2020

Design for Empathy:

How the Environment
Impacts a Cancer
Patient's Journey

HMC Architects

Acknowledgements

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DESIGN FOR EMPATHY:

How the Environment Impacts a Cancer Patient's Journey

INTRODUCTION

According to the World Health Organization (WHO), Cancer is the second leading cause of death globally, and is responsible for an estimated 9.6 million deaths in 2018.[1]

Globally, about 1 in 6 deaths is due to cancer. However, with more access to high-quality health care in the United States, the rate of cancer deaths is expected to keep going down mostly from lung and prostate cancer in men, breast cancer in women, and colorectal cancer in both sexes.[2]

Cancer medicine is changing every day with more advancements in diagnosis tools and treatments. In addition to gold standard treatments such as surgery, chemotherapy, and radiation, other innovations and trends in cancer treatments are:

- Precision cancer medicine/personalized medicine
- Targeted treatments
- Immunotherapy: defense systems
  - o Monoclonal antibodies
  - o Checkpoint inhibitors
  - o Cancer vaccines
    - Preventive (or prophylactic) vaccines
    - Treatment (or therapeutic) vaccines
  - o Cytokines
  - o CAR T-cell therapy
- Radioactive elements/ Brachytherapy

Technological advancements have also been also changing ways cancer is diagnosed and treated. Artificial intelligence and machine learning, nanoscale devices, liquid biopsy (a blood test to find cancer cells), and genomic profiling tests are just a few examples of how technology can help improve accuracy and speed of diagnosis, aid clinical decision-making, and lead to better health outcomes.

A recent study by Texas A&M's Department of Public Health summarizes the main emerging models of cancer care as:[3]

- **Hub and spoke model** in which technology is being leveraged in order to provide better access to care, regardless of patient distance from the main healthcare facilities.

- **Integrated practice unit model** in which services and practices are integrated by collocating clinical care services by effective market analysis and master planning.

- **Rapid learning model** in which technology is leveraged in order to access data across the system for research and advancements.

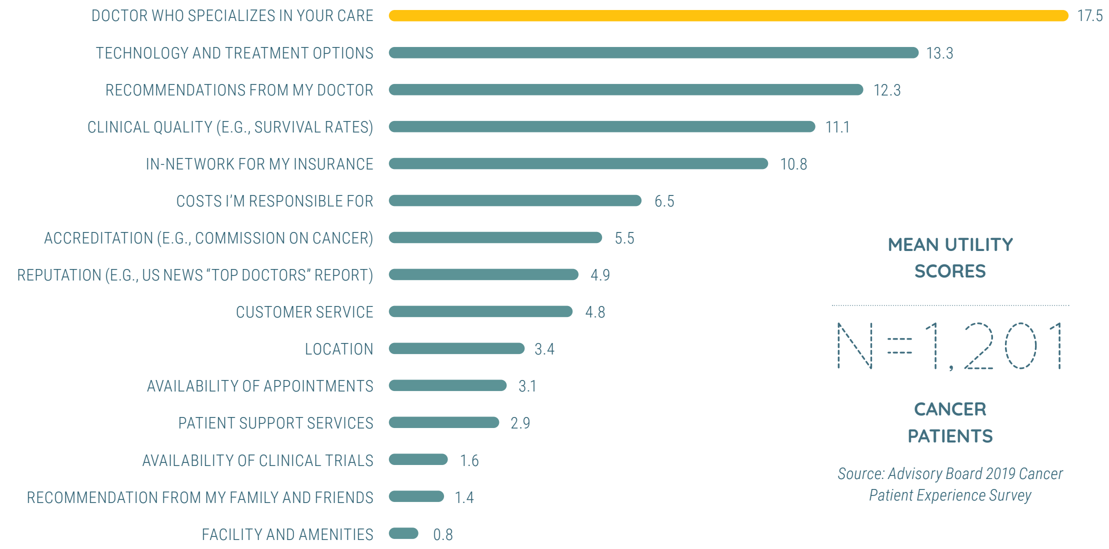
- **Tumor board review** in which coordinated care is facilitated by multidisciplinary team-based care for a personalized patient treatment plan.

- **Tiered model of psychosocial care** in which a holistic care environment is provided to improve access to information, peer and family support, behavioral health resources, and a high-quality physical environment that includes access to daylight and nature.

> **"The Advisory Board Cancer Patient Experience Survey shows that convenience and coordination is of the utmost importance as patients prefer multidisciplinary care clinics and collocation of all services in one building.**

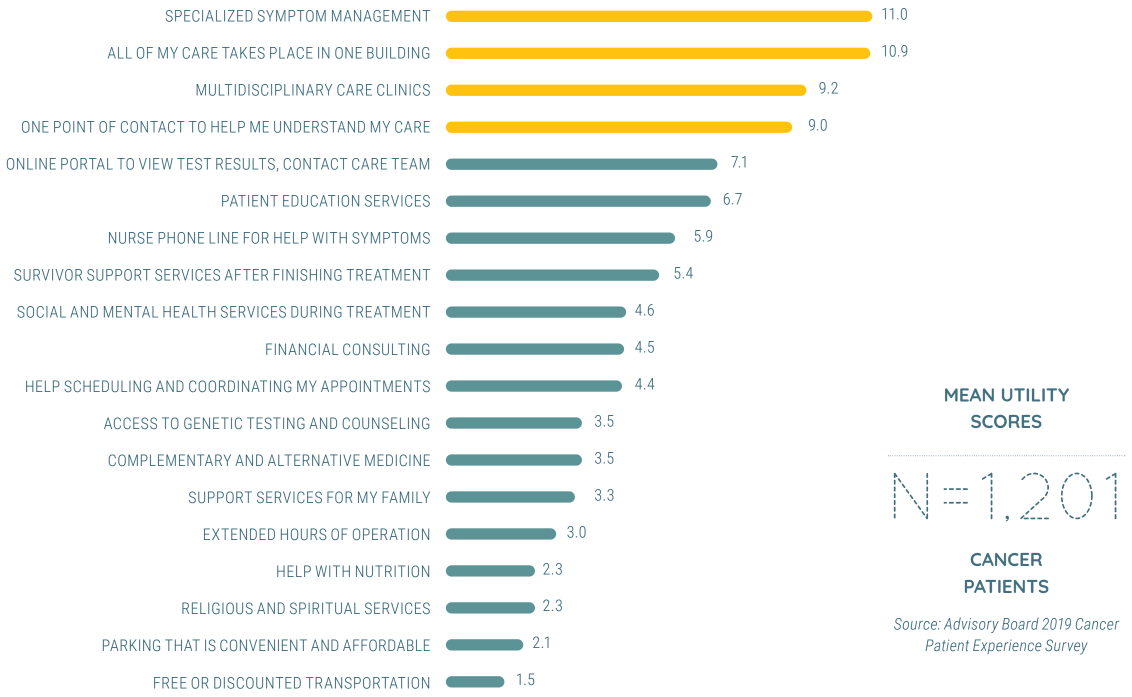
Future cancer care facility design is driven by advancements in technology and cancer medicine as well as current models of care delivery. Along with these main drivers, cancer patients and providers are two important design drivers for these facilities. Today's cancer patients are playing an important role in the decision-making process and require a personalized treatment plan specific for their unique, and complex medical conditions. In addition, cancer care facilities are trying to attract the best doctors to support a collaborative, coordinated and team-based care model. Results from a recent Cancer Patient Survey of 1,201 patients conducted by the Advisory Board in 2019 show that clinical quality is king, 52% of patients ranked "doctor who specializes in my particular cancer" as the number one factor when deciding where to go for care. The study also shows that convenience and coordination is of the utmost importance as patients prefer multidisciplinary care clinics and collocation of all services in one building.[4]

When deciding where to go for care, which feature is most and least important to you?



Source: Advisory Board 2019 Cancer Patient Experience Survey

Which services would have been most and least valuable to you?



Source: Advisory Board 2019 Cancer Patient Experience Survey

> "…the entire campus is centered around cancer care. Everybody is here for the same reason. This made us feel right at home…"

> “At HMC, we are committed to deliver human-centric design. Research can help guide our process and measure our success.”

A recent literature review of 10 studies (2000-2007) related to facility design and how the built environment relates to cancer diagnosis, treatment and survivorship showed 1) providing community-based cancer facilities can bolster easier access to care, 2) access to nature and healing greenery can improve satisfaction and quality of life for patients, staff, and visitors, and 3) spaces with natural lighting and controlled noise are associated with cancer patients’ wellbeing.[5]

A post occupancy evaluation of a cancer center including surveys of 62 patients and 66 staff members showed the importance of wellness features such as indoor plants, arts and murals, and access to a roof garden for patients, access to private and quiet spaces for staff, and ease of movement, thermal comfort, and natural light for both groups.[6]

A study of patient preferences on private, semi-open, or open environments for infusion treatment in an academic cancer center was conducted by surveying 166 and observing 252 patients. The result showed that private, semi-open, or open spaces were equally popular among patients as their needs for high-level privacy, quiet places to nap or sleep, social interaction, or access to nurses may be different depending on their physical and emotional states during their treatment period. The study also showed that participants who had access to positive window views reported significantly lower levels of stress and greater hope for recovery than other patients.[7]

Another study in a similar setting showed that a majority of patients (57%) prefer to talk to fellow patients and visitors during their treatment; however, patients with a higher level of perceived anxiety preferred to not communicate with anyone else during their treatment. The lesson learned is that it is important to design for flexibility to accommodate patient needs and preferences during the most vulnerable period of their life.[8]

> **Design for flexibility allows for socialization and a sense of community as well as patient privacy and respecting their quiet time.**

PURPOSE OF THE STUDY

At HMC, we value and invest in research because we are committed to deliver human-centric design. Research can help guide our process and measure our success. The main objective of this study is to understand the cancer care journey by identifying opportunities to enhance patient experiences and to implement lessons learned into our cancer care facility design and delivery process.

57%

A majority of patients prefer to talk to fellow patients and visitors during their treatment.

