Navigating the Complex Web of Cancer Caregiving

Designing Comprehensive Support Services for Family Caregivers of Cancer Patients

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MDes (Interaction Design)
Emily Carr University of Art + Design, 2022- 2024

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A CRITICAL AND PROCESS DOCUMENTATION THESIS PAPER SUBMITTED IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF
MASTER OF DESIGN

EMILY CARR UNIVERSITY OF ART + DESIGN

2024

Abstract

Cancer care in Canada consists of many stakeholders who function together and form a large network or system. Although the Canadian Medical Association in a collaborative effort between the Canadian Cancer Society, Statistics Canada and the Public Health Agency of Canada projected a high number of cancer diagnoses in the country in 2023, there are still loopholes in the care system that lead to difficulties, stress, and anxiety for patients and their family caregivers. (Canadian Cancer Statistics, 2023)

The complex nature of the structure affects both patients and family caregivers alike. Family caregivers usually accompany the patients, provide emotional support, and make important decisions throughout the care-giving journey. Additionally, they have the added responsibility of managing their own work and personal life. It thus becomes of utmost importance to ensure that navigating the system and understanding the next steps to be taken towards caregiving is not an added worry.

This thesis study aimed to examine and analyze the challenges faced by family caregivers while helping their loved ones to navigate the complex cancer care system in Canada, especially British Columbia. Starting with a systemic lens, this study explored possible tangents and challenges that these family caregivers face as they move through the system. This study uses a combination of secondary desk research and primary field research in the form of interviews to understand the problem space. Cause-effect loop mapping, stakeholder mapping, user journey maps, service blueprints were then used to understand, categorize, and organize the information within the research space.

Various sets of design opportunities are presented by this study. It offers possible design interventions, especially in the form of a service, facilitated by a digital tool like an app or website to support and empower family caregivers in British Columbia to better assist their loved ones throughout the journey.

Table of Contents

Table of contents

Acknowledgements

I am profoundly grateful to the many individuals who have contributed to the completion of this thesis.

To all my research participants who shared their personal stories and thoughts, without whom, this research wouldn't have been possible.

I extend my heartfelt appreciation to my supervisor Manuhuia Barcham, whose guidance was instrumental in shaping this work and navigating the challenges along the way. I am incredibly grateful to you for your understanding, flexibility and support throughout the journey.

To my internal supervisor Craig Badke for your guidance, motivation and advice that offered fresh perspectives.

To all my professors at Emily Carr University, whose expertise and knowledge have deepened my academic journey and provided invaluable ideas for my research.

To my manager Rock and my amazing team, especially Andy, Eliza, Conor and Dennis. Thank you for your support as I balanced my academic persuits alongwith professional responsibilities. A special thanks to Rock for always being so patient with the team, and for answering all of my doubts- research related or not.

To my MDes cohort, especially Dhanvi, Faizaan and Rhebsa, thank you for sharing these two years with me and for your contributions to these collaborative ideas.

To my housemates Soumya, Rubiya, Komal and our (permanent) house guests Abhinav and Aakash, for all the chai sessions and midnight conversations, and for always believing in me and my work. To all my friends in Mumbai for being my constant pillar of strength and comfort.

To Amal for constantly motivating me throughout the process and for helping me declutter my mind always.

To mom and dad for being my biggest champions. If not for your encouragement, I would never have been able to climb these stairs.

Land Acknowledgement

I would like to acknowledge that this research has been conducted on the stolen and unceded traditional territories of the Coast Salish people, the Musqueam, Squamish, and Tsleil-Waututh Nations. Unceded means that this land was never surrendered, relinquished or handed over in any way. I am grateful for being on these lands and for being able to conduct my practice and research here.

Preface

While growing up, I have witnessed multiple times, both through a personal loss and from an outsider's perspective, of how delays in accessing healthcare caused due to inefficient structures had proven to be fatal for individuals. Witnessing these incidents first-hand, and seeing how often this happened, I always wanted to make these systems and channels better and improve the overall experience for the patients and their families. Hence, when I ventured into the design field during my undergraduate years and discovered the field of healthcare design, I recognized this as an opportunity to make a meaningful impact through the designs I create. I explored and worked on various healthcare design projects during my undergraduate years, which made me realize the importance of technology and digital interventions in improving the care systems and making it efficient.

As an international student in Canada, one experience that was daunting for me was figuring out how the healthcare system here works. After having conversations with other fellow classmates and friends who were also international students, I realized that this was a shared experience. One other shared experience, even by the locals, was that of the waiting times for receiving care. Thus, I was determined to explore these tangents and understanding the system of care giving in Canada. Given the timeline, I wanted to narrow down the scope of this study. I did some quick research to understand existing loopholes in the health system here. This is when I came across distressing statistics regarding the growing number of cancer incidences in Canada, and a growing burden on family caregivers due to outpatient care facility settings. Looking at these statistics as not just numbers, but as actual humans suffering and in pain, I decided to dedicate my thesis to understanding the cancer care system, and to ultimately bring out a positive outcome targeted to help those involved.

List of Figures

Key Terms & Definitions

Family Caregivers	Family caregivers are the individuals who provide care and assistance to their family members who are unable to fully take care of themselves due to undergoing serious illness or other conditions. They are the unpaid caregivers who provide physical support (such as dressing, bathing, assisting in eating etc.) and emotional support to their loved one undergoing chronic or serious illness. (What Is a Caregiver?, n.d.)
Cancer-care System	A cancer-care system refers to the network of services and providers dedicated to the prevention, diagnosis, treatment and management of cancer care. This system encompasses of various stakeholders including primary healthcare providers, oncologists, radiologists, family caregivers of cancer patients and institutions that help provide cancer care such as hospitals, treatment centres etc.
System Mapping	System mapping helps designers and researchers to make sense of complex organizational systems and helps lay out all the relationships and interactions between the stakeholders in each system. This tool help researchers to zoom out and visualize the bigger picture within the system and eventually zoom in and deep dive into areas where most of the visual mess is being created which can also be the root cause of the challenges happening within a system. (What Is a Systems Map?, n.d.)
Optimizing Healthcare	Healthcare optimization involves improving healthcare systems, services, and procedures strategically to increase efficiency, quality, and patient outcomes. As part of this effort, evidence-based practices are applied, patient experiences are enhanced, healthcare costs are cut, and administrative functions are streamline, in order to provide high-quality, affordable, and accessible healthcare.
Omnichannel Healthcare Design	As healthcare technology has evolved, omnichannel healthcare design has become increasingly important. In order to achieve this, patients' journeys are being redesigned to incorporate various digital and physical touchpoints, creating a connected and seamless experience. (The Five Principles of Omnichannel Healthcare Service Design, n.d.)

Scope

With an emphasis on understanding the care system and building a service for the family caregivers of cancer patients, this thesis study aimed to provide insight into the challenges faced by these caregivers in navigating the complex journey, offering understanding into emotional, practical, and systemic aspects. Combining secondary desk research and primary field research through interviews with the family caregivers, this study is an attempt to having a holistic exploration of the problem space, ensuring that the caregivers' world view is taken seriously, and the root cause of various challenges faced by the family caregivers are identified.

Ultimately, this study also aims to create a comprehensive support system for family caregivers of cancer patients. The inspiration for this study comes from talking to various caregivers during my research. Their experiences guided how I designed the study and the service it proposes. The goal is to offer meaningful support to family caregivers facing the unique challenges of caring for someone with cancer. The stories shared by caregivers have shaped both the structure of the study and the design of a service that aims to provide practical and holistic assistance in their important role.

“Cancer is the leading cause of death in Canada, and 43 per cent of Canadians are expected to receive a diagnosis in their lifetime, according to the Canadian Cancer Society.” (Canadian Cancer Statistics, 2023)

“The increasing demand on cancer services (40% growth in Canada by 2030) is projected to overwhelm the cancer care system where there will be a significant shortfall in human resource capacity.” (Papadakos et al., 2023)

Introduction

Cancer care in Canada consists of many stakeholders who function together and form a large network or system of care. The complex nature of the structure affects both patients and family caregivers alike. Little work exists though exploring the impacts of this system of family caregivers. This thesis begins to fill this gap.

The focus of this research project has been to examine and analyze the challenges faced by family caregivers while helping their loved ones to navigate the complex cancer care system in Canada, focused particularly here in British Columbia. Starting with a systemic lens, this study explored possible tangents and challenges that these family caregivers face as they move through the system. This study then uses a combination of secondary desk research and primary field research in the form of interviews to understand the problem space. Cause-effect loop mapping, stakeholder mapping, user journey maps, service blueprints were then used to understand, categorize, and organize the information within the research space. Various sets of design opportunities are presented by this study emerging from the data gathered during my design research process.

This design opportunity provides possible design interventions, especially in the form of a service, facilitated by a digital tool like an app or website to support and empower family caregivers in British Columbia to better assist their loved ones throughout the journey.

a. Initial work

As I delved into the data concerning the increasing instances of cancer cases in Canada, it became clear that these numbers were not just abstract figures but rather a reflection of the profound challenges faced by individuals and families. The statistics served as a reminder of the emotional and practical hurdles that accompany a cancer diagnosis, highlighting the struggles and complexities that individuals and communities endure while navigating the intricacies of the healthcare system.

Understanding the gravity of the situation, it became evident that addressing the cancer care system's shortcomings was imperative not only from a clinical perspective but also from an empathetic standpoint. Each statistic represented a person, a family, or a community grappling with the devastating impact of this disease, underscoring the urgent need for a more comprehensive and supportive healthcare framework. Recognizing the human stories behind the numbers further underscored the significance of not just improving the system but also providing compassionate care and support for those affected by cancer in Canada.

The first step towards understanding the system was to look at it from a world view lens, and thus, I went ahead and mapped the cancer care system using a causal-effect loop system mapping.

System Mapping

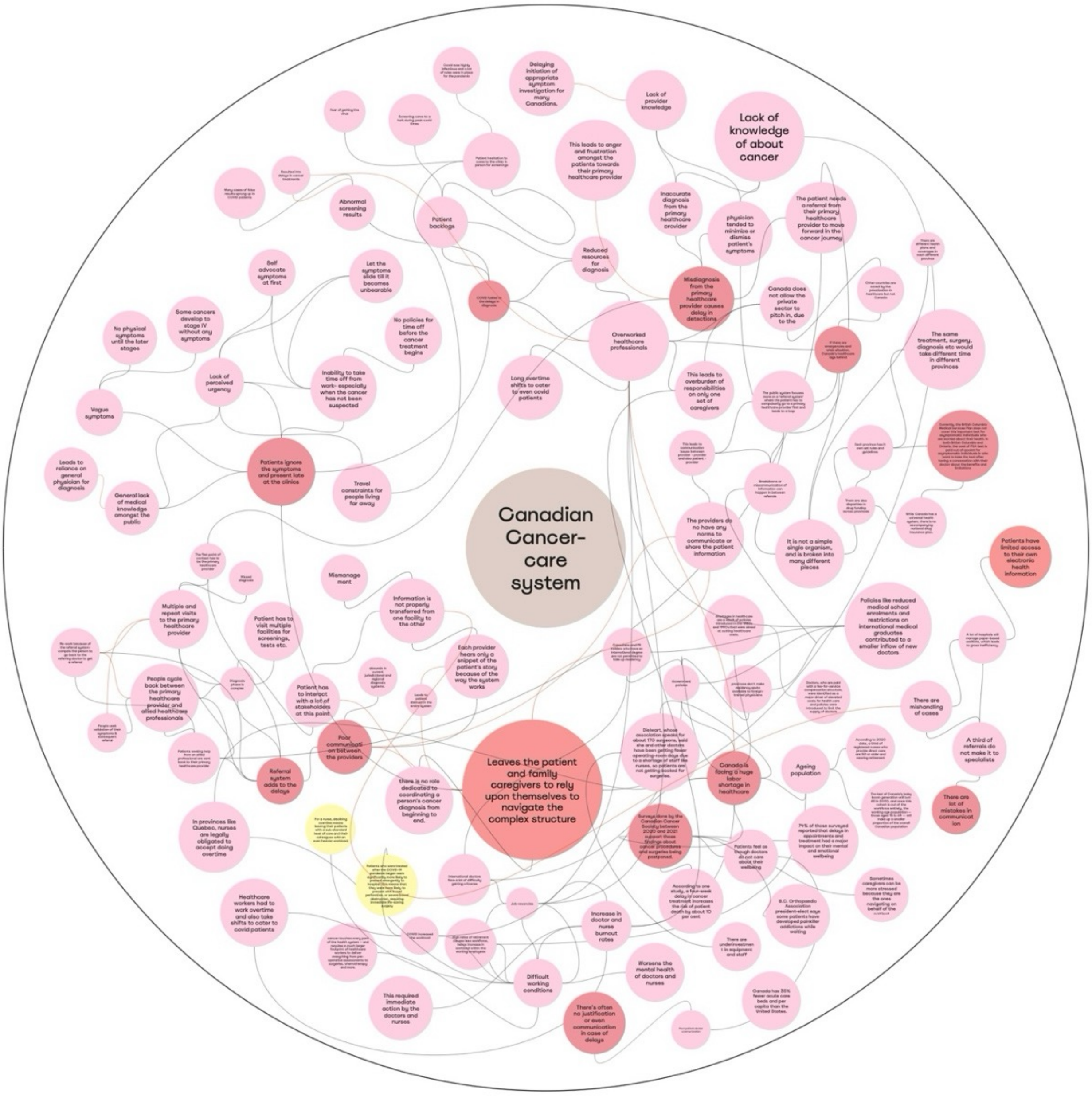


Figure 1: Causal effect loop (System mapping), 2024

System Mapping

System mapping via the causal-effect loops as shown in figure 1 serve as a metaphorical narrative, unveiling the intricate web of elements within the system of cancer care in Canada, especially focusing on the province of British Columbia. Making these causal effect loops as a part of the system mapping helped me gain a comprehensive understanding of the systems' structures, the various stakeholders involved in the same, their dynamics and interconnections, the interconnectedness between larger system challenges and smaller loopholes, which ultimately helped in empowering analysis of the cancer care system as a whole structure or system.

