

Cancer disease management system

Simplifying the chemotherapy journey

Submitted by: **Abhishek Yadav**
22M2268

Guide: Prof. Mandar Rane

Project 2
Communication Design 2022-24



Approval Sheet

This project report titled "Cancer disease management system" by
Abhishek Yadav Roll no: 22M2268 is approved for partial fulfilment of
the requirements of the Master of Design Degree in Communication
Design, IDC School of Design, IIT Bombay.

Project Guide: 

External Examiner: 

Internal Examiner: 

Chairperson: 
24/11/2023

Date: 24. 11. 23

Declaration

I declare that this written submission represents my ideas in my own words and where other's ideas or words have been included, I have adequately cited and referenced the original sources. I also declare that I have adhered to all principles of academic honesty and integrity and have not misrepresented or fabricated or falsified any ideas, data, facts or sources in my submission. I understand that any violation of the above will be cause of disciplinary action by the institute and evoke penal action from the sources which have thus not been properly cited or from whom proper permission has not been taken when needed.



Date: 24.11.2023

Place: Mumbai

Name of Student: Abhishek Yadav

Roll No. 22M2268

IDC School of Design, IIT Bombay

Acknowledgement

The completion of this project could not have been possible without the participation and guidance of many people. I am thankful to

Prof. Mandar Rane for his valuable guidance and support at various stages of this project. The suggestions and feedback in the project helped me a lot during this journey.

I am also thankful to **Prof. G. V. Sreekumar** for his feedback and suggestions during the project and presentations.

In addition, I want to express my gratitude to the patients, caregivers, doctors, medical researchers and hospital staff for their valuable time, ideas and experiences they shared with me. Thanks to Abhishek Kushwaha, Sarvesh Benkar, Shashank Kate, Aparajita Prasad, and Sandeep Verma for their valuable feedback and input on this project.

In addition, I am grateful to all my fellow communication design batchmates for their help during the process.

I want to thank my parents for always inspiring me.

Abstract

The Project was formed by discovering the challenges patients and their caregivers encountered during chemotherapy. Insights gathered from the participants during interviews helped provide a foundation around the problem, further guiding the solution. The approach during the Project included brainstorming ideas, generating scripts with different stories, developing visuals and crafting a video solution. The content was tested during the process and revised based on the feedback. Real-life stories narrated during the interviews were integrated, and elements of hope were added along with the data. The outcome of an explainer-illustrated video simplifies the journey. It reduces confusion by providing essential information along with common myths and misconceptions weaved together with the patient's story to give them hope, making it an understandable resource, easy to locate and information straightforward to digest in narrative format.

List of Contents

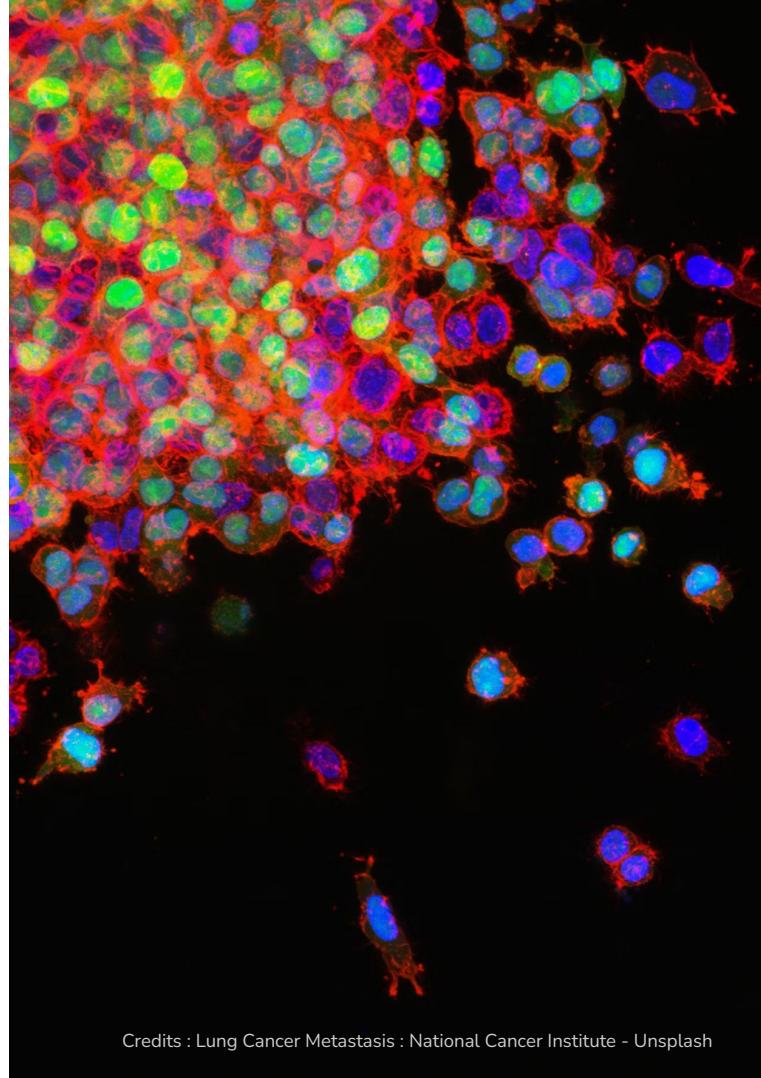
Introduction : cancer?	1	Chunking	30-31
The silent killer	2	What is included?	32-33
Journey to recovery	3	Video story ?	34
Why this topic?	4	Better for hospitals ?	35
Problem statement	5	Ideas	36
On-screen : Documentaries, Blogs Movies : Books	6-13	Scripts	37-43
Interviews	14-15	Storyboard	44-46
Quotes from the interview	16-17	Sound	47
Participants	18	Character	48
Insights	19-20	Design decisions	49
Sketches	21-22	Visuals	50-59
What about the existing solutions?	23-26	Learnings	60
Journey maps of patients	27-29	References	61

Introduction : Cancer?

“Cancer is a disease in which some of the body’s cells grow uncontrollably and spread to other parts of the body. ”

It is caused by an uncontrolled division of abnormal cells in any body part. It begins when cells grow out of control and crowd out normal cells, making it hard for the body to function as it should.

Cancer can start almost anywhere in the human body, consisting of trillions of cells. Usually, cells grow and multiply through cell division (when a parent cell divides into two or more cells called daughter cells) to form new cells as the body needs them. When cells grow old or become damaged or worn out, they die, and new cells take their place. Sometimes, this process breaks down, and abnormal or damaged cells grow out of control and keep multiplying. They crowd out the normal cells and may form tumours, which are tissue lumps.



The silent killer

“One in every nine Indians will develop cancer during their lifetime.”

- Study carried out by the ICMR-(NCDIR) National Centre for Disease Informatics and Research, Dec 2022

In India, the estimated number of incident cases of cancer for 2022 was around 14,00,000; lung, breast and oral cancers are the leading cancer sites in males and females. The national average of cancer cases for 2022 is 100.4 per 1,00,000. According to the (GLOBOCAN) Global Cancer Observatory estimates, there were 19.3 million incident cancer cases worldwide in 2020. India ranked third after China and United States of America.

Data From: Cancer incidence estimates for 2022 & projection for 2025:
Result from National Cancer Registry Programme, : Indian Journal of Medical Research. and, Indian Council of Medical Research



Journey to recovery

Many types of cancer treatment are available in India, and an **oncologist decides on various factors, including the type of cancer type, stage and the patient's condition, to choose the treatment option** . It can be one treatment or a combination of treatments, such as surgery with chemotherapy. A few common treatments on the journey to recovery are listed below:

Surgery involves physically removing tumours or cancerous tissues from the body. It often requires cuts through skin, muscles, and sometimes bone.

Chemotherapy is a treatment that uses drugs to kill cancer cells, and it works by slowing or stopping the growth of cancer cells, which divide and grow rapidly.

Targeted therapy targets proteins that control how cancer cells grow, divide, and spread while minimising harm to normal cells.

Radiation therapy (radiotherapy) is a cancer treatment that uses high doses of radiation to shrink tumours and kill cancer cells.

Immunotherapy is a cancer treatment that utilises the body's immune system to recognise, attack, and destroy cancer cells. It focuses on enhancing the immune system's natural ability to fight cancer.

Why this topic?

I selected cancer as the focus of my project due to the alarming severity and **unique challenges** in the Indian healthcare system. This disease is multifaceted, and its medicine and management present complex challenges at every step. It would allow me learn how to **empathise** with patients, deal with lots of knowledge, build content, solve issues and design a solution to simplify the data journey.

Another primary reason is **personal**, as my mother was diagnosed with B cell - non-Hodgkin's lymphoma, and this experience allowed me to closely observe and feel the physical and **emotional challenges** faced by the patients and their loved ones. In such challenging times, we met many problems with the data, dealing with suggestions, mental stress for the family and even financial issues. I got to know that this disease is something which the entire family fights. And the process involved, from diagnosis to the final treatment, is very lengthy and complicated.

While in the cancer ward and even during diagnosis, there were little to no details available, and even so, if we went on the website, we were bombarded with technical jargon and terminologies, which were in different directions. We went to public and private hospitals and discovered that it is a prevalent disease in India, but very little is known about its diagnosis and therapy. For example, we were not very convinced about radiotherapy, whether it would cause burns visible outside, or even about chemotherapy, which would be through the nasal channel, as one of our friends said. There were many instances where we felt like we were going and never knew where the path would lead to and not even whether the route on which we were walking was the right choice during the time, we had little and some wrong understanding about the process which further build many scenarios in mind.

Problem statement

Many cancer patients in India face serious challenges. They usually have little knowledge about cancer treatments and are extremely worried from the time of diagnosis till the final treatment process. This prevents them from making wise treatment decisions, an essential issue as they discontinue the treatment. Along with that money, paying for treatment is also challenging for a patient's family.

To address these issues, I'll use visuals to educate patients and their families about the cancer journey. They will find it simpler to make wise decisions as a result.

Evolved :

Understanding chemotherapy, battling common myths and misinformation and coping with mental stress and anxiety is challenging for many cancer patients and their caregivers. Existing information sources in hospitals, such as complex brochures, booklets or complicated website content, do not provide easily digestible guidance. People who turn to the internet feel lost and may require the correct information. Also, some refrain from talking to doctors about their concerns, making it harder to get clear answers.

Audience

General information to patients and caregivers in India who are either about to start or are in the process of chemotherapy (Male).

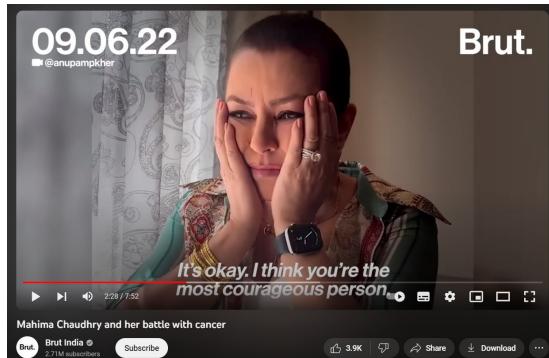
On-screen: Documentaries, talks and blogs

Mahima Chaudhry and her battle with cancer

"We are so terrified of the word cancer, which is why I didn't share it with my parents."

"Why even a wig? Why can't you just do the film just like you are." sometimes our colleagues help us by giving us strength—these lines. Anupam Kher spoke to Mahima, who was undergoing chemotherapy and had lost her hair. A line which filled her heart with tears and helped her gather the strength to come back to the screen again as she was.

Credits : Youtube Brut channel

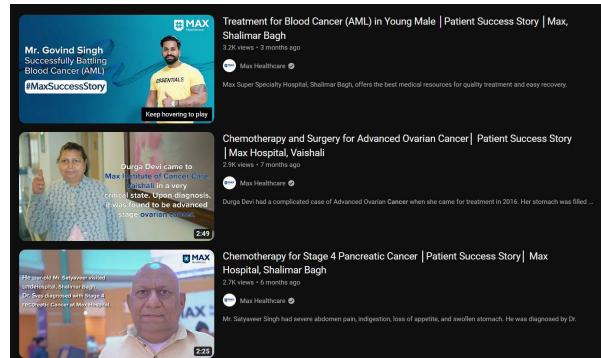


6

Max Healthcare (Max Super Speciality Hospital, Shalimar Bagh)

Collection of short stories of patients and doctors, telling viewers how they started and overcame this disease. Doctors also tell and inspire viewers about various treatments, making them aware of the treatment and process by giving real examples.

