Claremont McKenna College

Caring for Caregivers: Exploring Neuro-oncology Relationships and Spreading Collaborative Grief Support Using Human-Centered Design

submitted to
Professor Albert Park
and
Professor Fred Leichter

by
Anya Zimmerman-Smith

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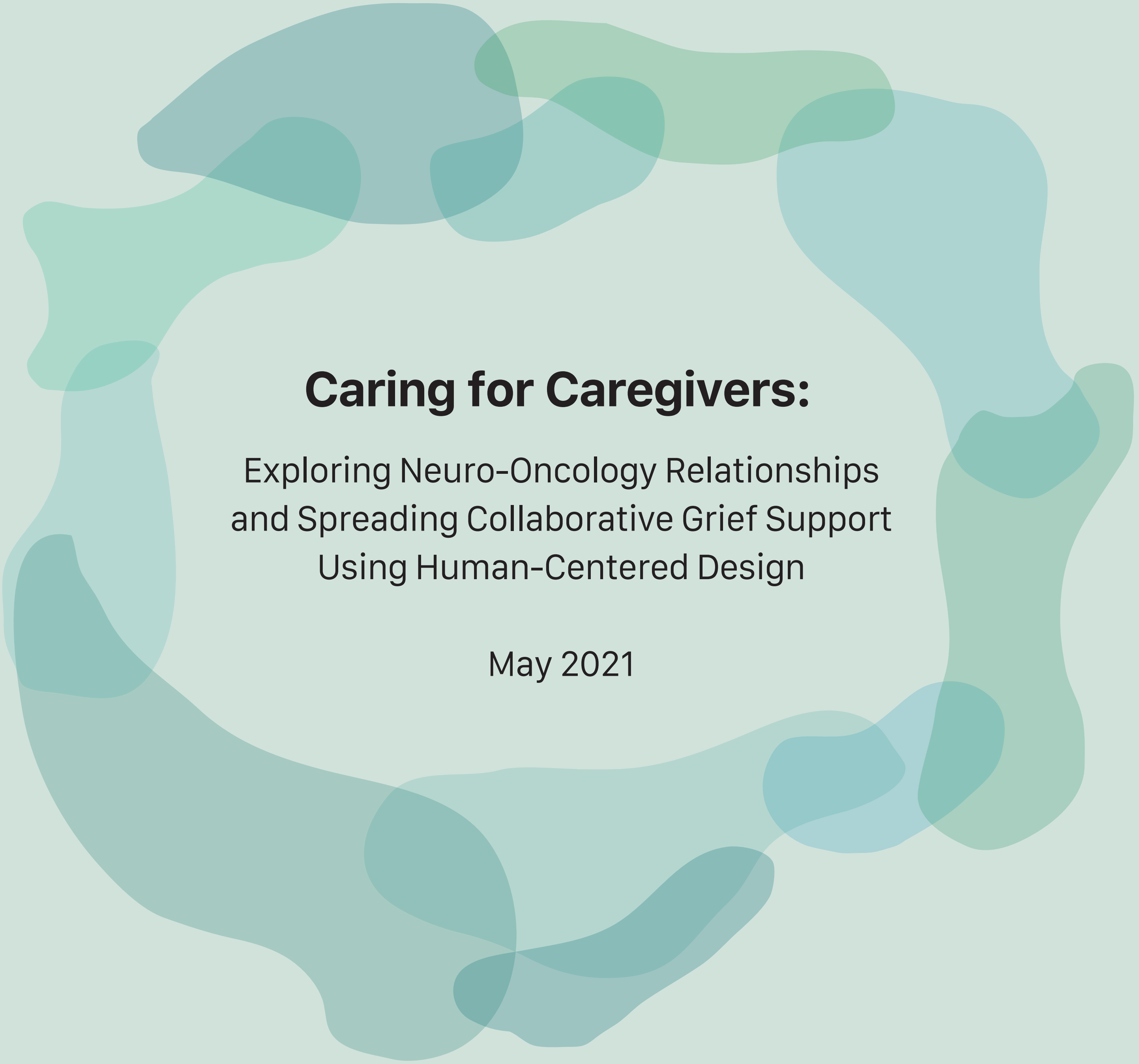

Caring for Caregivers:

Exploring Neuro-Oncology Relationships and Spreading Collaborative Grief Support Using Human-Centered Design

May 2021

Anya Zimmerman-Smith
Human Centered-Design Thesis
a.zimsmith1@gmail.com
anyazimmerman-smith.com

> *“I’ve often cried because of patients… to deny myself the tears would be to deny myself the human that I already was before and am after becoming a doctor.”*

Quote on grief as an oncology physician
2017, Quora

Abstract

02

As a college student studying Human-Centered Design (HCD), my goal for the culmination of my education was to have an impact in an area that was human, complex, and emotion filled. This project explored the need for healthcare professionals, specifically physicians and nurses working in neuro-oncology, to acknowledge their natural human grief in the face of patient death. In partnership with the UCSF Honor Project, my partner and I employed Human-Centered Design to establish practices and spaces for these communities to process their grief.

At the foundation of our work was the deeply dedicated medical professional who needs relief from the weight of witnessing so many patients pass. Preventing this were barriers of medical stigma around objectivity and emotion, time crunches, and a belief that one is either ‘built for the job’ or not. Through our research and ideation we created an informative video and implementation materials to convince neuro-oncology departments outside of UCSF to attempt the Honor Project and take seriously the benefits of a structured space for shared grief. Our materials were met with great support and the Honor Project was tested by several departments across the country.

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Introduction

The purpose of this project was to explore the people and impact of oncology navigation and examine the relationships between nurse and social work navigators of various kinds, physicians, caregivers, and patients. We were so struck by the impact of the work of the Brain Tumor Network (BTN) who we had worked for previously that we felt compelled to further explore the topic of oncology navigation more broadly. Nurse and social work navigators at BTN are incredible resources, providing invaluable, personalized research on treatment options, clinical trials, second opinions, transportation and more all while supporting patients and caregivers through the emotional ups and downs of a brain cancer diagnosis.

We wanted to see where else this type of service exists, if at all, and what the history of navigation is, so that we could further understand the navigator role and lend our efforts to expanding the offering and quality of this type of care in the U.S. Our goal was to understand this landscape as best we could so that we could design an intervention that would positively support and empower caregivers, navigators, nurses, or physicians.

Through our research we discovered that while there are navigation services in some places across the country, the roles differ greatly and there is little consensus as to what a navigator does and how they can be most helpful.

Midway through our project we discovered a wonderful program that attends to neuro-oncology staff grief. We had been interested previously in designing for navigators who are constantly confronted with emotionally difficult topics and situations and felt that this intervention, the Honor Project, was an excellent solution. With the blessing of the founder of the Honor Project, our work then focused on spreading this program and solving implementation problems practically and in regards to medical grief stigma.

Through our research we discovered a profound need for space for healthcare professionals to grieve. Their constant interactions with death were lodged in between the human need to emote and process, and a frequent belief that good medical decisions could only be made if such feelings were pushed aside.

01 Brain Tumor Network

Empathy - Users - Insights - Stakeholder Mapping

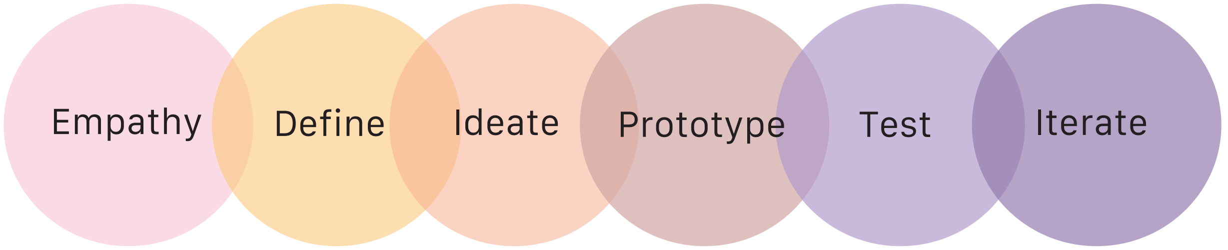
Human-Centered Design Process

To give a better understanding of the flow of our project and how it compares to a traditional Human-Centered Design Project I've created these two diagrams. A traditional HCD project starts with a topic of inquiry or a general problem brief and the designer goes through the stages Empathy, Define, Ideate, Prototype, Test, & Iterate. While it is quite normal for some of those steps to be looped back through several times, our project is essentially several full cycles through this design process in one.

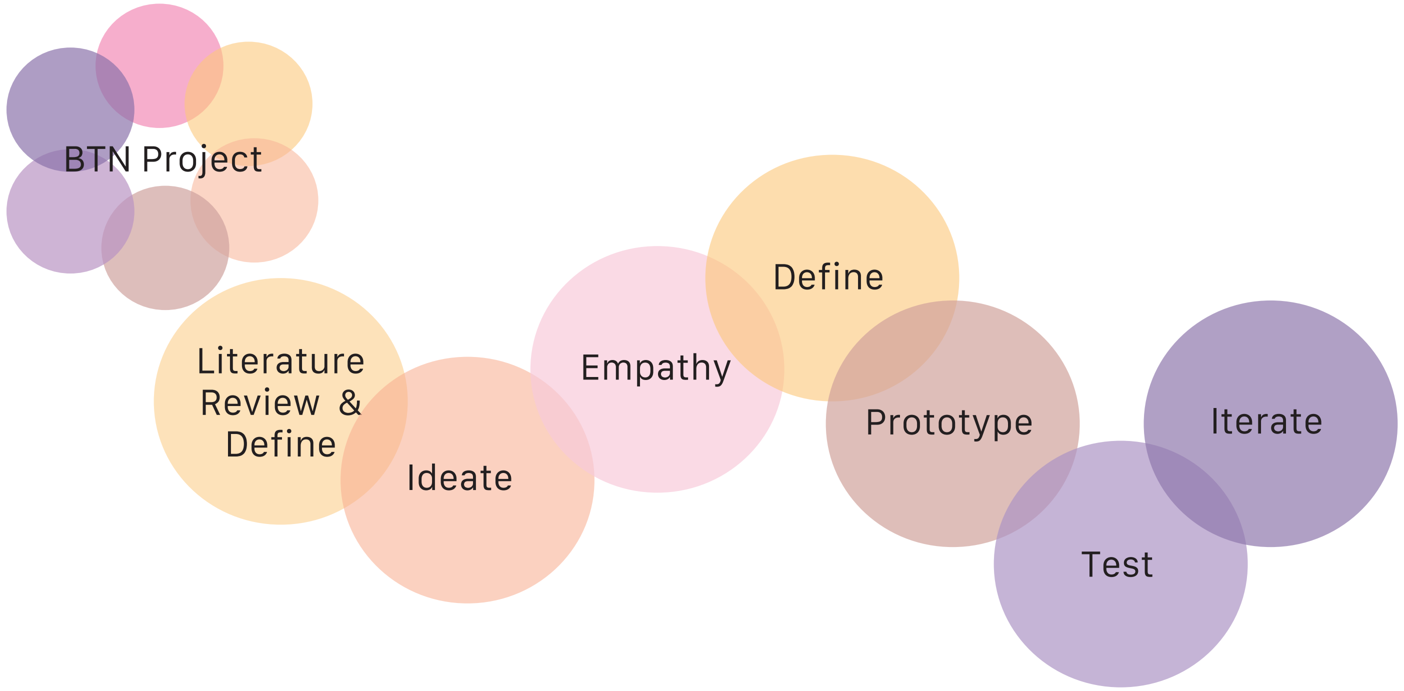
A prior HCD project with The Brain Tumor Network heavily informed the work done for my thesis. I see the connection between the two projects as an incredibly real life manifestation of the design process, discovering solutions when we were not expecting to, researching again later in the project, etc. The design process is messy but the strength of HCD framework is that it is malleable and can serve you in many different ways.