Analyzing causal effect loops helped me grasp the broader challenge of delays in accessing care. This delay was found to be rooted in factors such as a shortage of available medical professionals to address the increasing number of cancer cases. This scarcity of healthcare professionals placed mounting pressure on the entire system, affecting its overall efficiency.

In response to these pressures, **oncology care is evolving by providing more complex treatment regimens in the outpatient setting. These changes in oncology care place a greater responsibility on family caregivers.** (Papadakos et al., 2023) Due to changes in the healthcare system, the burden of cancer caregiving is increasingly shifting to these family caregivers. (Sun et al., 2019) Medical care in the past was hospital-centered that focused on fulfilling the clinical needs rather than the needs and anticipations of the consumers. However, recent changes in the user needs with respect to medical care in a changing social environment change in disease structure to chronic illnesses, for which individual health behaviors and management are important, increase in the perception of consumer rights, and advancements in the IT technology have all led to a paradigm shift from hospital-centered care to consumer-centered care. (Jo et al., 2019)

Thus, exploring the cancer care system provided insights into its often-overlooked but crucial contributors—the unsung heroes. In this context, **family caregivers emerged as pivotal figures, playing a vital role in ensuring smooth coordination within the care system. Despite their significance, these caregivers were frequently overlooked throughout the entire journey.** They acted as a protective shield for cancer patients, serving as key points of contact not only for the patients but also for primary healthcare providers, medical facilities, and specialists.

Research Question

How might we create a service for the family caregivers that will assist them throughout the cancer care journey and help them be better prepared for their role?

Project Objectives

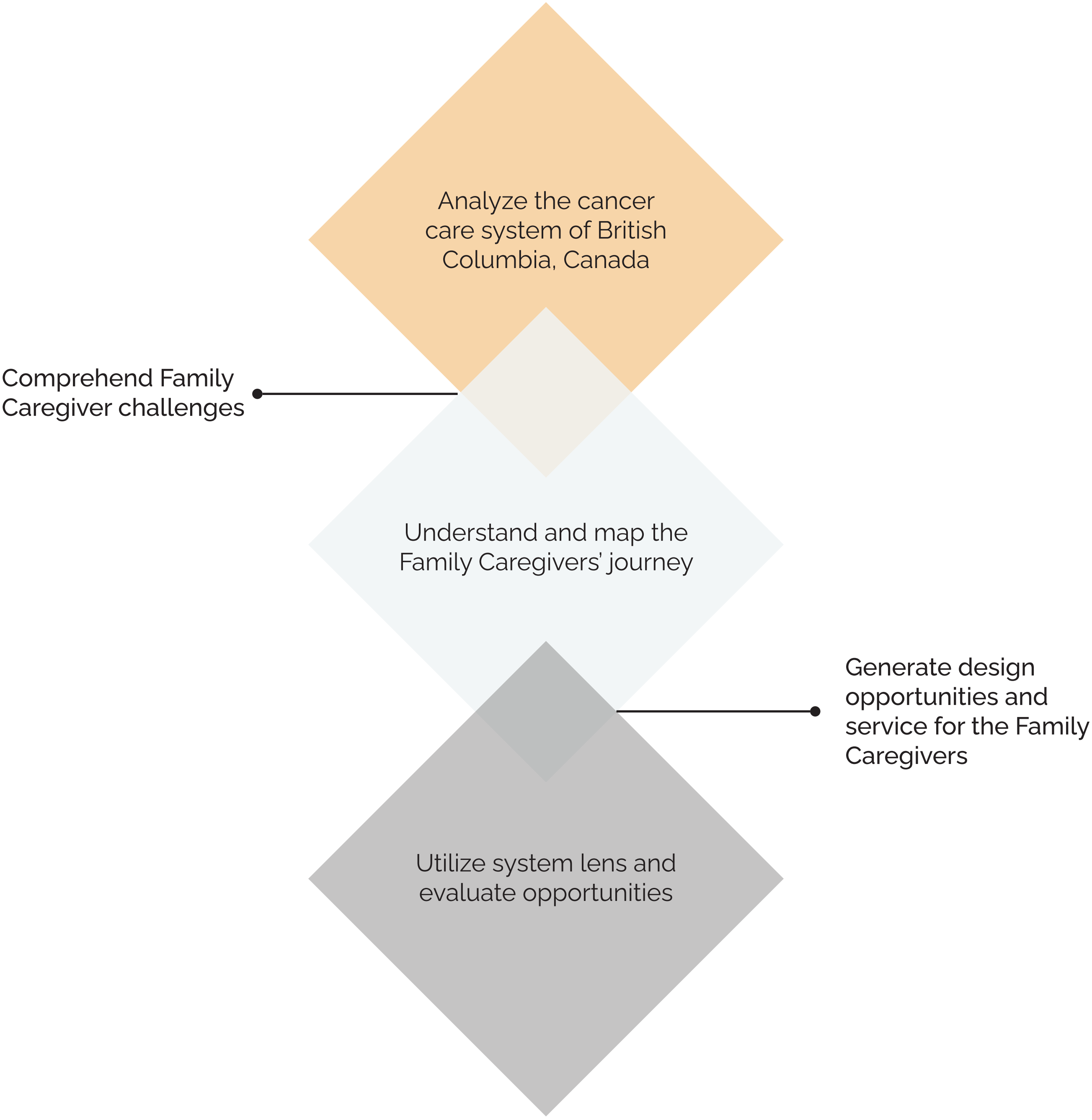


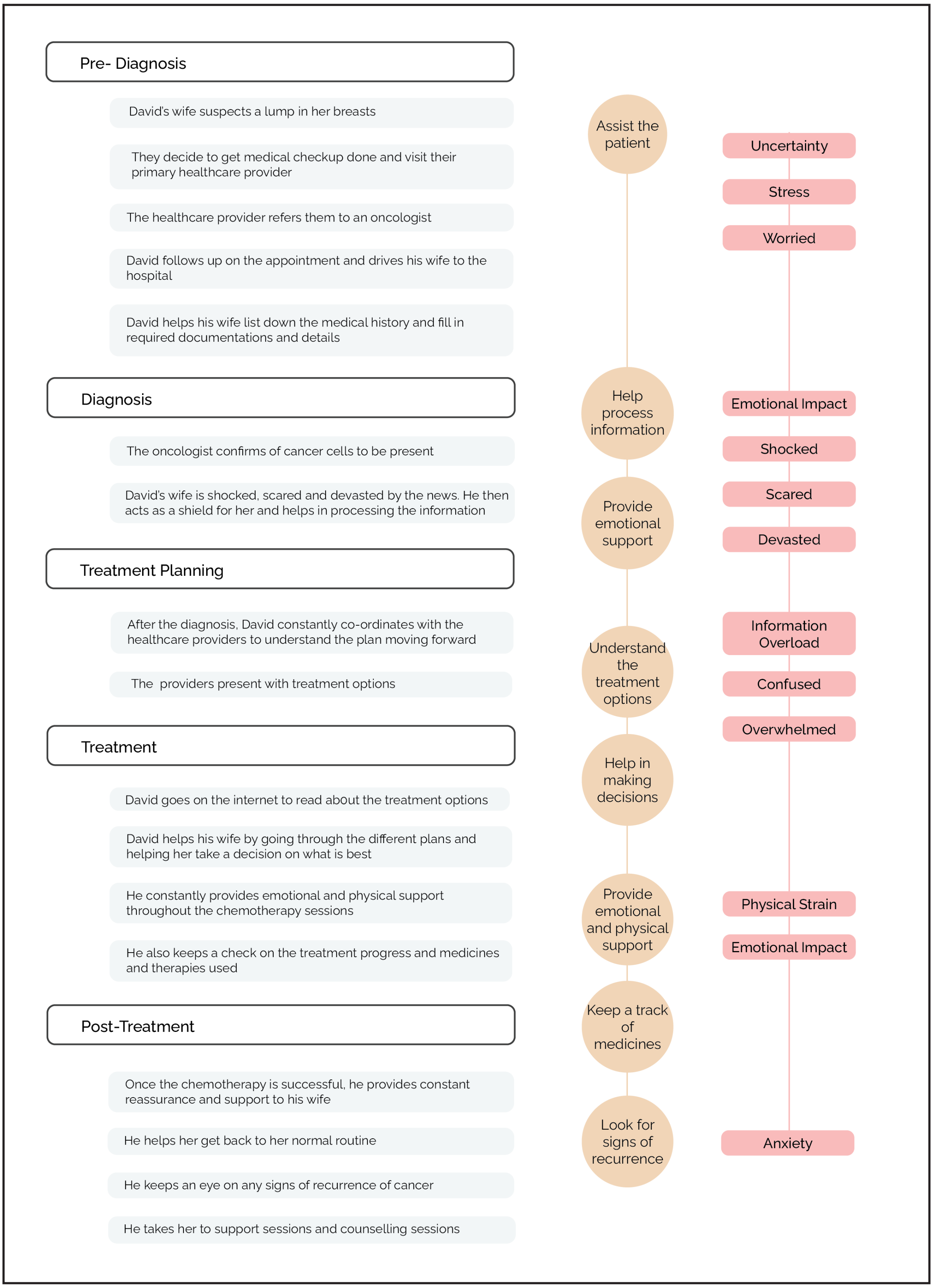
Figure 2: Project Objectives, 2024

Project Objectives

The diagram above (Fig. 2) depicts the primary objectives identified for this thesis study, and the secondary objectives that flowed from those that support the research, to ultimately fulfill the project goals. There objectives were:

Analyze the cancer care system of British Columbia, Canada	Map the system surrounding cancer care and identify the stakeholders and institutions involved and analyze these systemic factors within the Canadian cancer care framework to identify the challenges and pain points of the family caregivers and to analyze how these different stakeholders and their relationships ultimately affect the care-giving experience throughout the journey.
Understand and map the Caregiver journey	Journey mapping was essential to assess how family caregivers navigate the landscape of the cancer care system. Focus was mainly put on understanding their experiences in obtaining and comprehending crucial information related to the care of their loved ones, how the cancer care journey impacted them emotionally and physically; and what needs of the Family Caregivers were being neglected.
Utilize Systemic Lens and evaluate design opportunities	To apply a systemic lens in examining the challenges, considering not only individual experiences but also broader systemic issues and interactions among stakeholders in the healthcare system. Ultimately, designing a holistic service for the caregivers as the final project objective.
Comprehending Family Caregiver Challenges	To identify and better understand the diverse challenges faced by family caregivers in British Columbia while providing care to their loved ones within the complex cancer care system.
Generate Design Opportunities and service for the Family Caregivers	Brainstorm on various design opportunities aimed at addressing the identified challenges, with a particular emphasis on proposing a service via digital intervention, such as an app, to support family caregivers in their caregiving journey.

