 2ND APRIL '18 to 1ST JUNE '18

Signature

For ETHNOGRAPHIC MEDICAL RESEARCH PVT. LTD.
Authorised Signatory

19-06-2018

Date

ACRONYMS/ABBREVIATIONS

EMeRG	Ethnographic Medical Research Group
OOP	Out of pocket
MPCE	Monthly Per Capita Income
CAGR	Compound Annual Growth Rate
DRE	Digital Rectal Examination
TNM	Tumor Node Metastasis
CPAA	Cancer Patients Aid Association
CT	Computed Tomography
MRI	Magnetic Resonance Imaging
GP	General Physician
NHL	Non-Hodgkin's Lymphoma

Contents

Executive Summary	5
Organisation profile	6
Vision	6
Mission.....	6
Business Approach.....	6
Overview of operations	6
Introduction	7
Epidemiology of Cancer in India	7
Patient Journey Overview during cancer	12
Scope and Objectives of Study	16
Scope of the Study	16
Objectives of the Study.	16
Research Design and Methodology	16
Sampling Design	17
Observations:	18
Ethnographic observation of cancer patient pathway	18
Challenges faced by patients and oncologists during cancer treatment.....	19
Analysis:.....	23
Recommendations & Suggestions	28
Need Gap solution.....	28
Additional Recommendations	29
References	30

Acknowledgement

This report would have been quite impossible without the immense help and generating interest and satisfaction that had accompanied for the successful completion of the project would be incomplete without mentioning the name of the people who made it possible.

First of all, I express my sagacious sense of gratitude and obliged, to our Chairman Dr. S.D. Gupta, IIHMR University, Jaipur.

At the onset, I would like to express my sincere gratitude to Mr. Krishanu Bhattacharjee (Founding Director, Ethnographic Medical Research Pvt Ltd (EMeRG Pvt Ltd.) for giving me an opportunity to work on this project in their organization.

I would also like to express my deep sense of gratitude to my Project Mentor - Ms. Shivanthika, Project Manager, Ethnographic Medical Research Pvt Ltd (EMeRG Pvt Ltd.), Ms. Tanuja, Senior Engagement Manager, Ethnographic Medical Research Pvt Ltd (EMeRG Pvt Ltd.), Bangalore. Also extend my thanks to my faculty mentor Dr. K. Ranjan Prusty. I am greatly thankful to them for providing me their valuable guidance and their tireless support at all stages of the study, their advices, insinuation, positive with supportive attitude and continuous persuasion without which it would have not been possible to complete the project.

To place on record, I owe a debt of gratitude to all my teachers for grooming me. Also extend my thanks for my classmates and my parents for the inspiration needed to work with dedication and motivation throughout as an Intern at Ethnographic Medical Research Pvt Ltd (EMeRG Pvt Ltd.).

Sincere thanks to the respondents for giving their valuable time, support and providing the relevant information.

I hope that I can flourish the experience and knowledge which I have gained at the time of my internship and will make a valuable contribution in the Medical/Healthcare industry in coming future.

Executive Summary

In today's competitive world and emerging market everyone wants to know their position, their strength and weakness, so it is very essential to know opportunity to target the potential market, capture the market, understand need gaps and analyze from observation to sustain in these markets.

The objective of the project was

- To study the patient journey, pathway and their behavioral aspect that impact decision making, attitudinal changes in disease progression.
- To understand all challenges faced by patients during clinical interventions.
- To assess reasons and parameters that impact decision making, behavioral changes for discontinuation or switch in treatment.

The project was initiated in Bangalore cancer specialized hospitals and data collection was done from doctors, patients, hospitals and Insurance providers.

The project was started from 16th day of April onwards after knowing all the relevant information regarding the project, under the guidance of Mr. Krishanu Bhattacharjee (Founding Director, EMeRG Pvt Ltd). The first part of the project was to know about the Epidemiology, types, symptoms and available types of treatment and guidelines for cancer.

The next part of the project was to develop the discussion guide on the bases of few of the parameters which include all the questions to understand the signs & symptoms of cancer, treatment pathway of cancer, different challenges faced during treatment. Then the same information was probed from doctors using ethnographic observations with relevant discussion guide which includes cancer pathway, reasons for delay admission, reasons for drop out, challenges faced both by doctors and patients, therapy or treatment methods, use of different testing methods for diagnosis, cost for treatment, and any other patient support groups. This data was obtained from various cancer hospitals of Bangalore. Later secondary research on drugs available for chemotherapy and alternate treatment for cancer.

Semi structured discussion guide was made and analysis was carried to draw recommendations. The project was completed on 2nd of June.

Organisation profile

Vision

To deliver profound customer-insights to support *glocalized* business strategies in emerging markets. By providing the most accurate recommendations towards a Go/No-Go decision based on the cumulative sentiments of the market; we have helped clients save significant time and effort. By identifying new clinical applications, use-cases as well as customer segments, we have been helping global med-tech OEMs improve revenue stream in conventional markets and beyond. With deep-rooted understanding and appreciation of med-tech need-gaps, our recommendations are aimed at ensuring that the product/services reach their true potential by serving the right customer segments.

Mission

To enable creation of affordable and effective med tech solutions for emerging markets by providing profound customer and competitive insights to our clients. At EMeRG, we strive to bring customer-centricity back into business strategies. With a collective experience of several years spent within and around med-tech customers, the founding team at EMeRG stands for innovation in collaboration. We are sensitive to the cultures, ethnic backgrounds and idiosyncrasies related to the workflow within healthcare set-ups across emerging markets.

Business Approach

Publication DNA: Our publishing background helps us continuously monitor medical device market trends including customer need-gaps, policy changes, healthcare budgets, greenfield hospital projects etc.

Core team's understanding of medical devices market – Consultants and Analysts at EMeRG are adept at managing high-level yet fragile engagement scenarios with top medical professionals and industry participants while generating profound insights

Subject Matter Expertise: Our team ensures SME driven approach at every step of data collection/observation; assimilation and representation

Generating actionable insights: Our seasoned consultants with prior experience as Marketing experts with hospitals, med-tech OEMs and big pharma; as well as with clinical experience in hospitals help generate unarticulated insights

Co-creating value: Project team works as an extension of your core and functional units, ensuring real-time relay of insights and ideas in between various phases of the study; thereby co-creating value

Supportive implementation:

Complementary implementation of strategies based on respective areas of expertise

Overview of operations

Below are the area EMeRG have helped customers and MedTech firms to solve complex issues in healthcare.