Human Centered Design is a problem finding and solving discipline which draws upon and integrates insights from the fields of anthropology, sociology, psychology, history, design, and engineering. At the heart of HCD, practitioners are called upon to identify pressing problems, to iterate and test solutions. Leaders in HCD immerse themselves in the point of view and experience of those they are serving, then combine the resulting insights with the analytical, problem solving, and technical skills needed to translate them into real world solutions. To make a contribution via Human Centered Design it is necessary to be able to understand how people function, how problems arise and how environments affect people in them. Essential to HCD is the skill of navigating ambiguity and being comfortable working in the unknown.

Human-Centered Design Process Framework



Our Human-Centered Design Process



The Brain Tumor Network

Advanced Human Centered Design Independent Study, Aug-Dec 2020

Riley Knowles
Nathan Chun
Kaitlyn Paulsen
Diana De Rada Ocampo
Anya Zimmerman-Smith

Through the Sontag Center for Collaborative Creativity (The Hive), I worked with a team of students to redesign an aspect of the nurse navigation service the Brain Tumor Network (BTN) offers for caregivers & patients. Much of what we learned informed the conclusions and the decisions my partner, Kaitlyn Paulsen, and I made in this thesis project. To provide context for the thesis project the following is a brief overview of the work my team and I did for The Brain Tumor Network.

> *“Nurse and social work navigators at BTN provide personalized assistance to alleviate or eliminate the barriers that exist to patients accessing timely services and to fully understanding their treatment related options.”*

Empathy

To begin Human-Centered Design project we started our with the Empathy stage and interviewed:

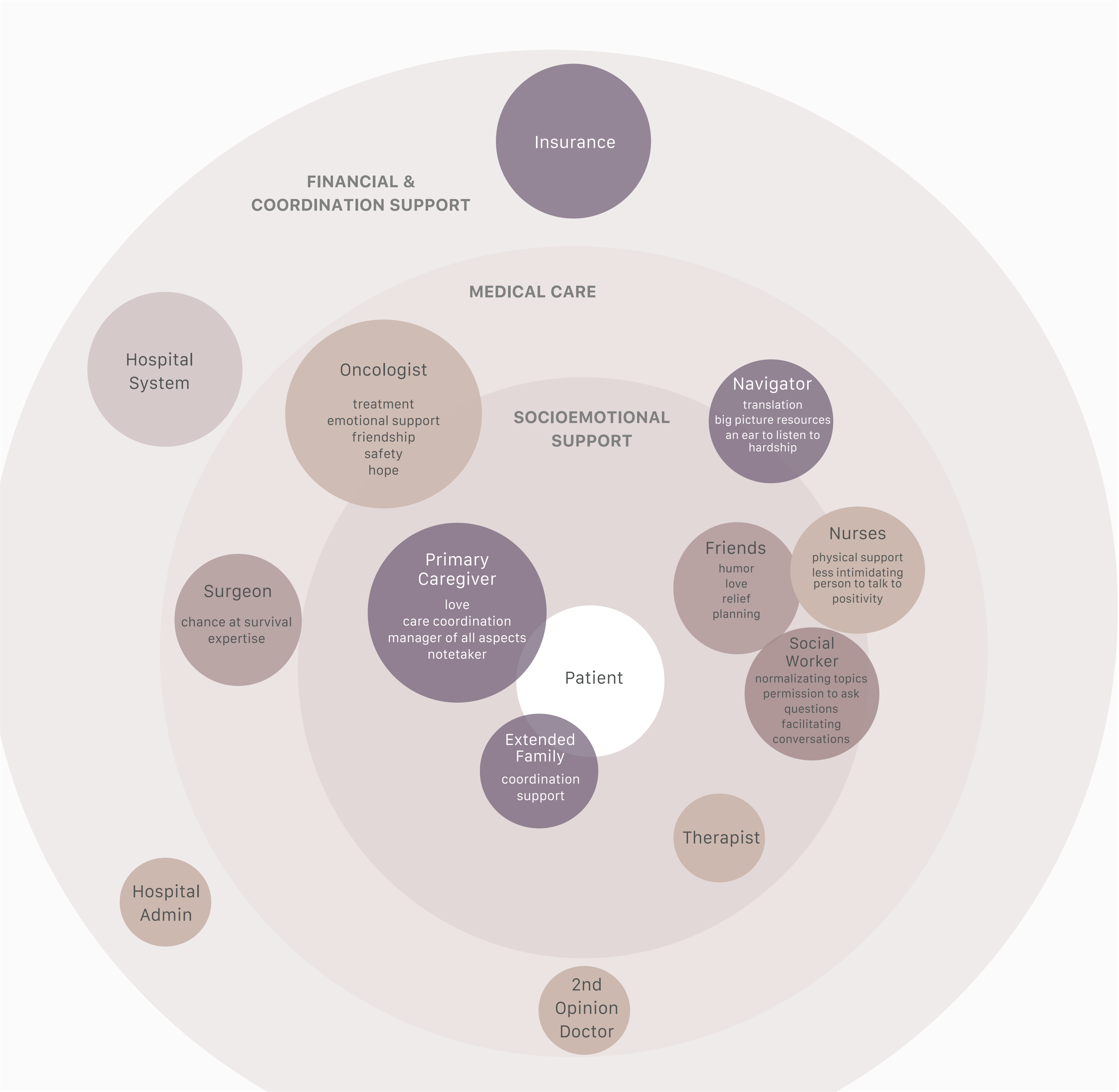
caregivers
patients
nurse navigators
social work navigators
doctors
palliative care nurses

From our interviews we learned that navigators support patients and caregivers by doing research on clinical trials, suggesting doctors for second opinions, providing transportation and emotional support services, discussing finance and insurance related issues, and translating medical jargon, diagnosis, and treatment information among so many other things.

We also learned that as an organization independent of any hospital or medical system, navigators have the unique ability to suggest resources from any institution that might be most helpful for the patient and have a bigger picture view of all the possible resources in neuro-oncology than a navigator within a hospital might have. Additionally, patients often come to BTN later in their brain tumor journey which allows BTN navigators to help them take a step back and make a wholesome evaluation of the options going forward.

> *"I just want to find the silver bullet that will solve everything for her but I know that's not possible."*
> *– CA, Caregiver*

Stakeholder Value Map



FINANCIAL & COORDINATION SUPPORT

Insurance

Hospital System

Hospital Admin

MEDICAL CARE

Oncologist
treatment
emotional support
friendship
safety
hope

Surgeon
chance at survival
expertise

2nd Opinion Doctor

SOCIOEMOTIONAL SUPPORT

Navigator
translation
big picture resources
an ear to listen to hardship

Primary Caregiver
love
care coordination
manager of all aspects
notetaker

Patient

Extended Family
coordination
support

Friends
humor
love
relief
planning

Nurses
physical support
less intimidating person to talk to
positivity

Social Worker
normalizating topics
permission to ask questions
facilitating conversations

Therapist

We used our stakeholder value map as a exercise to gain an understanding of the roles that different stakeholders play during a patient's brain cancer journey. Focusing on the value to the patient and caregiver, we found that often the caregiver is at the center of the system as much as the patient is. This is a result of the disease as it affects many patients cognitive capacities and much of the care coordination and support is taken on by the caregiver. The central role of the caregiver led to the realization that caregivers need to be taken care of as well in order to do what they need to do best. Many caregivers we spoke to regarded their navigators, nurses etc. as friends and drew strength from interaction that may not have seemed 'productive' to care providers but safe and understanding spaces for caregivers.

Define

Keeping with the HCD process, our next step was to Define who the users were with the most pressing and unique needs that we could design for to make the biggest impact.