Caregiver journey map



Pre- Diagnosis

- David's wife suspects a lump in her breasts
- They decide to get medical checkup done and visit their primary healthcare provider
- The healthcare provider refers them to an oncologist
- David follows up on the appointment and drives his wife to the hospital
- David helps his wife list down the medical history and fill in required documentations and details

Diagnosis

- The oncologist confirms of cancer cells to be present
- David's wife is shocked, scared and devasted by the news. He then acts as a shield for her and helps in processing the information

Treatment Planning

- After the diagnosis, David constantly co-ordinates with the healthcare providers to understand the plan moving forward
- The providers present with treatment options

Treatment

- David goes on the internet to read about the treatment options
- David helps his wife by going through the different plans and helping her take a decision on what is best
- He constantly provides emotional and physical support throughout the chemotherapy sessions
- He also keeps a check on the treatment progress and medicines and therapies used

Post-Treatment

- Once the chemotherapy is successful, he provides constant reassurance and support to his wife
- He helps her get back to her normal routine
- He keeps an eye on any signs of recurrence of cancer
- He takes her to support sessions and counselling sessions

Figure 3: Caregiver Journey Map, 2024

Understanding the Family Caregiver’s journey

Understanding the various roles and responsibilities of the caregivers at each stage of the caregiving journey was crucial, in gaining a perspective of what they go through and the challenges they face while fulfilling their role at each step. As seen in Figure 3, family caregivers act as the strong pillars for the patients to rely on right from the pre-diagnosis stage to the survivorship stage (Informal Caregivers in Cancer - NCI, 2011). The following insights were gained as I mapped the journey these caregivers take during the entire care-giving process.

Caregiver Responsibilities:

Caregiver duties included providing psychosocial support (supporting and motivating the patient), physical support (administration of medicine, bathing) etc. As an integral part of managing the symptoms, family caregivers actively monitored and assessed symptoms to timely recognize any treatment related side effects, assess the response to therapeutic interventions and recognize possible deterioration in physical status. Family caregivers are often the decision makers when it comes to treatment options, further steps to be taken etc. (Sercekus et al., 2014)

Interrelationship between patient and caregiver:

Informal caregivers are critical in the system of giving cancer care. They have a huge influence on how the cancer patient deals with their illness.
(Papadakos et al., 2023)

Research and theories have demonstrated the potential interrelationship between patient and informal caregiver outcomes. Caregiver well-being may be associated with patient clinical outcomes, such as perceived quality of care. In a study with 43 lung cancer patients and caregiver dyads, patient’s symptoms were positively correlated with caregiver burden, depression/anxiety, and quality of life. Patient’s depression/anxiety were also correlated with the caregiver’s emotional well-being. (Sun et al., 2019)

Understanding the Family Caregiver’s journey

Unpreparedness amongst the caregivers:

It has been reported that these caregiver duties are often new to the families and thus, they feel unprepared and unsupported. They also feel overwhelmed by the amount of information they receive as they have no prior knowledge about cancer or caregiving for cancer patients. They are often not trained for the job, which further leads to distress amongst them. “Caregivers are ill prepared for this transition in care delivery, particularly as they are expected to provide care requiring basic medical skills over an extended period.” Participants from the study reported to have feelings of “regret” for not knowing things sooner (Papadakos et al., 2023).

The majority of family caregivers are not prepared for their caregiving role. Information technology platforms, such as smartphone applications, are viewed as being potentially useful by caregivers for bridging information gaps in a timely manner. Family caregivers reported high usability ratings for ease of completion and support information from an electronic caregiver-reported outcome collection system. (Sun et al., 2019)

Unmet Needs of the Family Caregivers:

Multiple studies have shown that the diverse needs of the family caregivers are not being met, which in turn compromises on their quality of life and contributes to their distress. Around 10-15% of Family Caregivers report high distress which is more often severe than in patients. There are significant physical, emotional and social impacts on the family caregivers throughout the process of caregiving. Although Family Caregivers (CGs) are an important part of the care system, little effort is taken to help them feel supported throughout the journey. (Papadakos et al., 2023)

Family caregivers are members of an “invisible” workforce that provides support and direct care to cancer patients. (Sun et al., 2019)

In conclusion, the role of caregivers in the care giving journey is integral and multifaceted. It underscores the significance of a holistic approach to healthcare, where emotional, informational, and practical support from caregivers complements clinical care, thereby contributing to optimized patient outcomes and enhanced quality of life for those undergoing cancer treatment.

Unveiling stories of Family CGs

Following the establishment of a foundational understanding of the comprehensive cancer care system and the roles undertaken by caregivers throughout the entirety of the care journey, I proceeded to devise a recruitment strategy aimed at engaging in in-depth conversations with family caregivers. The primary objective was to gather firsthand accounts of their experiences. To facilitate this, a methodological framework was meticulously crafted. This framework was designed not only to gain a clear understanding of the prospective participants but also to outline effective strategies for their recruitment.

a. Methodology

Recruiting Caregivers as participants for the study:

To recruit appropriate participants for the study, screening tools were prepared in order to find participants that would match the criteria needed for the interviews for this thesis study. These screeners were sent out to people who had an experience in care giving for cancer patients within my known circle of friends and colleagues in Vancouver, Canada. Later, this pool of participants was increased using snow-balling technique as I connected with more family caregivers through the ones I interviewed. These family caregivers were later also approached for a participatory research workshop done for testing the concept and service designed, as per their consent.

As a part of planning for the in-depth interviews and workshops to be conducted with these family caregivers, I also prepared interview guides and questionnaires to ensure a smooth flow of the interview. Support links and resources were gathered for the participants, to support them in case they felt overwhelmed while narrating their experiences during the interview. Gathering these support resources and being prepared as a researcher to assist the caregivers was crucial before starting the in-depth interviews.

Research participants:

A total of six participants were recruited for this study. These participants predominantly belonged to the 25–40-year-old age group. These included graduate students and working professionals. All participants were the family caregivers of cancer survivors and cancer patients. The experiences of the participants ranged from being that of a few years back to even pertaining to the current healthcare scenario. This perspective gave me a more holistic understanding into the caregiving journey, and at the same time made me realize how little change has been bought into the patient-caregiver experiences throughout the journey in the past few years.

Most interviews were conducted in Vancouver, British Columbia and were conducted online or in person based on the participants' preference and availability.

b. Research Tools

In depth interviews:

In-depth interviews were conducted with the family caregivers of cancer patients and survivors, to gain a comprehensive understanding of the journey they had undertaken and to get a thorough grasp of their experiences and challenges in the same. These conversations lasted for around 45 minutes to an hour, where in the caregivers opened up about their journey, and gave insights into how harrowing their experiences have been, and how unprepared they felt.

Conversations with these family caregivers also gave me perspective into the emotional turmoil they faced and had to go through during the caregiving journey. Recognizing the human connection proved to be a significant realization for this thesis study, emphasizing the importance of emotional well-being and a sense of community during the entire care-giving journey.

Participatory research:

A brainstorming session was undertaken with the research participants for this study. The family caregivers I interviewed during exploratory research phase were reached out to and opinions were also taken to see if what they think about the term ‘caregiver’ and how they would want to be addressed as, in the care system. A mini brainstorming session was done with these family caregivers, wherein they were given different cards to choose from, and the most preferred was the term ‘Family caregiver’.

I shared with the caregivers the details of the envisioned concept and service, actively seeking their input. I walked them through the different stages of the proposed service, seeking their opinions to understand whether the features outlined were deemed helpful from their perspective or not.

Decoding the conversations

A few patterns and themes emerged after conducting the secondary desk research and after talking to the family caregivers of cancer patients and survivors. These patterns were identified through an affinity mapping exercise. Three key themes that emerged from the interviews were explored further. These themes also were found to be closely interconnected as a form a holistic system or a service.

a. Key Insights

Elevated distress experienced by family caregivers throughout their caregiving journey, which was concealed:

The interview data showed that family caregivers underwent major emotional and physical distress during the process of taking care of their loved ones. The caregivers noted an increase in the amount of stress and depressive episodes they had to face during the entire journey, not only while assisting and helping their own loved one in the journey, but also while watching other patients and their families suffer and be in pain in the hospital settings. Watching other patients, especially kids or younger patients, in the hospital increased their distress levels, and they felt quite overwhelmed having to experience it all firsthand.

One key aspect highlighted during these interviews with these caregivers was that they often had to hide these emotions or feelings during the caregiving journey as they did not want to burden their loved one and had to project a strong and happy face which further added to their emotional overload. Physical distress often also got translated into emotional burden and stress, as they had to continuously cater to the physical needs of the patients, in assisting them with daily tasks such as helping them bathe, get dressed, and also accompanying them to the hospital and care settings; all while managing their own personal and professional lives.

> *"My mental health was really bad. I just could not take it. I was crying a lot at that point, but I was not crying in front of her because I did not want her (cancer patient) to feel bad. That phase was horrible." - Participant 03*
>
> *"I was feeling very sad because I am very close to her, she is a person who I go to for anything. When I got to know she has this, I was at work talking to a client and I received a call from her, and she said that I have cancer. I started crying and couldn't stop. I cried my heart out but I kept saying her that it is okay, it is okay" - Participant 04*
>
> *"Chemotherapy takes 2 to 3 hours, so we had to wait in the waiting room and in this process, you see a lot of people there. Watching people suffer in the hospital spaces made it worse." - Participant 02*

a. Key Insights

Importance of social support in navigating through the care journey:

The research participants highlighted how having an individual who underwent the same journey in the past was very helpful for them, in terms of having guidance of what to expect next and to also ask questions about the process. This also highlighted how they felt a sense of support when they talked to someone who could guide and assure them about what to expect next in the process and who could help with navigating the journey. This made me realize the importance of having a social network to rely on during the journey and the importance of having the 'human' connection in the care journey.

> *"A family friend guided us a lot and helped us with the treatment and everything. She told us what to do and what not to." -Participant 05*
>
> *"We first looked out for good hospitals and people on Google. We considered 3 or 4 people, and we also consulted a friend of my granny who also had breast cancer in the past. We asked her how her treatment went and everything and she also guided us a lot. She is a survivor and she had cancer a while back and that's what I kept telling my granny that you will also feel good and better in a few months. So that was one motivation for my granny in the form of her friend." - Participant 04*

Family caregivers often felt that they had no prior knowledge about cancer or caregiving and felt highly unprepared and overwhelmed at first:

During the interviews it became apparent that the family caregivers often felt that they had little to no knowledge about cancer or caregiving for a cancer patient before their loved one's diagnosis. This led to feelings of being overwhelmed when they had to take on the role of caregiver for their loved one, and they also often felt that it would have been better if they had some quick information about the different aspects of the cancer care journey available to them.

> *"No one really learns or reads about these things prior to having to undergo a diagnosis" -Participant 01*
>
> *"It was completely new for us. Our family did have cancer patients in the past but not in close vicinity or anything, so this was completely new for all of us." - Participant 06*

a. Key Insights

Overall, it was seen that even after being such an integral part of the entire care journey, there were not many resources that these caregivers could rely on in the system. They lacked a safe space and a community which would be always available for these caregivers that would help them not only gain information about what to expect next and guide through their own journey but also at times act as a supporting shield in assuring that things would be alright in the end. There was a dire need of community aspect in the entire system for a smooth functioning of the caregivers' overall wellbeing and their needs.

> *"We do everything but are strangely invisible." - Participant 04*

Design Opportunities

Build a community of family caregivers of cancer patients and survivors:

After gaining the insights, one major opportunity area identified was to build a network of caregivers and give them a community to fall back on or rely on. One major concern that came across was that they lacked resources specifically dedicated to gain social support from other family caregivers of cancer patients, outside of their own network and circle, and how important it was for them during the entire journey. Thus, one important area identified for the service to be proposed for this thesis project was influenced by the idea of building a community or a network for the family caregivers and giving them an assurance that there is someone they could rely on.

Supporting and managing the Family caregivers' emotions:

Managing caregivers' mental state and emotions was also of importance when talking about supporting them in the care journey. Having easy access to therapist and specialist in caregiver health was one opportunity area that I identified based on the interviews I had with the family caregivers.

Providing the right information in an efficient manner:

Providing information to family caregivers was not enough in and of itself, instead it needed to be conveyed in an efficient manner, which would not lead to information overload. There had to be a way in which the caregivers would not feel very overwhelmed while going through the information and would also have the ability to ask questions they had and get answers for them, especially from people who had already been through the same experiences before. Online communities and forums out in the market were not specific for cancer caregivers, which meant that not all information was readily available for them.

a. Key Design tools and considerations

UX design tools and methods were taken into consideration while developing the idea of the service to be provided. Desk research was conducted to understand how to implement these tools while ideating on a concept, and how it can be used in service design and UX parameters.

Progressive Disclosure:

"In a system designed with progressive disclosure, the very fact that something appears on the initial display tells users that it's important." (Collins & Kishita, 2020). Progressive disclosure is a design thinking tool that emphasizes on the need to disclose or show information to the users in a step-by-step manner or in a way that does not overwhelm them. The idea behind the concept is to show only the necessary information at front and progressively disclose or give out information that is secondary to the user.

Human-centered design:

Utilizing a human centered approach was of utmost importance in this thesis project, given its sensitive nature and how it could have a direct and huge impact on the lives of numerous caregivers of cancer patients. Human centered design approaches emphasize having deep empathy for the people you are designing for and encourages brainstorming and sharing of ideas within the community you are designing for. This is one method that deeply resonated with me, and hence I also decided to include this tool in my research and design process.