METHODS

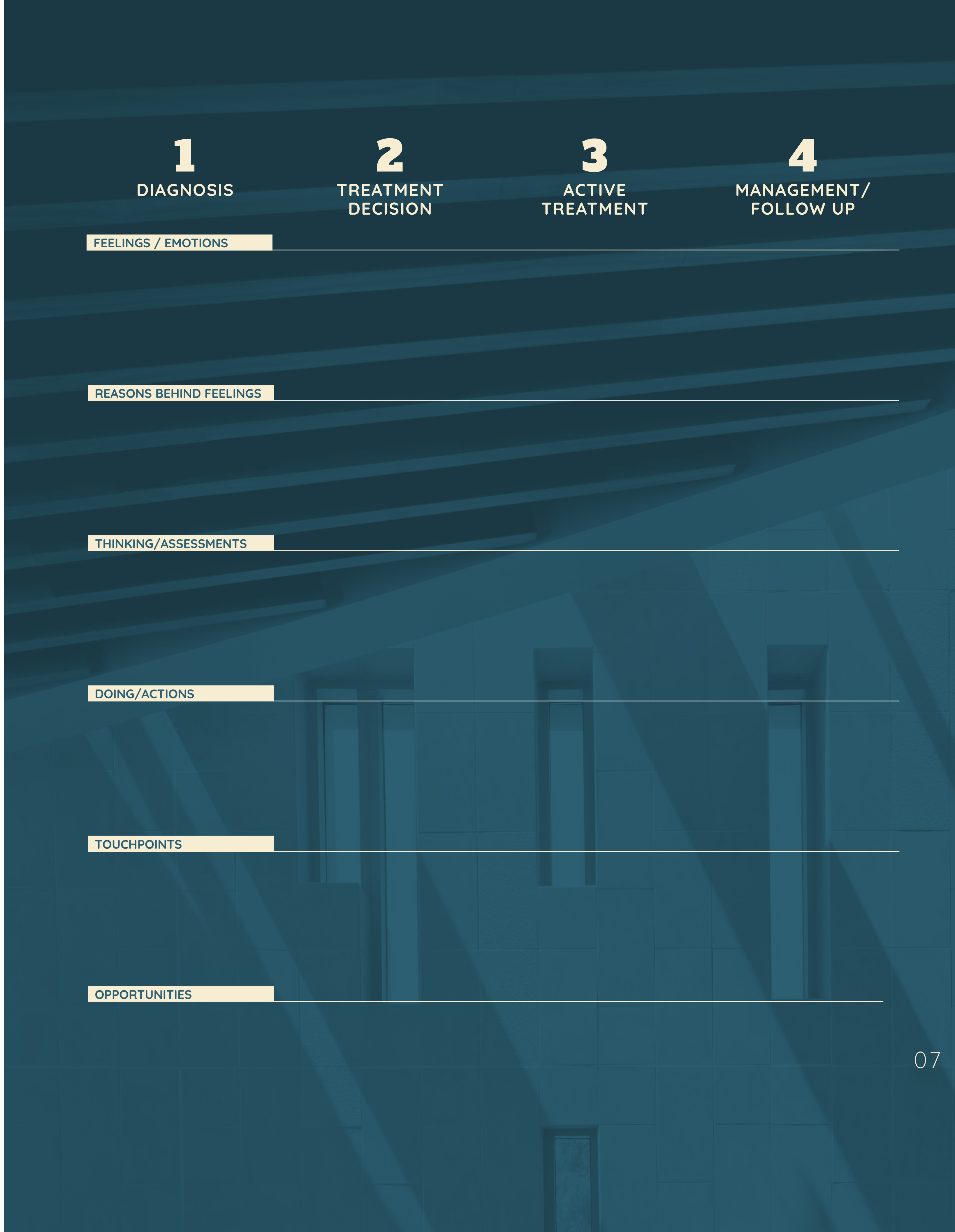
In our study, a unique methodology was implemented to understand and visualize a cancer patient's journey.

Our process started with **DISCOVERY**, where we explored emerging models of cancer care delivery, trends and innovations in cancer treatments, and empirical evidence on facility design for cancer patients. Second, **RESEARCH**, where we gathered the data and detailed stories told by cancer survivors or family members of survivors, including a parent of a pediatric patient. Third, **MAPPING**, where the stories were mapped based on stages, touchpoints, and actors and artifacts to understand patients' feelings, thoughts, and behaviors. Fourth, **COMMUNICATION**, where graphics were used to visualize patient pain points and needs. Finally, **OPPORTUNITIES**, where the map was used to identify gaps and generate new solutions to enhance the patient experience.

Using a snowball sampling method, we invited our own colleagues at HMC Architects who went through this journey themselves or with their family members to volunteer and tell us their stories. The recruitment email was approved by HMC's Human Resources department in order to comply with employee privacy and confidentiality. We received responses from a total of twelve individuals who agreed to participate in the study, in which six of them went through this journey for themselves, and six of them went through it with their parents, spouses, or children. In addition, we have interviewed a cancer care researcher who formerly worked at Cleveland Clinic.

Phone interviews were scheduled with all the participants and the interview questionnaire was shared with participants prior to the call for them to review and have some insight about questions to be discussed. The questions were organized into five major stages of care including diagnosis/pre-diagnosis, treatment decision, active treatment period, management and follow up, and end of life (if applicable). Questions were mainly asked about participants' feelings/emotions, thinking/assessments, doing/actions during each stage of care, along with their perspectives on how different touchpoints including people, places, and technology have impacted their experiences. Participants were also asked about any changes that could have improved their experiences and made their journeys smoother and more bearable.

Phone interviews were recorded with participants' consent and the recordings were destroyed after transcriptions were completed. Narrative analysis was used as one of the qualitative data analysis methods to organize the stories and experiences shared by participants in the sequence of different stages of care, under six categories as shown in the next page:



RESULTS

Cancer Care Journeys

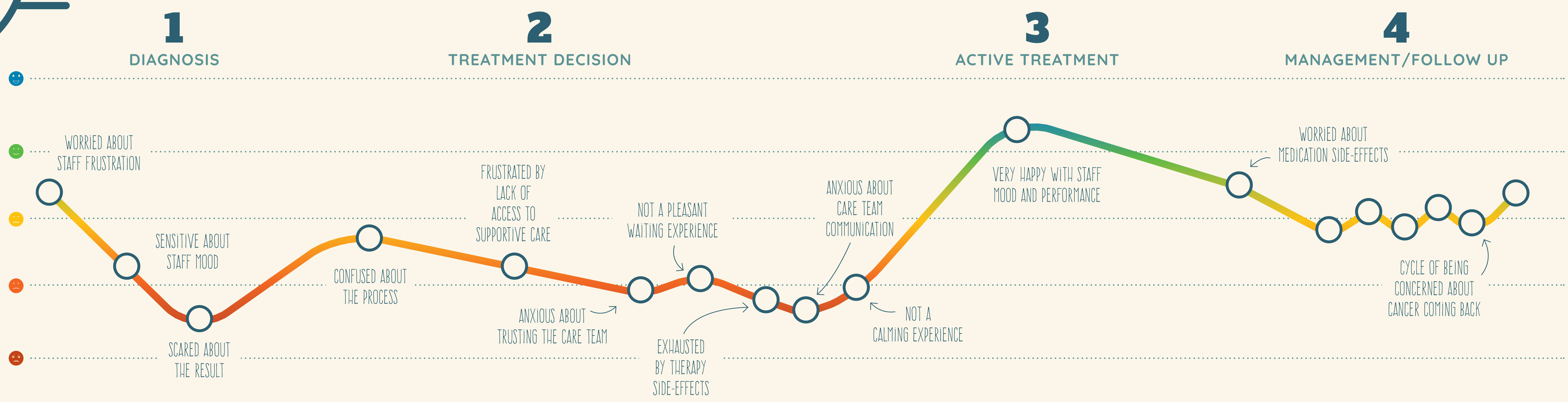
Through the Lens of Patients and Their Families

Touchpoints Key:

- Medical Team
- Friends & Family
- Internet
- Patient Portal
- Telemedicine
- Other Patients
- Environment
- Telephone
- Imaging Equipment
- Artists
- Therapy Dogs
- Insurance

Angelina AGE 58

An interior designer (and cancer survivor) observed the tremendous impact of material management on staff performance.



	1 DIAGNOSIS	2 TREATMENT DECISION	3 ACTIVE TREATMENT	4 MANAGEMENT/FOLLOW UP
REASONS BEHIND FEELINGS	• Shortage of highly trained staff at diagnostic stage. • Staff not being able to find supplies, or not knowing how to use imaging equipment. • Staff not having easy access to knowledge and materials.	• Not being fully supported or guided by the health system. • Not getting proper access to educational resources and support groups. • Not having one place to go for all the services related to alternative medicine like massage therapy, acupuncture, etc.	• Waiting area lacked comfortable furniture, located in uninspiring basement, and too close to restrooms. • Dated dressing room with hard surfaces and dismal colors. • Calming music and nature scene in the radiation room. • Medical team members were very nice despite the environment.	• A small spot was found, but its location made it difficult to do biopsy. Nothing could be done except to wait and have annual check-ups. Thinking positively that it was not cancerous.
THINKING/ASSESSMENTS	• Are staff stressed? • Are staff going to mess up? • Are staff going to miss something?	• How honest is the health system? • How can I trust my care team on the best treatment plan?	• Do care team members communicate with each other and share information?	• Will the cancer come back?
DOING/ACTIONS	• Annual tests including mammograms, sonograms, and biopsies. • Crying when sonogram technician reacted negatively to her scan.	• Doing research on her own. • Finding inexpensive alternative medicine. • Finding support groups.	• Going for radiation therapy on a routine basis. • Spending time in the facility waiting room.	• Multiple doctor visits per year. • Annual check-ups.
TOUCHPOINTS		www		
OPPORTUNITIES	• Education and training for new staff interacting with patients at diagnosis stage. • Standardization in design and planning to help improve staff performance and efficiency. • Optimal material management and operational flow to support staff performance, leading to higher quality patient care.	• Building a system of trust and honesty between care team and patients/family. • Having a system in place to fully educate patients/family about the process, access to support groups and alternative medicine. • Having a social worker with frequent check-ins during the process. • Providing a space to collect thoughts after receiving news and before leaving the facility.	• Collocating cancer care services in one place including supportive care. • Waiting room location with access to daylight, nature and comfortable furniture. • Soothing and comfortable dressing rooms. • Positive distractions in radiation room for a personalized experience.	• Leverage technology to streamline management/follow-up to alleviate patient stress about cancer coming back.

Roberto AGE 31

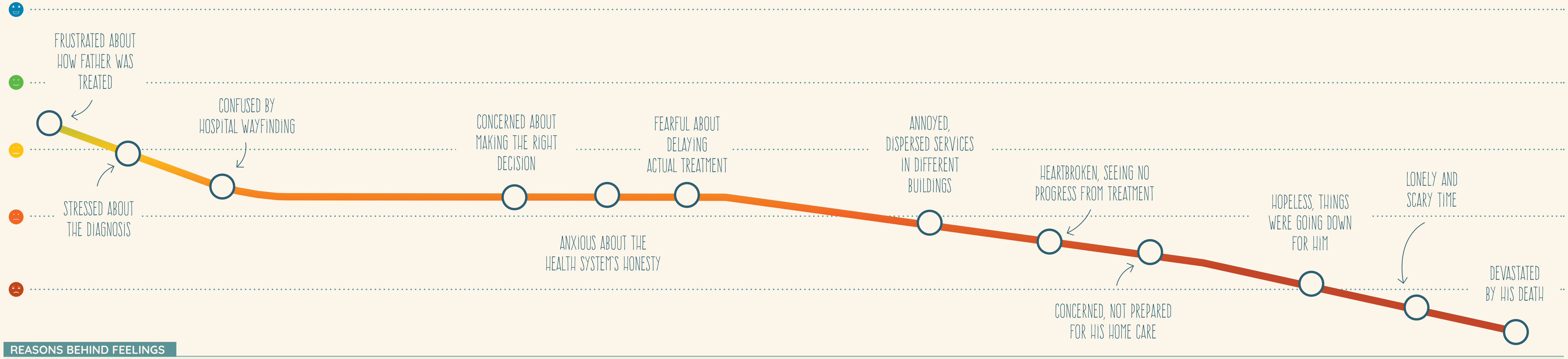
A son endured a heartbreaking ending of his father's (age 57) very short cancer care journey.