An empathetic, overwhelmed, and heroic caregiver — Needs to feel confident in his own understanding of his daughter's condition and care — Because he feels like it's his responsibility to discover what will save his daughter

Highly adept, caring, strong willed nurse navigator with a wealth of knowledge — Needs a way to synthesize and gather information at the same time or before a patient or caregiver — Because she knows she could change the course of poorly handled medical outcomes if only she had control/access

A caring, attentive, invested mother and hard-working nurse with incredible recall — Needs to be able to put her oxygen mask on before helping others — Because she feels that weathering the storm is just part of the job & that the advice she gives to caregivers doesn't apply to her

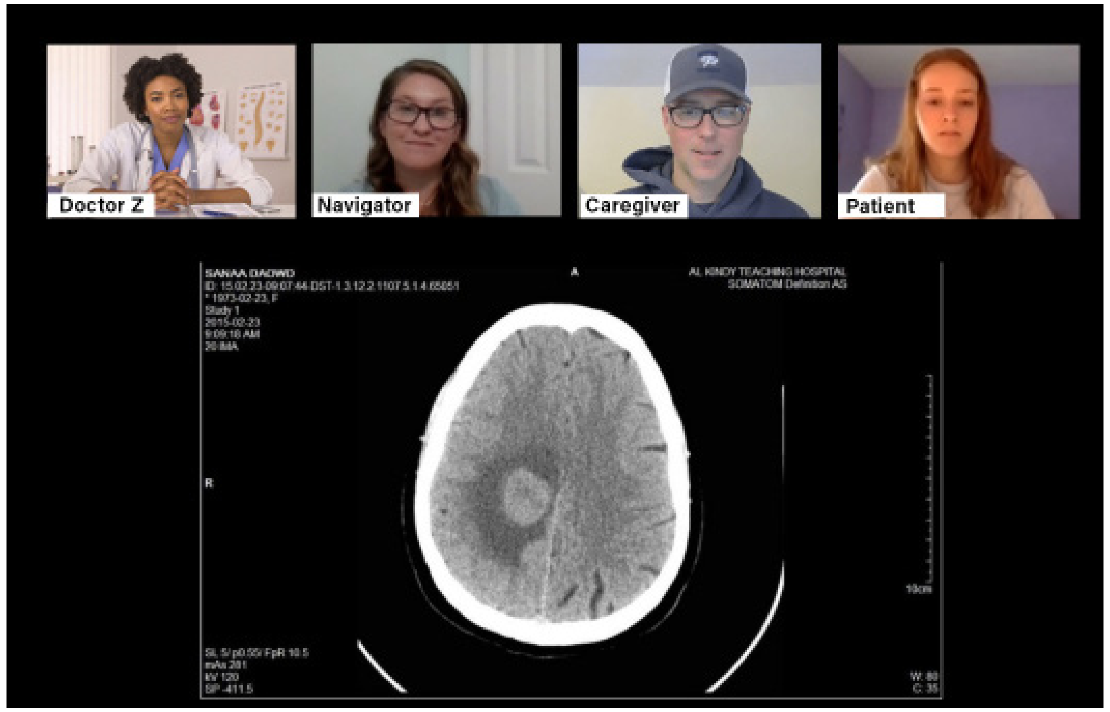
> *"If you keep it all in, in oncology, you will explode."*
>
> *– RS, Palliative Care Nurse*

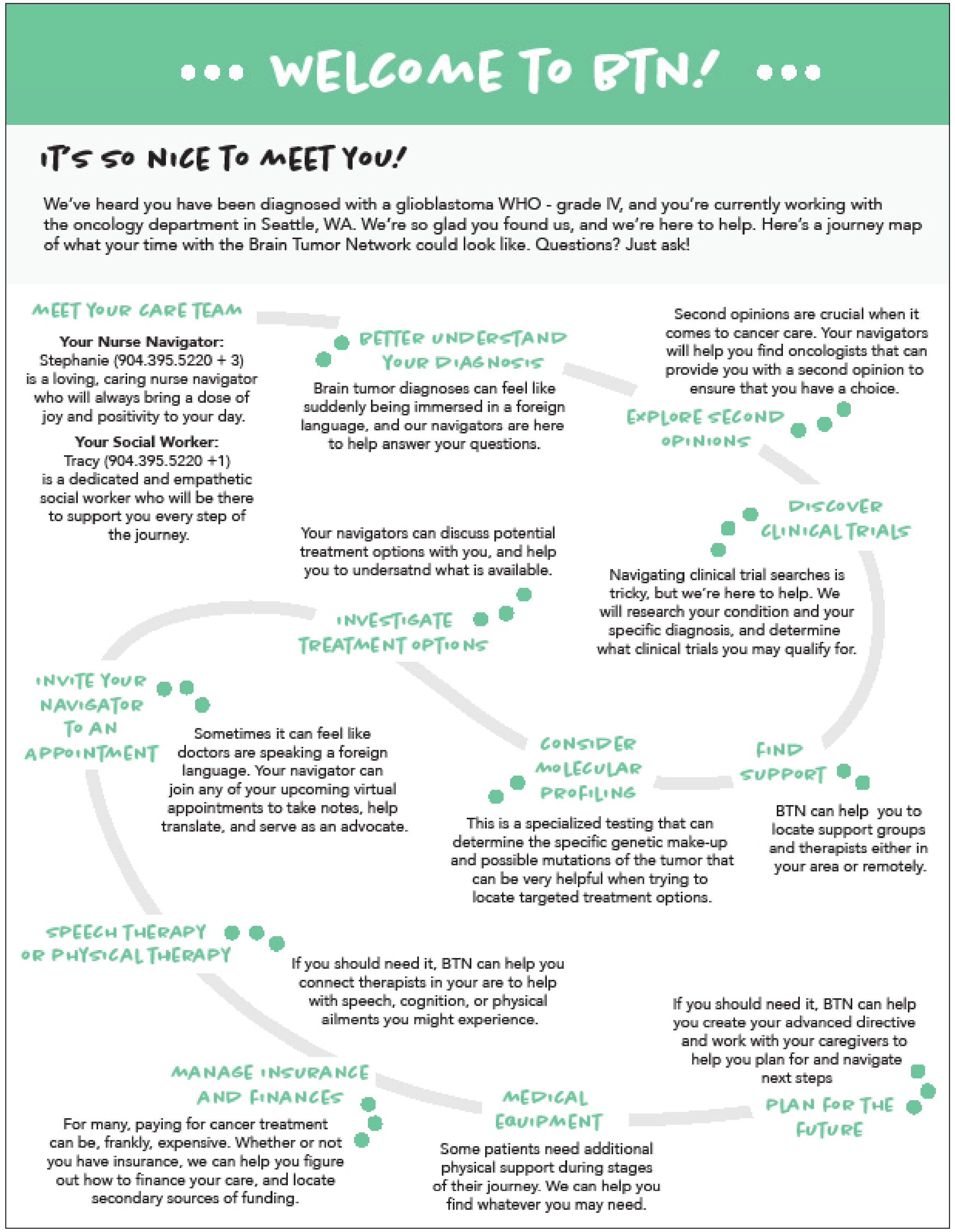
Prototype

After extensive ideating based on our users we reached two breakthrough concepts. The first was the ‘Navigator Sidekick’ which placed the navigator in video calls with the patient, caregiver, and physician. This solved the caregivers need for empowerment when it came to asking questions, a medically trained ear to take notes, emotional support and more. Additionally, having the navigator in the call diverted the need for the caregiver to relay all they heard in the appointment which often led to confusion, missed points, and use of precious time. The simplistic impact of this tool proved true as caregivers and navigators alike voiced strong support for it when we gathered feedback.

Our second breakthrough was the realization that caregivers often did not know what assistance they needed it until it was too late and that they often came to BTN looking for one thing, unaware of the plethora of services available to them. Our Brain Tumor Network Journey Map introduces BTN’s services in a way they did not have in the hopes that they can have more of an impact on a patient and caregiver’s journey from the beginning.

Navigator Sidekick





WELCOME TO BTN!

IT’S SO NICE TO MEET YOU!

We’ve heard you have been diagnosed with a glioblastoma WHO - grade IV, and you’re currently working with the oncology department in Seattle, WA. We’re so glad you found us, and we’re here to help. Here’s a journey map of what your time with the Brain Tumor Network could look like. Questions? Just ask!

MEET YOUR CARE TEAM

Your Nurse Navigator:
Stephanie (904.395.5220 + 3)
is a loving, caring nurse navigator who will always bring a dose of joy and positivity to your day.

Your Social Worker:
Tracy (904.395.5220 +1)
is a dedicated and empathetic social worker who will be there to support you every step of the journey.

BETTER UNDERSTAND YOUR DIAGNOSIS

Brain tumor diagnoses can feel like suddenly being immersed in a foreign language, and our navigators are here to help answer your questions.

EXPLORE SECOND OPINIONS

Second opinions are crucial when it comes to cancer care. Your navigators will help you find oncologists that can provide you with a second opinion to ensure that you have a choice.

DISCOVER CLINICAL TRIALS

Navigating clinical trial searches is tricky, but we’re here to help. We will research your condition and your specific diagnosis, and determine what clinical trials you may qualify for.

FIND SUPPORT

BTN can help you to locate support groups and therapists either in your area or remotely.

CONSIDER MOLECULAR PROFILING

This is a specialized testing that can determine the specific genetic make-up and possible mutations of the tumor that can be very helpful when trying to locate targeted treatment options.

INVESTIGATE TREATMENT OPTIONS

Your navigators can discuss potential treatment options with you, and help you to undersatnd what is available.

INVITE YOUR NAVIGATOR TO AN APPOINTMENT

Sometimes it can feel like doctors are speaking a foreign language. Your navigator can join any of your upcoming virtual appointments to take notes, help translate, and serve as an advocate.

SPEECH THERAPY OR PHYSICAL THERAPY

If you should need it, BTN can help you connect therapists in your are to help with speech, cognition, or physical ailments you might experience.

MANAGE INSURANCE AND FINANCES

For many, paying for cancer treatment can be, frankly, expensive. Whether or not you have insurance, we can help you figure out how to finance your care, and locate secondary sources of funding.

MEDICAL EQUIPMENT

Some patients need additional physical support during stages of their journey. We can help you find whatever you may need.

PLAN FOR THE FUTURE

If you should need it, BTN can help you create your advanced directive and work with your caregivers to help you plan for and navigate next steps

Brain Tumor Network Journey Map

Insights

After all of our work we came to the conclusion that these 5 insights were the biggest in the BTN space and the tools that we designed aimed to solve these needs in a variety of ways.

01 Navigators are instrumental translators, incredible information finders, and compassionate friends to patients and caregivers enduring difficult medical situations involving misunderstandings, bad timing, stress, and confusion.

02 Caregivers are superheroes and are at the center of the BTN care model, navigating complex situations and overloads of information, and relentlessly searching for the silver bullet to save those they are caring for.

03 Medical information is sorely in need of redesign and it’s language is almost impenetrable to those who do not “speak” it.

04 Caregivers and Patients come to BTN with a limited understanding of the wealth of resources the organization can offer them, and often do not know the services they need before they need them.

05 Restructuring to add different roles and re-envisioning their current organizational structure would allow BTN to grow and feasibly scale.

02 Understanding the Problem Space

Literature Review - Define - Systems Mapping

What Next?