Omnichannel healthcare design:

Omnichannel healthcare design focuses on creating seamless customer journeys and experience within a system by providing various touchpoints integrating both physical and digital interactions in the care journey. Key aspects of omnichannel health design includes utilization of data and technology, leveraging physical and digital touchpoints, and having continuous improvement and feedback loops. (The Five Principles of Omnichannel Healthcare Service Design, n.d.)

Service Outcome

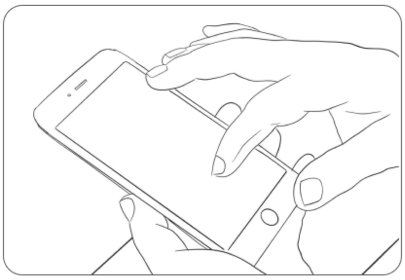
This proposed service is a unique and a holistic solution for family caregivers, particularly those dealing with the complexities of cancer care. It serves the family caregivers by having both physical and digital touchpoints or interventions, offering holistic support during the entire care giving journey.

The digital intervention in the form of an application serves as a rich source of information and emotional support for caregivers, using podcasts to offer two types of content. Firstly, it features interviews and knowledge sharing seminars in the form of podcasts with a range of experts – including healthcare workers, psychologists, and nutritionists – offering practical advice and insights for family caregivers. Secondly, it presents real life stories from cancer survivors and their families, providing inspiration and reflecting the experiences of caregivers. More than just an educational resource, the app is also designed to foster a strong and supportive community for caregivers. It encourages them to engage in discussions about podcast topics, share personal experiences, and find comfort in shared experiences. This community aspect is enhanced by organizing both online and in-person meetups, building a network of support and friendship that goes beyond the digital realm.

A key feature of the app is its continuous mental health support. Acknowledging the often-ignored emotional strain of caregiving, the app provides round-the-clock access to mental health professionals via a 24/7 helpline or chat service. This ensures caregivers can get immediate help and advice when they need it most. The app also offers scheduled therapy sessions with specialists in caregiver stress, grief, and emotional health.

In summary, this service offered in the form of an app is more than just a tool; it's a comprehensive support system designed to empower caregivers. It addresses their need for knowledge sharing, emotional support, community connection, and mental well-being, significantly improving the care they provide and their own quality of life.

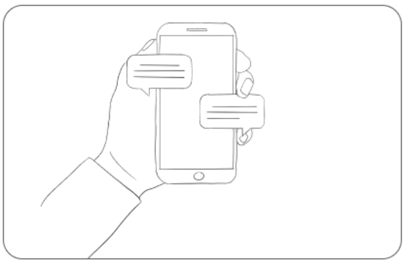
User Scenario



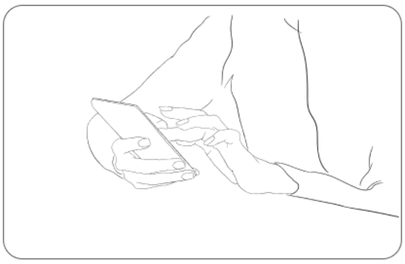
Discovering the App

Engaging with Podcast Content

Offline Meetups



Utilizing Mental Health Resources



Regular Use and Organizing a Meetup

Impact on Sarah's Life

Background:

32-year-old Sarah, an interaction designer, recently began taking care of her younger sister who is battling breast cancer. Although she loves what she does, it is extremely difficult for her to manage her job and taking care of her sister at the same time. She wants to find people going through the same thing and seek counsel on being a caregiver.

Discovering the App:

Sarah discovers the app through a social media group for caregivers of cancer patients. This gets her interested and she downloads it, aiming at finding information and getting a sense of belonging.

Engaging with Podcast Content:

On her way to work, Sarah listens to podcasts from the app, starting with episodes on managing the emotional aspects of caregiving. She finds the expert interviews particularly helpful, offering practical advice that she can apply immediately. She often listens to stories from other caregivers during lunch breaks and draws inspiration from them while feeling like she is not walking alone in her journey.

User Scenario

Community Involvement and Offline Meetups:

Sarah actively participates in online forums where she shares about her own experiences and learns from others. Empathetic responses as well as practical tips by fellow caregivers are a source of comfort to her. There is an announcement in the app about a local offline caregiver meetup shown by Sarah. As for Sarah, it is an interesting option since she has never met anyone face-to-face before; so, she registers for this event. At a community center there is a meeting place where she meets people who have lived through similar situations as hers in real life situations.

Utilizing Mental Health Resources:

Feeling particularly stressed one weekend, Sarah uses the app to connect with a mental health professional. The immediate support helps her navigate her feelings of anxiety and guilt

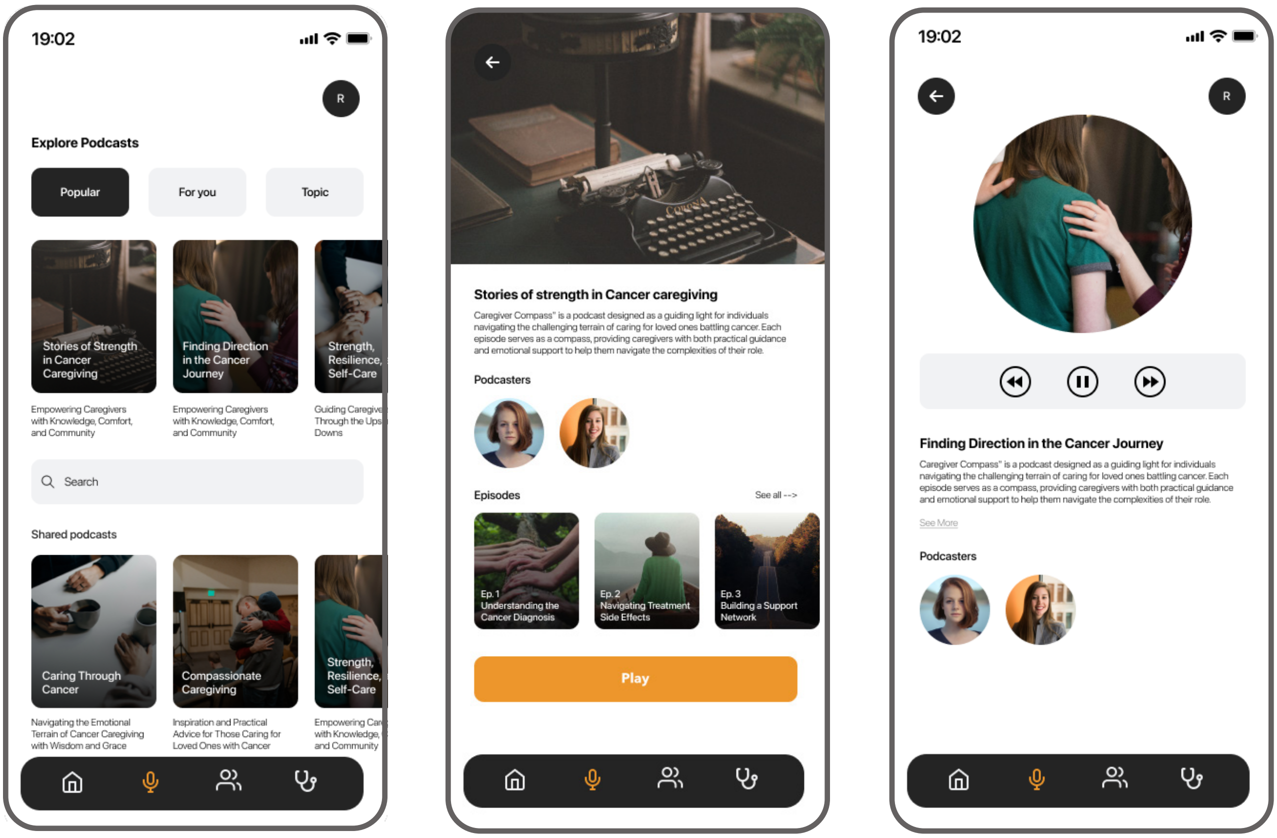
Regular Use and Organizing a Meetup:

Becoming a routine app user, Sarah is often involved in discussions and advice to new members. After her first positive experience at the meetup, Sarah organizes another local meeting for care givers through the app.

Impact on Sarah's Life:

The application thus becomes an indispensable part of her life by providing valuable information, emotional support as well as a sense of belonging. Meeting with people offline mainly contributes towards changing her in that it gives her local networks of support among fellow caregivers. This encourages her that she is not alone and thus she feels supported enough also giving out good care to her sister while taking care of herself well and maintaining her professional career.

Key Features



Caregiver Compass" is a podcast designed as a guiding light for individuals navigating the challenging terrain of caring for loved ones battling cancer. Each episode serves as a compass, providing caregivers with both practical guidance and emotional support to help them navigate the complexities of their role.

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Figure 4: High Fidelity Screens: Podcasts, 2024

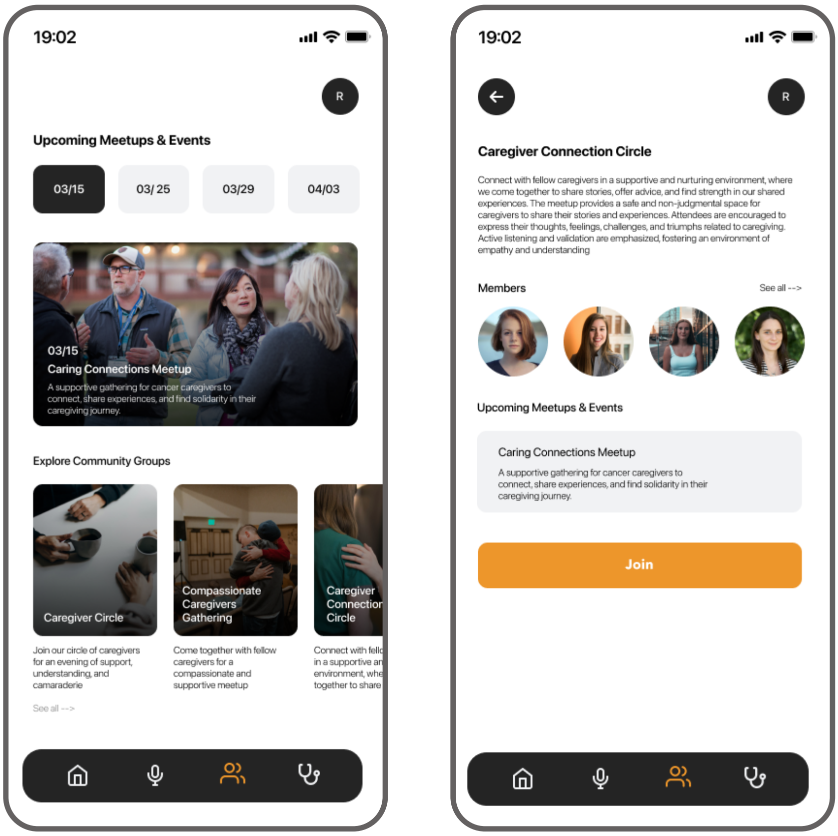
Self-Learning Podcasts

Within this podcast feature, self-learning delves into diverse issues and experiences, acting as a guiding medium.

Expert Interviews: Podcasts with healthcare professionals, psychologists, nutritionists, and other experts to share insights and practical advice.

Caregiver Stories: Real-life stories from cancer survivors and their families to offer inspiration, guidance, and hope.

Key Features



Upcoming Meetups & Events

03/15
Caring Connections Meetup
A supportive gathering for cancer caregivers to connect, share experiences, and find solidarity in their caregiving journey.

Explore Community Groups

Caregiver Circle
Join our circle of caregivers for an evening of support, understanding, and camaraderie

Compassionate Caregivers Gathering
Come together with fellow caregivers for a compassionate and supportive meetup

Caregiver Connectior Circle
Connect with fell in a supportive ar environment, whe together to share

Caregiver Connection Circle

Connect with fellow caregivers in a supportive and nurturing environment, where we come together to share stories, offer advice, and find strength in our shared experiences. The meetup provides a safe and non-judgmental space for caregivers to share their stories and experiences. Attendees are encouraged to express their thoughts, feelings, challenges, and triumphs related to caregiving. Active listening and validation are emphasized, fostering an environment of empathy and understanding

Members

Upcoming Meetups & Events

Caring Connections Meetup
A supportive gathering for cancer caregivers to connect, share experiences, and find solidarity in their caregiving journey.

Figure 5: High Fidelity Screens: Caregivers' community, 2024

Community of caregivers

The platform offers a community-oriented feature where caregivers can connect, interact, and convene with one another. It provides a platform for discussing episodes, sharing insights, and fostering connections based on the podcast's topics and themes. It will also facilitate in-person or virtual meetups based on location, enabling caregivers to connect with others nearby.