1 DIAGNOSIS

2 TREATMENT DECISION

3 ACTIVE TREATMENT

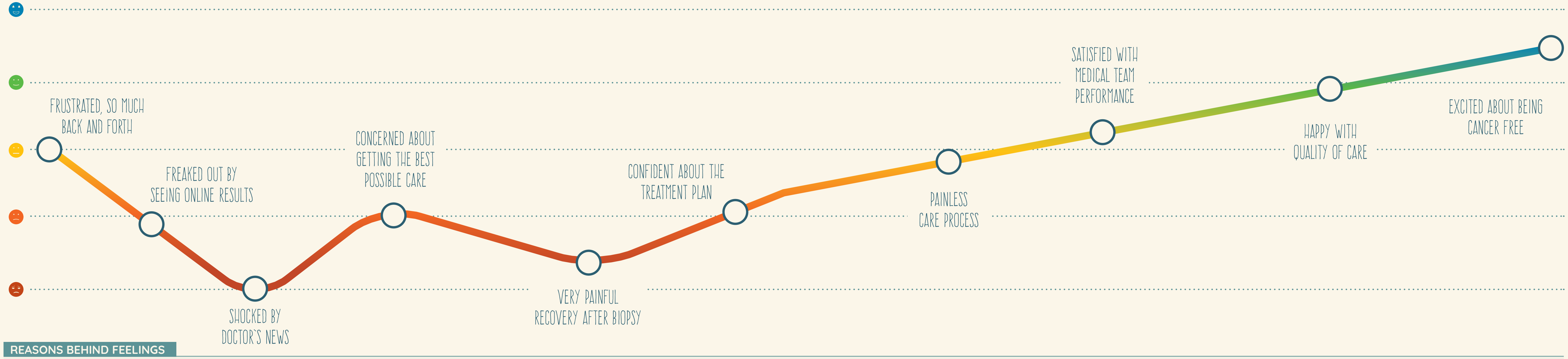
4 END OF LIFE



	1 DIAGNOSIS	2 TREATMENT DECISION	3 ACTIVE TREATMENT	4 END OF LIFE
REASONS BEHIND FEELINGS	• No smart waiting or text messages, long wait in room only to receive a note from the assigned doctor. • Being transferred to a hospital campus that was under construction, confused by chaos everywhere, terrible wayfinding.	• Very fast-paced process, no time to digest things that were happening. • Never felt they were given the right information, concerned about making the right decision. • Recovery after biopsy delayed the actual treatment process and the cancer was growing very fast.	• Old hospital with dark rooms and low ceilings. • Services were dispersed among various buildings, navigating campus from parking to doctor's office to pharmacy, etc. was a terrible experience.	• There was a huge gap in the process with patient care at home. Lack of support from health system in preparing and supporting the family with home care. • There was no support system in place from the healthcare team to preserve his dignity and respect.
THINKING/ASSESSMENTS	• Are we receiving the right information? • A lot of second-guessing on what to do next. • Everything was fine yesterday. Why did they decide to do an invasive biopsy and drill into his skull today?	• What is the right decision? • If it's cancer and it's growing, why are we waiting for actual treatment?	• Did my father receive the best possible cancer treatment? • Was there any clinical trial within or outside the health system that could have been implemented?	• He was just a shell of himself, being bedridden, not being himself anymore. • Very fast-paced process, diagnosis to end of life took only about three months. • Not enough time to reach for more treatment options.
DOING/ACTIONS	• After going to emergency room and getting a CT scan, first diagnosis was a stroke. • Sending him to another facility by ambulance for a biopsy.	• Doing Internet searches. • Doctor recommendation was a surgery after chemotherapy, but he never had the surgery as the cancer advanced so fast and he passed away after 3 months.	• Chemotherapy treatment for about a month. • After showing no progress with chemotherapy, they decided to stop treatment and take him home.	• Patient's wife was taking care of him at home. • A nurse was visiting him at home once a week.
TOUCHPOINTS		www		
OPPORTUNITIES	• Importance of wayfinding in big healthcare campuses for patients and family under stressful situations. • Leveraging technology to keep family informed about diagnosis, especially in such a fast-paced process.	• Having a system in place to provide educational resources to patients and family. • Building a system of trust and honesty between care team and patients/family. • Clear communication to inform patients/family about the process.	• Easy parking and wayfinding for patients and family under stressful situations. • Collocate all cancer care services in one building or in proximity to help patients and family navigate and find services.	• Having a support system for family members taking care of patients at end of life stage. • Providing mental health support for family members after losing a loved one.

Tamara AGE 62

Cancer survivor found friendship in her supportive, encouraging medical team.



	1 DIAGNOSIS	2 TREATMENT DECISION	3 ACTIVE TREATMENT	4 MANAGEMENT/FOLLOW UP
REASONS BEHIND FEELINGS	• So much back and forth between different doctors, as the issue couldn't be diagnosed. • The online patient portal was helpful except when seeing the result before their appointment created a lot of stress and anxiety. • Getting the news from their doctor was like a scary movie, being in a fog, not being able to see or hear anything.	• There was a concern about the quality of care; however, medical team gave them enough assurance and confidence to move forward with the recommended treatment plan. • Very painful recovery process after biopsy due to staying in bed for 3-4 weeks. • In the first appointment, a social worker gave them all the information they needed for the process.	• Radiation center was in the basement, but she didn't mind. • She had the same medical team throughout radiation therapy. She loved them and actually cried on her last day. They made the process special (even fun) and pain free. • Separate areas for female and male helped with privacy she needed.	• She had a delay in recovery because of staying in bed for 3-4 weeks and no one told her, she needed to force herself to get out of the bed and walk. • Her doctor couldn't access the online portal to see her test results – that made him very frustrated.
THINKING/ASSESSMENTS	• What is the problem? • Why are we seeing results before the appointment?	• Should we go somewhere else to get the treatment?	• I am being taken care of by an amazing group of medical team members.	• Why didn't anyone tell me about getting out of bed and walking for a faster recovery?
DOING/ACTIONS	• Visiting primary care doctor and then a specialist. • Going to an emergency room due to unbearable pain. • Getting referred to a surgeon for a biopsy. • Checking the online patient portal and seeing the result showing a cancerous tumor.	• Medical team recommended we NOT do Internet searches. • She received her treatment plan with a detailed explanation of everything she needed to know.	• Having home chemotherapy. • Going to the facility for radiation therapy every day except weekends for six weeks.	• Doctor visits every three months. Every six months if diagnosis is clear. After that, visits would be annual for the next 10 years.
TOUCHPOINTS				
OPPORTUNITIES	• Streamlining the process for a faster diagnosis stage. • Leveraging technology to benefit the patient, not making the process more stressful.	• Building a system of trust and honesty between care team and patients/family. • Clear communication to inform patients/family about the process. • Providing educational resources for patients/family.	• The medical team members can make a huge impact on patient experience; happy staff means happy patients. • Same medical team members for all treatment sessions can create a personalized experience.	• Develop a system for better communication between care team and patient for improved recovery process at home. • Leveraging technology to improve patient experience during the management and follow-up stage.

Luke AGE 42

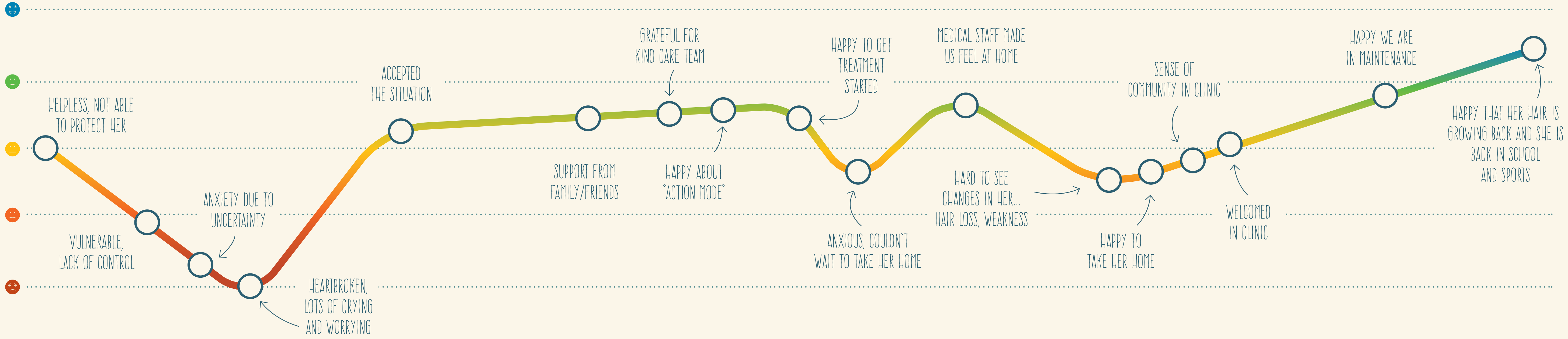
A father found acceptance and strength amid 8-year-old daughter's cancer care journey.

1 DIAGNOSIS

2 TREATMENT DECISION

3 ACTIVE TREATMENT

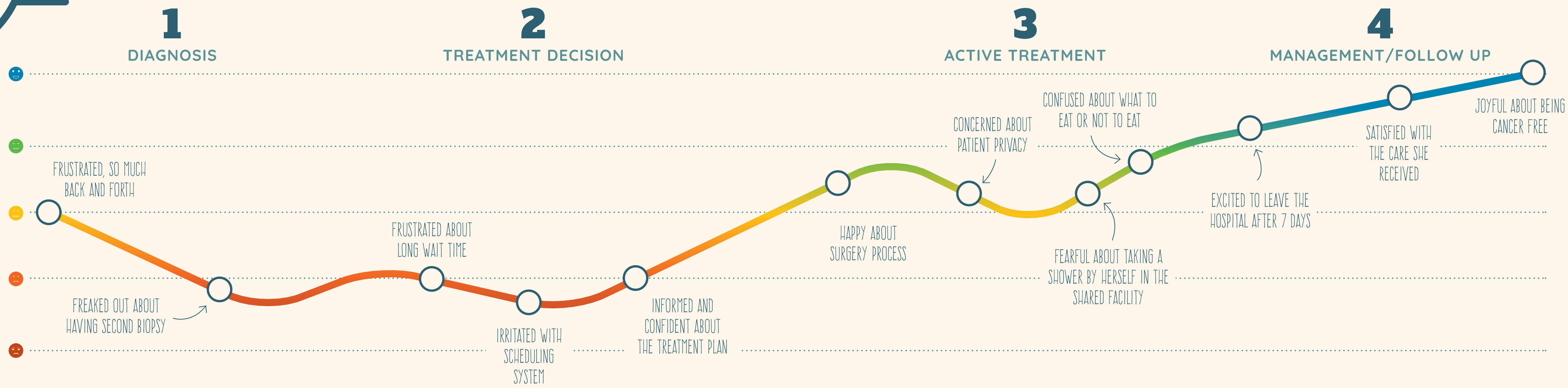
4 MANAGEMENT/FOLLOW UP



	1 DIAGNOSIS	2 TREATMENT DECISION	3 ACTIVE TREATMENT	4 MANAGEMENT/FOLLOW UP
REASONS BEHIND FEELINGS	• Not being able to protect her. • Lack of knowledge and uncertainty. • Lack of control over situation.	• Lack of lighting in the family room where they had the meeting with doctor.	INPATIENT • Nice playroom for kids in the unit. • Small patient room with lots of noisy equipment. • Not very comfortable for parents to sleep at night. • Nice healing garden, farmer's market on Fridays. OUTPATIENT • Clinic was well-designed and very child-friendly. • Therapy dogs, and an artist to work with kids on art projects. • Kids could choose their own treatment bay, a snack, and a movie to watch. • The treatment bay had star-like lights on ceilings.	• Perhaps clinic could have been closer distance to us for follow-up visits, but we loved our medical team, so we were ok with the long drive if that's what we had to do.
THINKING/ASSESSMENTS	• Will she survive? • How would we tell her older brother? • How do we tell our friends/family?	• How can we fully trust the medical team members? • What does treatment look like?	• Does care team communicate with each other and share information? • Will she lose her hair? Will she be in pain or suffer?	• Is the cancer coming back?
DOING/ACTIONS	• Taking her to an emergency room. • Doing a lot of testing. • Accepting the situation, educating themselves. • Surrounding her with positivity and comfort.	• Doctor visit to discuss her treatment plan. • Access to an entire care team including a social worker. • Access to outside support groups.	• Admission to the hospital for an inpatient stay. • Driving to a clinic once a week for chemotherapy • Learning to flush her PiCC line at home. • Sterilizing home to protect her immune system.	• Taking a chemo pill daily at home. • Visiting the clinic once a month. • Make-A-Wish Foundation contacted them about a trip to Walt Disney World in February.
TOUCHPOINTS				
OPPORTUNITIES	• Keeping family informed throughout the process. • A packet of information with all the resources family may need.	• Better lighting in rooms and hallways.	• Design features to make kids feel safe and happy. • Rightsizing patient room with comfortable family amenities. • Designing for visual and acoustic comfort. • Spa-like environment with nice background music • Personalization of patient experience. • Provide newer media equipment such as TVs, iPods, docking stations, current video games and movies.	• Proximity of outpatient clinic to patients for easier access to care during the management stage.