Inspired by what we saw in our work with The Brain Tumor Network, we thought, oncology navigation is such an impactful tool, does it exist elsewhere? How could we improve or spread it? This became the focus of the thesis project.

Since we had done a great amount of empathy work in our BTN project understanding people’s experiences with navigation our first step of this new HCD project was to do research on navigation more broadly.

> *“It is so helpful to be able to ask, ‘Can you please explain this to me in English and is it something that will help my wife?’”*
> *–Caregiver*

Literature Review

We conducted a literature review to gain a deeper understanding of the topic area and the landscape we had been exploring with the Brain Tumor Network. It was important to us to understand the history of navigation and the variety of navigation programs that had been tested and are currently in practice in the U.S. The information we uncovered aligned with much of the empathy work we had done in our previous project and served as foundational knowledge going forward.

From our research we learned that the first navigation program was established in Harlem, NY by Harold Freeman in 1990 based on findings from the American Cancer Society National Hearings on Cancer in the Poor.

The aim of the program was to improve health outcomes in vulnerable populations by eliminating barriers to timely diagnosis and treatment of cancer through the support of a nurse navigator. Freeman designed the program so that in-hospital nurses would help individual patients overcome:

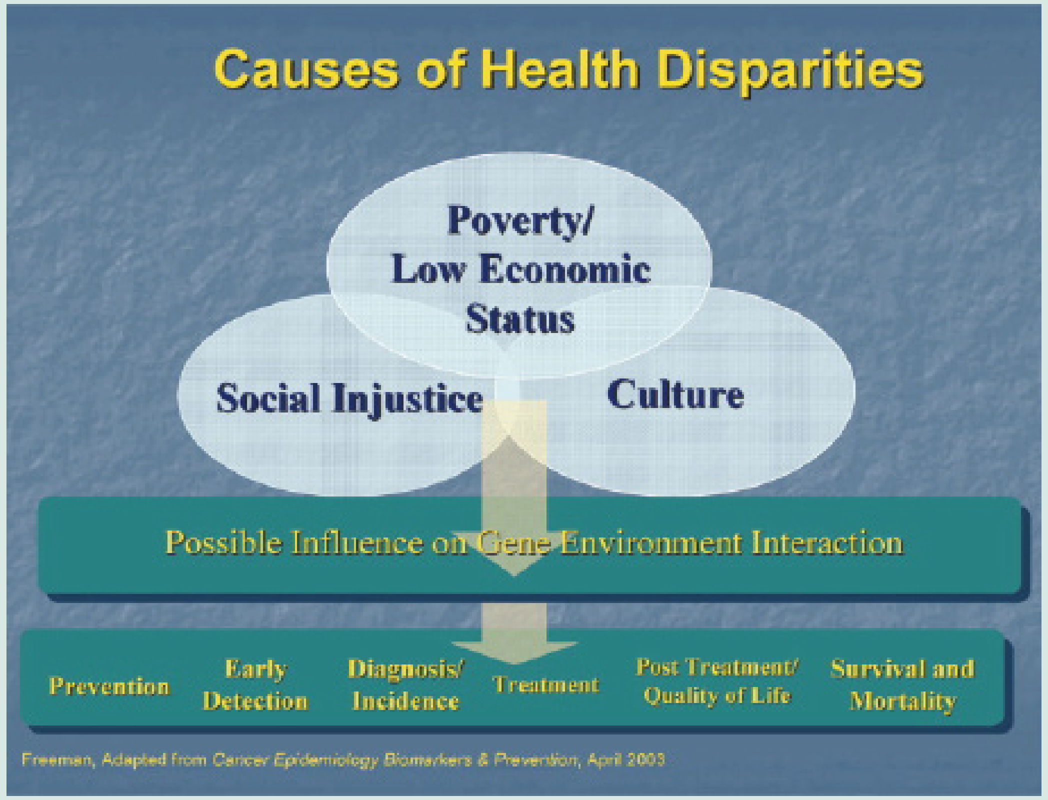
financial barriers

communication/information barriers

medical system barriers

fear, distrust, and emotional barriers

The program proved effective as cancer navigation services increased the five-year survival rate from 39% to 70% amongst breast cancer patients. These main barriers were echoed in the related studies and papers we read on navigation.



Causes of Health Disparities

Poverty/
Low Economic
Status

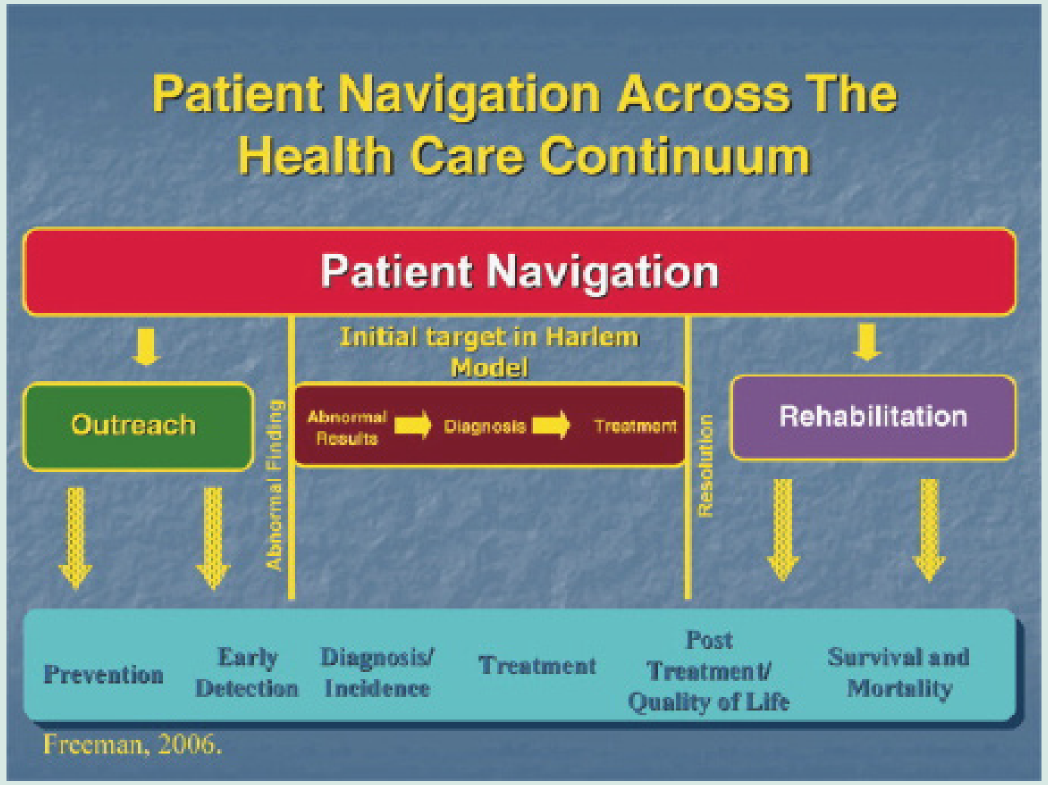
Social Injustice

Culture

Possible Influence on Gene Environment Interaction

Prevention
Early Detection
Diagnosis/ Incidence
Treatment
Post Treatment/ Quality of Life
Survival and Mortality

Freeman, Adapted from Cancer Epidemiology Biomarkers & Prevention, April 2003



Patient Navigation Across The Health Care Continuum

Patient Navigation

Initial target in Harlem Model

Outreach

Abnormal Results
Diagnosis
Treatment

Abnormal Finding

Resolution

Rehabilitation

Prevention
Early Detection
Diagnosis/ Incidence
Treatment
Post Treatment/ Quality of Life
Survival and Mortality

Freeman, 2006.

"History and Principles of Patient Navigation"
Freeman, 2011

Navigation Models

Through our research we found that oncology navigation does exist beyond BTN but that there is no one definition of what a navigator does. Navigation services in the studies we read all aim to achieve similar goals but come in a variety of forms. Beyond studies on the efficacy of navigation systems, we researched which major healthcare systems have oncology navigation services and the definitions of navigation that exist in the Academy of Oncology Nurse & Patient Navigators.

In the 30+ studies we read we saw three main types of naviation. In-hospital, independent organization, and lay navigation.

	In-Hospital Navigation	Independent Organization	Lay Navigation
Prevention	- no involvement	- no involvement	- fosters relationship between community and local physicians - healthcare literacy work
Screening / Early Detection	- coordinates screenings - explains results	- no involvement	- coordinates screenings for community members - explains importance of healthcare with cultural sensitivity
Diagnosis	- ensures connection with physician to understand diagnosis - provides information and hospital resources for next steps	- provides emotional support, translation to understand diagnosis - big picture next steps, 2nd opinion, treatment options	- link between patient, community physician, and cancer center - explains medical information in lay terms
Treatment	- schedules appointments - ensures follow ups occur and medical information is received	- advises on financials & insurance - reviews all possible clinical trials - gives transportation and socioemotional resources	- helps allay fear and distrust of medical system - emotional support - assists with scheduling
Post Treatment	- follow up check in calls - connects patient to quality of life resources	- follow up check in calls - connects patient to quality of life resources	- follow up check in calls - connects patient to quality of life resources
Survival & Mortality	- connects to in-hospital support groups	- provides grief resources - check up calls, emotional support	- knowledge of cultural practices around grief - provides emotional support

What is a Navigator?

Once we saw the variety of navigator roles that exist we layed out all we had learned about their duties to try and define oncology navigation and find a topic we could design for, either an aspect of navigation we could improve or configuration of navigation we could try to spread.