Key Features

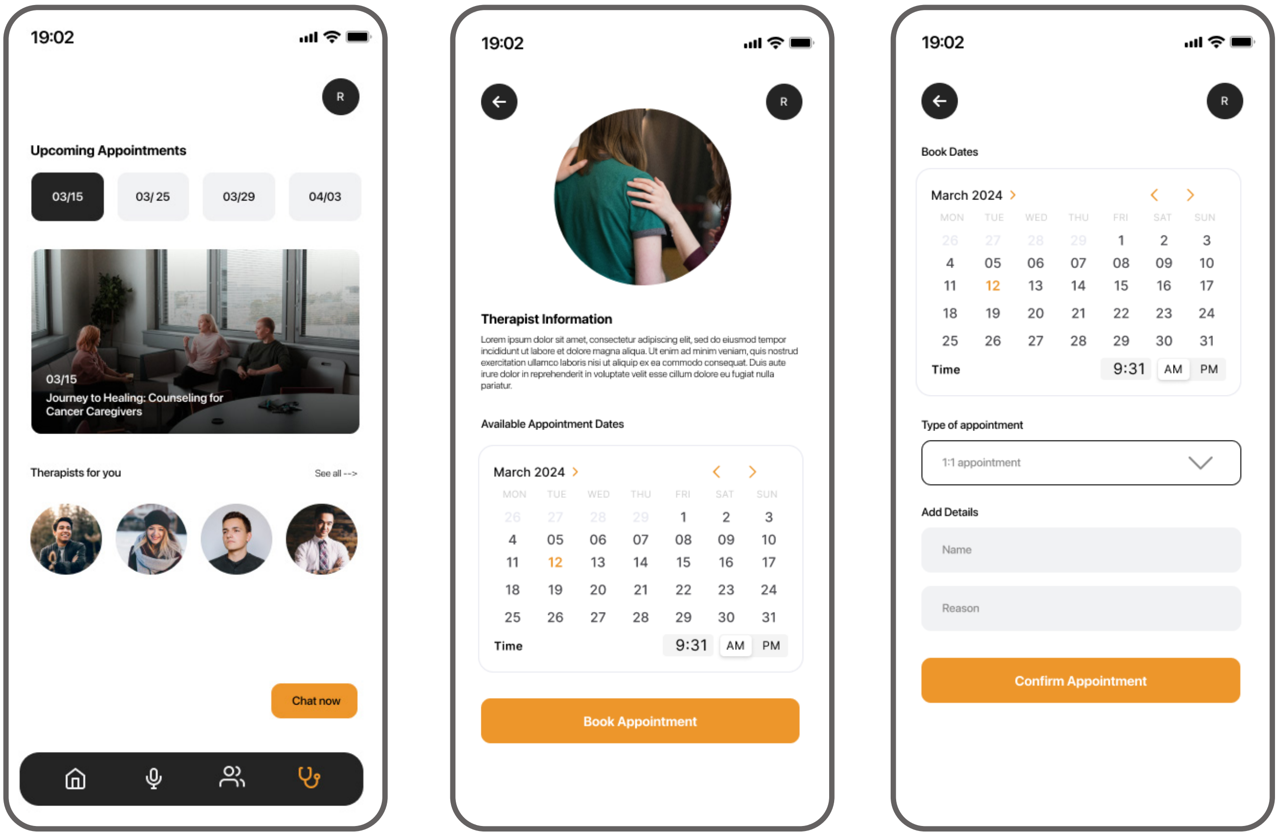


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Figure 6: High Fidelity Screens: Mental Health Therapist, 2024

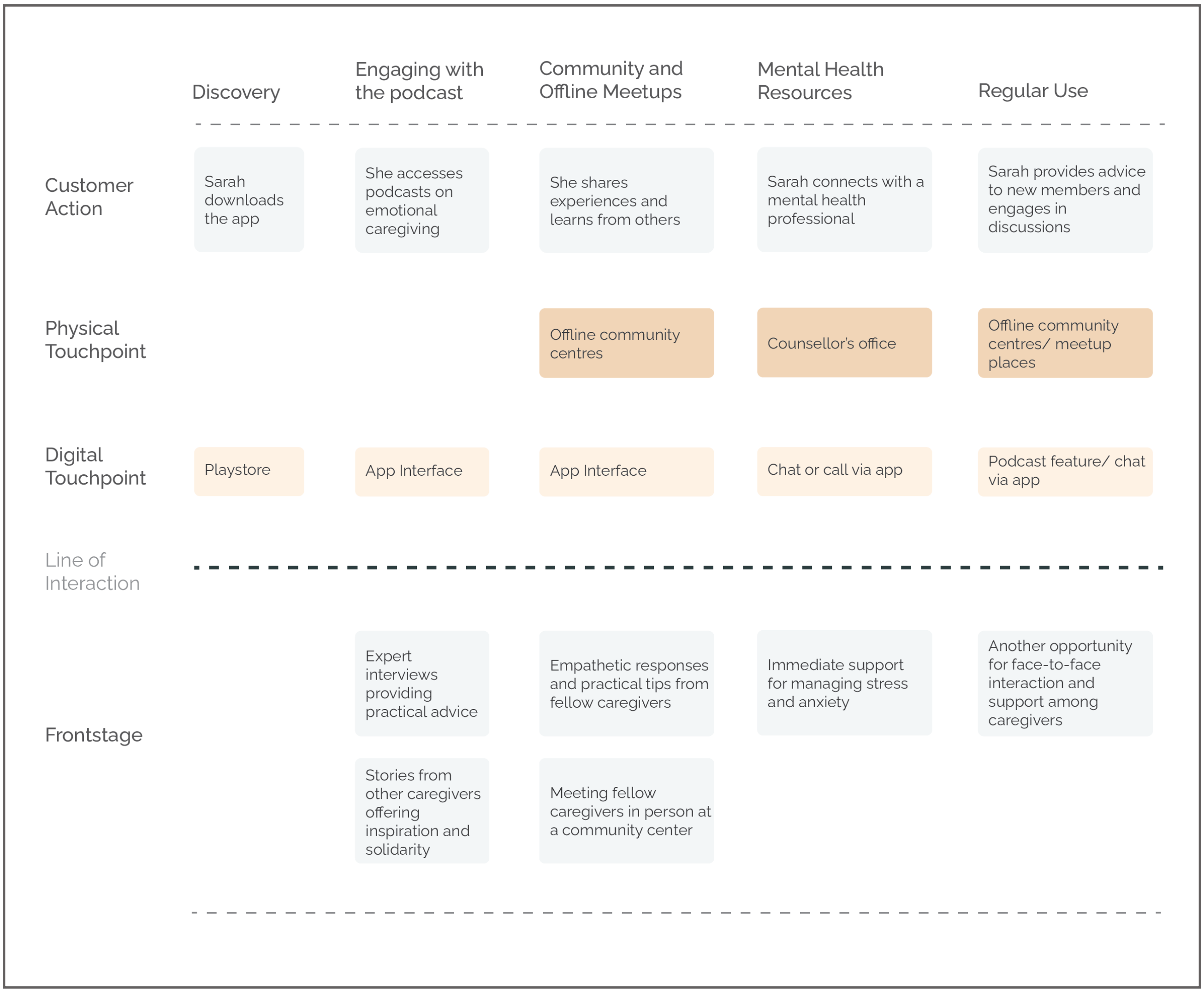
On call mental health therapist

A mental health provider that is always available.

24/7 Helpline or Chat: Immediate access to mental health professionals for emotional support, counseling, and guidance.

Scheduled Sessions: Option to book virtual and in-person counseling sessions with licensed therapists specialized in dealing with caregiver stress, grief, and emotional challenges.

Service Blueprint



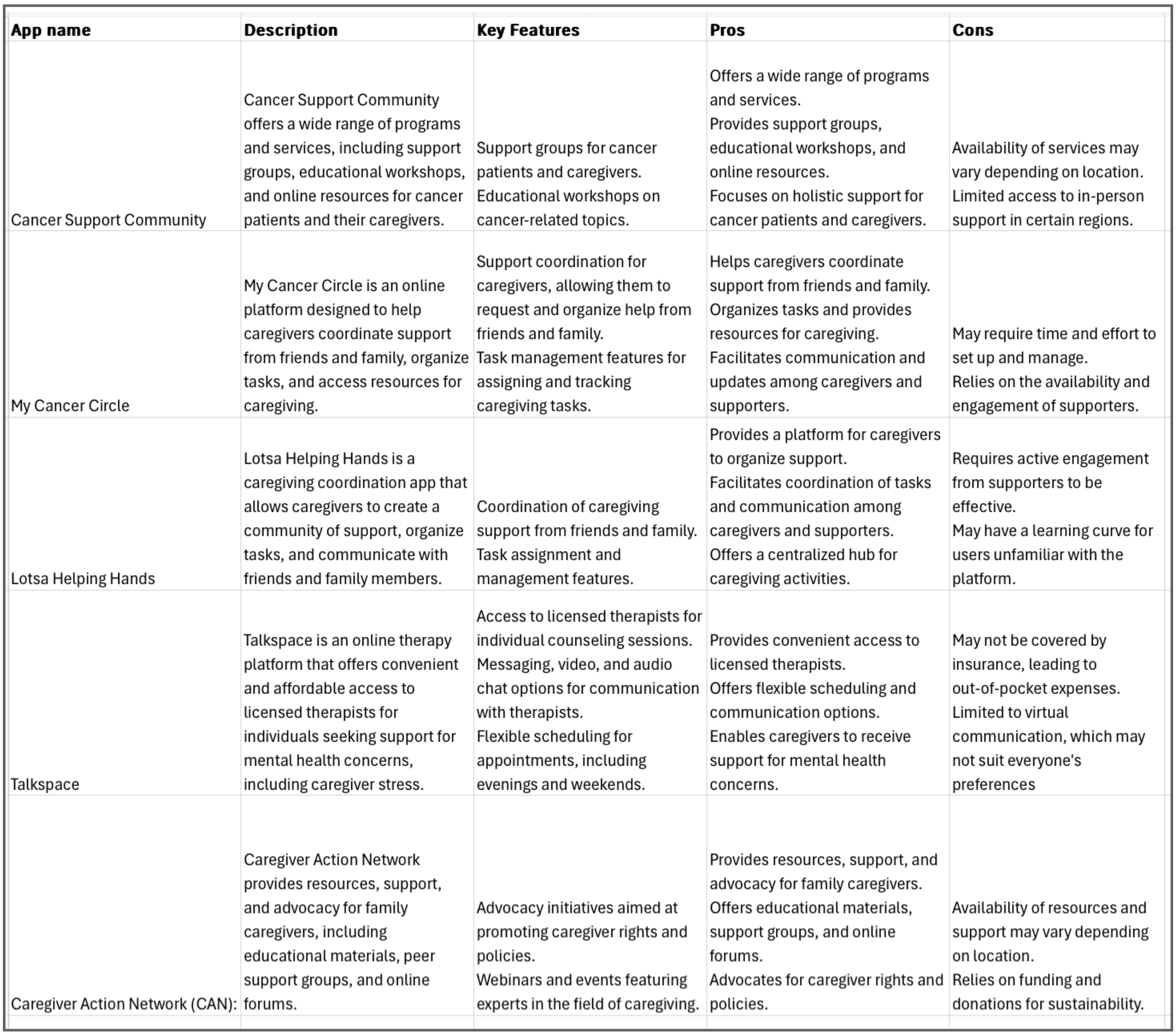
	Discovery	Engaging with the podcast	Community and Offline Meetups	Mental Health Resources	Regular Use
Customer Action	Sarah downloads the app	She accesses podcasts on emotional caregiving	She shares experiences and learns from others	Sarah connects with a mental health professional	Sarah provides advice to new members and engages in discussions
Physical Touchpoint			Offline community centres	Counsellor's office	Offline community centres/ meetup places
Digital Touchpoint	Playstore	App Interface	App Interface	Chat or call via app	Podcast feature/ chat via app
Line of Interaction					
Frontstage		Expert interviews providing practical advice Stories from other caregivers offering inspiration and solidarity	Empathetic responses and practical tips from fellow caregivers Meeting fellow caregivers in person at a community center	Immediate support for managing stress and anxiety	Another opportunity for face-to-face interaction and support among caregivers

Figure 7: Service Blueprint, 2024

A service blueprint is a diagram that visualizes the relationships between different service components — people, props (physical or digital evidence), and processes — that are directly tied to touchpoints in a specific customer journey. (Experience, n.d.)