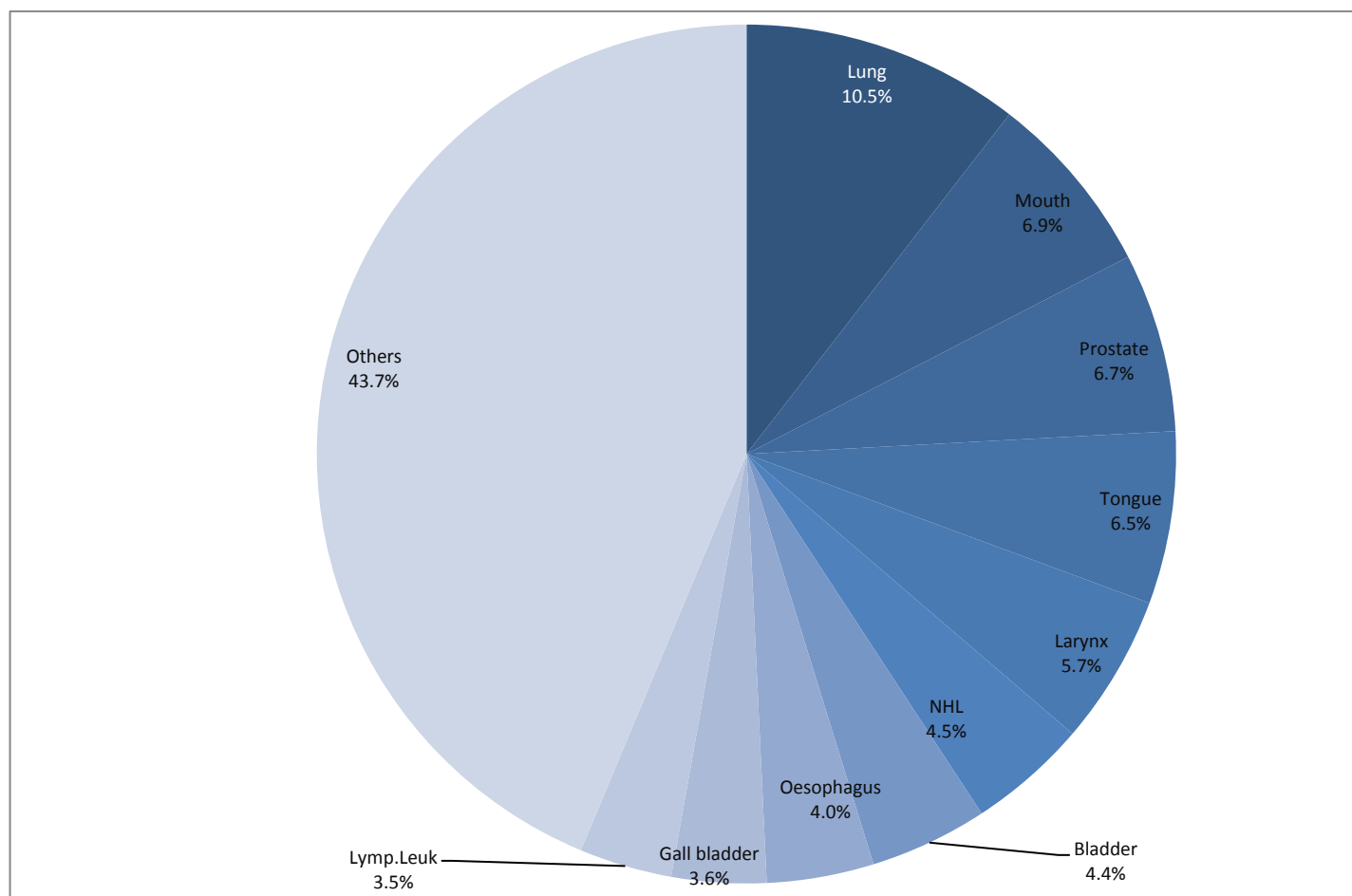
- Diabetes Management
- Cardiovascular devices
- Diagnostic Imaging
- Healthcare IT
- ICU equipment
- Maternal & Infant Care
- Medical consumables
- Nuclear Medicine Equipment
- Operating Room devices

Introduction

Epidemiology of Cancer in India

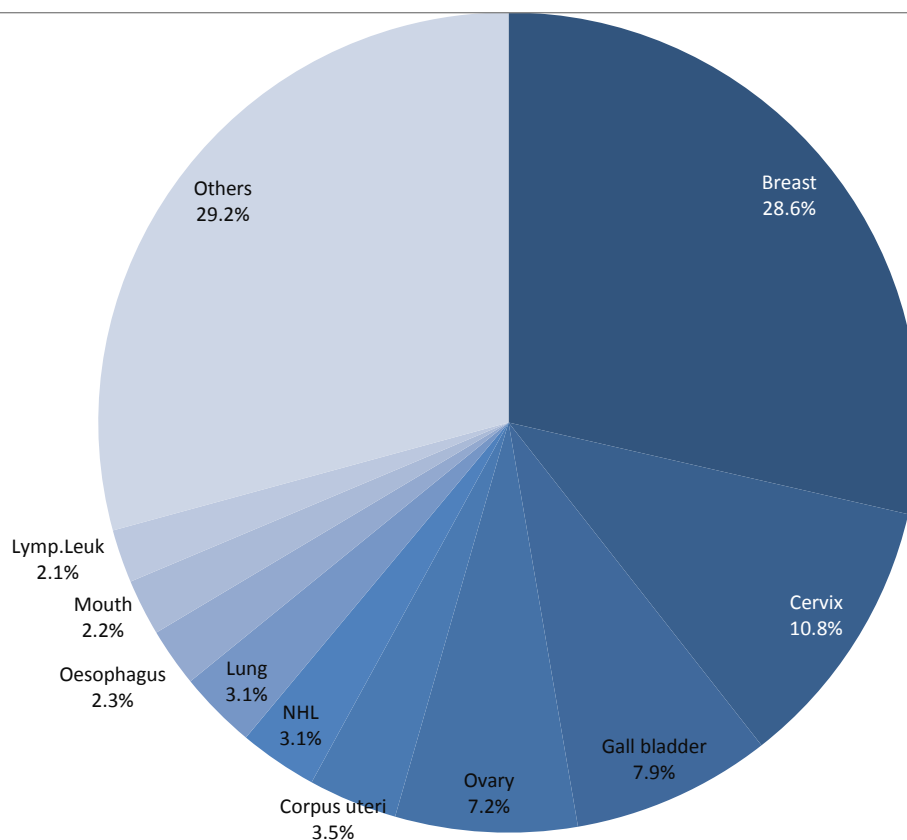
Cancer is wide spread disease in India. Every year cancer cases are increasing by 6%. India is becoming Cancer burden in world. As there are types of cancer and it also varies with gender. Slightly 1 billion of cases are diagnosed yearly. Incidence rates are also high.

India: Top 10 cancers in Male



Based on the population-based cancer registry, incidence of Cancer was found to be 1,057,204 in the year 2012.....