Leslie AGE 37

A cancer survivor recognized the value of patient privacy and family amenities.



	1 DIAGNOSIS	2 TREATMENT DECISION	3 ACTIVE TREATMENT	4 MANAGEMENT/FOLLOW UP
REASONS BEHIND FEELINGS	• A lot of back and forth with the scheduling team for her CT scan appointment. They actually scheduled her for a different type of scan first.	• She had to wait 2-3 hours in a very small consult room to meet with her surgeon. • Surgeon brought three residents into the consult room for their meeting. • More back and forth with scheduling team for her surgery and booking her for the correct operating room.	• Crowded and hectic environment. • Noisy family waiting room. • Small shared patient room and bathroom didn't allow for patient privacy. • She had to take a shower by herself in the shared shower facility, she thought that was very dangerous. • No place for her husband to stay overnight.	• She thought she had a surgical site infection. She was able to take a photo, send it to her surgeon, and they confirmed it was not an infection.
THINKING/ASSESSMENTS	• Am I scheduled for the right diagnosis test? • Do I have to do a second biopsy?	• Can I trust my surgeon for his recommendation? • Am I scheduled for the right surgery room?	• Where can my husband go during my surgery? • What should or shouldn't I eat after surgery? • Can my roommate and her family overhear my health information?	• Am I getting an infection in the surgery area?
DOING/ACTIONS	• She needed to have a CT scan and biopsy. • She was told they had collected insufficient material from the biopsy and might need to have another. She didn't want to do it again, so she met with the surgeon to discuss the issue.	• Since the tumor was well contained, the best treatment option was surgery. • Meeting the surgeon, he was one of the best in his field, so she was very confident about following his recommended treatment plan.	• Day of surgery, she overheard her nurse say that she had worked 12-hours straight and was very tired. • During the surgery, her husband couldn't find a quiet space in the hospital to wait. He was forced to go outside to find a calm place to collect his thoughts while he waited for her. • She had to recover in the hospital for seven days. • She met the nutritionist at the time of discharge.	• Follow up visit one-week post-surgery, and another 2-weeks later. • Check-ins by phone in the following months. • Using virtual care for a question regarding a possible surgical site infection.
TOUCHPOINTS	👤 👥 ⬜	👤 👥 ⬜	👤 👥 ⬜	👤 🖥 ⬜
OPPORTUNITIES	• Streamlining the scheduling process.	• Communication between team members should be integrated into a comprehensive system to improve patient care.	• Private patient rooms with toilet/shower and ample family amenities for overnight stays. • Using technology to improve access to information and entertainment. • Care coordination and supportive care model.	• Leveraging technology to improve patient experience during management and follow-up stage.

Audrey AGE 27

Spouse took control of husband's detrimental journey and made it a thriving experience.

FACILITY A

FACILITY B

	1 DIAGNOSIS	2 TREATMENT DECISION & ACTIVE TREATMENT	3 TREATMENT DECISION & ACTIVE TREATMENT	4 MANAGEMENT/FOLLOW UP
REASONS BEHIND FEELINGS	• Multiple diagnostic tests and delay in scheduling process. • Accidental release of technical test results to patient/family before doctor's appointment. • Miscommunication between health system and patient/family.	• Due to accidental release of test result, there was no time to digest the news and no denial stage. • No privacy in a shared patient ward. • No space for a family member to stay overnight • Unit was congested with no space for patients to walk. • Very busy nurses, not responsive to patient's calls.	• Facility A: Cancer center in basement, waiting area with no windows, dimly lit, dusty old fake plants, fish aquarium had a dead fish in it. • Facility B: Entire campus was designed for cancer care, free valet parking, welcomed by a nurse in the lobby, very responsive medical team, spacious unit with private patient rooms and ample family amenities (breakfast, towel and shower token) for comfortable overnight stay.	• Same friendly nurse for all the follow-up appointments. • Same exam room. • Very efficient scheduling system to line up all the appointments (back-to-back) in one day.
THINKING/ASSESSMENTS	• What is the problem? • Why is the diagnosis process taking so long? • Why are we seeing test results before our doctor's appointment?	• Should we consult with friends and families in the medical field? • What are our treatment options? • Can we trust the care team? • What will be the surgery outcome? • Is the tumor cancerous? • Should I be worried about busy nurses not being responsive to patient's call?	• During the follow-up appointment (Facility A), we already knew that we did not want to stay at this facility. • What are the steps to transfer my husband to another cancer center? • Transferring him to Facility B was one of our best decisions in this process.	• Medical team members are always ready for him.
DOING/ACTIONS	• Several doctor visits. • Doing different tests. • Checking online patient portal for test results.	• Calling friends and family members. • Setting up a surgery date. • Driving to the hospital in a rush after work due to nurse not being responsive to patient's call. Tracking busy nurses and asking for patient's needs. • Being rushed out of the unit at 10 p.m.	• During their follow-up appointment, they decided to change the facility. • Calling friends and family members. • Doing everything needed for his transfer to Facility B. • Having another surgery to remove more of the cancerous tumor.	• Since the cancer had metastasized throughout his body, he must go to a clinic for a monthly injection the rest of his life.
TOUCHPOINTS				
OPPORTUNITIES	• Streamlining diagnosis process to better communicate with patients/family. • Leveraging technology to benefit the patient, not creating more stress.	• Providing guidance for decision-making process. • Providing education to support patients/family. • Right staffing model for oncology inpatient units. • Designing inpatient units for patient privacy and family amenities.	• Improving experience from patient arrival to departure and all the stages in between. • Dedicated campus for all cancer care services. • Right placement of cancer center in the campus. • Patient privacy and family amenities.	• Personalized design for personalized medicine. • Same nurse, same exam room for follow up appointments. • Efficient scheduling system.

Gregory AGE 32

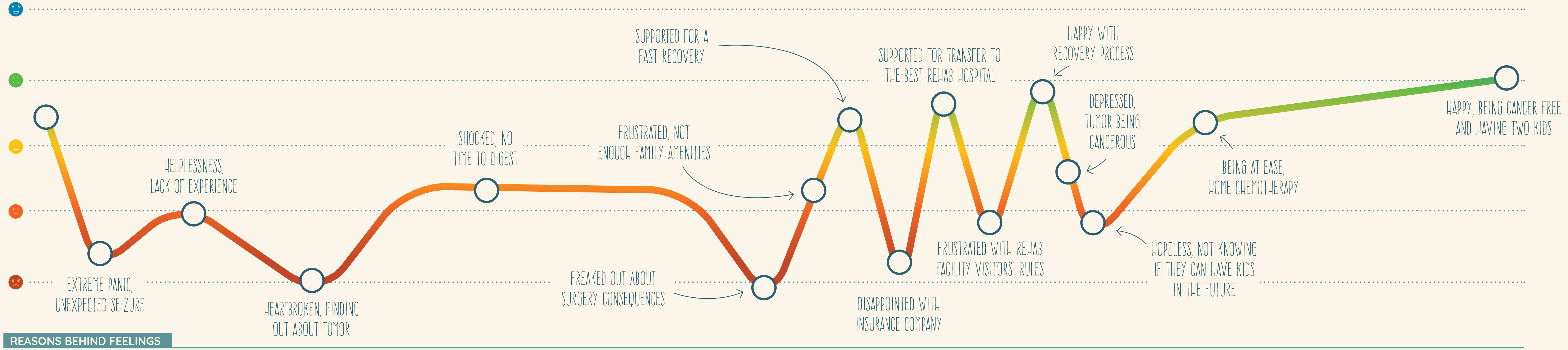
Cancer survivor finds inspiration and strength through support from his rock star wife.

1 DIAGNOSIS

2 TREATMENT DECISION

3 ACTIVE TREATMENT

4 MANAGEMENT/FOLLOW UP



REASONS BEHIND FEELINGS	• Wife seeing him have a seizure for first time. • Learning of his tumor and the urgency of brain surgery.	• Very quick process, no time to digest everything that was happening.	• Lack of information about surgery process and its consequences. • Shared patient room, no family amenities for his wife to comfortably stay overnight. • Supportive medical team, did everything for his transfer to best rehab hospital. • Restrictive rules for family visits in the rehab facility.	• Excited to be cancer free and since they waited so long to have kids, now they are very happy to have two healthy children.
THINKING/ASSESSMENTS	• With no symptoms at all, his wife didn't know why he was having a seizure.	• Very fast-paced process, no time to digest everything that was happening. • What would be the next steps?	• What would be the consequences of brain surgery on his future quality of life? • How long would rehabilitation take? • How fast would the recovery be? • What would be the impact of radiation and chemo treatments on their ability to have kids in future?	• Will the cancer be coming back?
DOING/ACTIONS	• After returning from an urgent care visit for an eye infection, he had a seizure in the car while his wife was driving. • She rushed him to the hospital where they thought he had a stroke. An MRI revealed it was a tumor.	• Visiting neurosurgeon to schedule surgery to remove tumor and do biopsy.	• Transferred to an ICU after his brain surgery. • After a few days, he was pushed to get up and walk, but had no balance and no motor skills. • Medical team worked hard with insurance company for his transfer to the best rehab hospital. • He had to go through 45 radiation treatments and then home chemotherapy for two years. • They were required to wait 6 months after treatment ended to try having kids.	• Doctor visits a couple of times a year. • Routine check-ups, blood tests, and MRIs.
TOUCHPOINTS			$	
OPPORTUNITIES	• Having a system in place that keeps family informed and educated throughout the very fast-paced journey.	• Clear communication to keep patients/family informed about the process. • Providing educational resources for patients/family.	• Single patient room with ample family amenities for their comfortable stay. • A balance between security and convenient family visits • Collocating all cancer care services in one place for convenience and better care coordination.	• Leveraging technology to keep patients on track about follow-up visits and check-ups.