Credits : Youtube Max Hospitals Channel



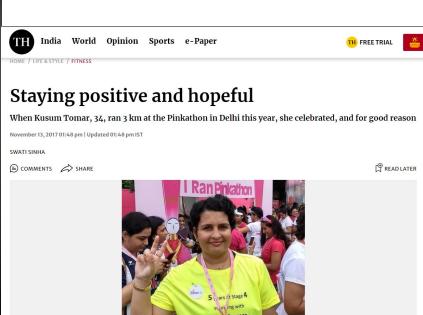
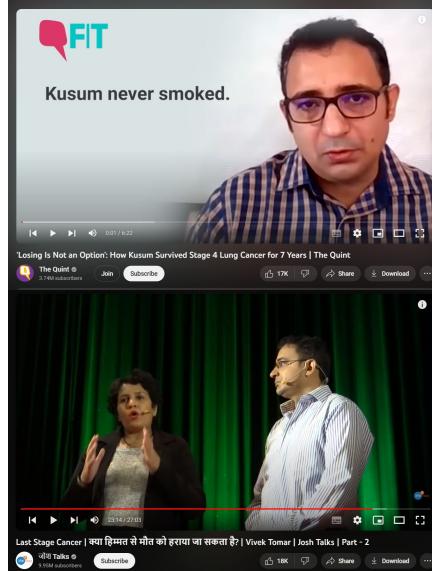
Kusum Tomar

At 29, Kusum Tomar was diagnosed with stage 4 lung cancer. Even though her cancer had gone to her brain, bones, and other parts of her body, and all the different obstructions, she defied all chances and lived for seven long years. To help individuals with cancer, they launched "Rise To Survive Cancer" in 2017. They co-founded "ALK Positive India," the nation's first lung cancer patient support organisation. Kusum continued in inspiring others despite her illness till her death in 2019 by giving talks and sharing her story.

Vivek, who aims to support cancer patients and improve access to healthcare in India, carries on Kusum's legacy. They think everyone can live fully with hope, courage, clinical research, and recent treatments. Their objective is to ensure that cancer patients in India receive the most outstanding care and assistance by international standards.

"Losing Is Not An Option" -

Kusum



**'I Am, and I Will':
Surviving Stage 4
Lung Cancer for 7
Years**

SAAKHI CHADHA
Updated: 04 Feb 2022, 7:30 AM IST

CANCER
5 min read

Like Share Save Comment

Credits : Top left Youtube The Qunit & Josh talks , Right <https://www.thequint.com/> , Healthpost.com, Q fit

Girish R Gowda

Girish R Gowda, a Bengaluru-based kickboxer, faced his most challenging opponent when diagnosed with leukaemia. Despite an initial mis-diagnosis, he underwent a hundred and three chemotherapy sessions and emerged victorious. Determined, he won his ninth nationwide kickboxing gold medal thirty-two days after his treatment. Now, he continues to motivate visually challenged women by training them in self-defence. His cancer battle taught him the value of strength and unity, fostering a deep connection with nature.

Credits : Youtube Happiest Health



8

Sonali Bendre

Sonali Bendre, a well-known Indian actress and author, bravely faced high-grade metastatic cancer. She underwent treatments, including surgery and chemotherapy.

She was open about her journey, communicating on social media channels and writing articles and blogs about her experiences; her story inspired many, emphasising the importance of staying optimistic during challenging times. Despite the challenges, she remained occupied and used her platform to raise cancer awareness.

Credits : Youtube India Today Conclave



Indian cancer blogs are full of stories filled with myths, challenges, triumphant battles, wrong diagnoses, choosing the wrong path, etc. They show how difficult it is for the patient and their family, everyone feeling scared and worried about different aspects, but the major one that takes away the sleep is the one question of whether their loved one will be fine. But the great thing is that these blogs and stories are about more than just problems. They are also about how individuals and their families find incredible strength and bravery to fight cancer. They also help clear up wrong ideas about cancer and show the importance of correct information.

Another understanding from these narratives is that this disease is not just about medicine. It is also about the emotional and mental strength to face it. It is about having the correct information and getting the best treatment.

Aman Bhargava In the 12th grade, Aman, experiencing pain in his thigh, had his carefree summer disrupted. After tests, he received an unexpected diagnosis of cancer. The fear of harsh internet statistics weighed heavily, mainly on his family. He decided to fight, leading to a long battle against cancer involving chemotherapy and surgeries. Aman found unwavering support from his family, especially his caregiver mother. Cancer didn't define Aman; instead, it prompted a pause, offering him a fresh perspective and a deep thankfulness for a healthy life surrounded by loved ones.

"I had cancer, cancer never had me". - Aman

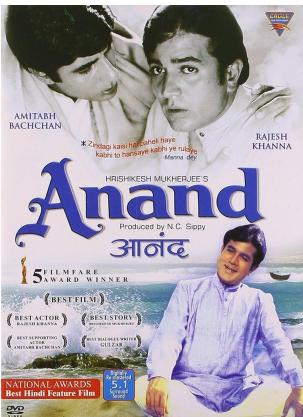
Movies

Anand

"Babumoshai, Zindagi badi honi chahiye, lambi nahi," a famous dialogue from the movie Anand, portrays the resilience and positivity of the character, Anand, who faces cancer with remarkable grace and a zest for life. The film illustrates how genuine human connections, empathy, and bonds can bring joy even in hardships.

The film also portrays his deep bond with Dr. Bhaskar, underscoring the importance of trust and empathy in the doctor-patient relationship.

Credits : Imdb Movie poster



10

The Fault in Our Stars

"Some infinities are bigger than other infinities" highlights that the impact of a person's life and love can grow far beyond their physical presence, even in the context of a challenging illness like cancer.

Hazel and Gus find love amidst their battles with the disease, from finding answers from an author living in the last few moments to ending with a letter saying Okay, Hazel while she was lying down and looking at the stars.

Credits : Imdb Movie poster



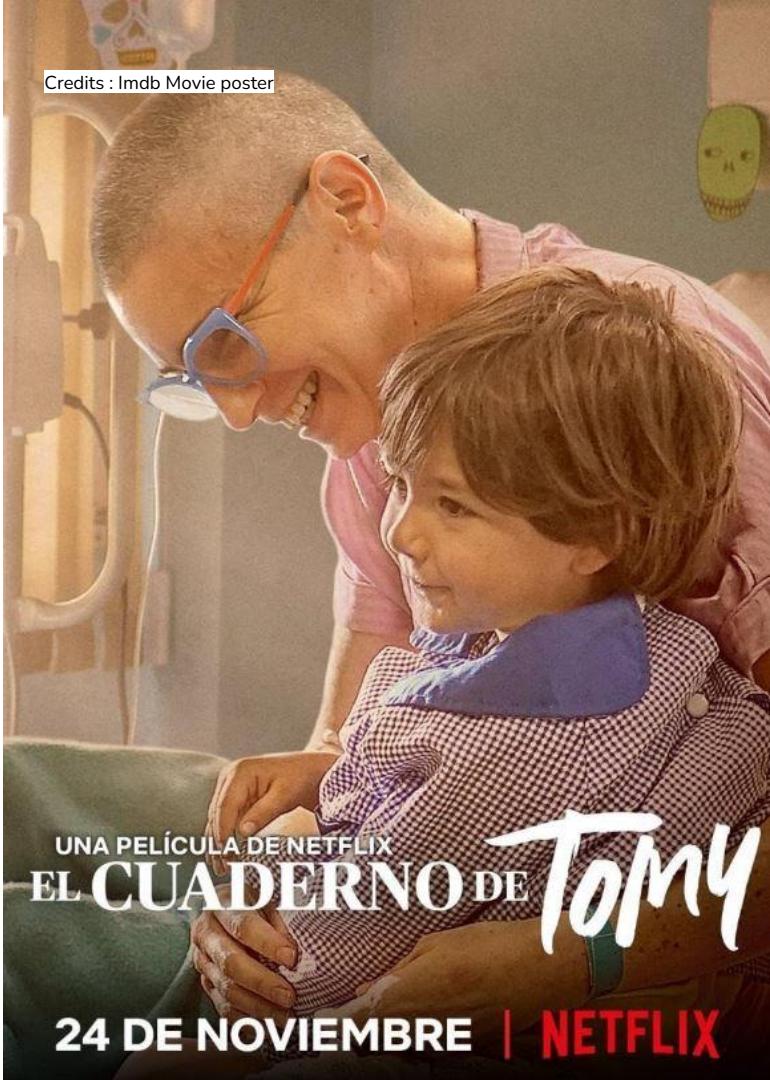
Notes for My Son

The true-story-based film "Notes for My Son" is about a woman diagnosed with cancer and her attempt to express with her child through written messages. The film focuses on the inspirational journey of a cancer family.

"Cancer is a battle we fight together, not alone" is a touching line from the film that highlights the significance of love and support from all companions and family members who act as caretakers for the mother and help manage various aspects of the disease.

The real-life event involved Heather McManamy, who died of cancer in 2015, leaving behind letters for her family, friends and, more specifically, her 4-year-old daughter Brianna.

Credits : Imdb Movie poster



DR SHUBHAM PANT

Books

FOOD MATTERS: The Role Your Diet Plays in the Fight Against Cancer - Book by Dr Shubham Pant

The author emphasizes the role of a nutritious diet in reducing cancer risk, enhancing therapy effectiveness, and enhancing overall well-being during cancer treatment.

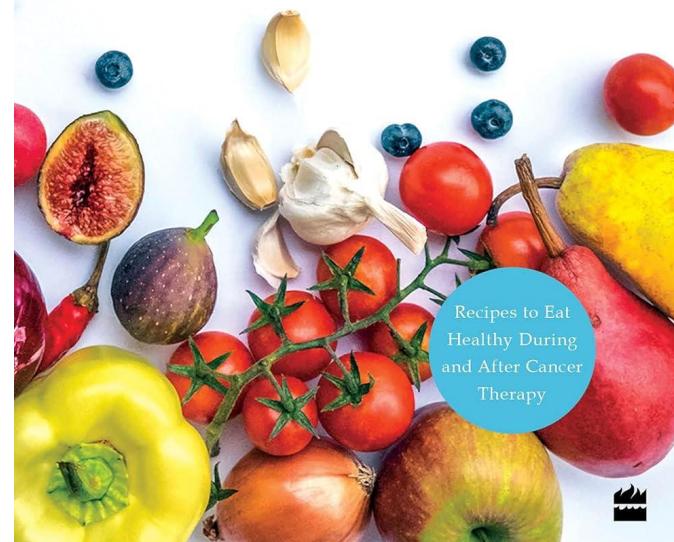
Proper hydration is crucial for general health and can play a supportive role in cancer treatment. Water helps flush out toxins, transport nutrients, and maintain bodily functions, all essential for optimal health during cancer treatment.

The book recognizes that cancer patients dealing with side effects like nausea or fatigue might find it beneficial to follow an "eat-little-and-often" strategy. This involves having smaller, frequent meals or snacks throughout the day to ensure proper nutrition and sustain energy levels.

Credits :Amazon : Food Matters By Dr. Shubham Pant
Book cover page

FOOD MATTERS

**The Role Your Diet Plays
in the Fight Against Cancer**



Cancer : Relation that never died - Aviral Jain

Avinash's patient wait for his beloved, adds a tender layer to this tale of strength, turning adversity into a testament of enduring love and hope.

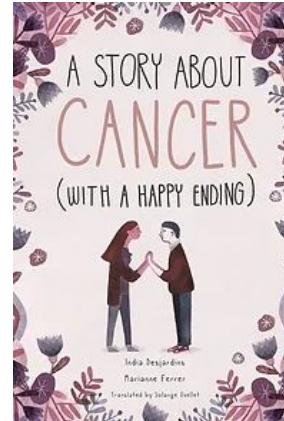


Credits :Amazon Cancer :
Relation that never died -
Aviral Jain Book cover page

13

A Story About Cancer With a Happy Ending- India Desjardins

Desjardins weaves a tale of hope amidst the challenges of childhood cancer. It offers a message of hope and inspiration for young patients and their families, reminding that there is always possibility of a happy ending.