India: Top 10 cancers in Female



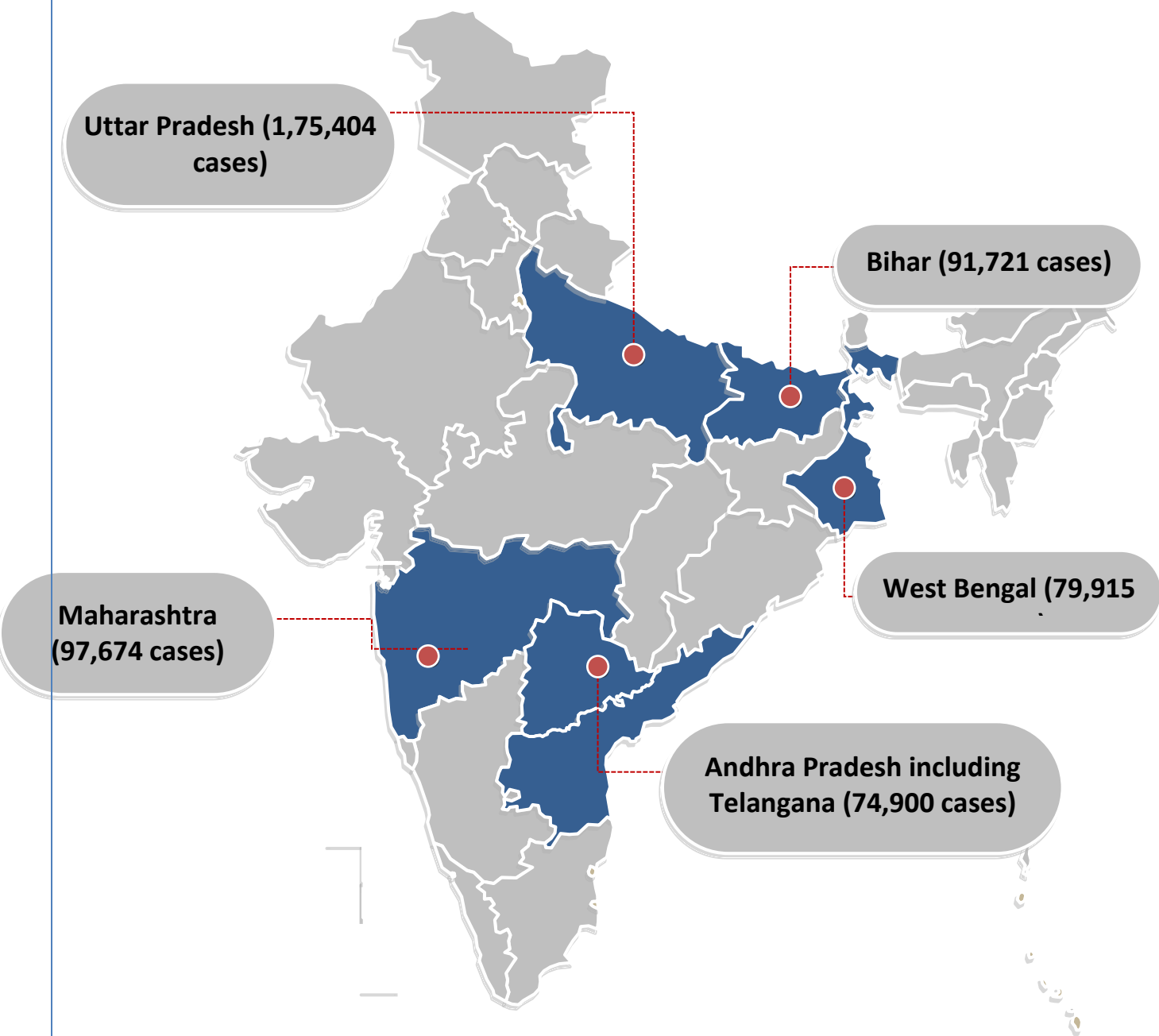
Key

NHL – Non- Hodgkin's Lymphoma

Lymph Leuk – Lymphoma. Leukaemia

Lung and breast cancer were the largest cancer types among males and females respectively. Geographically, Uttar Pradesh was the largest state reeling with maximum cancer incidence

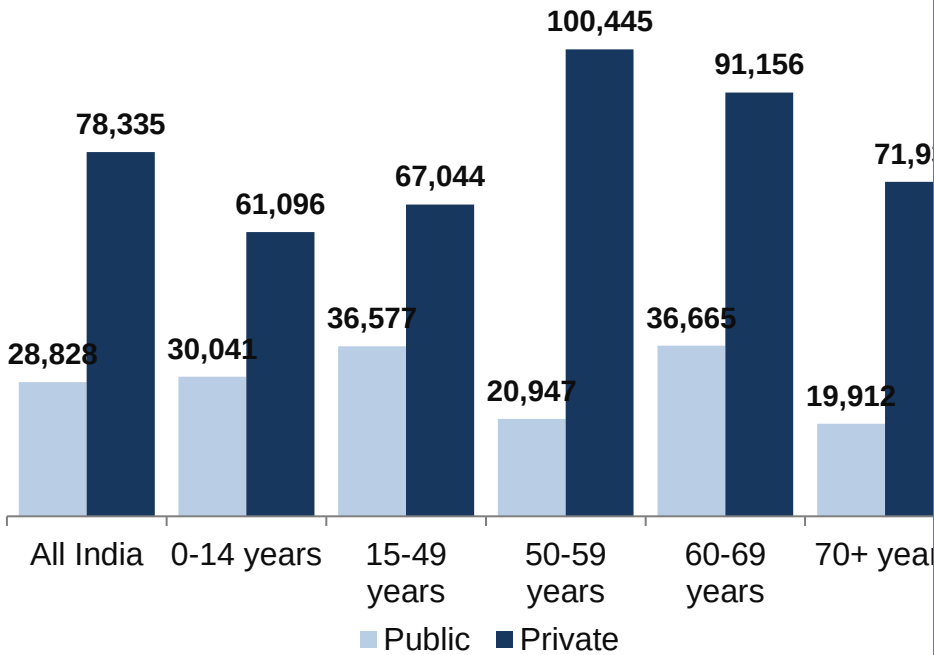
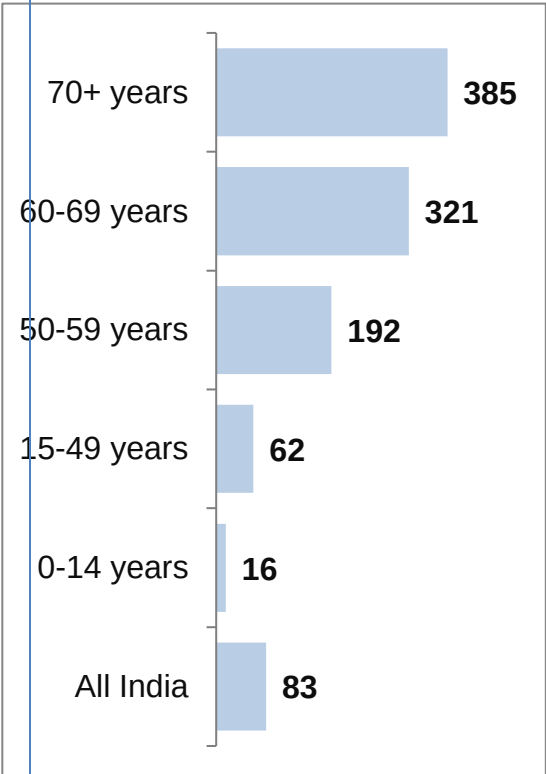
India: Top 5 states cancer incidences (2012)



Based on Cancer Index of India 2012

Overall prevalence and economic burden of cancer in India was highest for patients above the age of 60 years who pay more towards cancer treatment than the younger population...