Additionally, since navigator's duties spanned a wide range of topics and expertise, we wondered, is there one configuration of the navigator role that is most effective? After combining research from our literature review and prior interviews we saw that Navigator duties mainly fall into 4 categories:

Socioemotional Support
Care Coordination
Education & Health Literacy
Equity/Access to Care

Socioemotional Support

Subthemes

- emotional support
- stress management
- compassion
- decision making support
- family dynamic support
- empathy
- understandable communication

HMWs

- HMW quantify the impact that navigators have on socio emotional support
- HMW create structure for the social relationship between Navigator and patient or caregiver?
- HMW help NN's accept how close they are to their patients and the reality of their relationships
- HMW allow for patients and NN's to feel like they have a real relationship and not just a professional one
- HMW influence Navigators to pay attention to the emotional level of conversations with patients?
- HMW make empathy the first part of treatment for any condition
- HMW gain an understanding of Navigators feelings towards being emotional supports?
- HMW balance Navigators' desire to 'get things done' and patient's need for emotional connection?
- HMW recognize to the need of a patient needing someone to call and check in?
- HMW help NN's see the benefit in engaging with their patients on a human level and not professional

Directions

- Expand the use of support groups
- Create structure for emotional guidance of patients
- how to talk to a doctor class
- Publish information on the social impact of navigators
- Have navigators teach social / emotional skills to doctors

Data

- Lay navigators were a source of emotional support - "reflecting on this experience, we feel that they were not fully prepared for the stress related to caring for patients with cancer" #10
- "Our experiences show that the navigators helped to close the gap for patients to reach diagnostic resolution by providing logistical, social, and/or emotional support." #10
- Lay navigators being culturally attuned to the population led to them being trusted on an emotionally deeper level #10
- Relationship-building was also a critical aspect of patient care and called for the hiring of an experienced oncology nurse who possessed the appropriate clinical knowledge and sensibility to facilitate the development of a trustful relationship with patients #16
- Vital aspect of the program was the development of trusting and therapeutic relationships which patient improved well-being - through one-on-one relationships between the navigator and the patient #10
- In today's multifaceted oncology care environment, even with shared electronic medical records (EMRs), it is difficult for specialists to communicate, and the human dimension is lost when care is not adequately personalized; the attempts at efficiency perhaps serve system rather than patient.

Insights

- navigator takes holistic approach to help with a variety of issues
- navigator can be a source of comfort in an otherwise cold experience
- Should we rely on navigators to fill this gap or would it be better to teach doctors how to make space for emotional aspect?
- How much training is needed to provide adequate emotional support in these situations?
- Humans/nurses have inherent empathy skills but may not know how to handle the effect it will have on them personally
- Is there tension between oncology doctors and nurses because nurses tend to be closer emotionally to patients?
- Social experience of interacting with doctor is often really anxiety producing
- having a navigator coordinate care can reduce patient stress
- Lay navigator can provide a more nuanced emotional support if they are culturally attuned but may not be able to handle the effect on themselves
- Would it be better to have one navigator doing research tasks and one providing emotional support/ education?
- Maybe a team would be more efficient and effective than trying to teach one person to be the 'perfect' navigator
- we aren't taught how to interact with doctors - we see them as an entity not a person
- are nurses taught how to support patients emotionally or is it a byproduct of the position?
- Would navigator programs be more highly utilized if we could show the positive impact emotional support has on physical health outcomes?
- If we can't get navigators that are personally culturally attuned to their patient population how might we give them tools to better understand individuals environmental & cultural points of view?
- leads to so much stress for patients, who feel more comfortable engaging with navigator or nurse

Care Coordination

Subthemes

- bridge communication between patient and doctor
- patient advocacy
- care deliberation
- second opinion location
- treatment coordination between stakeholders
- appointment scheduling and immediacy of care

HMWs

- HMW cut the wasted time and tortured waiting out of the system
- HMW make being remote a benefit that helps them do their jobs better?
- HMW create a system that notifies bad news to people in the "right time" when they are with "the right people"
- HMW make the care coordination process more visual?
- HMW put the patient at the center of the care coordination
- HMW we increase empathy throughout the care coordination process?
- HMW make the care coordination process more automatic?
- HMW put the care back in care coordination
- HMW improve timeliness of care starting pre-diagnosis
- HMW employ a navigator for everyone regardless of condition
- HMW allow more time for treatment deliberation?
- HMW utilize the communication styles that work best for patient/doctor respectively

Directions

- Creating guidelines / structure for how Navigators should act/ be/help in call with doctors
- Create something to help caregiver communicate their needs and navigator communicate what they can help
- Creating more structure for the relationship between caregiver and navigator

Data

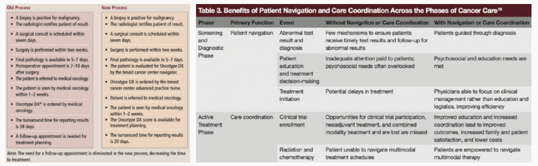


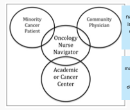
Table 3. Benefits of Patient Navigation and Care Coordination Across the Phases of Cancer Care

Note. The need for a follow-up appointment is eliminated in the new process, decreasing the time to treatment.

- They commented that the nurse navigator answered their questions and understood their situation, and 81% reported that the nurse navigator created coherence in their BC trajectory
- Role of N is to "Respect and augment the existing bond between the patient and her community physician by engaging the community physician as a partner and advocate for clinical trials." #16
- Navigation system was received favorably by cancer center which benefitted patients, primary care docs and Navigators in separate ways
- For community physician, role of oncology nurse navigator is to facilitate physician participation in CTs by keeping the physician informed about available trials, coordinating referrals to clinical investigators, and reducing community physician trial-related workload by providing in-office assistance with patient screening, treatment , follow-up, and symptom management #16
- In a trial out of Harlem Hospital, introducing cancer navigation services increased five-year survival rate from 39% to 70%
- Interestingly the entire multidisciplinary research team met regularly to discuss active cancer cases to strategize on navigation actions #10
- "The primary care community clinics and hospitals participating in the study established a system in which the navigators were integrated as part of the clinic team." #10
- Contributing to the success of the oncology nurse navigation program: building a noncompetitive relationship with providers that respected the relationship between community physicians and their patients #16
- Lay navigators essentially served as a "vital link" between the patients' providers, schedulers, social services department, and the patients' community #10
- In this randomized pilot study, we found that 83% of 139 women agreed to participate indicating that the intervention is meaningful to women with BC.
- Attention to Caseload Distribution: contributed to more effective use of financial and personnel resources, overall navigator morale and satisfaction through distribution of cases, and ultimately enhanced patient care. #10
- the program focused on adding value to the community practice by expanding the treatment options physicians were able to offer their patients #16

Insights

- pre-diagnosis
- diagnosis to consultation
- consultation to treatment
- treatment to end of life



- navigator can interact with community physician
- maybe navigator interfaces directly with doctors as well
- Further explore the navigator in call method
- In some cases it is more helpful to have the navigator be a part of the healthcare system but in other ways not
- How do we balance and make the most of both of these benefits?
- Benefits of navigator programs to cancer centers often need to be proven beyond just the benefit it provides patients - HMW explore and synthesize these benefits?
- Can we map out all the ways that various navigator roles coordinate care?
- BTN navigators mainly do research and provide resources but in-hospital navigators facilitate connections and appointments etc
- Could be helpful to further explore the relationship between doctor and navigator - working together or at odds?
- Would be helpful to ask navigators if they feel being part of the clinic team is helpful or having autonomy is better
- Depending on the type of navigator the care coordination tasks vary
- Do patients often engage in care deliberation twice - once with doctor and once with navigator? which is more helpful?
- Mere existence of navigator quickens amount of time between checkups/ procedures - catalyst for scheduling and moving things along

Education / Health Literacy

Subthemes

- healthcare system literacy / education
- cancer / personal diagnosis literacy
- medical terminology education
- navigating the digital healthcare space
- translation of medical information

HMWs

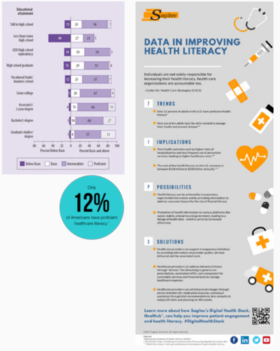
- HMW childlike education tools on cancer that will make it seem less scary for everyone
- HMW increase the comfort of engaging with the healthcare system?
- HMW educate the general public about cancer so that it is not so scary when it happens to people
- HMW help caregiver feel in control during research
- HMW intervene in healthcare literacy before it matters?
- HMW streamline the education process for cancer care
- HMW we make the conversations between patients and doctors more approachable
- HMW shrink the communication gap between doctor and caregiver / patient
- HMW we incorporate disease education into the patient's treatment
- HMW automate some of the decisions made where timeliness is important
- HMW we utilize the skills of those who have high health literacy
- HMW we rethink treatment as a learning opportunity

Directions

- Implement some form of translation tool
- dictionary of medical jargon / information for lay navigators to use to teach patients
- Make learning modules for learning about brain tumors

Data

- Through customized navigation strategies, guided by the nurse supervisor, it was anticipated that patients and their families would become empowered partners in their healthcare. #10
- "Navigators spent large amounts of time explaining how to get an appointment, how to figure out the financial steps of applying for charity or low-income assistance programs, or where support resources were located-detailed explanations were often needed" #10
- ★ High information demands placed on patients, lay navigators learned from nurses how to deconstruct information, made use of pictures and drawings, made glossaries of simplified information #10
- Lay navigators struggled with steep learning curve for Medical/Clinical terminology #10
- Lay navigators worked closely with project nurse supervisor and patient's primary oncology and nursing team members to accurately relay information #10



Insights

- age difficulty with literacy/tech
- biggest decision you'll make in cancer journey is when you are least educated

"I have signed a lot of papers without reading. I figure they ain't gonna give me nothing to sign if it's bad."

Ncbi

- does information need to be taught or presented in different ways depending on cultural environment?
- certain cultural attitudes toward healthcare may need to be considered when explaining healthcare systems and importance of certain medical steps

Equity / Access to Care

Subthemes

- broad community outreach
- financial / insurance barriers
- shifting / augmenting cultural perceptions and fears of healthcare
- connection to resources / awareness / education of resources
- health literacy education
- mitigating socioeconomic disparity

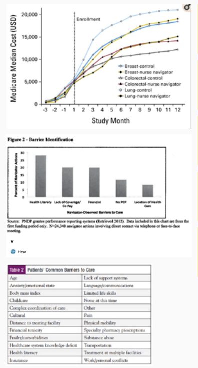
HMWs

- HMW provide resources to all patients without providing them all individual navigators?
- HMW we remove the financial barriers to care?
- HMW we encourage conversations with doctors about bias?
- HMW increasing knowledge of care increase access to care
- HMW identify the perceived barriers of care that aren't there?
- HMW shift cultural perceptions of doctors
- HMW identify communities that are in most need of care?
- HMW we make the financial barriers to care more upfront?
- HMW bring more medical attention into communities that need it most
- HMW we make the access to care more equitable
- HMW use navigators to facilitate discussions of access to care
- HMW mitigate socioeconomic disparity?