Credits :Amazon Cancer : A Story
About Cancer With a Happy
Ending- India Desjardins Book
cover page

Interviews

Nature of Interviews:

The interviews were initially designed to be formal and structured, following a set list of queries. However, after a few visits, it evolved into more unstructured and conversational exchanges. Patients and caregivers felt more comfortable, allowing for deeper insights and a more relaxed conversation atmosphere.

I used probing queries during the discussions to delve deeper into the meeting areas, encouraging the participants to share more nuanced insights and personal stories and enhancing the depth of the gathered data.

Areas of Discussion:

Their journey: Early symptoms to treatment

Current treatment process

Problems and challenges faced

Support Systems: Person, organisation, hospital, government, etc.

Awareness and Information: Tools to gather

Impact on their life

Mental Well-being: Stress, anxiety, sleep

Environment:

The interview area, often outside the hospital near the main entrance or the footpath, significantly impacted the quality and detail of answers. Patients and their caregivers were frequently found standing or walking outside, appeared more relaxed, passed the time, and were willing to engage in conversations, making a more comfortable space for sharing their stories.

Evolution :

My initial preparation for the discussions as formal discussions allowed me to establish a structured framework.

Elements of the discussion gathered from the framework developed with more unstructured interviews and meetings, including Myths and misinformation about treatment and side effects.

Diverse Participant Backgrounds:

The interview participants hailed from different regions and states, including Rajasthan, Bihar, Uttar Pradesh, and Maharashtra. It offered multiple viewpoints, journeys and experiences related to cancer treatment, healthcare facilities, and the issues faced by individuals from different backgrounds.

Quotes from the interview

- "Ek bare mein test kyu nhai hota ek hi test ko bar bar kara rahe hai ", "kabhi idhar kabhi udhar chakkar kaat kaat ke pareshan ho chuka hu ".
- "Gandi chiz hai bhaut halat kharab aur kar deti hai (about chemo)".
- "humse se thi jitna ban payage utna karange hi .. Inke bina kaise guzara hogा".
- "bhaishaab sab pareshan ho jate hai ghar mein maatam cha jata hai "
- "kaffi had tak thik hai aur kushi bhi hai lambi ladyai the bhaut par inhone himmat nhai hari ", "bhagwan yeh kisi ko na de yehi bolta hu mein tho".

"beti ne humesha paisa ho ya sab dekhna jaise bhi karke kara diya".

- "Kushi hai hume abb khud se aate jaate hai kisi ko sath nhai lana padhta bhaut din lage par abhi thik hai appke samne hai baal aur dhadi bhi vapis aaye hai .. doctoro ka hath jordh ke hum dhanywad karte hai".

- Mtalav tho hume nahi pata jo doctor sahab ne bola vase vase karaate rahe hum tho .. kahan samajhte bethenge bhatije ne dekha bhi tha kuch net par .. abb koi aur rasta bhi tho ho yehi ek dawai hai aur thik ho rahe hai symptoms (side effects) rethe hai dekhyie uska tho dekha jayage jaan bache pehele".
- "Humare bhaig ko tho bhaut ghabrat ho rahe the aur kahan se tho jaise taiase pauche hai".
- "hum kisi ko nhai leke aaye phele sab bola fial jayage isliye par chote doctor ne bataya assa nhai tha".



"Bimari se bhi khatarnak hai yeh chemo tho".

"Pareshani bhaut badh jate hai time ke sath kya kya dekhe patient ko dekhke khud ko dekhke".

"Hume tho laga tha sare hi hote honge [side effects]".

"Internet se aur thoda moda idhar udhar jo pata chal paye uspe hi nirbhar rethe hai hum".

Participants

Interviews involved patients or their caregivers who will start, undergo, or finish their cancer treatment. A total of 38 participants were asked, out of which 23 told me about their journey and situation and answered questions.

Four doctors and staff from a rural government hospital in Ahmedabad, Tata Memorial Hospital Mumbai, Hinduja Hospital, and Tata Memorial Hospital Varanasi also provided valuable insights and reading materials for this project.

Six of the patients/caregivers had discussions about who was getting treatments in Delhi, Gurugram and Himachal Pradesh.

Insights

Patients and their caretakers struggle with **myths and misinformation** about diagnosis and treatment, often passed down by friends or the internet. These misunderstandings lead to extreme stress and fear. One patient told during the interview about a myth he had that cancer could spread to their family members if they were in close contact with the patient or while sharing food, which the attendant later cleared. There were seven more similar instances of misinformation people had about the disease and chemotherapy where they had the source of data internet, and some said they heard from somebody who got chemo in the past.

One of them even gave me **wrong information**, which he sourced from his friend's text message, with all the noted points about symptoms, dos and don'ts. Some knew chemotherapy or radiation; the discrepancy is that in one, they burn and end cancer; in the other, they destroy it using medicines injected, a patient said.

Patients mentioned experiencing **depression and anxiety** during their **treatment journey**. Two patients even said **sleeping** was difficult due to the tension. Four **caregivers** said they never mentioned their mental condition, but they also had to undergo a lot of stress to handle all the financial and treatment factors. One husband feared losing his wife and said he could never handle the pain.

Nine Patients said that Cancer **therapy is costly**, and it was difficult to even go to a private hospital for treatment and consultation. Only one patient had **insurance**, which the company he was working for also took care of. Two of them were government employees and had some benefits from their respective departments. One patient told me about a BPL card and an Ayushman Bharat card, which significantly reduced his treatment cost.

Caregivers / Patients wanted to be **more informed about their treatment** and options. They tried to understand and actively participate in their healthcare decisions, knowing its good and bad sides.

When I asked about the **sources of information**, more than 60% said they referred internet and were unaware of hospital resources. Two people said they relied totally on their doctors and nurses and asked even the smallest of the questions from them. While others even cleared some myths or misinformation, they usually **checked online** or asked the person who had previously been through this disease.

While chemo saves lives, it often has **side effects** such as fever, nausea, hair loss, fatigue, etc. They depend on the patient's type of cancer and are distinct from person to person; out of nine patients who were in their initial cycles of chemotherapy, six believed that they'd get all significant symptoms slowly. Data sources: YouTube, hearing from other people, talking to other ward patients.

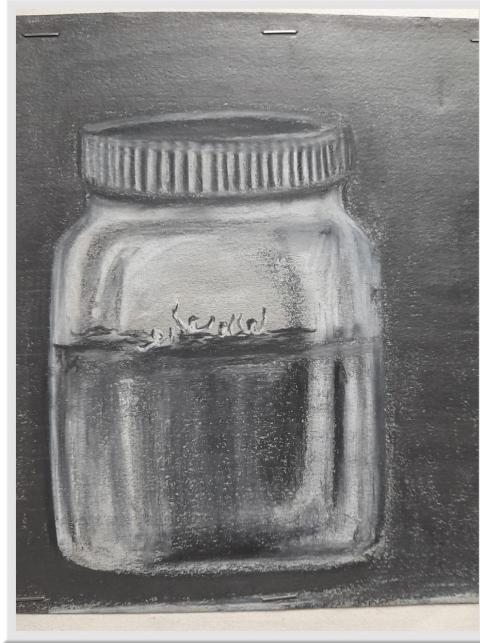
Cancer can make it hard to work for the patients, the **family's salary, or the business**. Without support, they couldn't manage. One male patient from Rajasthan told consumers in his general store reduced after the news spread in the locality about his disease. Two salaried individuals thought they couldn't continue their jobs and had to resign after radiation or chemotherapy.

The journey to Tata Memorial Hospital can be long and exhausting for patients from **distant regions** like Bihar, Rajasthan, and Uttar Pradesh. It's not just a physical distance; it's also the inspirational journey of leaving behind home and loved ones. Two Participants got emotional and talked about their families and days before they met them.

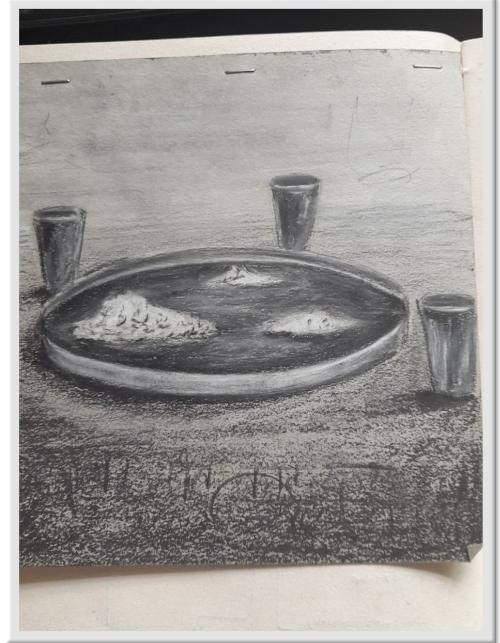
Self Sketched : While Observation and interview stage



A kid from Amravati during his treatment weak, mask torn, observing all patients in line quietly

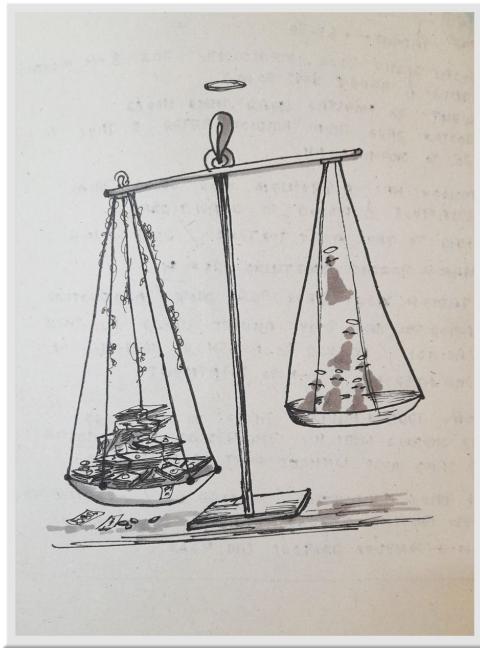


People trapped in the monsoon rain, unable to leave the shed and even walk, only getting medicines and lying or sitting in the corner of the main gate.



A family eating in a thali with three portions, a maximum of one with the patient and the other two caregivers eating a little.

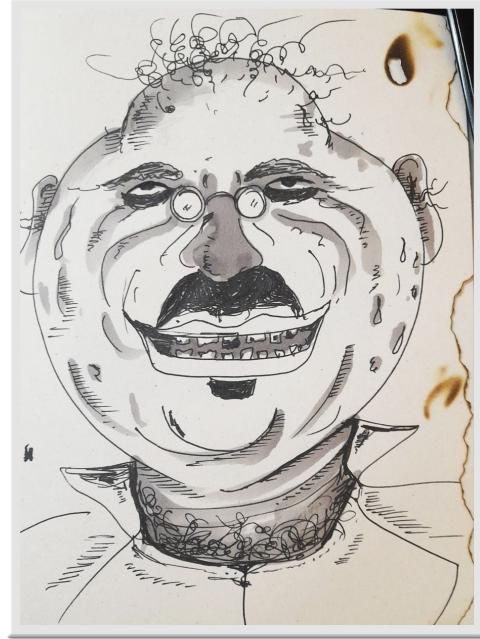
Self Sketched : While Observation and interview stage



“Paise vale ka sab hai humara koi mol
nhai hai idhar ...” - Patient's Husband



“Room mein alag alag rate ke hisab se hai
alishan .. sab khokla hai”



Devil auto-driver shouting at a patient
because she couldn't walk fast and cross
the road.

What about the existing solutions?

There are existing solutions like information posters, booklets, brochures etc. However, there are some critical problems associated with them. The information is complex and very difficult for a person to understand. Their availability also remains a substantial concern. In one of the hospitals I visited, there were different shelves for brochures and booklets; the problem was where to find them, it included everything in newspapers and publications. For chemotherapy itself, I got one flyer online. Even for some standard myths, hospitals have FAQ areas in patient booklets or videos, but a book of 50 pages filled with text is overwhelming for a patient or their caregiver.