Enrique AGE 47

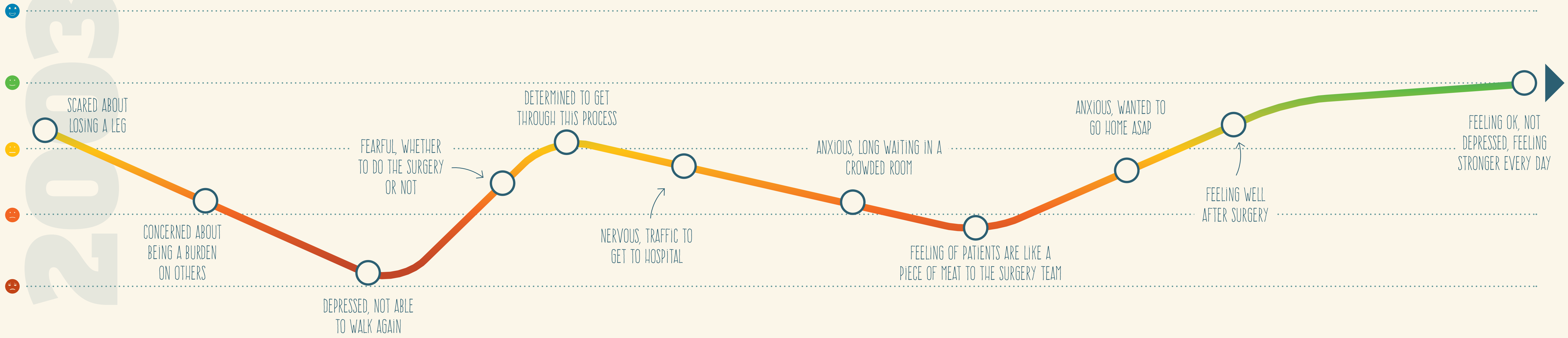
Cancer survivor finds resilience in experiencing this journey twice, 14 years apart.

1 DIAGNOSIS

2 TREATMENT DECISION

3 ACTIVE TREATMENT

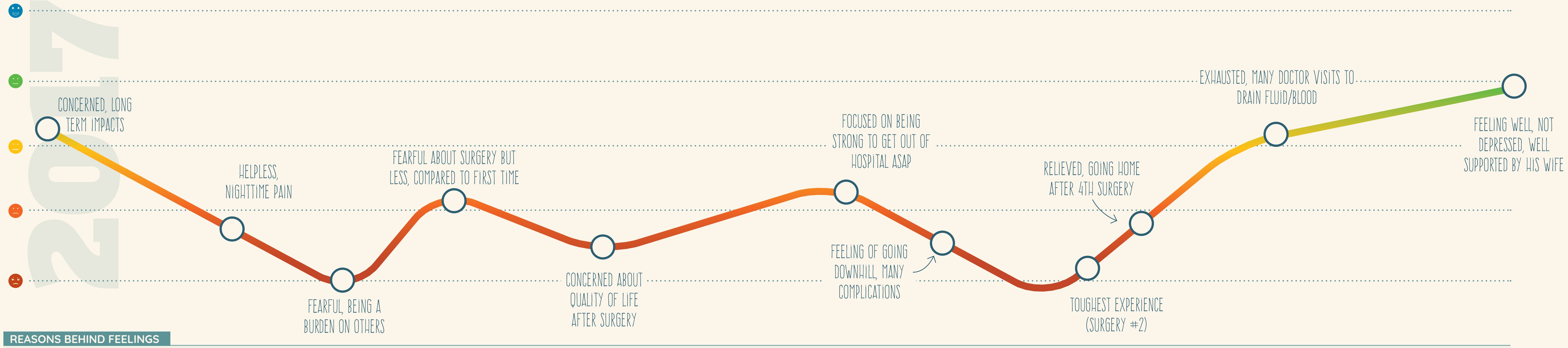
4 MANAGEMENT/FOLLOW UP



REASONS BEHIND FEELINGS	• Fear of losing one of his legs, either due to muscle resection or actual amputation.	• Not having a clear image of his ability to walk after surgery.	• The old hospital was not designed for ADA accessibility. • Patient toilet was the size of a small closet, he had to use public restroom in the public area of the hospital. • Better experience in his one-story house with enlarged bathroom.	• He was getting stronger everyday, he stopped visiting doctors.
THINKING/ASSESSMENTS	• Am I going to lose one of my legs, either due to muscle resection or actual amputation?	• What would be the proposed treatment options? • Is there a possibility for an amputation? • Would I be able to walk after surgery?	• Would I be able to walk after surgery?	• How long does it take to go back to a normal life?
DOING/ACTIONS	• Getting information from his doctor. • Doing internet searches on his own. • Doing multiple MRIs. • Going through a needle biopsy and a surgical biopsy.	• Working out a few weeks prior to the surgery to strengthen the other leg and upper body. • Getting affairs in order, including making paperwork available to his family	• Going for a surgery. • Waiting in a crowded waiting room with many other nervous and scared people waiting for their surgeries.	• Monthly doctor follow-up visits. • Physical therapy sessions. • Doctor visit for a moderate nerve damage – he was told nothing can be done. • He decided to stop visiting doctors.
TOUCHPOINTS	www			
OPPORTUNITIES	• Providing educational resources to patients/family about long term impacts on their quality of life. • Providing ample support to family to give patients enough mental space to focus on themselves.	• Providing mental health support to help patients focus on their present moments and stay positive.	• ADA accessible patient rooms and toilets. • Providing home care for patients to receive care they needed in the comfort of their homes. • Creating a hospital environment that gives the patient the comfort of their home environment.	• Having a system in place for management/follow-ups for patients with many medical complications.

Enrique AGE 47

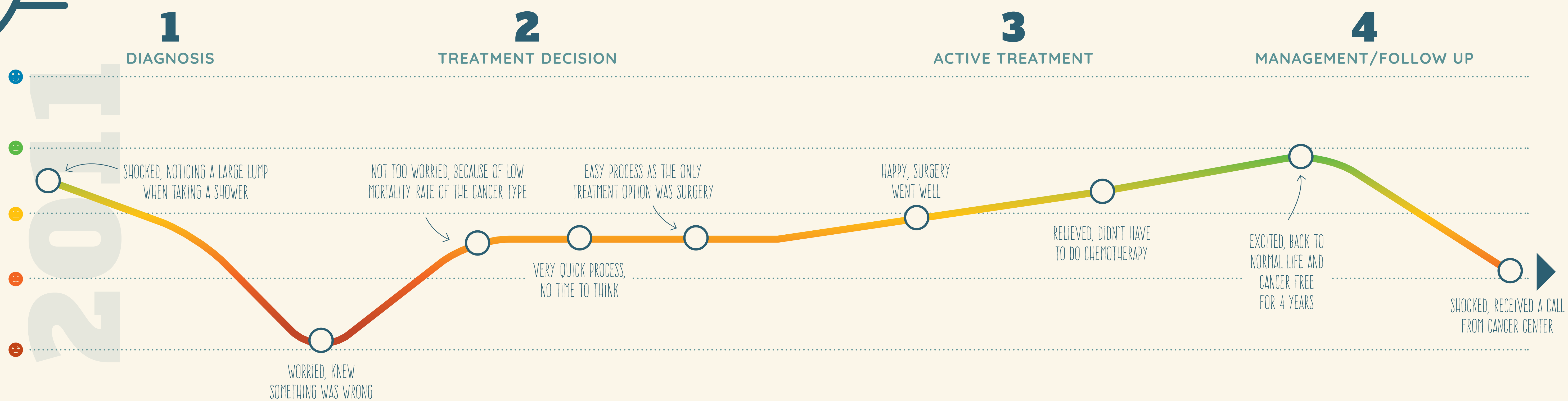
Cancer survivor finds resilience in experiencing this journey twice, 14 years apart.



	1 DIAGNOSIS	2 TREATMENT DECISION	3 ACTIVE TREATMENT	4 MANAGEMENT/FOLLOW UP
REASONS BEHIND FEELINGS	• Concerned about long-term effects on his wife's life and her ability to take care of family in his absence.	• Having the knowledge of future side-effects (from the first time) made him more concerned. • Removing the tumor could cause a lot of issues for his quality of life after surgery.	• Pre-op radiation didn't work, and tumor got 40% larger. • Many complications after the first surgery. • No consciousness during the second surgery. • Losing 35 pounds and becoming very weak as a result.	• Complications after surgery prolonged the "follow up" stage with multiple doctor visits.
THINKING/ASSESSMENTS	• What are the long-term effects on my wife's life and her ability to manage the family?	• What would my quality of life be after surgery? • Due to complicated conditions, nobody really knew what the best treatment option would be.	• What would the side effects be from this invasive surgery? • How soon after the surgery would I be discharged?	• How long would it take to get back to being functional and close to a normal life?
DOING/ACTIONS	• Getting information from doctor was critical because the type of cancer was unique and Internet searches weren't helpful. • Going to urgent care. • Doing a colonoscopy and multiple MRIs. • Going through a needle biopsy.	• Doctor visits to discuss the surgery and its consequences on his future quality of life. • Working out but not as hard as the first time in 2003, since he was older.	• Agreed to do pre-op radiation to shrink the tumor for less nerve removal during the surgery. • Going for radiation therapy every day for 30 days. • Going through four surgeries in three months with many complications.	• Doctor visits to drain excess fluid from the surgery sites. • Excess fluid build up finally stopped, no doctor visit at that point. • Living his life with the help and support of his wife.
TOUCHPOINTS	👨‍⚕️ 👥 ◻ www	👨‍⚕️ 👥	👨‍⚕️ 👥 ◻	👨‍⚕️ 👥
OPPORTUNITIES	• Providing educational resources to patients/family about long-term impacts on their quality of life. • Providing ample support to family to give patients enough mental space to focus on themselves.	• Providing mental health support to help patients focus on their present moments and stay positive.	• ADA accessible patient rooms and toilets. • Providing home care for patients to receive care they needed in the comfort of their homes. • Creating a hospital environment that gives the patient the comfort of their home environment.	• Having a system in place for management/follow-ups for patients with many medical complications.

Stuart AGE 44

A former pediatric oncology nurse finds honor in experiencing this journey for himself.