Directions

- working to creating knowledge of navigator services to certain populations

Data



- Barriers to care include financial barriers, lack of health insurance, communication and information barriers, medical system barriers, and fear/distrust/emotional barriers
- Healthcare is the number one cause of bankruptcy in America.
- Culturally attuned: "provide effective, equitable, understandable, and respectful quality care and services that are responsive to diverse cultural health beliefs and practices, preferred languages, health literacy, and other communication needs" #10
- Among all men and women, the 5-year survival for all cancers combined is 10% lower in the poor than in more affluent Americans
- Most cancer clinical trials (CTs) are only accessible at academic and cancer centers - most cancer patients receive treatment in their home communities where access to CTs may be limited
- They took time to get know the patients, listened to their concerns, identified ways to deconstruct and simplify health information in language specific terms
- this represented a positive step toward the repair of a "broken" healthcare system for eliminating myriad barriers to cancer diagnosis and treatment. #10
- Lay navigators were culturally attuned & familiar with the everyday situational realities of the communities they served
- Battaglia showed that patient navigation among minority, low-income patients in Boston had 39% greater odds of timely diagnostic follow-up w/ navigation #15
- mission of oncology nurse navigation was to provide office-based outreach to newly diagnosed minority patients seeking care in the offices of community physicians #16
- Overcoming barriers to minority patient participation in cancer research requires the development of cost-effective, evidence-based strategies to increase CT awareness and facilitate community-based recruitment of patients to cancer CTs #16
- Most current data shows improved cancer-related health outcomes with patient navigation involve programs that provide navigation during the screening and diagnostic resolution phases of early cancer management #15
- Residential distance from academic or cancer centers is a significant barrier to minority patient participation in cancer research. #16
- introduction of lay advocates into navigation programs is a relatively recent occurrence and reflects the need to recontextualize the patient's health care experience within the frame of the social determinants of health as well as disease processes #15
- "Especially in under-resourced and low-literacy settings, we have found that taking a community-based approach, by involving the target audience in the content creation process, is more likely to yield health education programs that are truly rooted in the contexts of the communities they intend to serve."
- Fillion reported significantly fewer hospitalizations among head and neck cancer patients who received patient navigation compared with a historical control group who did not receive patient navigation services at their institution #15
- Freeman's navigation model showed that patient navigation significantly improved diagnostic resolution of suspicious screening tests (88% received biopsy with patient navigation vs 57% without patient navigation) among low-income women in Harlem undergoing screening mammography #15
- In 1990, McCord and Freeman determined that an African American male in Harlem has less of a chance of surviving to age 65 than a male in Bangledesh
- Access barriers are exacerbated for groups of marginalised young people. For example, cost particularly affects low income and homeless young people, confidentially concerns and service location were more prominent for young people living in rural areas, discrimination affects gender and sexuality and gender diverse young people, and cultural issues were salient for refugee and Indigenous young people [4].
- shame, stigma, cost, transportation, and confidentiality were concerns identified through a study on marginalized groups in Australia

Insights

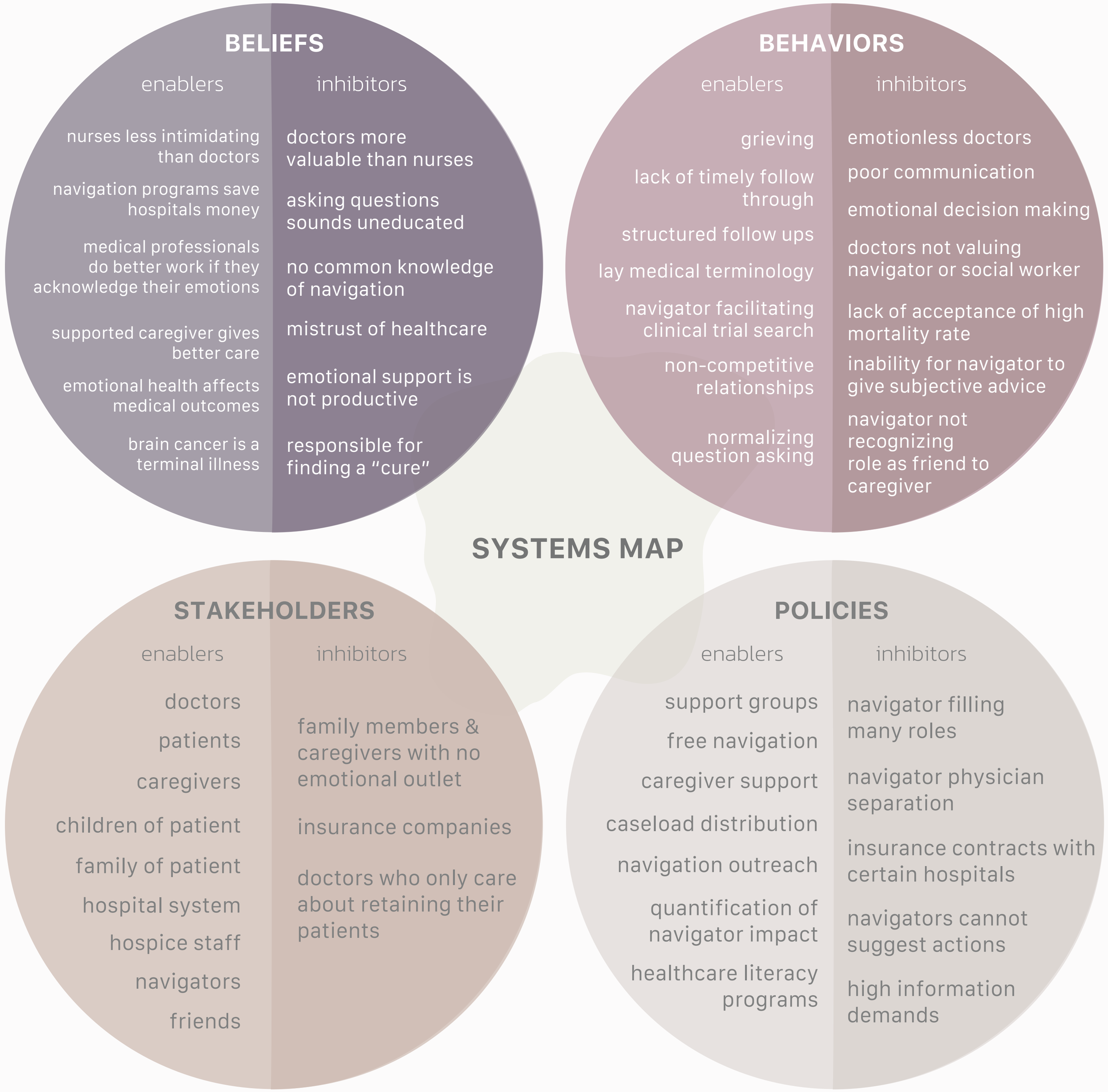
- fixing one barrier will not help because it is the confluence of barriers that hold people back

"If somebody can't afford the roof over their heads or food on their table, you can talk all you want about checking, getting your hemoglobin and being seen and following your diet, but if they have no money for food or the electricity is being turned off tomorrow, they're way more concerned about that."

- What if everyone had a cancer care team even if they didn't have cancer?
- Or if everyone knew what to look for (signs of cancer)?
- Steph: How do we intervene before we've even connected with the patient? It didn't have to go the way it did
- she wishes when patients get a diagnosis, they could get a ping from BTN. Patients wish they could've found out about BTN earlier
- Really helps to have navigators who are culturally attuned to who they are working with but if they aren't medical professionals then they face other issues such as medical jargon and content, and emotional coping strategies → How do you get the best of both worlds in a navigator?

System Mapping

To combine the insights we heard in our interviews with BTN and the research we did through our literature review we attempted to map out aspects of the oncology navigation system. We knew that every specific aspect of the system affected others and that we could not focus on designing for one problem without touching others so we felt it was important to take a look at the system as a whole.



SYSTEMS MAP

BELIEFS

enablers
- nurses less intimidating than doctors
- navigation programs save hospitals money
- medical professionals do better work if they acknowledge their emotions
- supported caregiver gives better care
- emotional health affects medical outcomes
- brain cancer is a terminal illness

inhibitors
- doctors more valuable than nurses
- asking questions sounds uneducated
- no common knowledge of navigation
- mistrust of healthcare
- emotional support is not productive
- responsible for finding a "cure"

BEHAVIORS

enablers
- grieving
- lack of timely follow through
- structured follow ups
- lay medical terminology
- navigator facilitating clinical trial search
- non-competitive relationships
- normalizing question asking

inhibitors
- emotionless doctors
- poor communication
- emotional decision making
- doctors not valuing navigator or social worker
- lack of acceptance of high mortality rate
- inability for navigator to give subjective advice
- navigator not recognizing role as friend to caregiver

STAKEHOLDERS

enablers
- doctors
- patients
- caregivers
- children of patient
- family of patient
- hospital system
- hospice staff
- navigators
- friends

inhibitors
- family members & caregivers with no emotional outlet
- insurance companies
- doctors who only care about retaining their patients

POLICIES

enablers
- support groups
- free navigation
- caregiver support
- caseload distribution
- navigation outreach
- quantification of navigator impact
- healthcare literacy programs