This information is not in one place, and even mental health issues which is often left unaddressed. At the same time, there are professionals in the hospital to help, but patients and caregivers are unaware of it. As for the participants I interviewed, only a few were seeking help, including none of the caregivers, which is a significant issue. When there is a lack of information from hospitals, patients start gathering information from their resources, such as the internet, and this often acts as a first step to misinformation.



CANCER & CHEMOTHERAPY

YOU CAN BEAT CANCER

P. D. HINDUJA HOSPITAL
& MEDICAL RESEARCH CENTRE

FIGHTING CANCER WITH CHEMOTHERAPY

What is Cancer?

Cancer involves abnormal growth of body cells leading to formation of tumour. It can spread through Lymph nodes or blood and is highly curable if detected in early stages.

What is the treatment of Cancer?

Depending on type of tumour and its stage, our treating Oncologist will chart out the best treatment for you which can be surgery, chemotherapy and radiotherapy.

What is Chemotherapy?

Chemotherapy is a type of cancer treatment used to destroy cancer cells.

Is Chemotherapy painful?

No, The pain could be only due to insertion of a needle for destroying cancer cells by giving anticancer medicines.

Are there lot of side effects of Chemotherapy?

Depending on drugs used and patient's condition like stage of the disease, nutrition, age etc, side effects may vary greatly. Your Oncologist will explain and guide you what side effects to expect and how to prevent them. Please note that side effects are usually temporary.

Is Chemotherapy life long?

No, It is given as number of cycles which is decided by your Oncologist.

What facilities are necessary for Chemotherapy?

To ensure safe delivery of chemotherapy, you must receive it in a setting where trained doctor, chemotherapy nurses and ICU setting is available.

Are there medicines available for preventing Chemotherapy side effects?

Yes, plenty of medicines are available to prevent many of the side effects. Chances of vomiting or lowering of WBC counts are minimal these days.

Are there Non-Chemotherapy options available?

Yes, Non-Chemotherapy options are available but that will be decided by your treating Oncologist.

What is to be done after completion of Chemotherapy?

Regular follow up with your treating Oncologist will help to keep you healthy and safe.

Chemotherapy Care at P. D. Hinduja Hospital, Khar

- Personalized care
- Individualized cubicle in daycare with cardio scope monitoring
- Flexibility of timing in day care
- Trained nursing staff for administering chemotherapy
- Safe environment due to availability of Biosafety cabinet



Credits P.D. Hinduja Hospital Oncology Department, Mumbai - Chemotherapy <https://www.hindujahospital.com/>

Frequently Asked Questions



Department of Preventive Oncology
Tata Memorial Centre
Mumbai, India.

Patient information booklet

A.Chemotherapy

1. What is chemotherapy?

Chemotherapy is the use of drugs to kill cancer cells. Certain drugs are effective in reducing the size of some head and neck tumors. These drugs travel through your bloodstream and also help destroy cancer cells, which may have spread to other areas of the body. All patients with head and neck cancer do not receive chemotherapy and there are specific indications for the same. It is given intravenously i.e. thru a small needle into your vein. If you have to receive chemotherapy, a medical oncologist will direct this aspect of your care.

2. What is the schedule of chemotherapy?

Chemotherapy implies treatment with drugs. The schedules of these drugs are strict and the doctor will tell you in detail about how they are to be taken. Take time to understand the frequency, dose and the gap between two cycles.

Chemotherapy improves survival, leads to organ preservation, increase chances of definitive treatment and quality of life. Sometimes, chemotherapy can be expensive. For those who cannot afford to buy the drugs the social service department will provide drugs at subsidized rate. You may ask your doctor to



Name _____
Case Number _____

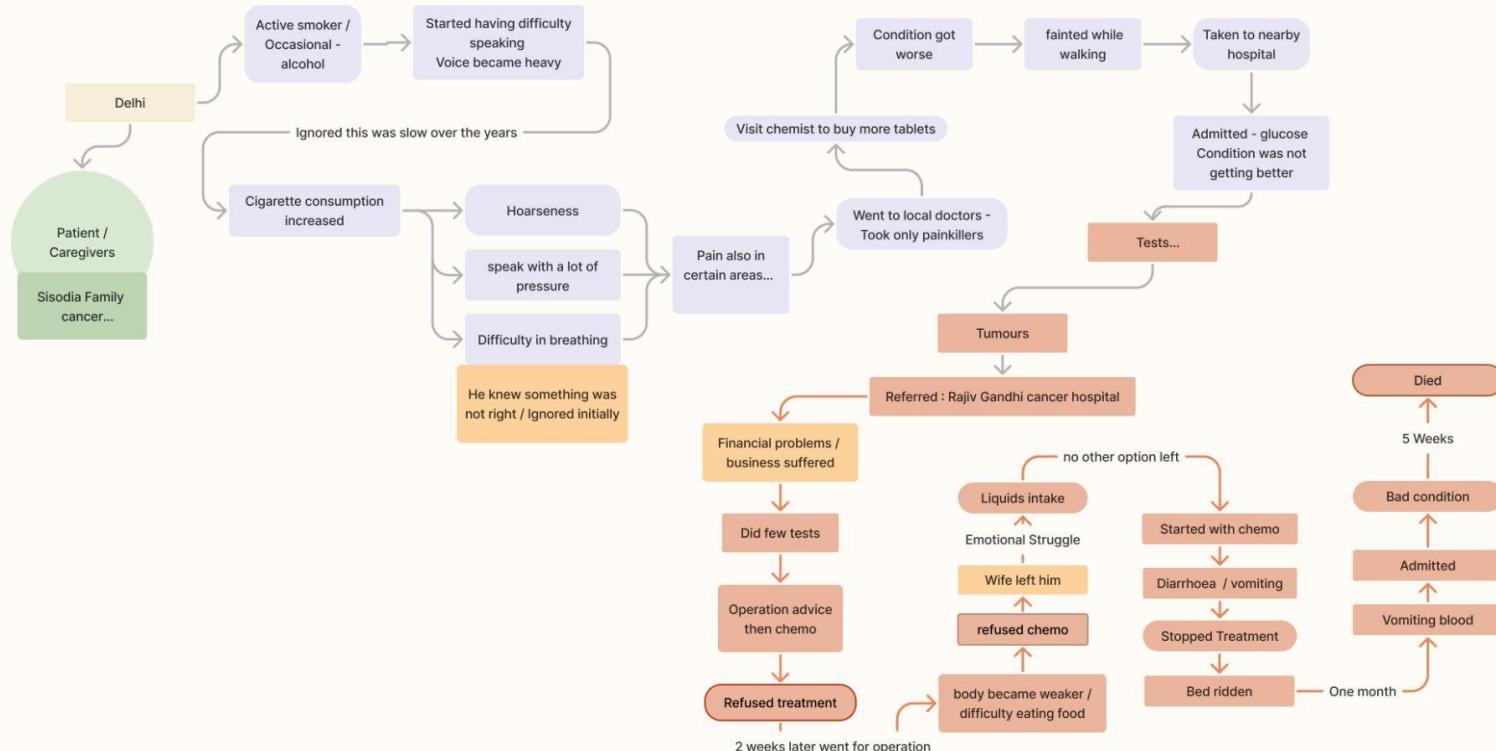
Credits : Tata Memorial Hospital, Mumbai, FAQs, Patient information booklet and Patient Guide Book

Journey maps of patients

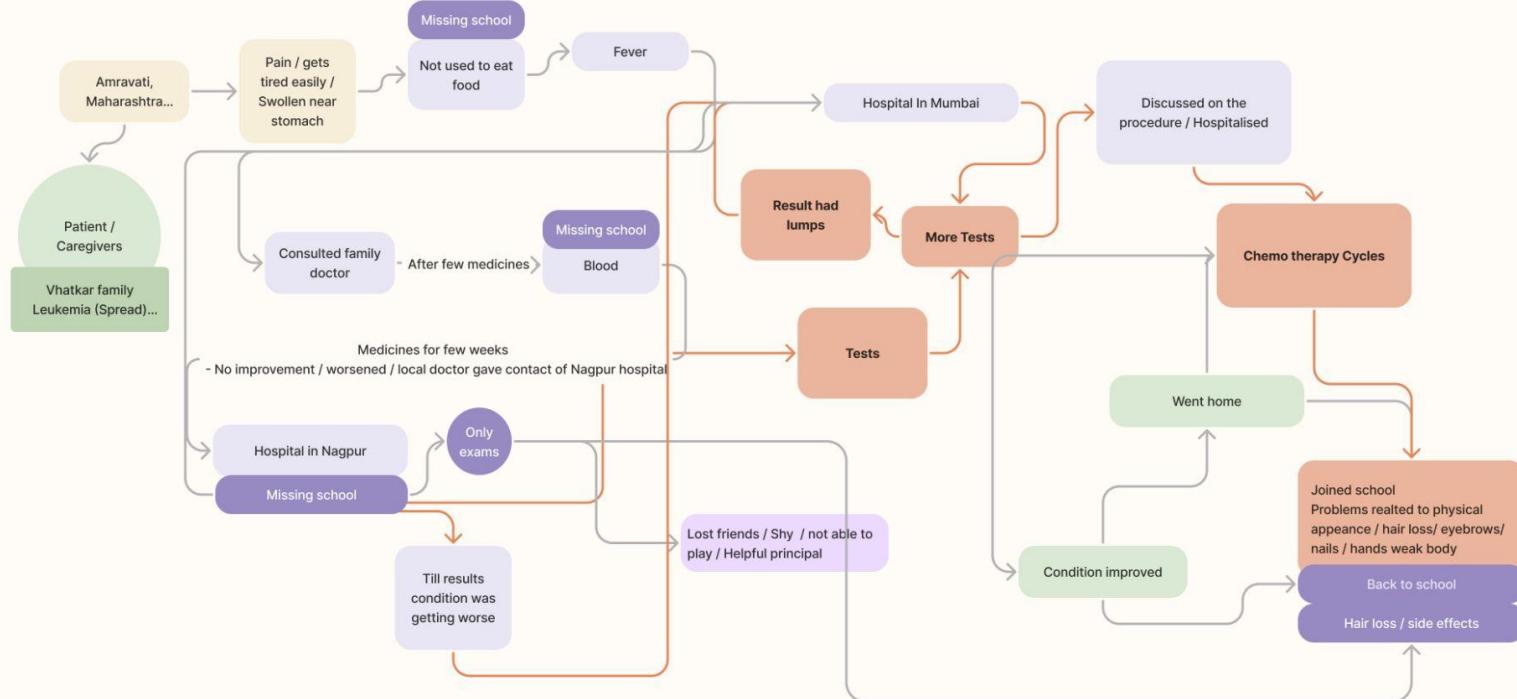
Journey maps illustrate a person's experiences and stages from the moment they get early symptoms to the end of their cancer therapy. Phases including diagnosis, treatment planning, surgery, chemotherapy, radiation therapy, healing and survivorship can all be a part of this map as per the patient's journey. It also emphasises essential decision points and the various mental and physical difficulties encountered at each stage, like financial burden, problems due to physical changes, etc.

These were valuable tools for understanding the patient's viewpoint, spotting pain points, and improving the general cancer treatment experience.

These cancer journeys served as the storyline's foundation, adding elements from them. The narrative gains depth and authenticity by understanding the highs and lows, moments of fear and hope, and the support systems in place. Patient journey maps act as a guide, ensuring the story reflects the real struggles and triumphs patients face.