India: All India | Prevalence per 100,000 persons in 2014



India: Age Group | Average Hospitalization Expenditure (INR) in 2014

Age of an individual is strongly correlated with cancer prevalence. The elderly age group has almost five-times higher prevalence than the population aged 15-24 years

India exhibits a strong trend of preferring private hospitals for treatment of cancer; undeterred by the need to pay twice/thrice of the expenses incurred at public hospitals.

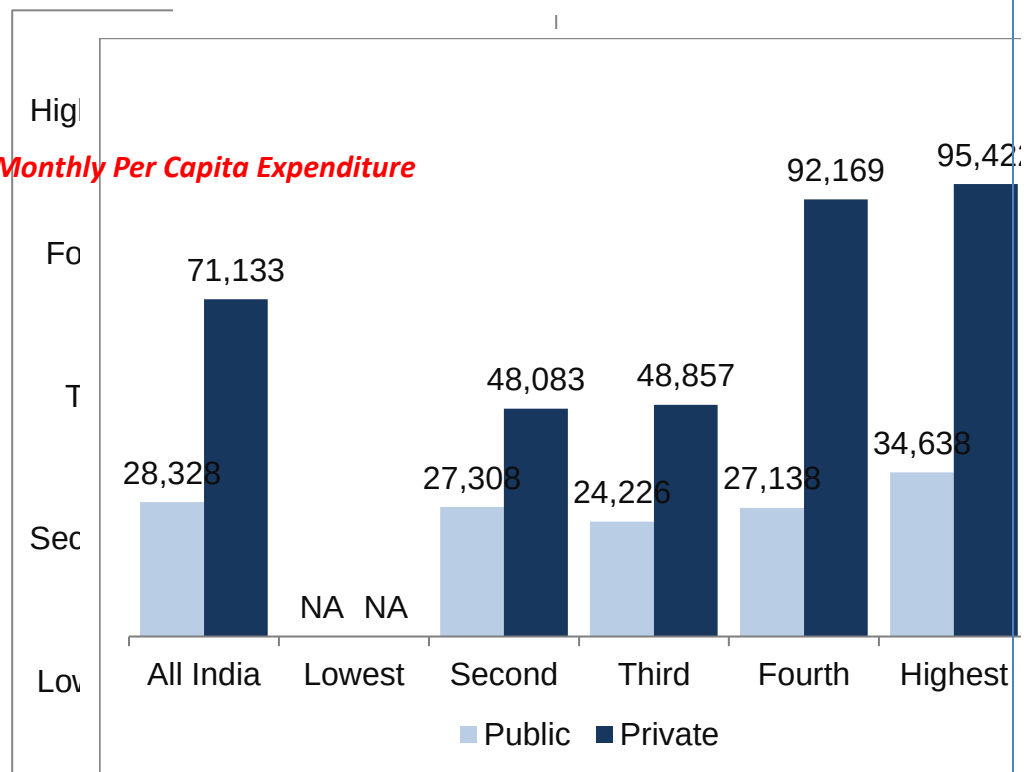
Based on economic classification - cancer prevalence was higher amongst the richer households, while raising questions around potential underreporting amongst the poor

Age of an individual is strongly correlated with cancer prevalence.

Th India: All India | MPCE* quintile in 2014
fi the population aged 15-24 years

India: MPCE* quintile | Average Hospitalization Expenditure in 2014

**Based on Monthly Per Capita Expenditure*



Treatment seeking may be higher among richer households and therefore the cancer cases among poor may be underreported due to social, attitudinal and financial issues.

The odds of cancer prevalence among individuals from highest MPCE quintiles are 3.8 times that of those from the lowest MPCE quintile.

Patient Journey Overview during cancer

These affected patients wouldn't realise until they find these symptoms as critical and also reported by doctors in diagnosis.

Initial Symptoms

The signs and symptoms vary for Solid Tumours and Blood cancers

Solid Tumours	
Blood Cancers	
1. Prolonged fever	1. Prolonged Fever
2. Nausea	2. Nausea
3. Chills	3. Chills
4. External Lumps	4. Leg Pain
5. Fatigue	5. Infection
6. Pain in affected area	6. Bleeding
7. Loss of Appetite	7. Anemia
8. Anemia	8. Fatigue
9. Swollen Glands	9. Swollen Glands
10. Weight Loss	10. Weight Loss
11. Cough or Hoarseness	11. Excessive sweating especially at night
12. Skin Changes	12. Bone pain or tenderness
13. Sores that do not heal	13. Swollen lymph nodes, enlarged liver or spleen
14. Indigestion or trouble swallowing	14. Tiny red spots on the skin (petechiae)
15. Change in Bowel Movement	

Physicians face major hurdles while diagnosing cancer during initial stages as the symptoms that manifest are common and indistinguishable from other ailments. This leads to a significant proportion of cases being overlooked

Guidelines for Solid cancer/Colonoscopy

1. Patient History

- Patient should be counselled regarding family history and risk assessment.
- Family history includes Familial adenomatous polyposis (FAP) and Hereditary nonpolyposis colorectal cancer (HNPCC)

2. Physical Examination

- A digital rectal examination (DRE) to confirm the presence of rectal tumours
- However, negative examination does not rule out colorectal cancer

3. Blood Tests

- These tests include complete blood counts, liver and kidney function tests, carcinoembryonic antigen (CEA) tests, and carbohydrate antigen 19.9 (CA19.9)

4. Colonoscopy

- Sigmoidoscopy followed by complete colonoscopy, provided if there is any significant finding on sigmoidoscopy
- Complete colonoscopy (essential) should be attempted in all patients before or after surgery (within a 3-month period, if index colonoscopy has not been completed)

5. Histopathology

- Histological confirmation of primary neoplasms is preferable, but if this is not feasible, histological confirmation of the metastatic lesion is mandatory before definitive therapy

6. Radiology

- **Colon cancer:** X-ray, USG and Abdominal CT are essential scans. Whereas, CECT and PET-CT are desirable
- **Rectal cancer:** X-ray, USG, Abdominal CT and CECT of pelvis are essential scans whereas MRI of pelvis, endoscopic ultrasound, chest CT, abdominal CT and PET-CT are desirable