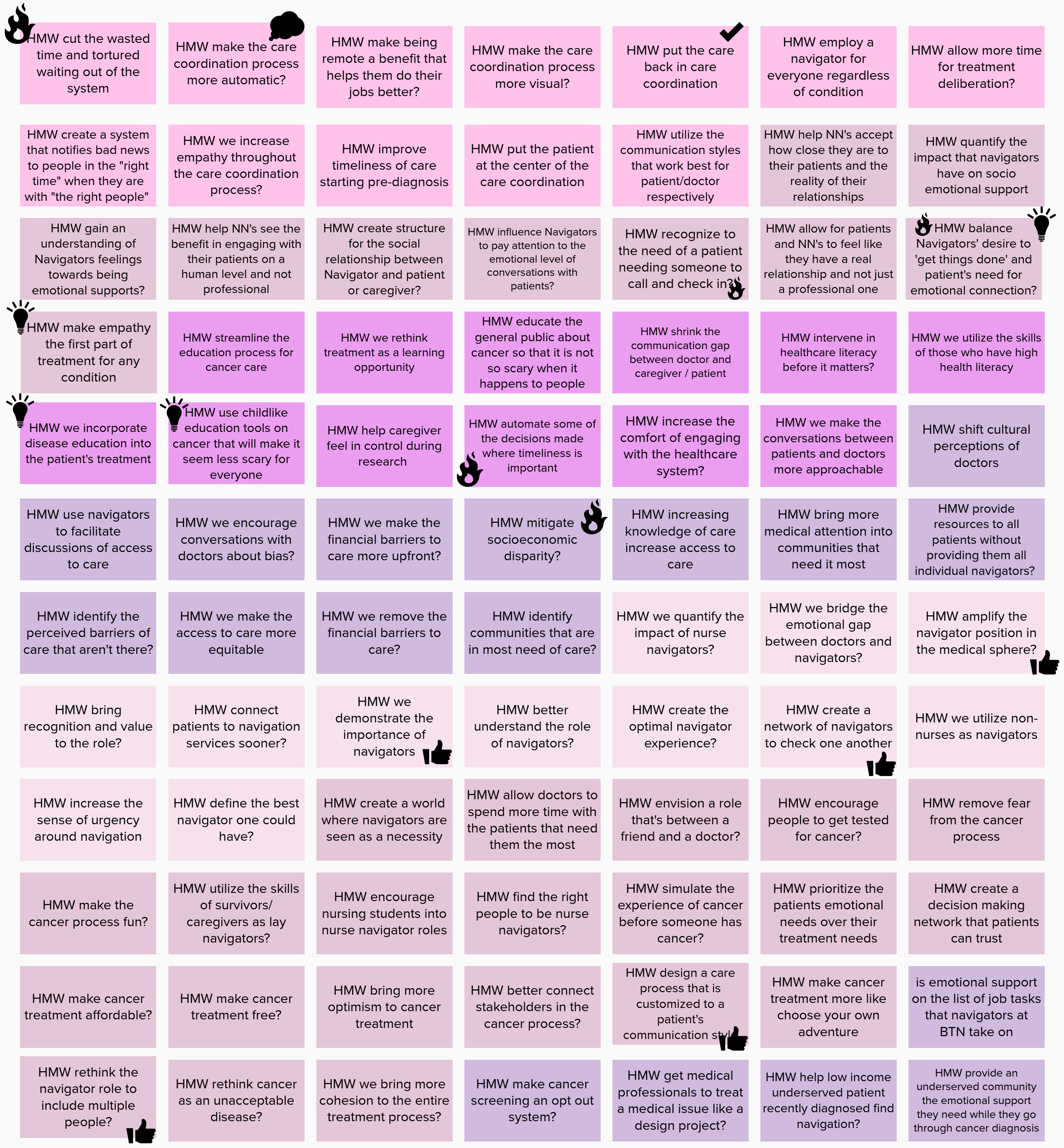
inhibitors
- navigator filling many roles
- navigator physician separation
- insurance contracts with certain hospitals
- navigators cannot suggest actions
- high information demands

Areas of Opportunity

With the whole world of oncology navigation open to us we needed to narrow our focus to a specific problem space to ideate and prototype for. We did this by writing How Might We questions, creating 2x2 frameworks to understand types of actors in the system, and defining emerging themes and directions that could use attention.

We landed on several topics that we were interested in pursuing:

- Equity / bringing navigation to underserved communities
- Helping navigators deal with the emotional support their jobs require them to do / the heavy topics they deal with
- Amplifying the importance of navigation in the medical world



HMW cut the wasted time and tortured waiting out of the system	HMW make the care coordination process more automatic?	HMW make being remote a benefit that helps them do their jobs better?	HMW make the care coordination process more visual?	HMW put the care back in care coordination	HMW employ a navigator for everyone regardless of condition	HMW allow more time for treatment deliberation?
HMW create a system that notifies bad news to people in the "right time" when they are with "the right people"	HMW we increase empathy throughout the care coordination process?	HMW improve timeliness of care starting pre-diagnosis	HMW put the patient at the center of the care coordination	HMW utilize the communication styles that work best for patient/doctor respectively	HMW help NN's accept how close they are to their patients and the reality of their relationships	HMW quantify the impact that navigators have on socio emotional support
HMW gain an understanding of Navigators feelings towards being emotional supports?	HMW help NN's see the benefit in engaging with their patients on a human level and not professional	HMW create structure for the social relationship between Navigator and patient or caregiver?	HMW influence Navigators to pay attention to the emotional level of conversations with patients?	HMW recognize to the need of a patient needing someone to call and check in?	HMW allow for patients and NN's to feel like they have a real relationship and not just a professional one	HMW balance Navigators' desire to 'get things done' and patient's need for emotional connection?
HMW make empathy the first part of treatment for any condition	HMW streamline the education process for cancer care	HMW we rethink treatment as a learning opportunity	HMW educate the general public about cancer so that it is not so scary when it happens to people	HMW shrink the communication gap between doctor and caregiver / patient	HMW intervene in healthcare literacy before it matters?	HMW we utilize the skills of those who have high health literacy
HMW we incorporate disease education into the patient's treatment	HMW use childlike education tools on cancer that will make it seem less scary for everyone	HMW help caregiver feel in control during research	HMW automate some of the decisions made where timeliness is important	HMW increase the comfort of engaging with the healthcare system?	HMW we make the conversations between patients and doctors more approachable	HMW shift cultural perceptions of doctors
HMW use navigators to facilitate discussions of access to care	HMW we encourage conversations with doctors about bias?	HMW we make the financial barriers to care more upfront?	HMW mitigate socioeconomic disparity?	HMW increasing knowledge of care increase access to care	HMW bring more medical attention into communities that need it most	HMW provide resources to all patients without providing them all individual navigators?
HMW identify the perceived barriers of care that aren't there?	HMW we make the access to care more equitable	HMW we remove the financial barriers to care?	HMW identify communities that are in most need of care?	HMW we quantify the impact of nurse navigators?	HMW we bridge the emotional gap between doctors and navigators?	HMW amplify the navigator position in the medical sphere?
HMW bring recognition and value to the role?	HMW connect patients to navigation services sooner?	HMW we demonstrate the importance of navigators	HMW better understand the role of navigators?	HMW create the optimal navigator experience?	HMW create a network of navigators to check one another	HMW we utilize non-nurses as navigators
HMW increase the sense of urgency around navigation	HMW define the best navigator one could have?	HMW create a world where navigators are seen as a necessity	HMW allow doctors to spend more time with the patients that need them the most	HMW envision a role that's between a friend and a doctor?	HMW encourage people to get tested for cancer?	HMW remove fear from the cancer process
HMW make the cancer process fun?	HMW utilize the skills of survivors/ caregivers as lay navigators?	HMW encourage nursing students into nurse navigator roles	HMW find the right people to be nurse navigators?	HMW simulate the experience of cancer before someone has cancer?	HMW prioritize the patients emotional needs over their treatment needs	HMW create a decision making network that patients can trust
HMW make cancer treatment affordable?	HMW make cancer treatment free?	HMW bring more optimism to cancer treatment	HMW better connect stakeholders in the cancer process?	HMW design a care process that is customized to a patient's communication styl	HMW make cancer treatment more like choose your own adventure	is emotional support on the list of job tasks that navigators at BTN take on
HMW rethink the navigator role to include multiple people?	HMW rethink cancer as an unacceptable disease?	HMW we bring more cohesion to the entire treatment process?	HMW make cancer screening an opt out system?	HMW get medical professionals to treat a medical issue like a design project?	HMW help low income underserved patient recently diagnosed find navigation?	HMW provide an underserved community the emotional support they need while they go through cancer diagnosis

03 The Honor Project

Needs - Impact - Barriers - Implementation

The Honor Project

01 Workplace intervention for multidisciplinary team in medical settings with high mortality rates

02 Decorative shelf in staff-only area; team members invited to write the name of the patient on a card and place on shelf

03 Addresses grief through once monthly meetings

04 Each patient’s name said aloud, moment of silence, & invitation to share memories, reflections

05 Occasional song, poem, or reading shared

06 Shared chocolate to “ease the bitterness of death, and remind us of the sweetness of life”

Surprise Solution

After all of our research and efforts to narrow our focus we felt that we needed to interview more individuals on the topics we were interested in going into to gain further direction. Through our interviews we spoke with Rosemary Rossi, a clinical social worker in the neuro-oncology clinic in the UCSF Brain Tumor Center. We learned about the Honor Project, a meaning-centered team intervention to address the loss and grief staff working in neuro-oncology experience.

Rosemary, the Honor Project founder, saw the impact of the program at UCSF and wanted to spread it to other hospitals. Since designing for navigators dealing with the emotional heaviness of their jobs had been a previous interest of ours, we were excited by the existence of this program. With Rosemary as our co-designer, we took on the project of figuring out how to get other neuro-oncology clinics to see the Honor Project’s benefit and implement it.

Is There a Need?