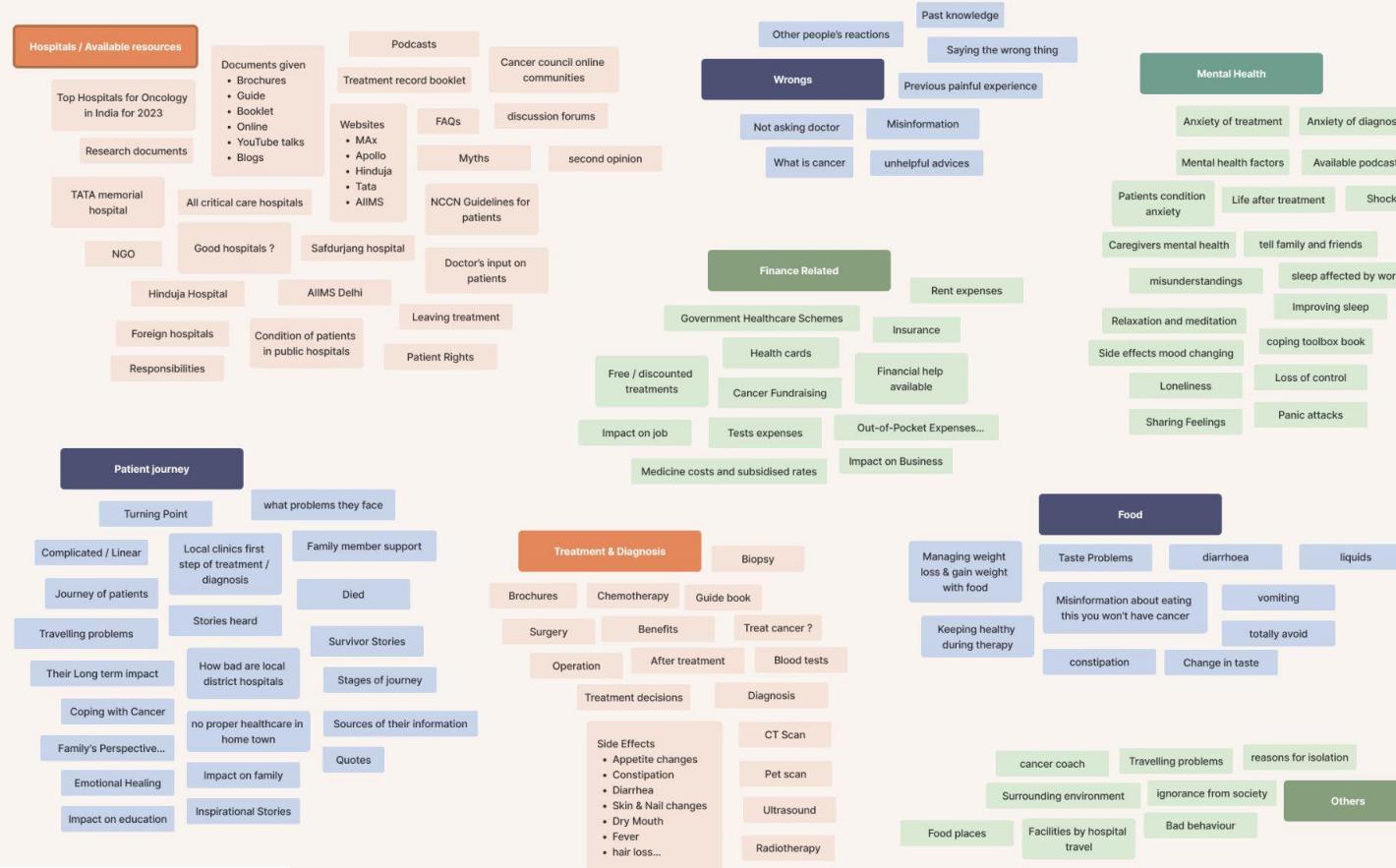
Journey maps of patients :: Tool used FigJam



Journey maps of patients :: Tool used FigJam

Chunking

Chunking, breaking down data into smaller, manageable chunks, has helped me structure and organise the information. At the same time, it gave me a clear view of the content and materials at hand and building connections, making it easier to identify the gaps.



Chunking process : Tool used FigJam

What is included?

Chemotherapy

- Meaning
- How it is given
- How it works
- Benefits
- Treatment
- Side effects (Change in taste, vomiting, diarrhoea, constipation, dry mouth, Fever - Checking regularly, hair loss)

Myths & Misinformation

- Chemo is worse than the disease
- Hair will never grow back again
- It can spread to others / Communicable
- Cannot eat before chemo
- same chemo given for all cancers
- Wrong Internet information
- I will get all the symptoms listed

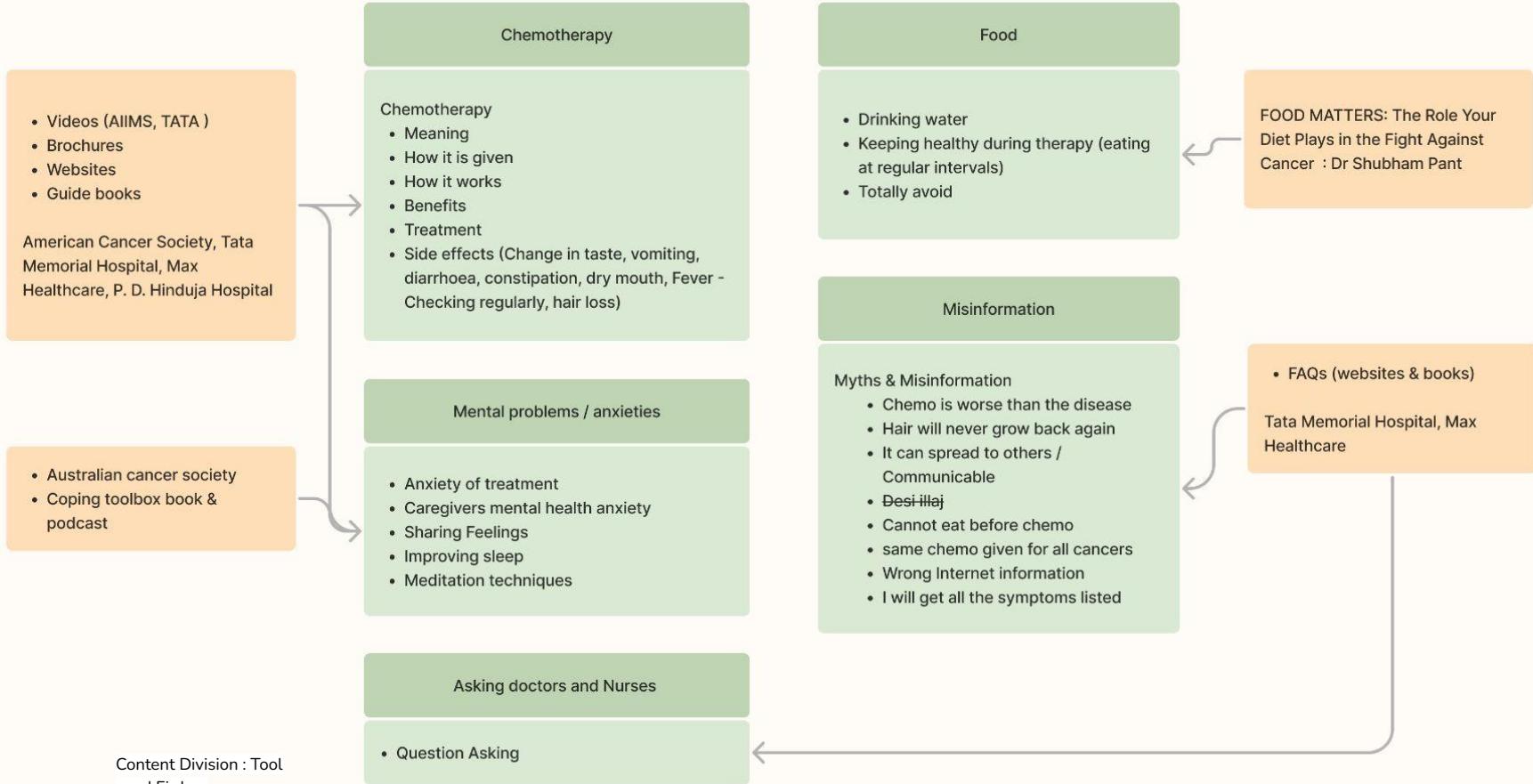
Food

- Drinking water
- Keeping healthy during therapy (eating at regular intervals)
- Totally avoid

Mental Health

- Anxiety of treatment
- Caregiver's mental health anxiety
- Sharing Feelings
- Improving sleep
- Meditation techniques

Asking doctors and Nurses



Video story ?

Why Video?

There may be an initial cost to the videos, but in the long run, they are cost-effective as printing numerous copies of materials like booklets, brochures, and guides can become costly. Once made, they can easily be duplicated and shared on all official channels of the hospital, creating a digital presence from verified sources.

Video stories convey feelings effectively along with information. Patients relate to others who have been through chemo. Videos are available anytime and at any place. Users can save it or visit it on the hospital website or channel, while print materials can get lost or are not easily accessible.

Why Story?

Complex information is often simplified and made more accessible in narrative structures, which engage and capture users' attention, making them more likely to absorb and retain the information.

They are easier to digest information than booklets filled with medical jargon. Thus, essential details can be conveyed in an easy-to-understand manner, helping the viewers relate and visualise.

Better for hospitals ?

Coming from a verified source and readily available on digital platforms can also be an important source of advertising for hospitals.

No cost of printing (Existing - Guides, brochures, books)

Boosted goodwill: enhanced reputation

The patient journey is simplified with better and easily understood information.

Reducing myths and misinformation, thus giving better treatment.

Story : source of inspiration

Ideas

Conversation between two patients

- Shah and his family have myths, misconceptions and worries about chemotherapy.
- Himmat tells them his individual story, and the doctor and nurse educate them about chemotherapy and the importance of seeking accurate information.
- They discuss mental health, proper sleep, and eating patterns for patients and caretakers, and the nurse gives some easy tips for him to practice.
- Shah and his family learn to address their fears, express them to medical staff, and debunk cancer-related myths.

Cancer Hero: Himmat

- In a clinic setting, a doctor hosts a show called "Cancer Heroes" where cancer survivors share their journeys.
- Himmat, a cancer survivor, is asked to the show to discuss his chemotherapy journey.
- The doctor on the show educates the audience about chemotherapy and clearing myths, highlighting the significance of accurate information.
- Himmat's story and positive attitude inspire the audience and encourage other patients to fight cancer with perseverance and knowledge.
- The story ends with Himmat returning to his post office for work, and his colleagues applaud and support him for his brave journey.

Script 1

Hospital Chemo therapy ward

Shah ne siskiyan lena shuru kare aur uski biwi baju mein bethi hai haath
pkard ke

H : Appko kon sa cancer hai ?

Pushpa – Inko lung cancer pata chala hai aur appko

H : Lung cancer tha kaafi haad tak bethar ho gaya hu, app itne pareshan
kyu hai kuch dard vgarah ho raha hai kya inhe?

(most common cancer in India / later linked with tobacco)

Pushpa : Nhai dard nahi Chemo lagage inhe pheli bar ajj, tho abb sab
bhagwan ke hi haath mein hai, pura sharir khatam ho jata hai,
baal nikal jate hai zindgai bhar ke liye, bimarai se kam buri nahi chemo bhi
(myths – Chemo is worse than the disease / Hair fall and never grows /
Symptoms kills the body)

H : nhai nhai sabke symptoms alag hote hai

Doctor checking patients and coming towards them –

ekdum thik kaha aapne sabke symptoms alag hote hai .. dekhkyie
(showing in a poster on wall), Chemo mein dawaiyo ko cancer cells marne
ke liye istemal kiya jata hai ...isko bimarai ka ilaj karne ke liye aur cancer ke
lakshan kam karne ke liye istemal kiya jata hai ...

Aur injection se kabhi naso mein kabhi dawai doctor apke cancer,
uska stage, baki koi aur bimari uske hisab se de sakta ..

(poster on the wall with major types) bikul pareshan nahi hona hai
appko sab thik hoga (Info – What is Chemo / chemotherapy works
against cancer / How it is given /)

Appki report tho badyia aaye hai .. 2 chemo aur baki hai bas Mr. Singh
H : Appki hi mehrabani hai doctor sahab sab Doctor : namaste gesture

Shah : Vase app kahan se hai

H : Mein Roorkee se hu

Shah - baap re itne door... pata kaise aur kab chala tha aapko

H : Mein ek dakyia hu tho har roz ke tarah kam khatam karke ghar aa
raha tha kuch dino se chati mein dard badhne laga tha aur us din bukar
bhi ho gaya.. Aagle hi din mein sujata ke sath pados mein ek doctor ke
gaya aur dawai le aya par 1 hafta koi aram hi nahi huya.