7. Staging

- Tumours are staged according to the Union for International Cancer Control (UICC)'s Tumour Node Metastasis (TNM) staging system

8. Pathological Examination

Pathologic examination should include (essential) determination of the following:

- Tumour grade, depth of penetration, Number of positive lymph nodes and number of lymph nodes evaluated (a minimum of 12 lymph nodes should be evaluated), lymph vascular invasion, perineural invasion, extra nodal tumour deposits, status of proximal, distal, and radial margins

9. Treatment

- **Operable disease:** Primary surgery with or without adjuvant chemotherapy
- **Locally advanced disease, primary curative resection unlikely:** Consider preoperative chemotherapy
- **Isolated metastatic disease:** Consider resection of primary disease followed by mastectomy with or without neoadjuvant and/or adjuvant chemotherapy
- **Widespread metastatic disease:** Palliative chemotherapy, supportive care

Guidelines for Blood cancer/Lymphoma

1. Patient History

Accurate diagnosis requires a combination of the following:

- Detailed patient history, clinical examination, and various investigations
- Morphological assessment is the first step in the diagnosis of NHL.

2. Diagnosis

- Diagnostic modalities include morphology, cytochemistry, Immunohistochemistry, Flow cytometry, Cytogenetics and Molecular diagnostics

3. Diagnostic tests

The diagnostic modalities could be applied to different tissue samples as follows:

- Peripheral blood and bone marrow aspirate specimens
- Lymph node and extra nodal tissues
- Bone Marrow Trephine Biopsy
- Body fluid samples

4. Staging Work-up

- Clinical, Haematology, Biochemistry, serology and radiology examinations to be considered
- **Radiology:** CXR, Chest and abdominopelvic computed tomography (CT) with oral and intravenous contrast (unless coexistent renal insufficiency)

5. Staging

- The staging system used for adult high-grade lymphomas is based on the **Ann Arbor System**.

6. Treatment

- Treatment is based on histologic subtype, extent of disease and age of patient.
- In case of **Discordant** (2 separate sites and separate lymphoma types), **Composite** (single site with 2 discrete lymphoma types) and **Transformed** (second lymphoma developing out of previously known lymphoma) lymphomas, treatment is given at the most aggressive phase of disease

7. Relapsed Lymphoma

- Many chemotherapy regimens exist for the treatment of relapsed NHL. Patients who are suitable for autologous transplantation should not receive highly myelotoxic regimens for fear of depleting stem cell reserve
- Chemotherapy regimens for potential candidates for stem cell therapy: DHAP, ESHAP, GDP, GemOx, ICE, MINE

8. Follow Up

- Patients should be followed up every 3 to 4 months for the first 2 years, followed by 6 monthlies for the next 3 years and then annually

Scope and Objectives of Study

Scope of the Study

The project scope involves the study to conduct ethnographic observations at Cancer centers to understand the disease progression, patient behavior, affordability and key factors influencing patient decisions beyond prescription drugs and therapy.

The project scope also involves the finding various patterns and analyse those need gaps to produce better treatment without patient drop-outs.

Objectives of the Study.

The objective of the project was

- To study the patient journey, pathway and their behavioral aspect that impact decision making, attitudinal changes in disease progression.
- To understand all challenges faced by patients during clinical interventions.
- To assess reasons and parameters that impact decision making, behavioral changes for discontinuation or switch in treatment.

Research Design and Methodology

Research Design

Ethnographic and Observatory Study Design.

Research Methodology

Secondary Research

- Creation of detailed listing of Hospitals providing Oncology Services in Bangalore.
- Understand disease progression
- Typical patient pathways
- Treatment guidelines for key cancer types.
- Additional online/offline support accessible to patients

Primary Research

- Observatory study within depth qualitative interviews were conducted for oncologists, patients and care givers.
- Sample size was 10 oncologists and 50 patients.
- In addition, interviews with nurses, insurance providers are considered in study.

Ethnography Observation

The following observations were made while shadowing clinicians and patients:

- Patient doctor interactions
- Patient behavioural patterns at various stages of disease progression
- Healthcare infrastructure
- Interactions of patient/caregiver with support staff

Sampling Design

Sample Size

The sample size has been 10 doctors along with 50 patients and other stake holders like nurses and insurance providers. Conclusions had been arrived at using the response of the discussion guide.

Sampling Method

In this ethnographic research project, Sampling method was convenience and purposive sampling.

Sampling Area

Specialized hospitals and cancer centers in Bangalore are the sample area where feasibility of patient and doctor interview can be conducted and high rates of patients with cancer are found in these areas.

Observations:

Ethnographic observation of cancer patient pathway

1. Initial Symptoms

- Patient notices preliminary symptoms such as prolonged fever, nausea, chills, external lumps, and fatigue

2. First point of contact

- Patient consults physician (GP) nearby, or a family doctor for the treatment of initial symptoms

3. Initial Diagnosis

- The GP/physician prescribes routine blood tests-Hemogram/CBC, Vitamin Profile, and other tests based on the symptoms
- Based on test results GP refers patient to an Oncologist

4. Additional tests

- Oncologist prescribes additional blood tests/scans after gauging symptoms
- Advanced testing methods such as cytogenetic tests may also be employed at this stage

5. Radiology/Nuclear Medicine

- Oncologist prescribes a combination or all of the following scans to confirm diagnosis:
- CT, MRI, Ultrasound, PET/CT, Biopsy

6. Diagnosis & Staging

- Upon confirmation of cancer, the Oncologist proceeds to stage the condition based on size of tumor and degree of metastasis

7. Treatment

Based on nature and location of tumour combined with other patient factors – the oncologist adopts a combination of the following:

- Primary surgery with adjuvant or non-adjuvant chemotherapy
- Preoperative chemotherapy
- Surgery with/without chemotherapy
- Palliative chemotherapy, supportive care

8. Follow-up

- Routine blood tests and PET/CT scans are conducted periodically (as often as once in every 3-6 months) depending on patient's response to treatment

9. Relapse

- Oncologist typically recommends additional cycles of chemotherapy and/or radiotherapy

Challenges faced by patients and oncologists during cancer treatment

Challenges faced by patient during the course of diagnosis and treatment vary in magnitude across the prognosis and treatment pathway.