The service blueprint map presented in Figure 7 illustrates the comprehensive landscape of both physical and digital touchpoints that family caregivers or cancer patients may encounter while engaging with the service. This visual representation serves as a crucial link in comprehending how the service operates from the perspective of end users, particularly family caregivers in the context of Canada. By mapping out these touchpoints, the blueprint facilitates a clear understanding of the user journey, helping to identify any gaps between the physical and digital components. This process is instrumental in devising strategies to enhance the overall user experience and streamline the service delivery for family caregivers or cancer patients in the Canadian context.

Market Analysis



App name	Description	Key Features	Pros	Cons
Cancer Support Community	Cancer Support Community offers a wide range of programs and services, including support groups, educational workshops, and online resources for cancer patients and their caregivers.	Support groups for cancer patients and caregivers. Educational workshops on cancer-related topics.	Offers a wide range of programs and services. Provides support groups, educational workshops, and online resources. Focuses on holistic support for cancer patients and caregivers.	Availability of services may vary depending on location. Limited access to in-person support in certain regions.
My Cancer Circle	My Cancer Circle is an online platform designed to help caregivers coordinate support from friends and family, organize tasks, and access resources for caregiving.	Support coordination for caregivers, allowing them to request and organize help from friends and family. Task management features for assigning and tracking caregiving tasks.	Helps caregivers coordinate support from friends and family. Organizes tasks and provides resources for caregiving. Facilitates communication and updates among caregivers and supporters.	May require time and effort to set up and manage. Relies on the availability and engagement of supporters.
Lotsa Helping Hands	Lotsa Helping Hands is a caregiving coordination app that allows caregivers to create a community of support, organize tasks, and communicate with friends and family members.	Coordination of caregiving support from friends and family. Task assignment and management features.	Provides a platform for caregivers to organize support. Facilitates coordination of tasks and communication among caregivers and supporters. Offers a centralized hub for caregiving activities.	Requires active engagement from supporters to be effective. May have a learning curve for users unfamiliar with the platform.
Talkspace	Talkspace is an online therapy platform that offers convenient and affordable access to licensed therapists for individuals seeking support for mental health concerns, including caregiver stress.	Access to licensed therapists for individual counseling sessions. Messaging, video, and audio chat options for communication with therapists. Flexible scheduling for appointments, including evenings and weekends.	Provides convenient access to licensed therapists. Offers flexible scheduling and communication options. Enables caregivers to receive support for mental health concerns.	May not be covered by insurance, leading to out-of-pocket expenses. Limited to virtual communication, which may not suit everyone's preferences
Caregiver Action Network (CAN):	Caregiver Action Network provides resources, support, and advocacy for family caregivers, including educational materials, peer support groups, and online forums.	Advocacy initiatives aimed at promoting caregiver rights and policies. Webinars and events featuring experts in the field of caregiving.	Provides resources, support, and advocacy for family caregivers. Offers educational materials, support groups, and online forums. Advocates for caregiver rights and policies.	Availability of resources and support may vary depending on location. Relies on funding and donations for sustainability.

Figure 8: Market Analysis, 2024

After analyzing several services and applications designed to assist individuals with navigating the complex cancer care system, an interesting observation emerged. These platforms focused primarily on fostering a supportive community for cancer survivors and patients. The unique needs of family caregivers associated with these cancer patients were not adequately addressed.

It is noteworthy that even applications or services purportedly designed for family caregivers were inadequate. They did not function as holistic tools that could address the entire caregiving journey. Existing offerings did not appear to offer the comprehensive features essential to support family caregivers during the challenging and nuanced tasks associated with caring for those affected by cancer. This apparent oversight underscores a critical gap in the provision of resources and tools specifically designed to meet the multifaceted needs of family caregivers in the context of cancer care.

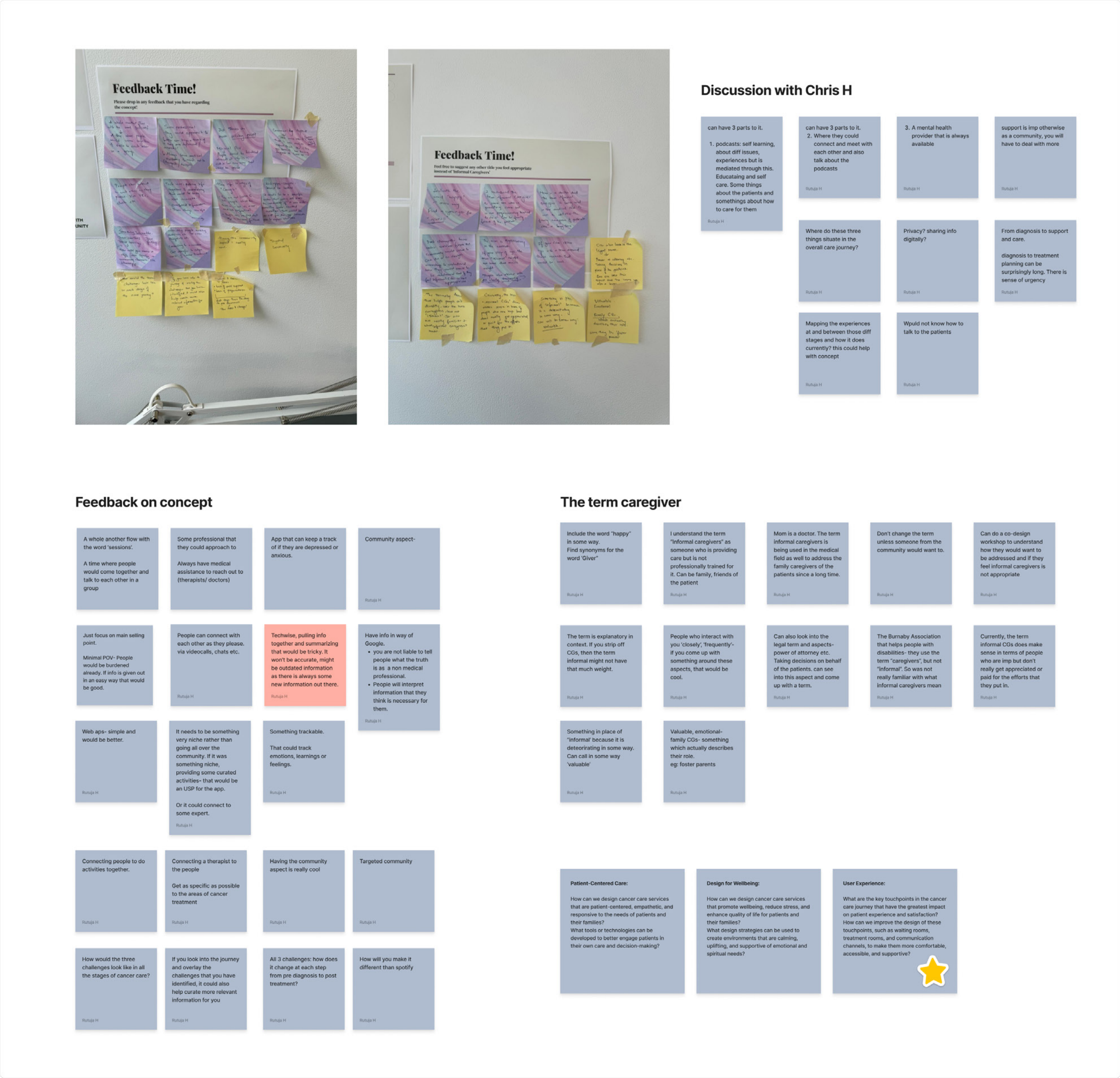
Concept Testing

During the development of the service, alongside the participatory research done to finalize on the term for referring the caregivers, concept testing was also conducted with these family caregivers of cancer patients to gather their feedback and improve the service. The three main features of the service were presented to the participants, and their opinions were sought to determine if they believed this service would be beneficial for future family caregivers of cancer patients, based on their own experiences.

The feedback from all research participants was overwhelmingly positive. They found the feature of organizing meetups with other family caregivers particularly valuable. This aspect was seen as a significant benefit, providing a platform for mutual support and connection. The inclusion of audio podcasts for knowledge dissemination was also well-received. Participants noted that podcasts were a convenient and effective way to absorb information, as they could listen to them anytime and anywhere, even while multitasking with other duties. Lastly, the availability of on-call mental health therapists was highly appreciated. Participants recognized the importance of having easy access to professional support whenever needed, emphasizing the value of immediate mental health assistance for family caregivers.

> *"So, therapy will be really useful, definitely that is one. Community- as I told you that I was waiting, and I met a lot of people and that is also a community that is happening. Community was also in sharing; helps you be prepared. There were patients who came for sessions, and they were let to be known that you will experience hair fall and everything. Podcasts- everyone nowadays are listening to podcasts, so even if you are not currently caring for a cancer patient, you can listen to it and be prepared for anytime."*
> *- Participant 06*
>
> *"My aunt used to read a lot of articles, then my brother me and my aunt would exchange whatever we found, and we used to sit and talk, we used to discuss about what approach would be better."*
> *- Participant 04*
>
> *"100% it will be useful for us, especially to gain knowledge, because nobody is ready for such a thing especially for such a tragedy in life. Nobody would have such knowledge beforehand, so having something handy would be a great idea."*
> *- Participant 01*

Figure 9: Concept Testing Feedback (a), 2024.



Discussion with Chris H

can have 3 parts to it.

1. podcasts: self learning, about diff issues, experiences but is mediated through this. Educataing and self care. Some things about the patients and somethings about how to care for them

Rutuja H

can have 3 parts to it.

2. Where they could connect and meet with each other and also talk about the podcasts

Rutuja H

3. A mental health provider that is always available

Rutuja H

support is imp otherwise as a community, you will have to deal with more

Rutuja H

Where do these three things situate in the overall care journey?

Rutuja H

Privacy? sharing info digitally?

Rutuja H

From diagnosis to support and care.

diagnosis to treatment planning can be surprisingly long. There is sense of urgency

Rutuja H

Mapping the experiences at and between those diff stages and how it does currently? this could help with concept

Rutuja H

Wpuld not know how to talk to the patients

Rutuja H

Feedback on concept

A whole another flow with the word 'sessions'.

A time where people would come together and talk to each other in a group

Some professional that they could approach to

Always have medical assistance to reach out to (therapists/ doctors)

App that can keep a track of if they are depressed or anxious.

Community aspect-

Rutuja H

Just focus on main selling point.

Minimal POV- People would be burdened already. If info is given out in an easy way that would be good.

People can connect with each other as they please. via videocalls, chats etc.

Rutuja H

Techwise, pulling info together and summarizing that would be tricky. It won't be accurate, might be outdated information as there is always some new information out there.

Rutuja H

Have info in way of Google.

- you are not liable to tell people what the truth is as a non medical professional.
- People will interpret information that they think is necessary for them.

Rutuja H

Web aps- simple and would be better.

Rutuja H

It needs to be something very niche rather than going all over the community. If it was something niche, providing some curated activities- that would be an USP for the app.

Or it could connect to some expert.

Rutuja H

Something trackable.

That could track emotions, learnings or feelings.

Rutuja H

Connecting people to do activities together.

Rutuja H

Connecting a therapist to the people

Get as specific as possible to the areas of cancer treatment

Rutuja H

Having the community aspect is really cool

Rutuja H

Targeted community

Rutuja H

How would the three challenges look like in all the stages of cancer care?

Rutuja H

If you look into the journey and overlay the challenges that you have identified, it could also help curate more relevant information for you

Rutuja H

All 3 challenges: how does it change at each step from pre diagnosis to post treatment?

Rutuja H

How will you make it different than spotify

Rutuja H

The term caregiver

Include the word "happy" in some way.
Find synonyms for the word 'Giver"

Rutuja H

I understand the term "Informal caregivers" as someone who is providing care but is not professionally trained for it. Can be family, friends of the patient

Rutuja H

Mom is a doctor. The term informal caregivers is being used in the medical field as well to address the family caregivers of the patients since a long time.

Rutuja H

Don't change the term unless someone from the community would want to.

Rutuja H

Can do a co-design workshop to understand how they would want to be addressed and if they feel informal caregivers is not appropriate

Rutuja H

The term is explanatory in context. If you strip off CGs, then the term informal might not have that much weight.

Rutuja H

People who interact with you 'closely', 'frequently'- if you come up with something around these aspects, that would be cool.

Rutuja H

Can also look into the legal term and aspects- power of attorney etc. Taking decisions on behalf of the patients. can see into this aspect and come up with a term.

Rutuja H

The Burnaby Association that helps people with disabilities- they use the term "caregivers", but not "informal". So was not really familiar with what informal caregivers mean

Rutuja H

Currently, the term informal CGs does make sense in terms of people who are imp but don't really get appreciated or paid for the efforts that they put in.