Fir dhere dhere saas lene mein doqaat hone lage kam bhi thik se nhai
kar pata tha tabhi **ek dost Gudas ne salah di ki beedi pene ke vjagah se**
hoga tho band kar do humne vo bhi band kar di **Not to eat**

Sujata – Thik hi the vo .. **Aur idhar bhi jo doctor ne bola bikul nahi**
peeni na na daru na koi tambakoo

Radha - ekdum sahi kaha bhabi mein bhi inhe yehi bolti hu **yeh sab bilkul band**

Not to eat – Emphasis on this information

H - Haan haan abb sab band hai

Uske kuch waqt bad ... Humare adhakari ne fir 1 hafte ke chuti deke ilaj karane ke salah di Mein Sujata ke sath ek bade haspatal gaya kuch test ke bad unhone sidha cancer bata ke operation bolkar 6 lakh ka karcha bata diya ... Hum toot gaye ekdum andar se ..

Abb avantika humare bacche uske shadi ke ummar ho jayage itna kahan se late paisa ...

Fir padosi ne hi bataya desi illaj ke bare mein usme kuch dawai dete hai baba us se thik ho jata hai hum chale gaye ... Udhari se 1 mahiney tak chale aur halat aur bigard gaye ek din ulti mein khoon aya.

Myths / misinformation - Desi illaj karane se thik ho jayage

Jis din Avantika ko yeh baat pata chala usne bhaut ghussa kara aur fir hume idhar leke chale aaye ..

Test huye sab bataya doctor ne aur abb bas 2 chemo ke cycle baki hai aur cancer bhi lagbhag kahtam ho chuka hai ..

Shah : **Bhaut dar laga hoga na** aur chinta hi itne ho jate hai is dooran appne kasie himmat jutaye

Mental health

H - lo aa gaye Avantika ...

Isne darne hi nhai diya hume ..

A - chalo chalo ..

Time ho gaya

bottle abhi tak bhare hai kya papa .. pata hai kitna zarori hai na..

H : yelo beta .. drinks water

Drinking water is important for chemo patients – Emphasis on this information by introduction of new character

yeh Shah uncle hai beta yeh puch rahe hai ki kaise humne dar ko kam kara

A - Namaste uncle : **Hume dar un chizo ka lagta hai jinke bare mein hume pata na ho appke man mein jo bhi sawal ho unko doctor nurses sab se puch sakte hai**

Mental health + Clearing Myths / misinformation

Aur dusra app aur aunty dono hi **bhaut pareshan** ho jate honge hol dijaye aur **sare baatien kisi ko bataye koi bhi ho**

Mental health- Talking things out Nurse DeSousa placing the water jug

Aur app kal acche se soye bhi nhai the mughe guard sahab ne bataya Shah : jo vo sab chizo ke tension ..

Nurse DeSousa – **jo bhi chinta laga kare sab app ek paper par likh lijye aur fir man halka hone ke bad letiyie aur appne saason par dhyan dijayaie yar fir koi bhi ek chiz light par dhyan lagayage aur dehyiega kaise nind nahi aate ..**

Aur appke liye bhi jo patients ke sath hote hai unke liye bhi muskil samay hota hai din bhar bhaga daudi tho app bhi yehi kara kijyie

Mental health – Proper sleep Caregivers & patients

Aur App chemotherapy ke liye aate hai tho kuch fruit le aaya karyie kaffi wait karna padhta hai tho itne time tak bhuk nahi lagage

Shah : chemo tho **khali peet hote hai na ?**

Myths / misinformation

Nurse : Yeh appko kisne bola (little souting)

Shah : **yeh message se isme sare chize hai kya karna hai kya nahi**

Nurse : dikhaye Myths

Misinformation

Nhai nhai yeh sab galat hai app kha sakte hai kahana aur **asse chizo** par bikul vishwas nhai karna jo bhi puchna ho appko doctor se hi puchna

Dekhyie aur jo symptoms isme sare hai jaise ulti, kamzori, baal jhadhna, peet kharab, bukhar aur bhi yeh sabke liye alag hota hai ..
Kabhi kabhi kam symptoms rethe hai kabhi kabhi zayada ...

Yeh galat information bikul nhai dekhna

(Info – common symptoms of Chemo & its **Misinformation**

Shah : ji thik hai mein dhyan rakhunga

Nurse leaves the scene

H : yeh thoda daatati hai par dil ke bhaut acche hai

Shah : haha haanji

H : yeh likyie faal kahyaie ... bhook zayda nhai lagte ekdum se issliye thoda thoda kahana padhta hai is se sharir bhi tandrost bana retha hai
eating food at regular intervals

Avantika : tandrosti tho thik hai **papa par abhi tho leke ayi hu acche se dho kar hi kahana chayaie** doctor ne bola tha na rukyie mein laye

Washing fruits before eating

(wents to wash)

Shah : beti bhaut dhyan rakhte hai .. **Par app isko ward mein kyu aane dete hai isko bhi ho gaya tho**

Myth / Misinformation

H : koi bhi tarike ka **Cancer failata nahi hai** .. Tho assa nhi hai appss fail ke sabko ho jayage

Yeh likyaie

Shah : shukryia beti

Shah: accha ji

Arey itne deer baat ho gaye app se naam hi puchna rehe gaya ..

H : mera naam hai **Himmat** hai

Final script

1. Mein har roz ke tarah post office se daak leke jaa raha tha
2. ek din khaasi aur bhukar huya pados ke doctor se dawa li par aram nahi tha
3. Fir kuch dino ke bad saas lene mein diqaat hone lage hospital dikhaya aur test karaye tho pata chala
4. cancer hai aur doctor ne jab illaj chemo bataya tho mein aur ghabra gaya ..
5. *background voices baal urdh jayange .. sharama ji ko bhi yehi lagi the .. ulti .. bukar .. bimari se bhi khatarnak ha*

6. Dr. kya huya Himmat ji
7. Chemo sir .. vo bhaut kuch ulta sidha suna hai iske bare mein tho thoda

(Asking doctor/nurse : Cancer care team)

8. Dr. rukyie ghabryie maat mein appko samjhata hu tho chemothreaphy ya chemo dawai hai jo cancer cells marte hai

(Meaning of Chemotherapy : American cancer society)

9. yeh cancer cells ko marne ka ya grow karne se rokne ka kam karte hai
10. aur injections aur pills ke roop mein di jate hai

(How it is Given : Tata Memorial hospital)

11. Iske side effects doctor Sahab
12. Ji .. yeh dekhyie cancer ke cells teji se failti hai abb chemo jo sharir mein teji se badh rahe cells hote hai unpar vaar karte hai isme sharir ke kuch aur cells jo jaldi bhadhti hai un par asar ho jata hai jinkin vajah se side effects hote hai
13. Yeh sabke liye aalg hoye hai par बालों का झाड़ना, उल्टी, दस्त, कब्ज़, बुखार yeh kuch common hai aur zaoori nahi hai ki sare hi ho kisi ko kam hote hai tho kisi ko zayda

(Side effects)

(Why does chemo cause side effects?) I will get all the symptoms listed

14. Aur appko ghabrne ke baat nhai hai app humse kuch bhi lage tho bataye hum uske liye dawai denge appko.

(Asking doctor/nurse : Cancer care team) Anxiety of treatment

fade

15. samajhke man shant huya aur mein is jangh mein Chemo ko hatiyar bana ke chal padha...

16. Ghabharat fir bhi the ki kaise lagagi itne badi dawa kitne dino tak

17. Fir nurse se samjhaya ki yeh cycles jisme kuch waqt treatment chalata hai aur uske bad kuch waqt aram taki appki body side effects se recover kar paye.

18. Aur bikul na daru na tobacoo, na birdi na ciggratte

What Not to eat Chemotherapy is given in cycles why is the rest period important in chemotherapy?

18. Treatment shuru huya aur meri bimari ke baat jab logo ko pata chale tho sab dosto ne kuch na kuch bataya **mano sab hi doctor ho**

ek ne tho **message** bhej diya ..

19. *Background voices, messages, calls*

20. usme kaise cancer ko harane ke sare nuskhe likhe the .. par usme yeh likha tha ki chemo se phele kahana nahi khana chayie aur mein kha kar gaya tha pheli chemo ke liye mein dar kar aur nurse madam se pucha.

21. Kha sakte hai !

22. Unhone meesage dekha aur bola ki in sab chizo par bikul vishwas nhai karna ..

kuch bhi raha tho doctor sir phele hi bata deneg

aur cancer na sath khanae se failata hai na sath rehne se .. internet ke chizo par bharosa nahi karna kuch bhi sawal ho tho hum logo se puchna Okay..

It can spread to others / Communicable Can't eat before
chemoInternet information (Asking doctor/nurse : Cancer care team)

22. chemo chadt rahe — same scene
23. kuch symptoms huye .. bukar .. ulti .. thakan par doctor ne dawai di aur kaffi aram bhi huya
24. chinta rethi the nurse ne samjha ki hum log **psychologist ya appne doctor** se baat kar sakte hai aur kuch asaan tarike bataye jaise agar nind na aaye tho kal kam karne ki list banana aur fir leet kar appna dhayan ek jagah par lagana light ho ya koi kirdki ...

Talking to a Psychologist or Cancer care team

Improving Sleep

25. aur koi bhi chiz jo pasandidar ho usko karna mene jaise kavitaya likhi the .. aur baki dhayan lagane ka jo tarkia humare liye kam kare ..
26. Unhone Meera ko bhi yeh sab karne ke liye bola
27. Meera bhaut dhayan rakhte the bukhar check karna .. bhook nhai lagte the tho dhere dhere thoda thoda kahana bich bich mein khilati the aur khass taur se zaoari chiz paani ka bhi dhayan rakhte the.

Checking fever Drinking water **Eating little at regular intervals**

Meditation **Hobby or interest for pastime**

28. In sare chizo ke sath baat karke appne feelings share karna kabhi phone par kabhi dost ya ristedar ya fir bagal vale patients bhaut man halka hota tha

Sharing Feelings by talking

29. Chemo Jari rahe aur mein Dehere dhere bethar hone laga
- 30 Doctor ko dikhana tha aur us intezar mein line mein bethe ek patient se meri baat huye usko chemo lagi mughse kam aur vo mughse jaldi thik ho gaya ... Yeh mene doctor sir se pucha
- 31 Unhone bataya ki patient ka cancer uska stage uski condition dekhke faisala karte hai ki kon sa ek ya ek se zayda treatment best rehagyge
- 32 Unhone meri report dekhi aur mein phele se bhaut bethar ho gaya tha

The same Chemo is given for all cancer

33. Meri chemo puri ho gaye

Kuch waqt bad hi report ek dum normal aaye usko dekhkar mere aakhon
mein fir ek baar asson the par is bar kushi ke ...

(crying face - changing environment)

34 . tho yeh thi meri khanai doctor sahab

35 . Dr. Keshav : bhaut bhaut shukryia Himmat singh ji cancer heros
mein apni kahani batane ke liye .. app hum sabke liye ek inspiration hai ..

himmat's colleagues watching his video he returns to office and they
start clapping.



1 Post Office / Job



2 Local Clinic



3 Hospital



7 Suma Hui



7 Papering



8 Diagram (Cells)



4 Test Report / Cancer



5 Thoughts / Chemo / Cancer Myths



6 Doctor Notes



10 Injection



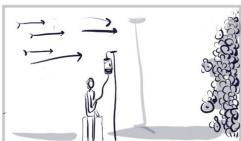
10 Pills



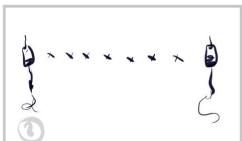
11, 12 Side Effects



13, 14 Side Effects (Pain)



15/16 Fight with Cancer (Waking - Dreams)



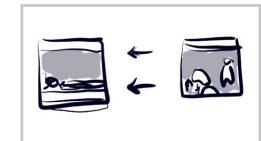
17 Rest Period / Cycle



21 Marriage / Sewing / Misunderstanding



21 Advice



22/23 Chemo / Side Effects / Medicines



18 Not to eat



18 Treatment



20 Misinformation



24 Noting / Mental Health



27 Dhyan / Meditation



27 Closing Eyes



Convict/Concussion



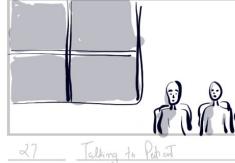
Mara



Favourite Hobby / Internet



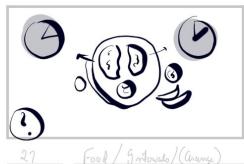
Chemo Planest Complete



Talking to Patient



Doctor Explaining



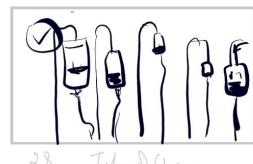
Food / Gotohada / (Annoy)



Water



Talking



Type D Chemo



Report



Mara



Cannulation



CarrieKris Show



Watching Video



Chilling



Improved Storyboard Self sketched

Improved storyboard with transitions and effects sequence.