1. Financial Challenges

- Patients living in rural areas lack access and financial support required to visit specialized centers for advanced methods of diagnosis
- Patients often cannot afford advanced tests such as cytogenetic testing which provides a detailed analysis of the disease condition; This causes oncologists to rely on less accurate methods of diagnosis
- Uninsured patients exhibit heavy reliance on out-of-pocket healthcare payments which adds to financial strain; sometimes leads to abrupt patient drop-out
- Cancer patients largely rely on distress financing mechanisms to receive cancer treatment; at this stage the patients would have typically exhausted all sources of finance
- Patients cannot avail treatment at private hospitals; hence would seek treatment at government hospitals or trust-based hospitals
- Patient would have already exhausted monetary assets for treatment of cancer, leaving limited assets to fund treatment for relapse
- Availability of insurance cover for relapse is negligible under general health insurance

2. Attitudinal Challenges

- Certain symptoms are perceived to be “relatively common” (such as fever, fatigue etc.) which leads to procrastination and delay in diagnosis
- Patients may have limited understanding of cancer and its diagnosis; they also fail to seek a second opinion
- Patients deny positive cancer diagnosis (refusal to believe that they might have cancer)

- Based on various unreliable sources (internet and hearsay), patients develop fear of potential side-effects of therapy; this may lead to adoption of alternate modes of treatment such as Ayurveda
- Patients may be of the opinion that the cost of treatment is an unnecessary waste of assets as death is imminent
- Patients may not be able to adapt to the changes in lifestyle (such as dietary and travel restrictions)
- Patients exhibit low pain threshold to the continued treatment process
- The cancer treatment regime often causes patients to slip into depression – social reclusion being one of the common behavioural changes
- Patients face emotional/psychological issues due to the relapse of cancer; it also causes them to lose hope
- Patients prepare for imminent death
- Care-givers often abandon patients or exhibit resentment towards patient which further reduces patient morale

3. Clinical Challenges

- Physicians misdiagnose these common symptoms; which in turn provides flawed assurance to patients. This leads to patients refraining from a second opinion
- Several regional Government hospitals tend to postpone diagnosis/treatment (caused due to heavy patient load and increased wait time) of cancer patients leading to worsening of their condition
- The depleted financial status, combined with the lack of motivation, propel the patients to either refuse treatment or adopt supportive therapy

4. Informational Challenges

- Patients fail to understand the requirement of certain diagnostic tests such as Complete Blood Count (CBC) being conducted periodically
- Due to lack of awareness, several patients believe that cancer is a contagious disease
- Patients have a mind-block that cancer and its treatment will hamper their ability to fulfil professional duties efficiently

5. Socio-Cultural Challenges

- Section of patients opt for Ayurveda, Homeopathy or home remedies at this stage to treat “common symptoms”. This delay leads to a subsequent worsening of their condition (advancement of cancer)
- Fear of social stigma for a positive cancer diagnosis causes patients to avoid confirmatory diagnostic tests
- Patients fear social stigma caused due to side-effects (such as loss of hair, effect of cancer on personal/family reputation) and discontinue treatment

6. Dependency Challenges

- Observed in Geriatric Cases - Care-giver(s) refuse to obtain treatment for the patient – as they perceive the trade-off between expenditure on treatment and length of survival to be non-equitable
- Lack of emotional and psychological support from care-giver(s)
- Continued dependence of the patient may add emotional and psychological burden on the caregiver leading to unknown negligence as well as seclusion of the patient

Challenges faced by patient and physician (oncologists) during the course of diagnosis and treatment vary in magnitude across the prognosis and treatment pathway.

- Despite the presence of high-end facilities, India's cancer survival rate is cited to be one of the lowest. This can be attributed to disparity in terms of healthcare access, lack of awareness and significant prevalence of misdiagnosis in cancer
- *“Doctors at small centres lack the orientation to diagnose cancer...However sometimes patients also lack clarity in relaying the symptoms, which worsens the case” - Oncologist, SMC, Bangalore*
- A section of patients are misinformed with regards to cancer and are unwilling to undergo diagnosis. Additional time and effort is required on the doctor’s part to address such misconceptions

- Conducting follow ups for tests missed out during inter-departmental miscommunication
- *Some patients would have obtained information from Google, their relatives, neighbours and such, but never first hand...- Oncologist, HCG Hospital, Bangalore*
- Lack of awareness amongst patients towards importance of periodic diagnostic checks leads them to mistrust the oncologists
- Doctors have to address any misconceptions the patients may have regarding side-effects, social stigma, etc.
- Unwilling patients may require excess counselling (added time and effort) from the oncologist
- Patients become overdependent on their oncologist for informational and emotional support
- Oncologists spend additional time and effort in providing informational and emotional support at the stage to motivate them as well
- They also spend time to understand the reasons for drop-out and offer solutions such as participation in clinical trials, free drugs scheme, etc.
- *Most of my patients are middle class patients but enter the low-socio economic bracket after they are diagnosed with cancer and then having borne the treatment cost.” -Oncologist, SMC, Bangalore*
- Relapse cancer patients are mentally precarious - exhibit minimal motivation to continue treatment as they perceive it to be “not effective” Hence highlighting the need for specialised counsellor adept at handling relapse patients
- *Maximum patient drop-out is during relapse; because the drugs are also very expensive, by then it becomes unaffordable and mostly they are bankrupt. ”-Oncologist, SMC, Chennai*

Observations in Patient drop out

Patient has Initial symptoms, Visits general physician

- Patient is ignorant to the actual cause of fever and other symptoms
- Misdiagnosis by General Physician

Patient undergoes diagnostic tests

- Patient fears cancer diagnosis
- Patient does not live in the proximity of a testing facility/does not have means to travel

Treatment Phase 1 (Drop at initial stage)

- Patient fears side-effects of treatment

- Patient cannot afford prescribed treatment

Treatment Phase 2 (Drop at mid-way)

- Patient is not able to tolerate side effects
- Can no longer afford treatment
- Moves to alternate therapy

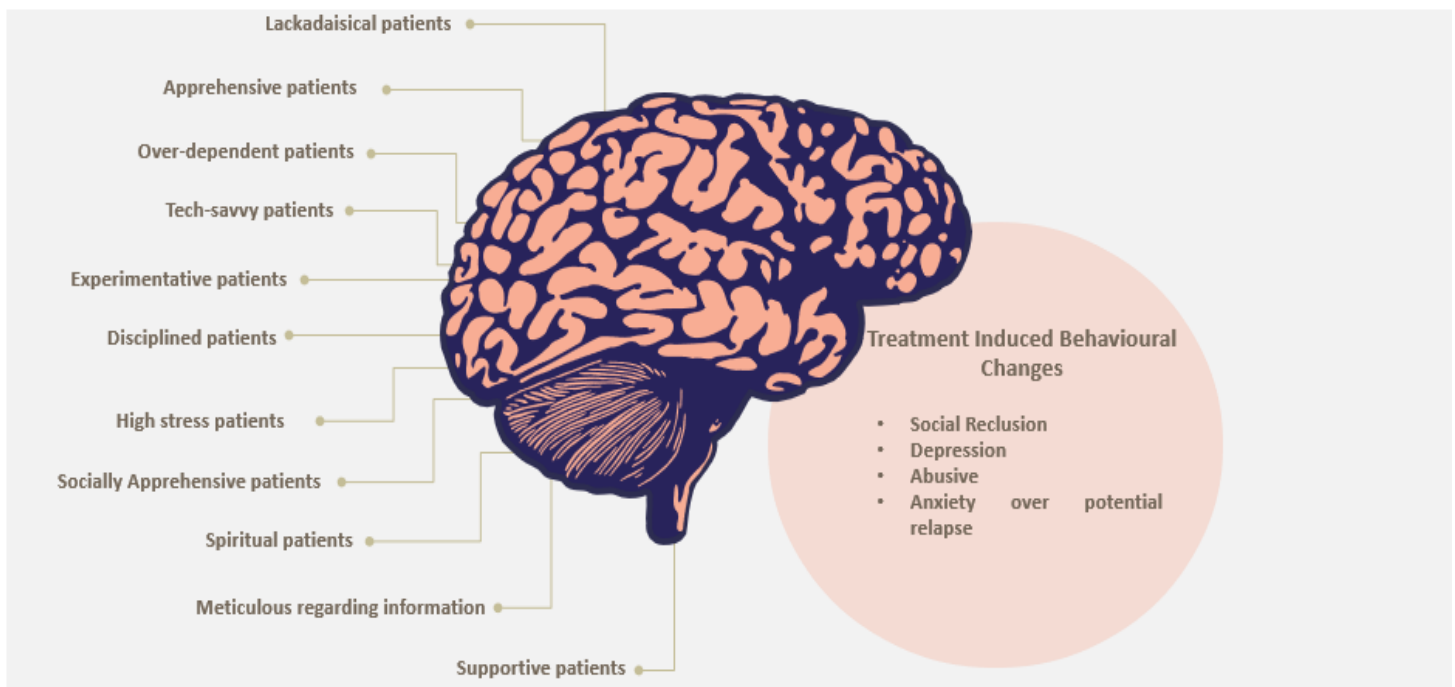
Treatment Phase 3 (Relapse stage)