	1 DIAGNOSIS	2 TREATMENT DECISION	3 ACTIVE TREATMENT	4 MANAGEMENT/FOLLOW UP
REASONS BEHIND FEELINGS	• Being a nurse, he knew something was abnormal. • He wasn't too worried about it; he knew that type of cancer has a low mortality rate.	• Very quick process, he didn't have time to think about his options; he trusted his doctor for his decision.	• Surgery went well and he didn't have to go through chemotherapy.	• He received a call from the clinic after his 2015 CT scan and at that moment, he knew his cancer was back.
THINKING/ASSESSMENTS	• Being a nurse, I knew this was abnormal. I knew something was wrong. • I knew that I needed to call the clinic in the morning asking them for an immediate appointment. • After seeing results, I knew that type of cancer has a low mortality rate, so I wasn't too worried about it.	• What do I need to do? • How quick do I need to decide? • How fast do I need to have the surgery?	• Do I need to do chemotherapy?	• I thought almost 4 years out, doing a follow-up CT scan is not a big deal.
DOING/ACTIONS	• He noticed a large lump when taking a shower. Immediately, he called his clinic for an appointment. • Being a clinician himself, he asked for an ultrasound. • Nurse called and asked him to see a urologist. He called for an appointment and they said they needed to see him right away. • Before his appointment, the doctor went to his office and told him about the result.	• His doctor really wanted to take care of the tumor immediately. • He was asked to come back the next day for his surgery to remove the cancerous tumor.	• He had surgery the next day. • He had a follow-up visit with the oncologist and urologist a few days later. • They said there's a low probability (less than 10%) for the cancer to return. Given the option of chemotherapy, he declined.	• He had to have routine screenings (X-rays) for next several years. • He had CT scans in 2012, 2013, and 2014. • He was late for his 2015 CT scan. The day after he had the scan, the clinic called, and he knew something had changed.
TOUCHPOINTS				
OPPORTUNITIES	• Leverage technology to keep patients/family informed, especially in a fast-paced process. • Provide support that family needs to give patients mental space to focus on themselves.	• Creating comforting experiences for patients. An example is having music in the procedure room. • Medical staff can make a huge impact on the patient experience. Human contact from a nurse was mentioned as a key driver in creating a personalized experience.	• Flexible infusion bays allow for socialization, a sense of community, patient privacy, and space for family visits • Bathroom location with visual and acoustic privacy. • Ample patient amenities; they spend all day in the clinic. • Services should be accessible for all patients at any point in the continuum of care.	• Leverage technology for telehealth and virtual care to extend mental health support for patients/family at this stage. • Leverage technology to track patient's follow-up visits for several years to alleviate their concern over cancer occurring again.

Stuart AGE 44

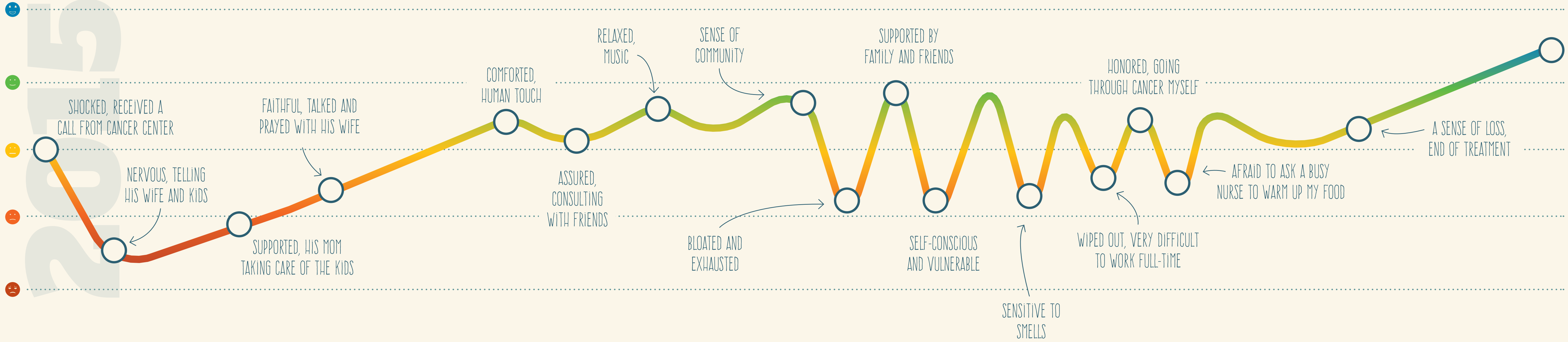
Cancer survivor endures this journey for the second time, while designing a cancer care facility.

1 DIAGNOSIS

2 TREATMENT DECISION

3 ACTIVE TREATMENT

4 MANAGEMENT/FOLLOW UP



	1 DIAGNOSIS	2 TREATMENT DECISION	3 ACTIVE TREATMENT	4 MANAGEMENT/FOLLOW UP
REASONS BEHIND FEELINGS	• He was very nervous because he didn't know how the cancer would proceed this time and was anxious about telling his wife and four kids.	• He was comforted by his nurse holding his hand during sedation. He was asked for his music preference to be played in the procedure room. • Prep/recovery bay was very tight, no space for family. • There was a bathroom connected to the procedure room, and he was concerned about infection control.	• Sense of community. • Connection with others and enough space for quiet time. • Very small infusion bays. • Not enough family amenities. • Very accessible nurse station for patients/family. • Sensitivity to smell due to chemotherapy. • Difficult to work full-time.	• Having a treatment plan with routine visits to a healthcare facility creates a routine for patients and when the treatment process ends, this bring a sense of loss and state of depression. • Concern of having the cancer back especially when it came back once.
THINKING/ASSESSMENTS	• How are we going to deal with cancer for the second time? • How is cancer going to proceed this time? • How am I going to tell my wife and four kids?	• What is the best treatment option? • Is it chemotherapy? • What would be the protocol? • How should I prepare myself for infusion?	• It is a hard experience for the spouse. They watch you in pain while they're helpless. • Years ago, I was a nurse for pediatric oncology patients, so it's an honor in many ways to go through this journey myself.	• Cancer came back once, will it come back again?
DOING/ACTIONS	• He had a CT scan and was asked to see his doctor. • His mother took care of his kids so he could talk with his wife about it. • He took his wife out; they talked and prayed.	• He talked with his oncologist about treatment options and protocols. • He consulted with his friends. • He had a CT guided biopsy and a port-a-cath placed in his chest for infusion.	• Treatment plan was nine weeks of chemotherapy. • He always had visitors during his treatment time. • His kids tried to comfort and support him. • He was working full-time.	• He had to have routine screenings the next several years. • He had labs and CT scans every six months. Once clear, then labs and CT scan annually. If annual exams were clear, then labs and CT scans would be done every two years.
TOUCHPOINTS				
OPPORTUNITIES	• Leverage technology to keep patients/family informed, especially in a fast-paced process. • Provide support that family needs to give patients mental space to focus on themselves.	• Creating comforting experiences for patients. An example is having music in the procedure room. • Medical staff can make a huge impact on the patient experience. Human contact from a nurse was mentioned as a key driver in creating a personalized experience.	• Flexible infusion bays allow for socialization, a sense of community, patient privacy, and space to family visits. • Bathroom location with visual and acoustic privacy. • Ample patient amenities; they spend all day in the clinic. • Services should be accessible for all patients at any point in the continuum of care.	• Leverage technology for telehealth and virtual care to extend mental health support for patients/family at this stage. • Leverage technology to track patient's follow-up visits for several years to alleviate their concern over cancer occurring again.

DISCUSSION

> “Time is of the essence in diagnosing and treating cancer.”

Cancer care is a long-term process, with a series of phases. The initial phase, diagnosis, brings a shock and the patients’ introduction to the cancer care process.

The next phase is the treatment decision process in which patients need the most direction and guidance to decide on their best treatment plan. The active treatment phase will be a different experience depending on the type of treatment – it can be a one-time surgery, routine infusion and/or radiation treatments, or taking the treatment at home. Finally, the follow-up and management or the end of life phase considers how treatment fades over time after survival, or how family and friends, especially children losing their parents or siblings at early ages, are coping after death of a loved one. The components of care that patients need to access at a particular time will be different based on the stages they are at and the treatment protocols and strategies they need to undertake. It is crucial to locate resources in a way that make them easily accessible over that continuum of care, but also easily accessible in the moment when they’re needed.

Patients shouldn’t have to search for services. The services should come to the patient, or the services should be easily accessible for anybody, at any point in the continuum of care. For example, it is key how to locate nurse navigators, social workers, case managers, nutritionists, financial aid team members, and all the other supportive functions that support the continuum of care. What we place at the entry point of the cancer center would be different than those support spaces that we need to distribute throughout the building. This is how we can build a cancer canter with a comprehensive experience. Understanding the complexity of the emotional and physiological changes that a patient goes through during their treatment is the key to design for a successful project. Space should be designed to be intuitively changed to meet patient needs and preferences at different stages of care. For example, providing community spaces with cozy nooks and corners as well as private rooms gives infusion patients options to choose based on their physical and emotional states at a given time.

Diagnosis. At this stage, most patients and family members described their feelings as being shocked, fearful, anxious, vulnerable, helpless, confused, and frustrated. Their main concerns focused on three main areas: what is the problem? will I/he/she survive? and why is the diagnosis process is taking so long? So, the main reasons behind their feelings of being shocked, scared, and confused were caused by a lack of knowledge and uncertainty, lack of control over situation and an unnecessary long diagnosis process.

> *Time is of the essence in diagnosing and treating cancer.*

For many in this stage, diagnosis started with an emergency department or a doctor visit, following up with many diagnostic tests, including imaging and surgical biopsies. Most health systems have implemented online patient portals to release and communicate information with patients on their testing results. In two cases, we have heard patients had accidentally been looped into a conversation that was supposed to be only between the radiologist and the doctor, and this created a lot of stress and anxiety for patients and families at this very sensitive stage of care. So, the lesson learned is:

> *Technology shouldn’t be implemented just for its own sake. Technology shouldn’t be forced because it is new and cutting edge. It should be implemented when it supports needs and functions, and therefore, can enhance user experience. We should ask: what meaningful value does it provide? is it the right technology for the need at the time? and does it prove to meet the needs? is it cost-effective, or is it just a waste of time?*

During the diagnosis stage, due to lack of knowledge and confusion, patients and family members tend to do a lot of research on the internet or by reaching out to their families and friends in medical fields. Our participants mentioned that their main touchpoints at this stage were members of their medical team, families and friends, internet, online patient portals, phone calls, and the environment.

Opportunities to improve the patient and family experience at this stage include streamlining

> **“…and after lots of crying and worrying, we began to realize that what (our daughter-patient) needed most from us (parents) was STRENGTH…**

> “
>
> Cancer care facilities need to be comfortable and welcoming since they are the second home to so many cancer patients spending many hours in these places…

the diagnosis process, leveraging technology to communicate and keep the patient and family informed, and providing support for family members to give patients enough mental space to focus on themselves and also give families the mental power to support their patients.

> *… and after lots of crying and worrying, we began to realize that what (our daughter-patient) needed most from us (parents) was STRENGTH…*

Treatment Decision. At this stage, both positive and negative feelings were expressed depending on experience. Based on how the health system managed care and communication at this stage of care, patients and families expressed being scared, nervous, and frustrated as well as being determined, informed, confident, and assured. Their thoughts focused around three main questions: what do I need to do? how can I trust my medical team and their proposed treatment plan? and how does the treatment impact my quality of life in long term? The main reasons behind the expressed feelings were because they did not have enough time to digest all that was happening in a very fast paced process, whether they were guided and supported by the health system or not, and whether they had enough trust and assurance in their medical team’s experience and expertise.

Similar to the diagnosis process, if there is not enough education and guidance from the medical team, patients and family members tend to do a lot of research on their own by searching on internet or reaching out to their families and friends in medical fields. Several stories showed how detailed explanations of treatment options and protocols have facilitated and expedited the decision-making process for patients and family members at this stage of care. The role of a social worker, a health coach, or a patient liaison becomes crucial in improving the experience by educating and supporting patients and families on every step of the process. Our participants mentioned that their main touchpoints at this stage were members of medical team (social worker), families and friends, internet, and the environment.