Sound

Editing was done in Adobe Audition. Sound plays a vital role in spreading the video in different languages; thus, while documenting the dialogues in Hindi, I recorded with a buffer time of 1 to 2 seconds, pausing after breaks at regular intermissions so that the details in other languages is not reduced due to time restrictions. Fillers like background sound when Himmat first heard about chemotherapy can also help reduce or increase the time frame.

Character

Himmat character, and in total, there are three further timeline options designed when he's undergoing chemotherapy, first being fit and then slowly losing his hair along with skin colour changes. Audiences can see some notable changes in his character throughout the video.

Clothing- : Traditional Indian attire : For characters, I've picked clothing like a kurta for Himmat as in the story. He also explained his love for poems, which made him wear traditional short kurtas and standard hospital gowns while in the hospital.

Hair Style- : His long, curly hair with a beard makes some signs evident; the purpose in the video remains to give a precise message, which is seen when he loses his hair. While growing back, they are in beautifully arranged patterns like a small child whose mother cares and combs.



Tool used : AutoDesk Sketchbook

Design decisions

In my design decisions, I chose lavender as the primary shade for the show, symbolizing the universal ribbon for all kinds of cancer. This colour is a unifying element, emphasizing the collective fight against cancer. The architectural structure of the building illustration draws inspiration from the head post office in Roorkee and the civil hospital, creating a familiar and comforting environment. Elements like the kalava (a sacred thread) representing hope, were incorporated, reflecting the insights gained during interviews.

Using brush strokes as supporting elements aids user understanding, and the background colours play a subtle yet impactful role. The shifting shades from light to dark mirror Himaat's inspirational journey, and the consistent lighter peach shade: for the doctor, represents positivity and safeguards health. Specific events, such as receiving misinformation, are emphasised in darker red shades, transitioning to more light hues when corrected by the nurse. Attention to details like clothing, styles, and accessories ensures relatability for the audience. The gradual depiction of Himaat's physical transformation, from long hair to baldness and regrowth during the talk show, adds a graphical narrative layer.

In another design aspect connected to medical decisions, I referred to Cancer Research UK's diagram for cancer cells to structure the representation of cancer cells and normal cells. This scientific framework provides a clear understanding of the intricacies of cancer cells. Additionally, I utilized Dr Stevan Stankovski's diagram from the University of Novi Sad, available on ResearchGate, to detail the components of a chemotherapy bottle. This includes the pole/stand, bottle/bag, spike, air valve, drip chamber, and cannula.

These design decisions aim to give accurate information and make complex medical information available, visually engaging and more touching for the audience.