- Neglects post-treatment medication and routine testing plan as patient believes that the cancer is cured
- Can no longer afford treatment

Analysis:

Patient patterns and behaviour in Cancer treatment

Key behavioural patterns exhibited by cancer patients are mostly innate while a few are developed during the course of the cancer treatment.



Patient behaviour which impacts the cancer treatment either positively or negatively and analysed few patterns as

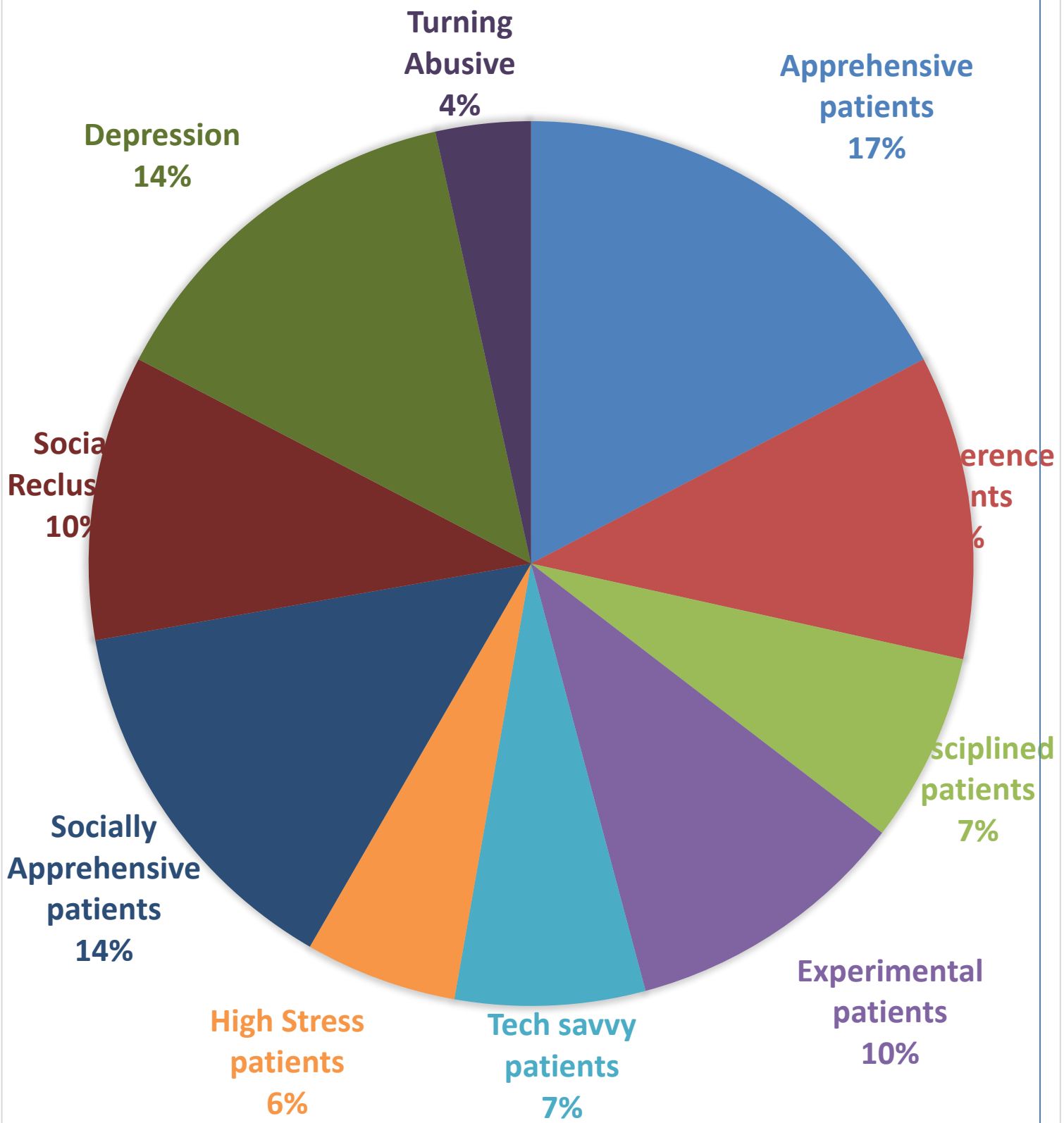
1. **Apprehensive patients:** *"I Don't Have Enough Trust in my Oncologist and The Treatment Plan Prescribed"*. Specifically, amongst the middle-class and upper-middle class economic groups - patients are wary of trusting the oncologists completely with the diagnostic and treatment plan. They would seek second opinion from other oncologists and adhere to the treatment only if satisfied or else continue to seek treatment outside.
2. **Lackadaisical patients:** *"I Will Come for The Treatment Based on my Own Convenience"*. Oncologists have noticed certain section of patients (literate and illiterate) to exhibit various levels of disregard towards the disease condition; hence leading to a delay in administering timely treatment.
3. **Disciplined patients:** *"Doctor, You Tell me what Should be Done"*. Oncologists notice the prevalence of unwavering faith amongst patients (who have been referred by a cancer survivor or typically belong to

lower and lower-middle class income groups or pediatric cases) towards the diagnostic plan, treatment and follow-up schedule.