Rutuja H

Something in place of "informal' because it is deteorirating in some way. Can call in some way 'valuable'

Rutuja H

Valuable, emotional- family CGs- something which actually describes their role.
eg: foster parents

Rutuja H

Patient-Centered Care:

How can we design cancer care services that are patient-centered, empathetic, and responsive to the needs of patients and their families?
What tools or technologies can be developed to better engage patients in their own care and decision-making?

Design for Wellbeing:

How can we design cancer care services that promote wellbeing, reduce stress, and enhance quality of life for patients and their families?
What design strategies can be used to create environments that are calming, uplifting, and supportive of emotional and spiritual needs?

User Experience:

What are the key touchpoints in the cancer care journey that have the greatest impact on patient experience and satisfaction?
How can we improve the design of these touchpoints, such as waiting rooms, treatment rooms, and communication channels, to make them more comfortable, accessible, and supportive? ★

Figure 10: Concept Testing Feedback (b), 2024.

Conclusion

In conclusion, this thesis examined the complexities of cancer caregiving in Canada, focusing particularly on the experiences of family caregivers in British Columbia. Having highlighted the gaps in the cancer care system and recognized caregivers' significant challenges, this study led to the creation of a unique and holistic solution, a digital intervention — a comprehensive app that supports caregivers and empowers them throughout their caregiving journey. In addition to offering educational resources, this app fosters a supportive community and offers mental health support to ease caregiver burdens. By ensuring caregivers receive the support they need to provide the best care for their loved ones while also prioritizing their own health, this project will ultimately contribute to a more compassionate, effective cancer care ecosystem.

Future Scope

In this research, I delved into the significant impact of cultural and geographical factors on the management and operation of cancer care systems by caregivers. My exploration highlighted the pivotal role these elements play in shaping caregiving practices. However, the study did have a number of limitations, particularly because of barriers in recruiting participants from varied geographical backgrounds within the time constraints of the study. Future research with a broader range of participants from a broader geographic range could greatly enhance the depth and breadth of this research, making it more comprehensive. By addressing these aspects, the resulting research might be able to offer more targeted and effective solutions, tailored to diverse audiences and their specific needs in the context of cancer care. This approach has the potential to make my work more relevant and impactful across various cultural and geographic domains.

Other future scopes specifically related to the app would also include:

Naming the app is one crucial next step for this project. Not naming the app in this thesis document was an intentional step, since I wanted to have the caregiver's opinion in the naming. A similar activity to the one conducted for finalizing the term "Family Caregivers" as to address the caregivers will be done with the pool of participants to understand what they would want the app to be called as.

Advanced interactive features such as real time question answering sessions by an expert to answer the questions submitted by listeners in a Q&A format could be incorporated in the podcasts. This would enable more interactive and personalized experiences through voice recognition technology. Multilingual support would enable the inclusion of different languages in the podcast, helping the product to reach a wider global audience.

Research and education partnerships are one way through which we can supply the most recent research and cancer educational content with academic institutions as well as research organizations. We could also create special series or episodes that are about recent studies as well as developments.

The utilization of VR/AR technology to come up with immersive educational and support experiences is among them. For example, virtual support groups or simulated scenarios that help caregivers understand complex medical procedures. On top of cancer care, other chronic diseases can be encompassed by this approach so that a broader range of people can benefit from it.

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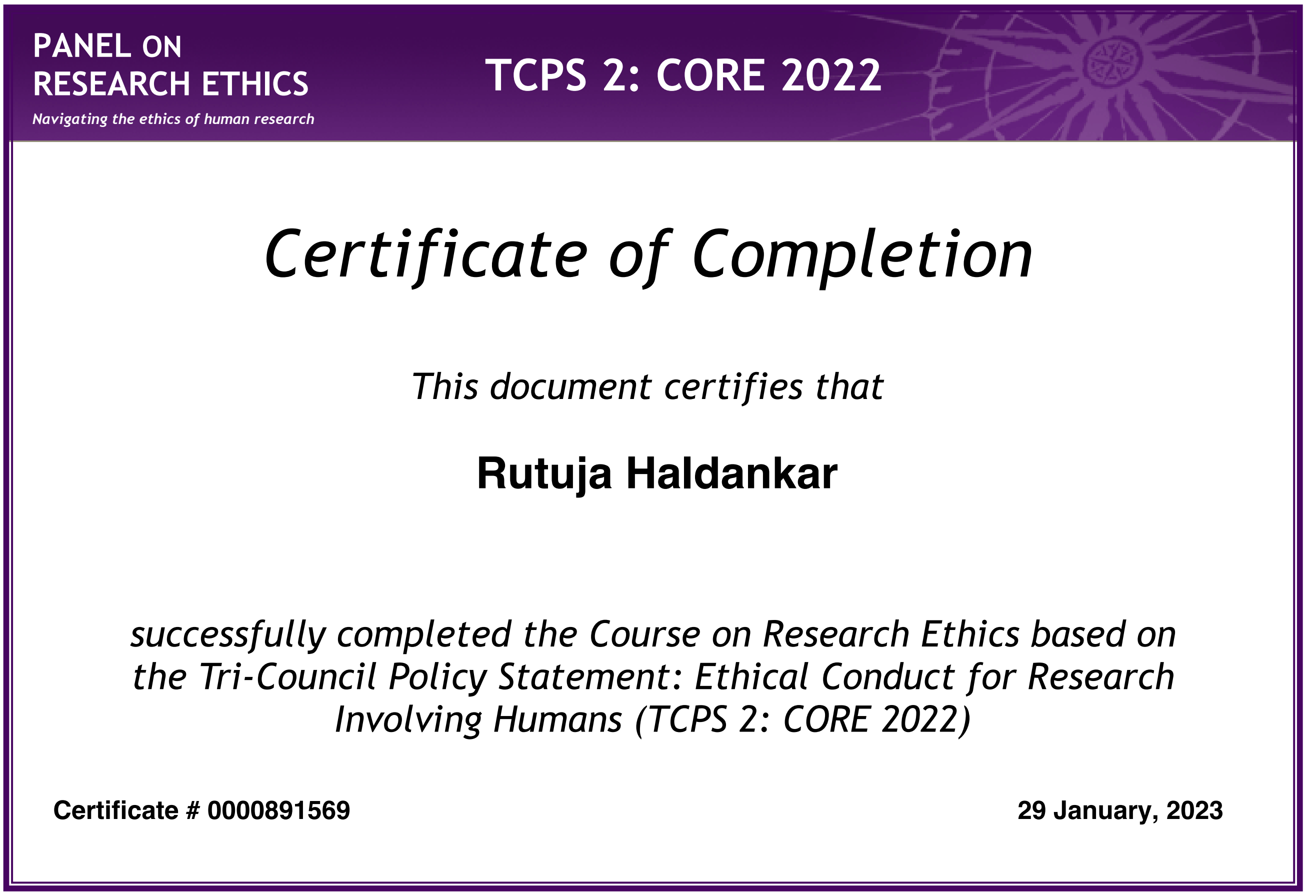
Appendix

a. TCPS certificate



PANEL ON
RESEARCH ETHICS
Navigating the ethics of human research

TCPS 2: CORE 2022

Certificate of Completion

This document certifies that

Rutuja Haldankar

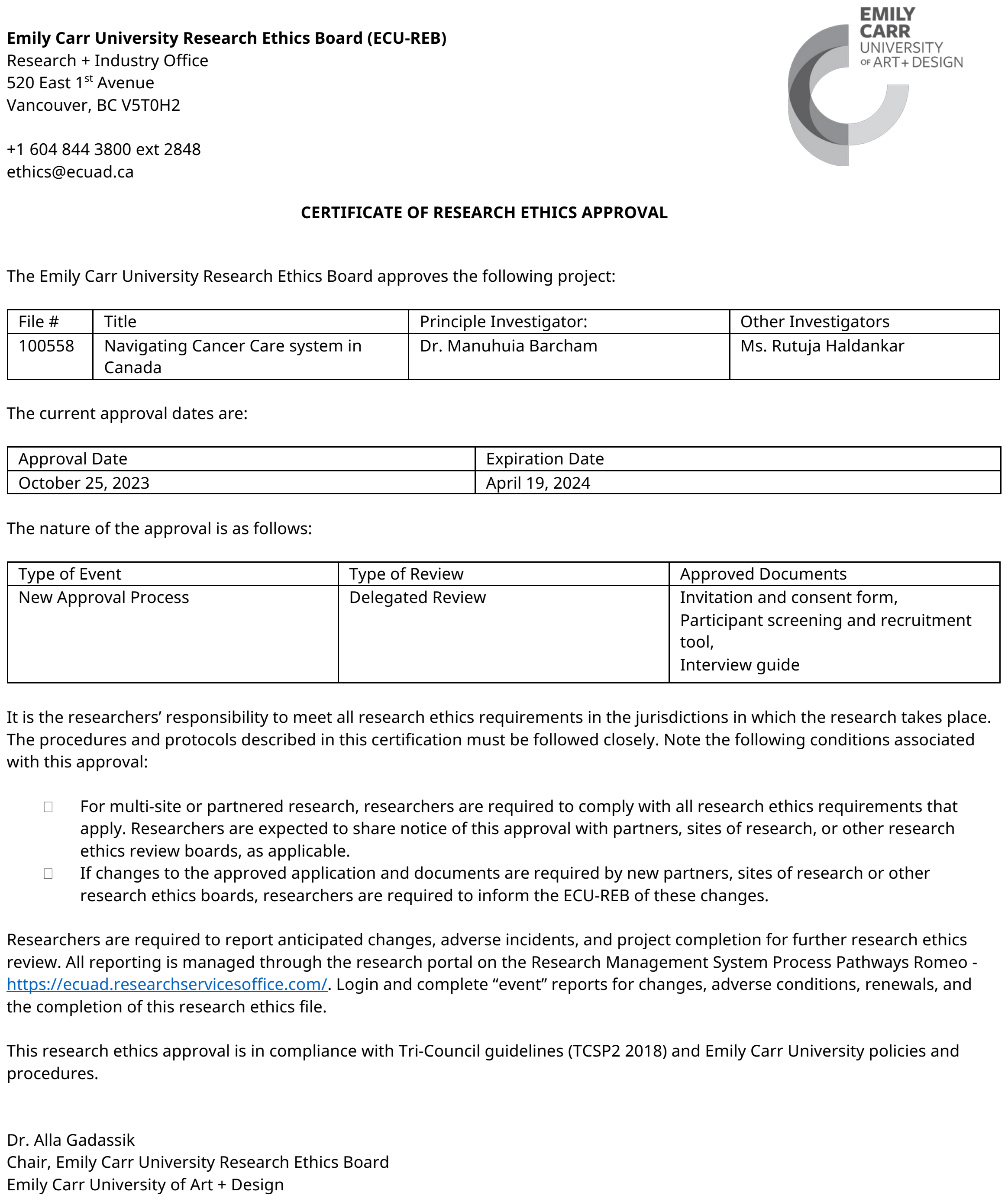
successfully completed the Course on Research Ethics based on the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS 2: CORE 2022)

Certificate # 0000891569

29 January, 2023

Figure 11: TCPS 2 Certificate of completion, 2024.

b. REB approval certificate



Emily Carr University Research Ethics Board (ECU-REB)
Research + Industry Office
520 East 1st Avenue
Vancouver, BC V5T0H2

+1 604 844 3800 ext 2848
ethics@ecuad.ca

CERTIFICATE OF RESEARCH ETHICS APPROVAL

The Emily Carr University Research Ethics Board approves the following project:

File #	Title	Principle Investigator:	Other Investigators
100558	Navigating Cancer Care system in Canada	Dr. Manuhuia Barcham	Ms. Rutuja Haldankar

The current approval dates are:

Approval Date	Expiration Date
October 25, 2023	April 19, 2024

The nature of the approval is as follows:

Type of Event	Type of Review	Approved Documents
New Approval Process	Delegated Review	Invitation and consent form, Participant screening and recruitment tool, Interview guide

It is the researchers' responsibility to meet all research ethics requirements in the jurisdictions in which the research takes place. The procedures and protocols described in this certification must be followed closely. Note the following conditions associated with this approval:

- For multi-site or partnered research, researchers are required to comply with all research ethics requirements that apply. Researchers are expected to share notice of this approval with partners, sites of research, or other research ethics review boards, as applicable.
- If changes to the approved application and documents are required by new partners, sites of research or other research ethics boards, researchers are required to inform the ECU-REB of these changes.

Researchers are required to report anticipated changes, adverse incidents, and project completion for further research ethics review. All reporting is managed through the research portal on the Research Management System Process Pathways Romeo - https://ecuad.researchservicesoffice.com/. Login and complete "event" reports for changes, adverse conditions, renewals, and the completion of this research ethics file.

This research ethics approval is in compliance with Tri-Council guidelines (TCSP2 2018) and Emily Carr University policies and procedures.