One of the main recommendations to improve the patient and family journey at this stage is to build a system of trust and honesty between the medical team and the patients/family. Trust in health care relationships is a key ingredient of effective, high-quality care. Another recommendation is to have a system in place to fully educate the patients/family about the process, everything that they may experience, and all the resources that they may need physically (diet, nutrition, physical activity), emotionally (support groups, yoga, meditation), and financially. The physical environment should also support the patients in this stage. Providing a space specifically for patients/family who just heard some difficult news, received some tough information, and needed a moment to collect their thoughts before leaving the facility is important in boosting their emotions by giving them an environment to digest the information and accept the situation. This space will tremendously benefit from elements of hope such as natural light, access to nature, and music.

Active treatment. At this unpredictable stage of care, patients’/family emotions can be expressed anywhere between being nervous, fearful, hopeless, heartbroken, painful, exhausted, vulnerable, to being comforted, relieved, and supported. The majority of their thoughts were focused around three main questions: what would be the outcome in short and long terms? is my care being coordinated among medical team members? how is my family accommodated/supported during my treatment? At this stage, the patient experience is tremendously impacted by the physical environment in which they received care, the amenities and support available for their family members, and whether or not they had a caring, communicating, and coordinating medical team along the process. They mentioned that their main touchpoints at this stage were members of the medical team (residents/fellows in teaching hospitals), other patients, families and friends, artists, therapy dogs, and the environment.

For example, one of our study participants described the cancer center being down in the basement, with a dim waiting area with no windows, with dusty old fake plants, and a fish tank with a dead fish in it. At that moment, they made the decision to receive care at a different health system. The patient’s spouse told us a heartbreaking statement:

> “
>
> …in the elevator going down to the basement… he said ‘look, they’re already putting us underground,’ and that’s kind of what it felt like….

> **…you can paint the prettiest color on a wall, but if you don't have materials management and operational flow figured out you are failing the patient…**

> *"… in the elevator going down to the basement, he (patient) was joking, but it was kind of true. He said look, they're already putting us underground and that's kind of what it felt like…"*

In several stories, we heard about shared patient wards where "teeny tiny curtains" were supposed to provide patient privacy, where there was not enough space for a family member to pull up a chair next to the patient bed, where no family amenities provided for an overnight stay; hence, family members had to commute to the care center every day to visit their patients. We heard stories of very crowded patient units with staff shortages where the family members had to rush back to hospitals after work because they were scared of not having nursing staff attention and support for their patients.

We also heard how small infusion bays with a bathroom located right in front of them, could impact cancer patients who are very vulnerable and need sensory comfort more than any other time in their life. We heard how intimidating radiation oncology equipment can be for patients, particularly pediatric patients who need positive distraction during their treatment.

At the same time, we heard positive stories about how caring and welcoming nursing teams transformed patient and family experiences by creating a sense of community that brought tears to patients' eyes when the treatment period was over. We heard stories about how private patient rooms with enough family space to stay overnight, with the ability to shower in the morning and order their breakfast off of a menu, gave a sense of peace to patients by seeing their families being supported and content while spending time in hospitals. We heard how one health system got very creative in providing pediatric care by bringing therapy dogs and artists to spend time with kids while they are in hospitals.

The active treatment phase would be a different experience depending on the type of treatment –whether it is a one-time surgery, going through infusion and radiation on a routine basis, and/or taking the treatment at home. However, the opportunities to improve the patients'/family journey can overlap, starting from free valet parking, to easy wayfinding, and even enough attention to material management.

> *… you can paint the prettiest color on a wall, but if you don't have materials management and operational flow figured out you are failing the patient …*

Patients prefer to receive all of their cancer care services in one place, in other words, a campus that is entirely centered around cancer care. A spa-like environment that brings joy and comfort to patients who have very vulnerable senses due to their treatments and associated side effects.

> *The healthcare facility needs to be comfortable and welcoming since it is the second home to so many cancer patients spending many hours in these places…*

Space should be designed to be intuitively changed to meet patient needs and preferences at different stages of care. It needs to accommodate quiet time and privacy as well as socialization and connecting with others.

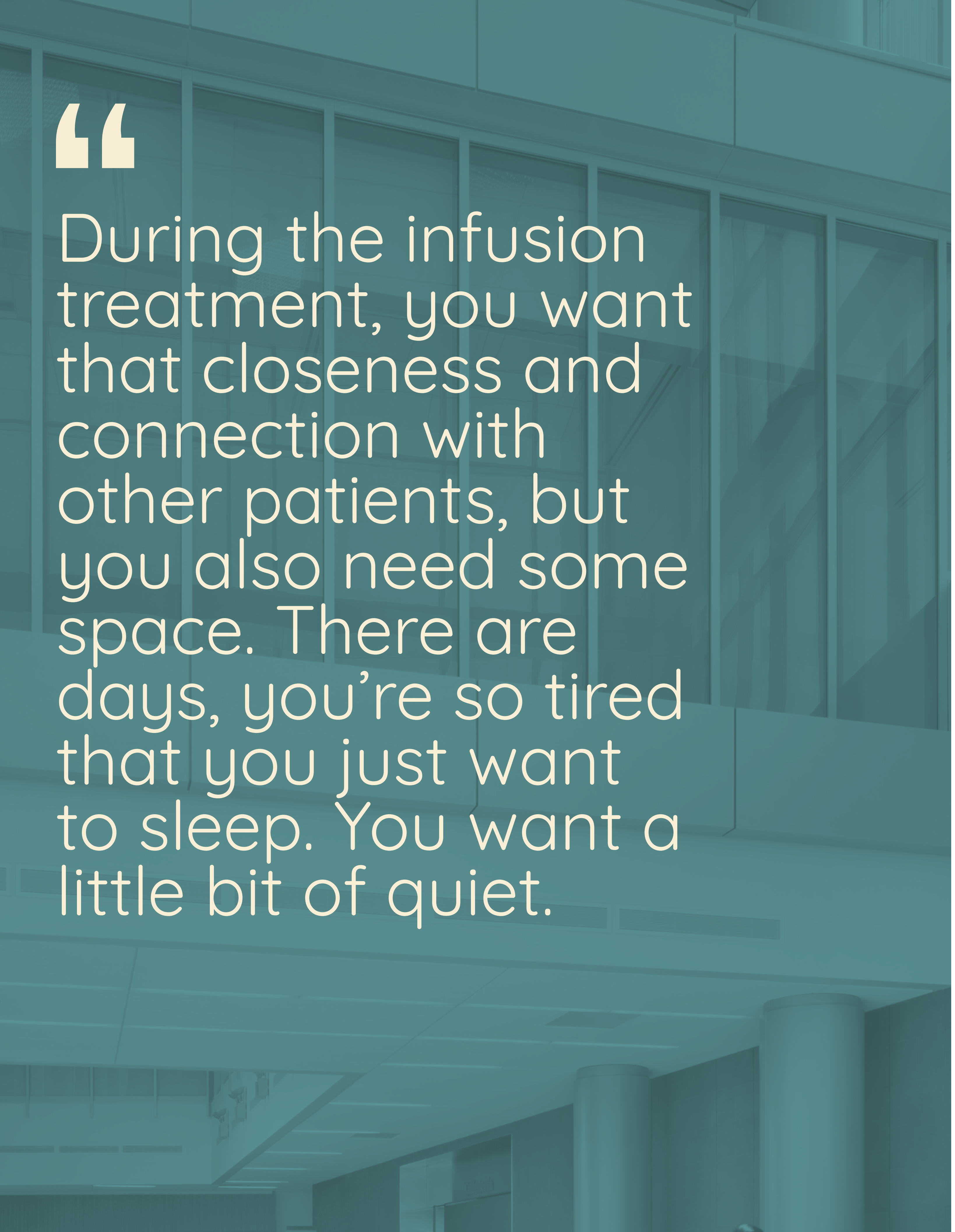
> *During the infusion treatment, you want that closeness and connection with other patients, but you also need some space. There are days, you're so tired that you just want to sleep. You want a little bit of quiet.*

Design for personalization should be provided to give patients control and autonomy over the environmental features such as lighting, acoustics, and temperature. Design for a holistic model of care should address both mental and physical health by providing spaces for alternative care such as yoga, meditation, acupuncture, and massage therapy. Design with access to natural light, nature, fresh air and soothing music can bring hope to patients going through a difficult time.

> *The nurse asked me what music I want (in the procedure room)… she picked Bob Marley, which was one of my favorites… having that music while I was being sedated and kind of drifting off asleep was really comforting.*

Family members have a tremendous impact on the patient journey. Providing ample amenities for them to visit and stay with patients is key for patient happiness and peace.

> Staff were very nice despite the environment; they remember you…



> During the infusion treatment, you want that closeness and connection with other patients, but you also need some space. There are days, you're so tired that you just want to sleep. You want a little bit of quiet.

> *It's probably harder for the spouse to deal with you going through cancer than you going through cancer... because you're dealing with it and they're helpless... they watch you in pain, weakness, and exhaustion, they become emotionally drained individuals.*

> *It was hard to see her brother watch his sister go through these changes (hair loss, weakness, etc). We only hoped they would both make it through this unscathed.*

Happy staff means happy patients; a staff-centered design where they can seamlessly work, communicate and coordinate as a team, and at the same time benefit from health-promoting respite areas with opportunities to access daylight, nature, fresh air and healthy food can remedy burnout, promote wellbeing, and as result improve patient and organization outcomes.

> *Staff were very nice despite the environment; they remember you ...*

Management/Follow up or End of life (if applicable). At this stage of care, depending on the outcome of the treatment stage, emotions were varied from being hopeless, lonely, and devastated to feeling stronger, excited, and relieved. However, being fearful was one of the shared feelings among those who survived, taking care of a dying patient at home, or the loss of a loved one. The majority of thoughts focused around three main questions: will the cancer come back? how long does it take to go back to my normal life? how should we preserve patient respect and dignity dying at home?

Having a treatment plan on a routine basis becomes a part of patients' everyday life, being done with the treatment stage can bring a sense of loss for most patients. Several patients expressed that they strangely felt depressed when the treatment was over because they lost that sense of community that had been created by nursing staff and other patients during the stage of active treatment.

> *It was really a weird feeling ... a sense of loss that I was no longer going to this place (clinic) ... that had become a part of me in so many strange ways. People had become part of my experience...*

We heard about being hopeless in caring for a loved one dying at home, being devastated of losing a family member or a friend, and dealing with mental health issues after losing a loved one. On the other hand, we heard how cancer survivors came out stronger than they were before; they were very excited to go back to their normal life. However, the fear of cancer coming back is always with most of them, especially if it had come back once before.

At this stage, patients are either receiving treatments on a routine basis (patients with metastatic cancer), or doing routine check-ups and doctor visits (survivors). Family members might be taking care of a loved one dying at home. We heard routine check-ups and mental health support have been delivered via telehealth or virtual care. Participants mentioned that the main touchpoints at this stage were members of medical team, families and friends, online patient portals, virtual care, phone calls, and the environment.

One of the main recommendations to improve the patient journey at this stage is to leverage technology to use telehealth, virtual check-ins, and e-visits to streamline the management and follow-up process. Having a smart system in place for patient management and follow-ups will alleviate the fear of most survivors of having the cancer return. Having a support system for family members caring for a loved one at home is crucial in helping them to manage their patients while preserving their respect and dignity during final days of their lives. After a patient's survival or death, the journey is not over, providing mental support for cancer survivors, for family members after patients' death, especially younger children losing their parents, or even for their caregivers is tremendously important in managing the repel effect of cancer which can touch, not just the lives of patients, but their families, colleagues and health providers.