4. **Experimental patients:** *“I Am Willing to Try the Experimental Drugs”* Across all economic groups; there are sections of patients who are open to experimental drugs based on the oncologists’ assurance. Such patients account for high representation in clinical trials managed by oncologists.
5. **Tech savvy patients:** *“Internet Suggests That for my Condition I Should Be Prescribed This Drug”*. Doctors observe majority of their educated patients to be struggling with pre-conceived notions about their conditions. The information would have been typically obtained from the internet. Doctors have to spend additional efforts towards convincing such patients on the prescribed therapy regime.
6. **High Stress patients:** *“I Am Unable to Visit My Office and Work For 9 Hours”*. Working patients also believe due to the chemotherapy/radiotherapy regime, they may not be able to perform their professional duties. The doctors, however encourage these patients to continue to execute their professional duties and avail leaves only during the therapy sessions.
7. **Socially Apprehensive patients:** *“Since I Have Contracted Colon Cancer, Will My Son Also Get It?”* Majority of the patients show reluctance to declare their diagnosis to members outside the family as they fear the social stigma attached to the condition. The patient misunderstanding is of the following types -
 - Congenital implications: Patients believe cancer to be transmitted congenitally.
 - Contagious: Patients believe cancer to be transmitted via physical contact.
8. **Social Reclusion:** Some cancer patients demonstrate social withdrawal and avoid interactions with members outside family. In certain cases, patients reduce interactions with the primary care-giver as well leading to further mental distress.
9. **Depression:** Certain segments of patients also tend to develop a negative attitude towards the diagnostic and treatment process; and some even exhibit reluctant participation in the treatment plan. Oncologists note that this could prove to be harmful if left “un-counselled”.

10. **Turning Abusive:** Some cancer types may cause memory loss, confusion and introduce changes to the patient's personality. Patients reeling with such changes often tend to get abusive towards care-givers, family members, support staff at hospitals, etc.

BEHAVIOURAL ANALYSIS OF CANCER PATIENTS (DOCTORS VIEW)



Additional behavioural analysis of Cancer patients

1. Majority of patients exhibit strong inclination towards spirituality mainly in the form of praying and meditation
2. Scientific research papers prove that patients with a strong sense of spirituality are better able to adjust and cope with illness.
3. A research paper titled, *Spirituality in the cancer trajectory*, published in the Annals of Oncology, April 2012 notes the following:
4. Spirituality is an essential element of person-centered care and a critical factor in the way patients with cancer cope with their illness from diagnosis through treatment, survival, recurrence and dying.
5. Spirituality can be a powerful positive force in helping patients reframe their illness, find greater meaning in life, and recognize what is ultimately important and of value to them.
6. Cancer patients who are on the path of recovery often tend to visit the cancer hospitals and meet fellow cancer patients on a voluntary basis; thus, leading to more open discussions between patients. Typically, cancer patients are observed to be less inhibited in disclosing their problems with these cancer survivors.
7. In a stark contrast to tech-savvy patients, another segment of cancer patients strives to seek scientifically backed information regarding their condition. These patients, independently, seek support from online/offline support groups, pharma companies, and other entities.

Recommendations & Suggestions

Need Gap solution

Financial

1. Patients often cannot afford cytogenetic testing where proposed partnerships between pharma companies and hospitals to identify potential drug users – and provide free testing/subsidy to patients.
2. Financial distress often compels patients to seek treatment at facilities where awareness towards providing availability of subsidized care and alternate financing schemes can encourage patients.
3. Limited availability of funds often leads to higher patient drop-out that can be reduced by introducing patients to patient support group and subsidized patient accommodation for cancer at hospital can reduce drop-out.

Attitudinal

1. Lack of understanding of cancer symptoms leads to a delay in diagnosis. It can only be reduced by self-awareness and initiatives lead by healthcare system.
2. Relapse of cancer causes patients to undergo severe mental distress (causing them to lose hope).

Informational

1. Social media can be tapped to educate the public on the importance of a doctor prescribed diagnostic plan to avoid baseless anxiety that can make think patient about periodic diagnostic testing.
2. Public Educational programs to eradicate misconceptions related to cancer, its symptoms and treatment methods as patients has lot of misconception about cancer. (e.g. cancer is contagious)
3. Introduction of chat bots will help patient to have a conversation with the bot and reduce the burden on doctors.

Clinical

1. Medical awareness programs to be conducted amongst General Practitioners for cancer related symptoms and encouraged to refer patient to cancer centers that can reduce misdiagnosis and false assurance.
2. Encouraging relapse patients to undergo clinical trials to motivate patient's financial condition a bit easy.

Socio-Cultural

1. Social stigma caused due to side effects from treating cancer can also be point for drop-out or self-restriction from society which can be reduced in tier II and tier III cities by creating awareness about treatment and side effects.
2. Faith based patient support for patients and care-giver(s) are to be made available to tackle their situation in society.

Dependency

1. Continued dependence of the patient may add emotional and psychological burden on the caregiver leading to unknown negligence as well as seclusion of the patient.

Additional Recommendations

1. **Home-care services:** A nurse to aid and monitor the patient for several days post discharge from the hospital. This service is likely to benefit the patient and the care-giver.
2. **Patient monitoring system:** As the patient has shown a history of complications during procedures, a rigorous patient monitoring scheme may aid in avoiding future complications. Home care devices could be provided to the patient to monitor vitals which could be relayed real-time to the doctor.
3. **Patient support programs** for transplant patients - buddy programs, building hobbies, etc.
4. **Pooled transport services** could be provided to patients to avoid incurring travel costs.
5. **Knowledge Platform:** Once a patient has received a positive diagnosis, a knowledge platform can be made available to them so that decisions can be made with complete understanding of the consequences.

References

1. [http://www.cancerindex.org/\(12/4/2108\)](http://www.cancerindex.org/(12/4/2108))
2. Economic burden of cancer in India: Evidence from cross-sectional nationally representative household survey, 2014.

Rajpal S¹, Kumar A¹, Joe W¹.

3. <https://data.gov.in/keywords/monthly-capita-expenditure>
4. Inequity in out-of-pocket payments for hospitalisation in India: Evidence from the National Sample Surveys, 1995–2014. (Authors AnamikaPandey^{ab}LyndaClarke^bLalitDandona^{ac}George B.Ploubidis^d)
5. Disease and age pattern of hospitalisation and associated costs in India: 1995–2014
6. <https://www.cancer.gov/about-cancer/diagnosis-staging/symptoms>
7. <https://www.cancer.gov/publications/dictionaries/cancer-terms/def/solid-tumor>
8. <https://www.leukaemiacare.org.uk/support-and-information/information-about-blood-cancer/blood-cancer-information/signs-and-symptoms-of-leukaemia/>
9. STANDARD TREATMENT GUIDELINES ONCOLOGY, Ministry of Health & Family Welfare Govt. of India. Dr Anil K.D ‘Cruz Director and chief Head and Neck services, Mumbai.