Dr. Alla Gadassik
Chair, Emily Carr University Research Ethics Board
Emily Carr University of Art + Design

Figure 12: REB approval, 2024.

c. Interview Questions

Ice-breaker questions:

1) Can you tell me a little bit about your relationship with the cancer survivor?

2) How has the cancer journey impacted your family dynamics and relationships?

  a) What are some of the strengths and resilience that you have witnessed within your family throughout this experience?

In-depth questions:

3) How did you and your family navigate the process of gathering information and making decisions about treatment options and healthcare providers?

  a) How was your experience with the same?

  b) What resources did you rely on to get information for the same?

4) Can you share any specific challenges or obstacles that your family encountered while supporting your loved one through their treatment?

  a) How did you overcome these challenges?

5) What support systems or resources did you or your family rely on for assistance throughout the cancer journey? Were there any gaps in the support available to your family?

6) How did the experience of caregiving impact your family's daily routines, responsibilities, and roles?

  a) Did you face any challenges with the same?

Concluding question:

7) Reflecting on the entire interview and your family's cancer journey, is there anything else you would like to share or any important aspect that we may have missed?

d. Information Architecture for the app

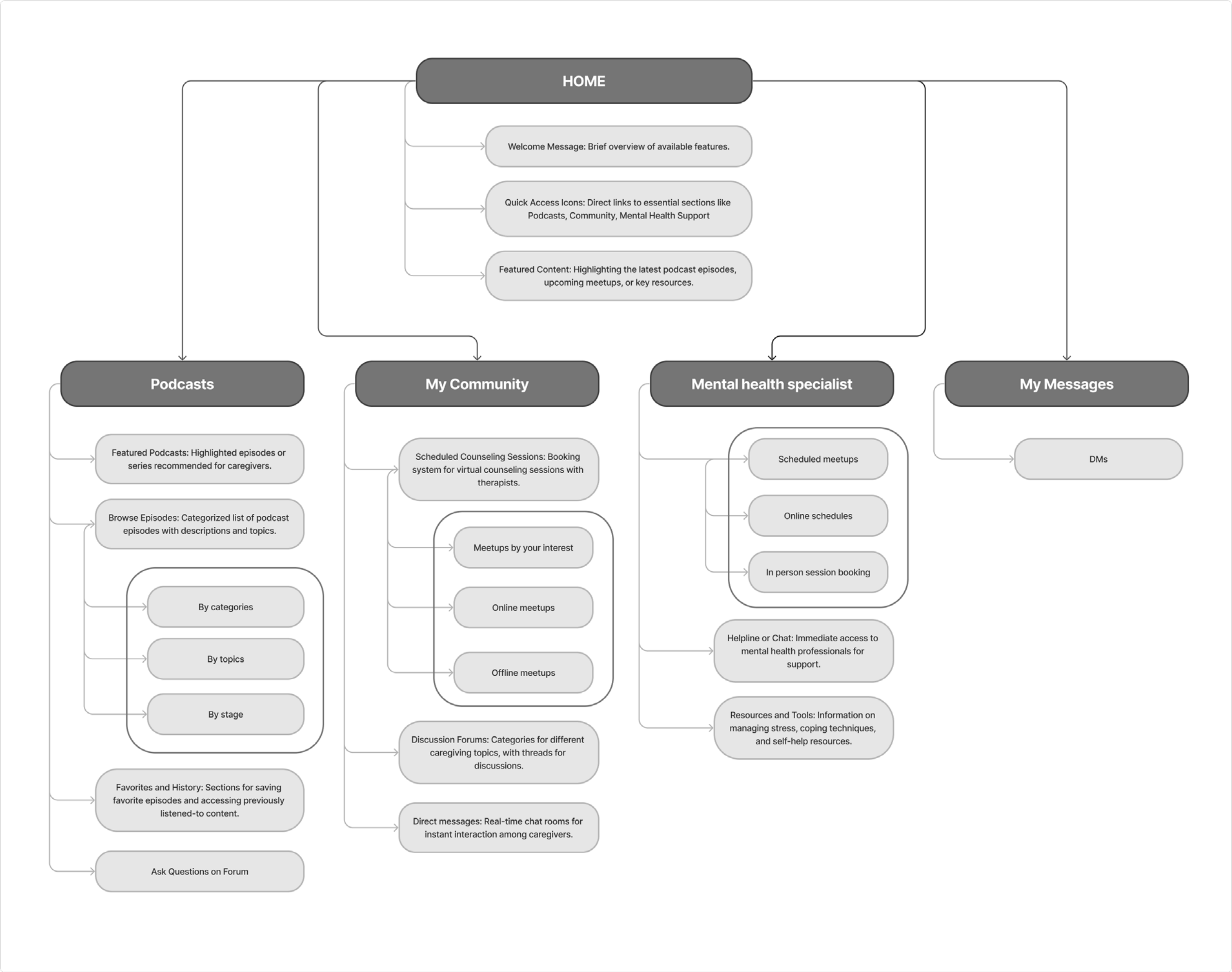


Figure 13: Information Architecture, 2024.

e. User Flow for the app

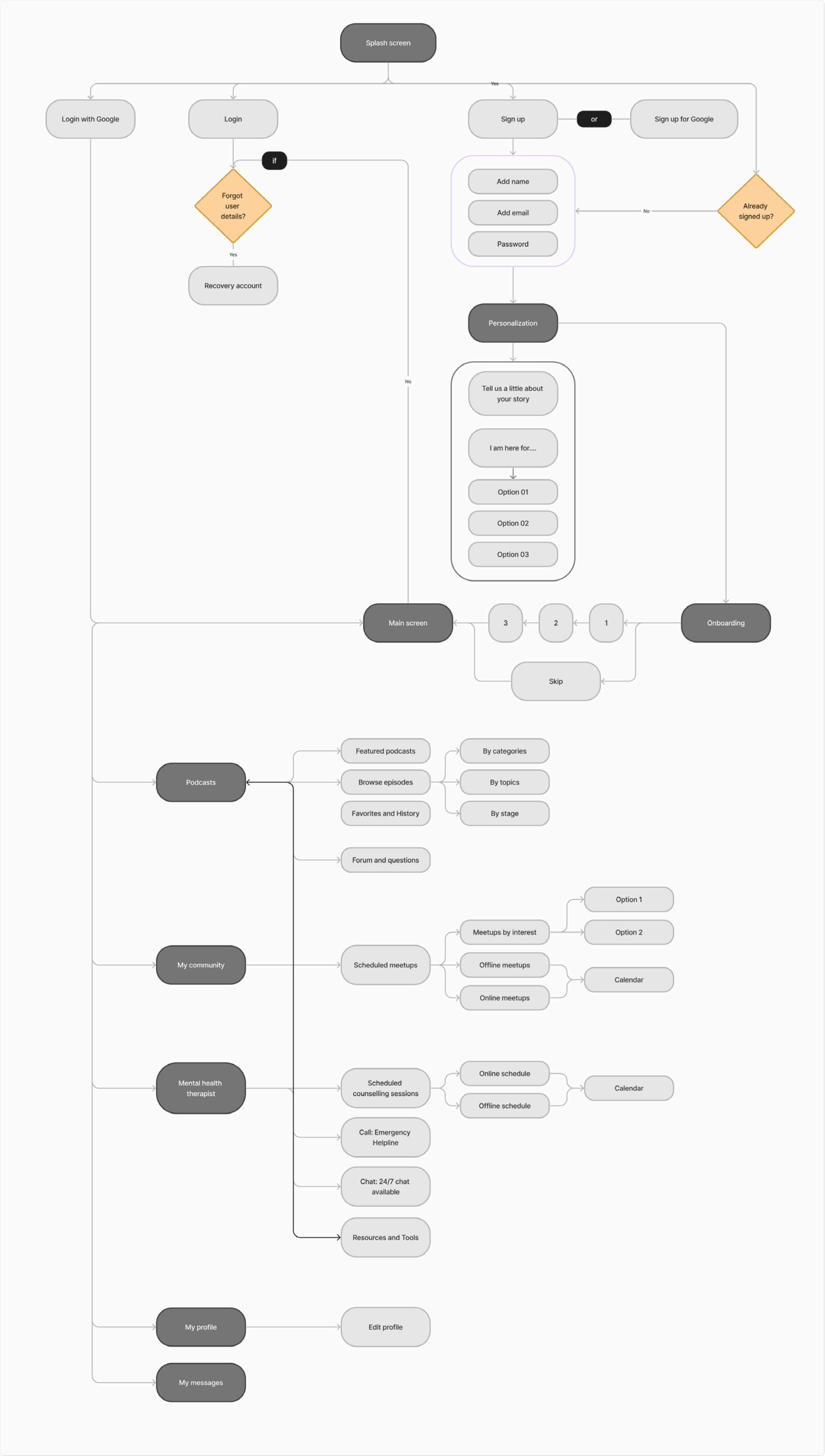


Figure 14: User Flow, 2024.

f. Low Fidelity Mockups

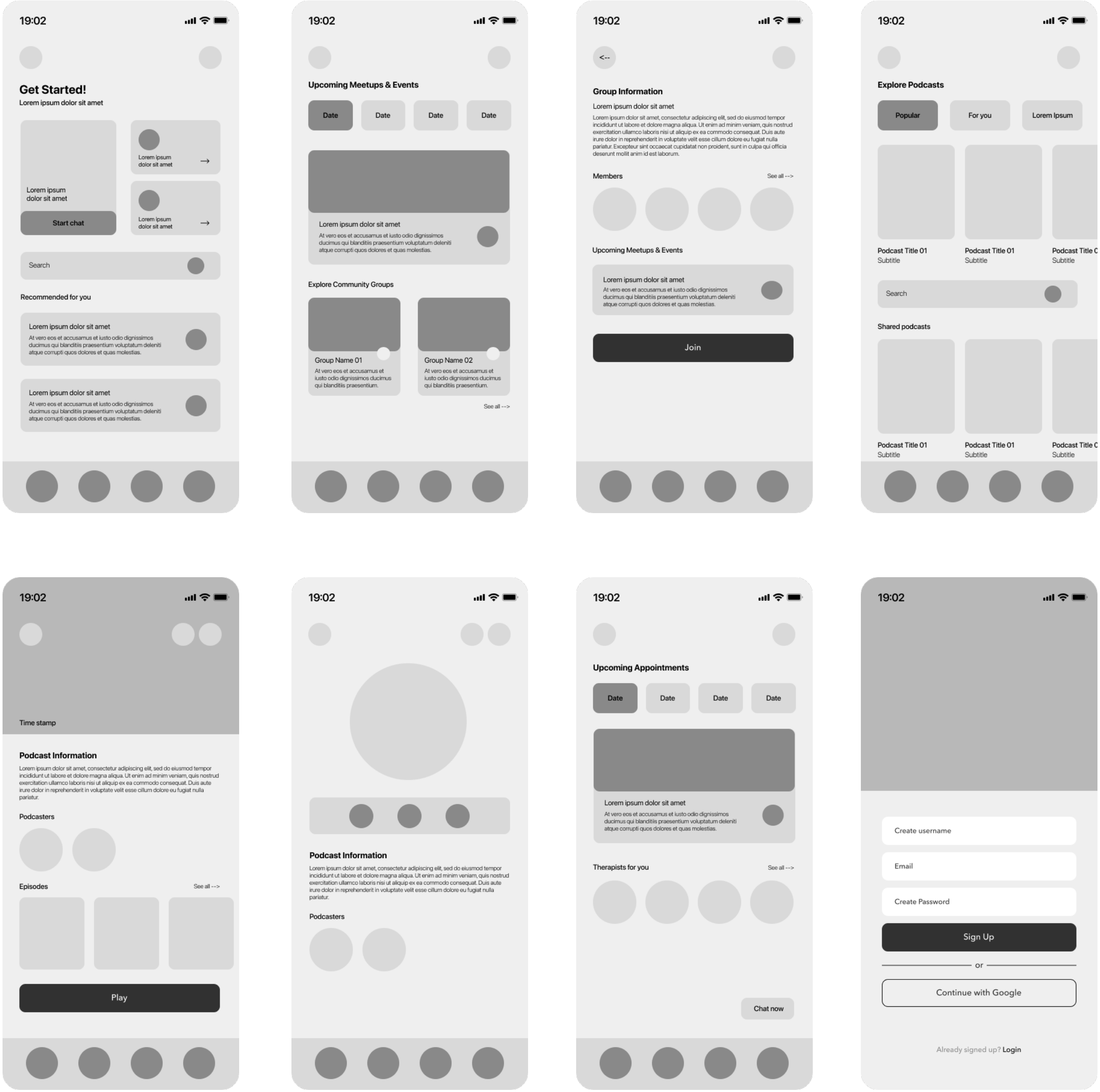


Figure 15: Low Fidelity Mockups, 2024.