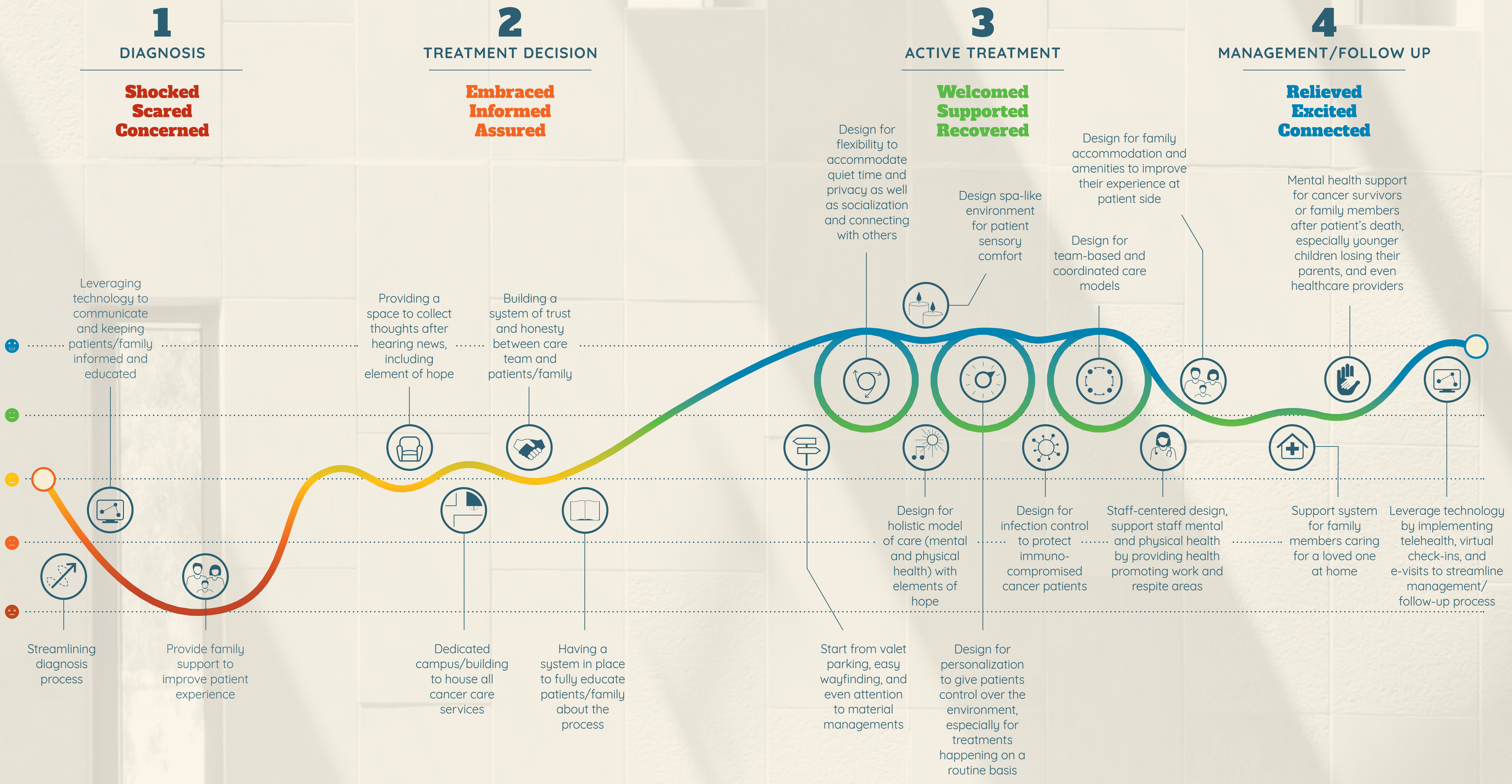
It was really a weird feeling... a sense of loss that I was no longer going to this place (clinic)... that had become a part of me in so many strange ways. People had become part of my experience...

Summary of all Patient Journeys

	1 DIAGNOSIS	2 TREATMENT DECISION	3 ACTIVE TREATMENT	4 MANAGEMENT/FOLLOW UP END OF LIFE
FEELINGS / EMOTIONS	Shocked, Panicked, Frantic, Scared, Fearful, Freaked out, Concerned, Worried, Anxious, Nervous, Sensitive, Vulnerable, Helpless, Heartbroken, Depressed, Confused, Stressed, Frustrated	Shocked, Anxious, Nervous, Fearful, Frustrated, Painful, Accepted, Embraced, Determined, Grateful, Connected, Informed, Comfortable, Confident, Assured	Anxious , Nervous, Annoyed, Confused, Fearful, Exhausted, Fatigued, Painful, Helpless, Hopeless, Disappointed, Depressed, Heartbroken, Vulnerable, Welcomed, Comforted, Painless, Peaceful, Relieved, Connected, Supported, Satisfied, Content	Concerned, Hopeless, Sense of loss, Lonely, Fearful, Devastated, Stronger, Painless, Satisfied, Excited, Content, Connected, Relieved
REASONS BEHIND FEELINGS	• Long diagnosis process • Lack of knowledge and uncertainty • Lack of control over situation	• Not enough time to digest everything happening in a fast paced process • Enough/lack of trust and assurance in medical team experience and expertise • Fully/not fully guided and supported by the health system	• Cancer care services in basement with no daylight or views • No patient privacy • Chaotic healthcare environment, difficult parking and wayfinding • No family amenities/support • Sense of community for treatments happening on a routine basis • Caring and supportive staff made all the difference • Miscommunication and lack of coordination among medical team members	• Having a treatment plan on a routine basis becomes a part of patients' everyday life, end of treatment phase brings a sense of loss for patients • Hopeless in case of caring for a loved one dying at home • Devasted in case of losing a family member or friend • Excited and stronger in case of survival • Also fear of cancer coming back especially if it came back once
THINKING/ASSESSMENTS	• What is the problem? • Will I/he/she survive? • Why the diagnosis process is taking so long?	• What do I need to do? • How can I trust my medical team and their proposed treatment plan? • How does the treatment impact my quality of life in long term?	• What would be the outcome in short and long terms? • Is my care being coordinated among medical team members? • How is my family accommodated/supported during my treatment?	• Will the cancer come back? • How long does it take to go back to my normal life? • How should we preserve patient respect and dignity dying at home?
DOING/ACTIONS	• ER/Doctor visits • Doing tests, including imaging and biopsy • Checking online patient portals for results, if applicable doing research on internet	• Doing research on their own • Consult with friends/family in medical field • Discussing with medical team about treatment options and protocols	• Going through a few surgeries or going to infusion and radiation on a routine basis, in a few cases, taking the treatment at home	• Receiving treatment on a routine basis for patients with metastatic cancer • Routine check-ups and doctor visits for survivors • Caring for a friend or family member dying at home
TOUCHPOINTS				
OPPORTUNITIES	• Streamlining diagnosis process • Leveraging technology to communicate and keeping patients/family informed and educated • Provide family support to improve patient experience	• Building a system of trust and honesty between care team and patients/family • Having a system in place to fully educate patients/family about the process • Providing a space to collect thoughts after hearing news, including element of hope, such as natural light, access to nature, and music	• Dedicated campus/building to house all cancer care services • Start from valet parking, easy wayfinding, and even attention to material managements • Design spa-like environment for patient sensory comfort • Design for flexibility to accommodate quiet time and privacy as well as socialization and connecting with others • Design for personalization to give patients control over the environment, especially for treatments happening on a routine basis • Design for holistic model of care (mental and physical health) with elements of hope, such as natural light, access to nature, and music • Design for infection control to protect immuno-compromised cancer patients • Design for family accommodation and amenities to improve their experience at patient's side • Staff-centered design, support staff mental and physical health by providing health promoting work and respite areas • Design for team-based and coordinated care models	• Leverage technology by implementing telehealth, virtual check-ins, and e-visits to streamline management/ follow-up process • Support system for family members caring for a loved one at home • Mental health support for cancer survivors, family members after patient's death, especially younger children losing their parents, and even healthcare providers

The Ideal Patient Journey

Based on the study results, we summarized our recommendations for an ideal patient journey. Our hope is that caregivers, administrators, operational managers, and designers can work together to implement the ideal journey to better support patients and their families so they have better experiences and outcomes.



1
DIAGNOSIS

Shocked
Scared
Concerned

2
TREATMENT DECISION

Embraced
Informed
Assured

3
ACTIVE TREATMENT

Welcomed
Supported
Recovered

4
MANAGEMENT/FOLLOW UP

Relieved
Excited
Connected

Streamlining diagnosis process

Leveraging technology to communicate and keeping patients/family informed and educated

Provide family support to improve patient experience

Providing a space to collect thoughts after hearing news, including element of hope

Dedicated campus/building to house all cancer care services

Building a system of trust and honesty between care team and patients/family

Having a system in place to fully educate patients/family about the process

Start from valet parking, easy wayfinding, and even attention to material managements

Design for flexibility to accommodate quiet time and privacy as well as socialization and connecting with others

Design for holistic model of care (mental and physical health) with elements of hope

Design spa-like environment for patient sensory comfort

Design for personalization to give patients control over the environment, especially for treatments happening on a routine basis

Design for infection control to protect immuno-compromised cancer patients

Design for team-based and coordinated care models

Staff-centered design, support staff mental and physical health by providing health promoting work and respite areas

Design for family accommodation and amenities to improve their experience at patient side

Support system for family members caring for a loved one at home

Mental health support for cancer survivors or family members after patient's death, especially younger children losing their parents, and even healthcare providers

Leverage technology by implementing telehealth, virtual check-ins, and e-visits to streamline management/follow-up process

Automation
Flexibility
Health & Safety

COVID-19

The COVID-19 pandemic will change how we design healthcare facilities and more importantly how we design facilities to protect immunocompromised cancer patients who are extremely vulnerable to infections. Here are a few strategies to respond to this type of crisis in future:

General approach:

1. Automation as a key strategy to reduce human to human contact, from building automation technologies (automatic doors), to robotic material managements, to automation in cleaning procedures (UVD light robots)
2. Flexibility in different settings to accommodate surge in case of crisis, in built environment (acuity adaptable/universal patient rooms), in staffing models (cross-training hospital nurses), and in care delivery methods (telehealth)
3. COVID-19 taught us how precious and vital nursing staff are for our society and public health in case of crisis so we can see more focus on their health and safety in terms of programs, policies, and even the way we design the built environment

Specific approach:

- Minimize waiting, waiting nooks, RIFD technology to track and alert patients
- Use of real-time location system (RTLS) to track patients, staff, and equipment
- Touch-less building technology (automatic doors, hands-free light switches and temperature controls, voice recognition elevators)
- No-touch automated disinfection technologies such as UVD lighting
- Research effectiveness of self-disinfecting surfaces and antimicrobial fabrics and finishes
- Leverage outdoor areas to accommodate social distancing by encouraging people to spread out
- If possible, receiving cancer therapies, such as chemotherapy, at home
- Telehealth, virtual check-in, and e-visits when possible, particularly for care management after recovery and follow-ups
- Virtual support groups/educational resources like online meditation and yoga classes to boost mental health for cancer patients/family during these crisis

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For any questions
or follow-ups, please contact:

Adeleh Nejati
adeleh.nejati@hmcarchitects.com

HMC Architects