Illustrated Visuals

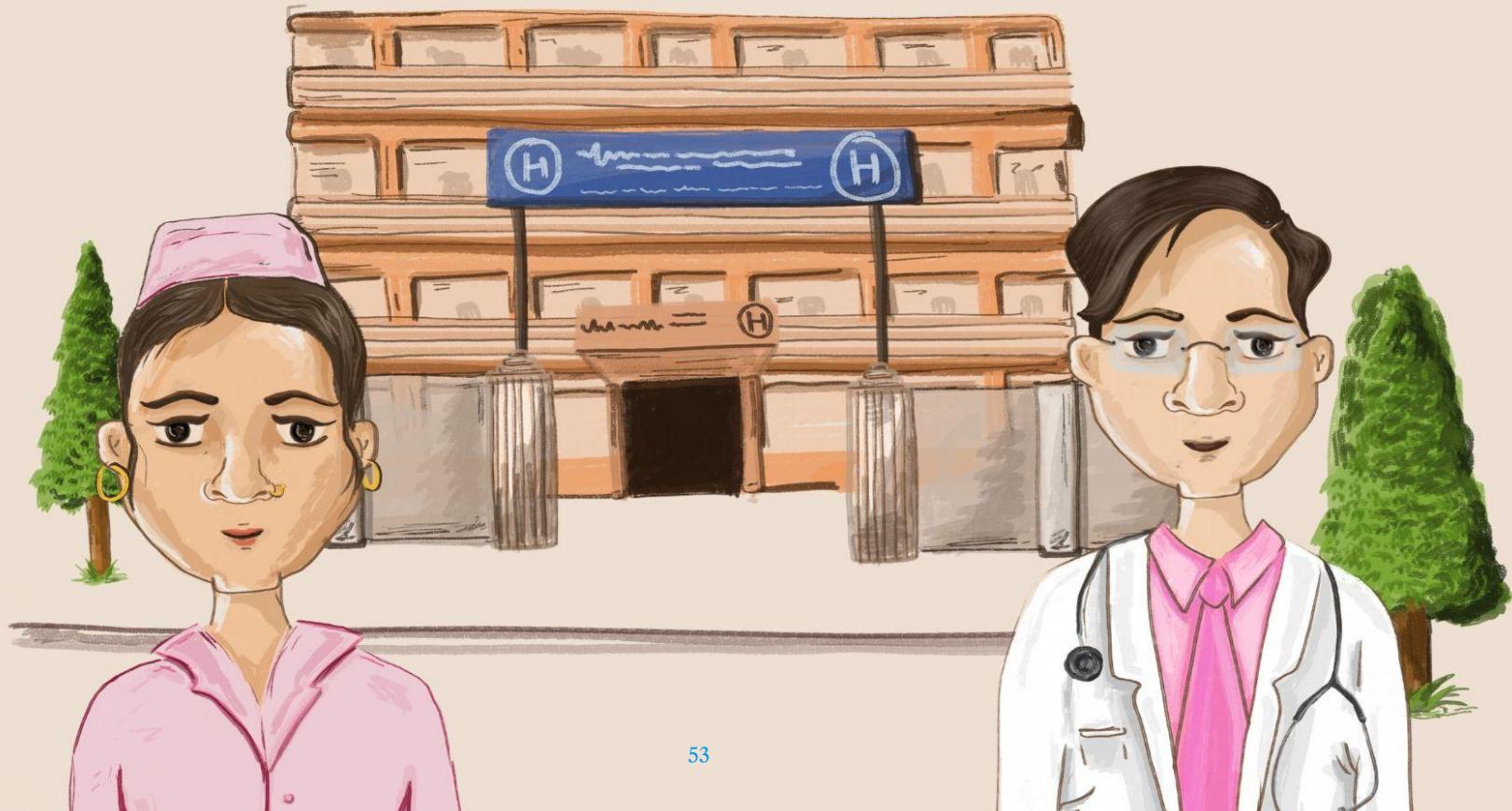




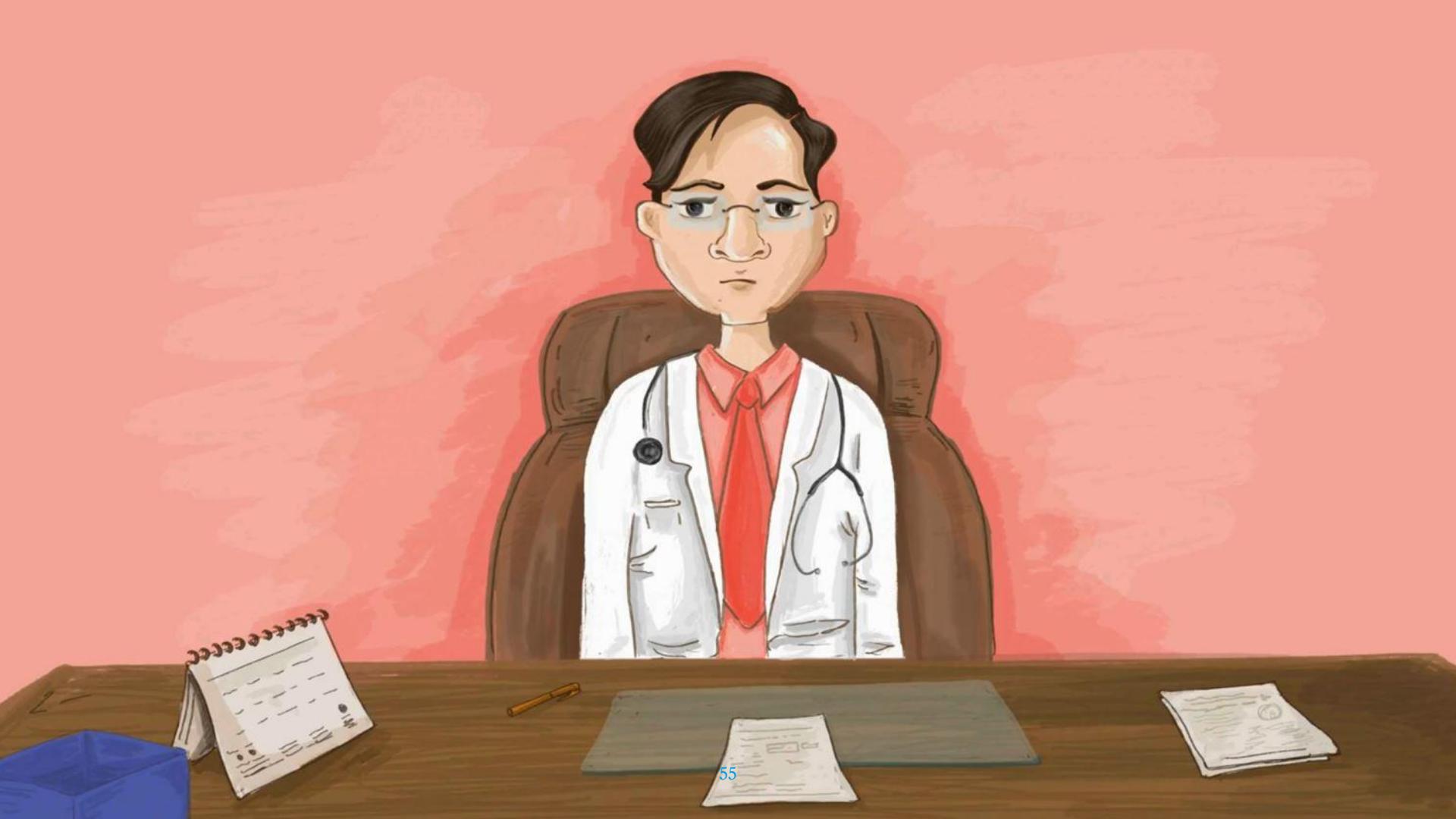
CANCER HEROS

Himmat Singh

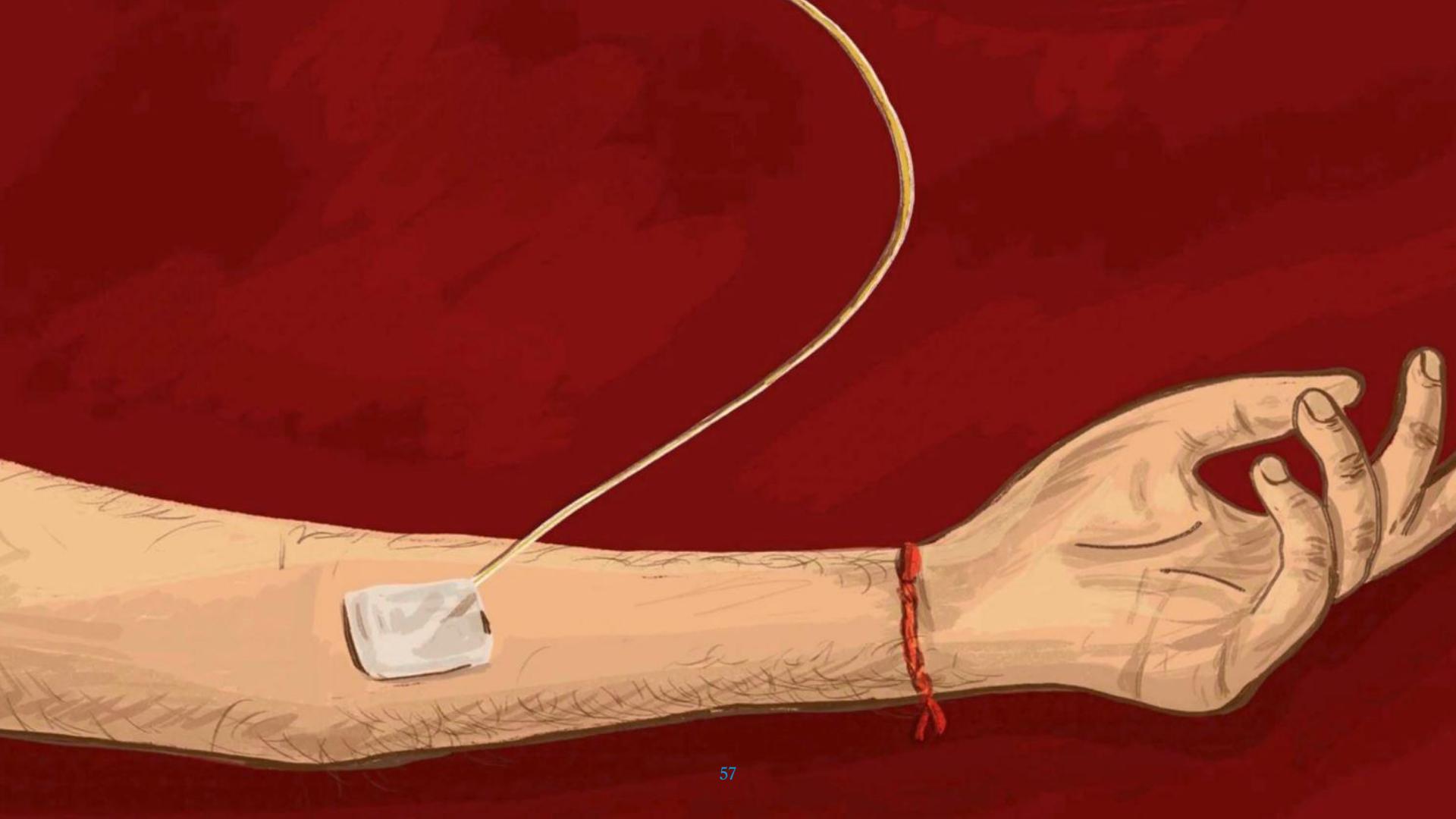


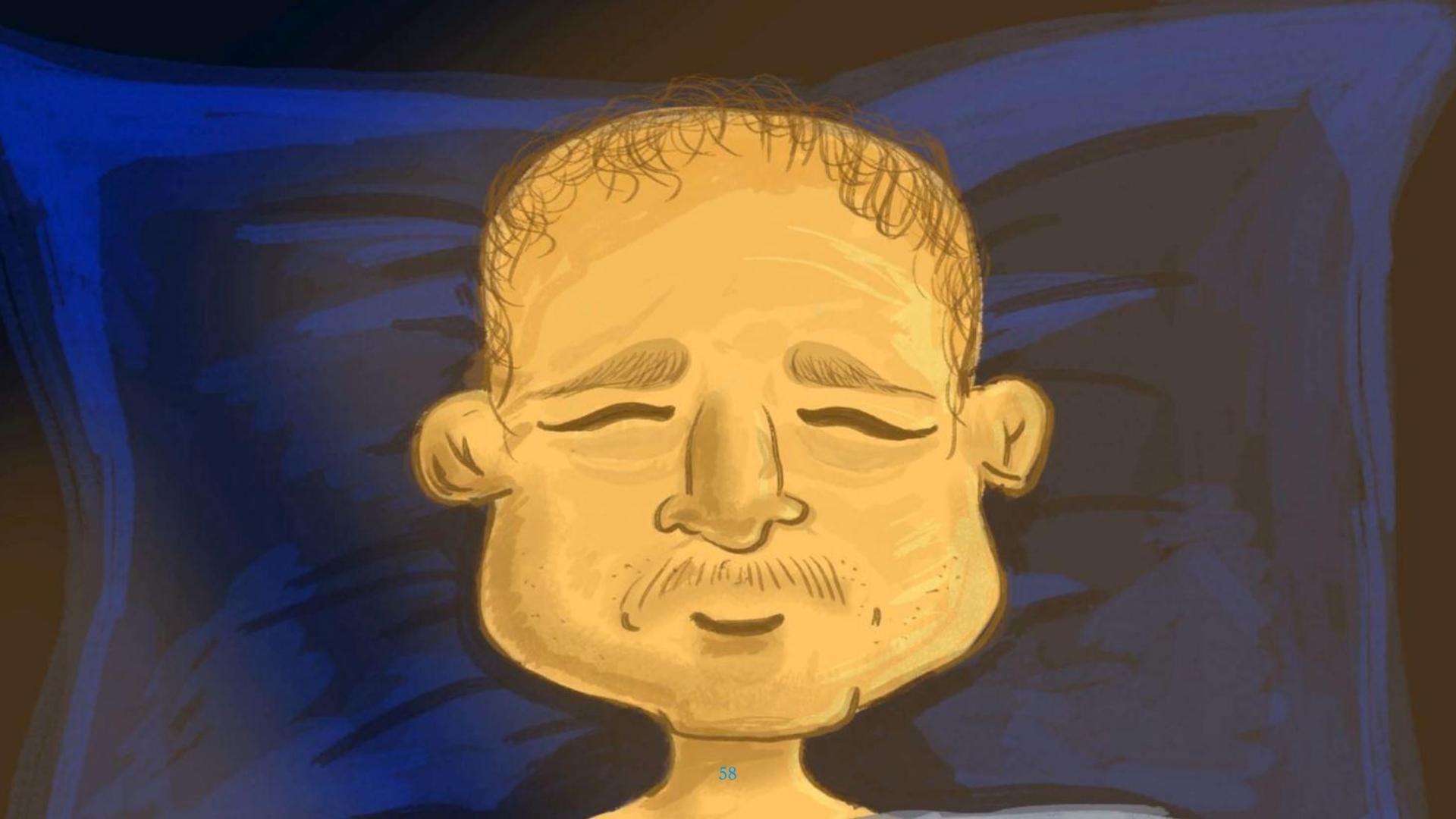


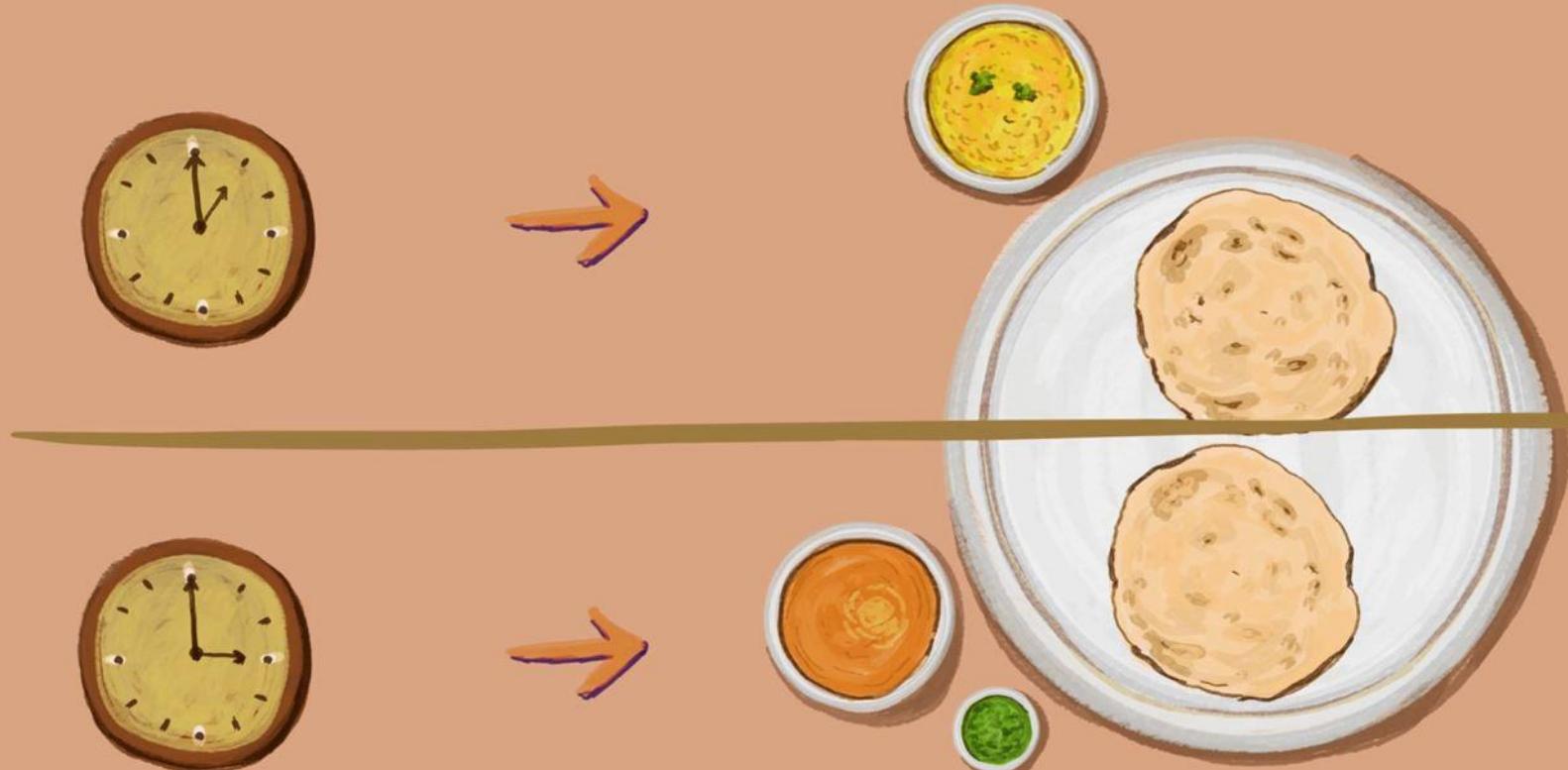












Learnings

- Jumping directly on the final solution with proper user understanding is incorrect; without users, our interpretation is biased towards our own experiences.
- Do not trust assumptions or previous experiences- My assumptions are based on my experiences; reality changes with time and could be different from what I assumed.
- Chunking information to find a way is the only solution to avoid confusion in extensive information.
- Sometimes, during the process, it is essential to modify the strategy and keep it open for future changes as the systems differ every time.
- Finding the right time to initiate a discussion and location to ask or interview patients is critical; it impacts the quality.
- Sometimes, even the wrong way gives a path to walk, like I stated, working on the illustrated stories of cancer patients, which later led to a narrative form of providing information.
- Having discussion areas in mind is important; otherwise, an extended interview or a discussion can have little to no good information.
- It is crucial to know when to stop; the Internet is like an ocean. I kept digging for more and more but, in the end, came back to the original verified sources.
- Making lives a little easier is also an important change in patients' lives.
- Future scope for growth is possible during the process, as it gives more freedom. I tried fitting content as per languages, providing additional time.
- Adding elements I observed during the discussions and visits adds importance to the content, and viewers can connect more.
- Exploring and trying new graphic styles is also suitable for personal learning.
- Problem finding is easy and, at the same time, challenging. I assumed the solutions which impacted my preference but was later corrected.

References

- <https://tmc.gov.in/>
- <https://www.hindujahospital.com/>
- <https://onlinecommunity.cancercouncil.com.au/>
- <https://www.cancer.gov/>
- <https://www.cancer.net/>
- <https://www.cancerresearchuk.org/>
- <https://www.who.int/>
- <https://www.cancer.org/>
- <https://www.nhs.uk/conditions/chemotherapy/>
- <https://www.cancercenter.com/treatment-options/chemotherapy>
- <https://cancer.ca/en/treatments/treatment-types/chemotherapy>
- <https://www.britannica.com/science/chemotherapy>
- <https://www.fortishealthcare.com/>
- <https://www.maxhealthcare.in/>
- <https://main.icmr.nic.in/>