To tackle the problem of spreading the Honor Project we needed to do empathy research in 3 areas:

Need for Grief Support Services in Neuro-Onc/Oncology beyond UCSF
Impact of the Honor Project at UCSF
Barriers to Implementation

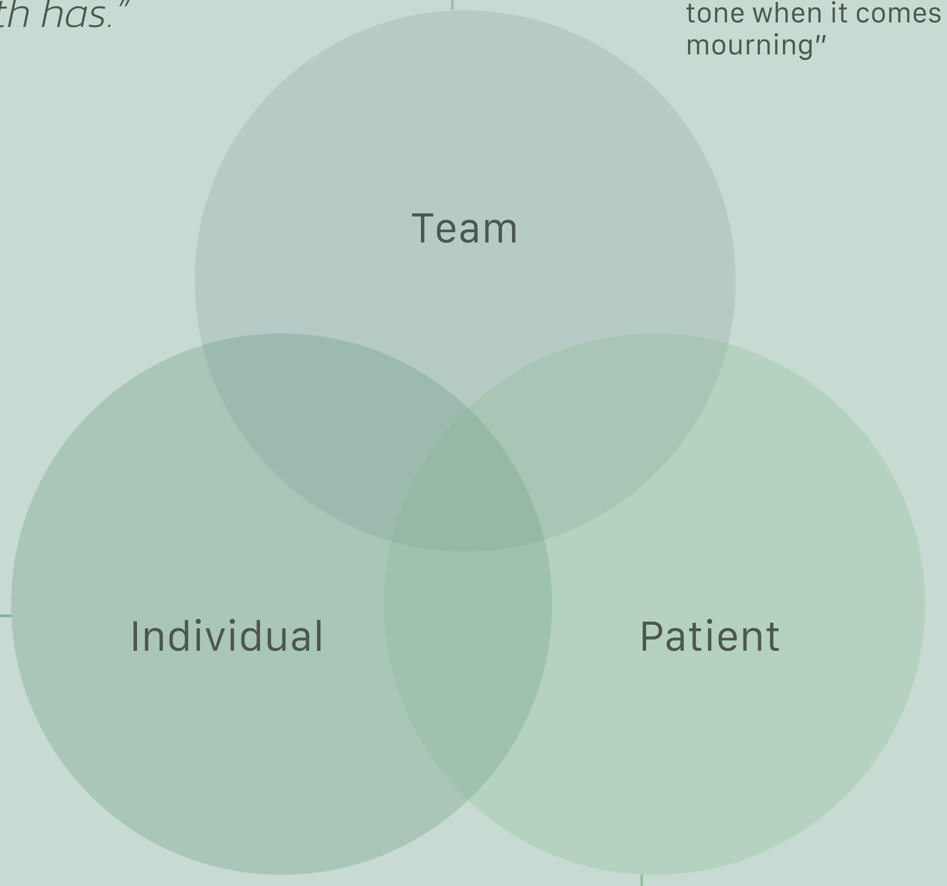
By combining insights from interviews during our Brain Tumor Network Project and with UCSF staff, information from studies, and oncology team members experiences posted on Quora we were able to gain a full understanding of the culture and sentiments around how medical providers deal with working in settings with high mortality rates.

We wanted to see, is there a need for something like the Honor Project? In the areas of grief impact personally on medical providers, on medical teams, and subsequently on patients and their families, the answer was a resounding yes.

“We are physicians not robots, we have every human emotion every other person on earth has.”

“The unique thing about grieving for me as a physician is that I usually have to grieve alone.”

“Sometimes you might feel a power dynamic between different staff members; higher ups set the tone when it comes to vocalized mourning”



“As physicians, we’re so inundated by the needs of others that we fear becoming overwhelmed. But detaching ourselves from normal human emotions leads only to burnout, not relief.”

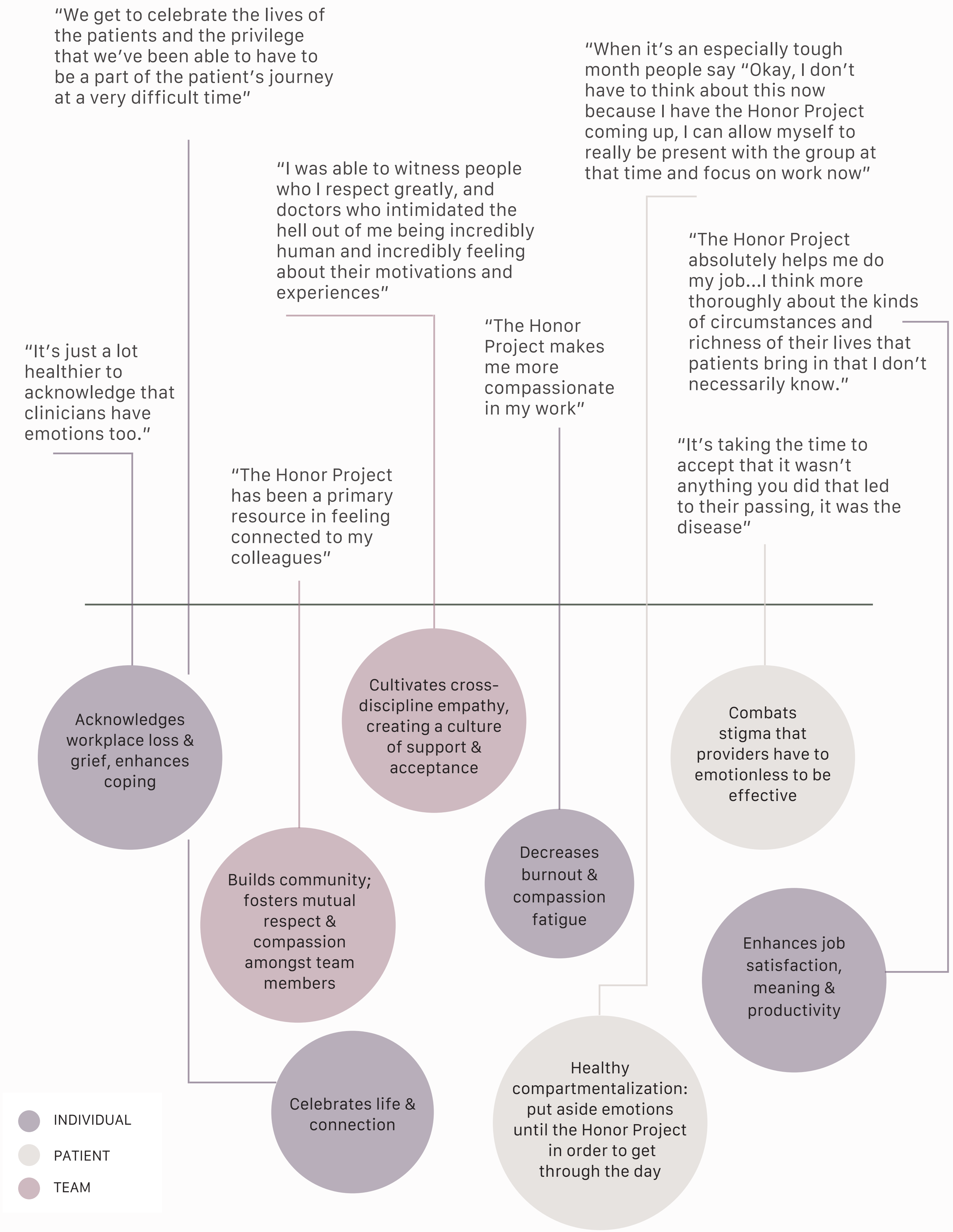
“Oncologists are trained on loss from a patient and family perspective but not trained on how to deal with the loss ourselves”

“When I stop crying, it will be time for me to retire. So, yes, I cry every single time a patient dies. All of my patients matter to me as people, and I mourn their loss.”

“Discomfort with their grief can affect decisions with subsequent patients”

“Tension between growing close enough to care about the patients but remaining distant enough to avoid the pain of the loss when the patient dies”

“Withdrawal from patients & difficulty communicating with patient and their family”



"We get to celebrate the lives of the patients and the privilege that we've been able to have to be a part of the patient's journey at a very difficult time"

"When it's an especially tough month people say "Okay, I don't have to think about this now because I have the Honor Project coming up, I can allow myself to really be present with the group at that time and focus on work now"

"I was able to witness people who I respect greatly, and doctors who intimidated the hell out of me being incredibly human and incredibly feeling about their motivations and experiences"

"The Honor Project absolutely helps me do my job...I think more thoroughly about the kinds of circumstances and richness of their lives that patients bring in that I don't necessarily know."

"It's just a lot healthier to acknowledge that clinicians have emotions too."

"The Honor Project makes me more compassionate in my work"

"It's taking the time to accept that it wasn't anything you did that led to their passing, it was the disease"

"The Honor Project has been a primary resource in feeling connected to my colleagues"

Acknowledges workplace loss & grief, enhances coping

Cultivates cross-discipline empathy, creating a culture of support & acceptance

Combats stigma that providers have to emotionless to be effective

Builds community; fosters mutual respect & compassion amongst team members

Decreases burnout & compassion fatigue

Enhances job satisfaction, meaning & productivity

Celebrates life & connection

Healthy compartmentalization: put aside emotions until the Honor Project in order to get through the day

● INDIVIDUAL
○ PATIENT
● TEAM

Impact

With the knowledge that there was a need for support when it comes to dealing with grief for medical providers we needed to ensure that the Honor Project addressed and impacted the same areas of need.

We did this by interviewing a wide variety of staff members at UCSF who participate in the Honor Project.

clinical social worker
clinical trial coordinator
social work resource coordinator
clinical nurse specialist
neuro-oncology nurse
neuro-oncologist
neuro-oncology supportive services coordinator

In order to show other clinics that the Honor Project could solve the needs their team members were facing we gathered data to back our claim up.

Empathy Mapping

Throughout the steps of our project we used empathy maps to break down the information we gathered in interviews into insights that would further our broad understanding of the problem space. Breaking down information in this way brought to light assumptions, actions, beliefs, and emotions that may not have been directly spoken by the individual but were clear through allusion, inference, body language, or tone.

In this interview for example, we were able to gather that the neuro-oncology clinical social worker we spoke to feels strongly that grief acknowledgement among healthcare workers is important and when laying the information out visually could see the connections between her career history, personal experience, and that belief.

SAYS

- “I thought, wow, I don’t know if I can do this job if there’s not something that I can change here around grief”
- "I’m really grateful you asked about the Honor Project, I feel so proud of it"
- “When we push something out, what we resist persists”
- “My role is about giving permission, normalizing and lifting prohibitions to speak about things”
- “In the face of someone’s death, the whole person would come to life, it was beautiful”
- “Sometimes it feels like my role is as a waterpaper basket, I was like am I your handmaid or something?”

THINKS

- Realized there was no space to process grief together for the medical pros
- Thinks emotion can often skew balancing quality of life vs aggressive treatment
- Is more attuned to the emotional aspects of the situation because she was a private psychotherapist before
- Thinks caregiver support & open lines of communication are so important to help emotion not trump logic
- Thinks it’s important for doctors to process grief especially because they’re usually told to not ever get emotional
- Thinks healthy compartmentalization is helpful to continue working in an environment with so much loss

DOES

- Did a training with Zen hospice caregiving programming so knows the importance of addressing grief
- Half working on the caregiver program, half direct interfacing with patients
- Focuses on making an emotional connection with caregivers so they know they’re not alone on the journey
- Picks up on questions or topics that caregiver is not ready to talk about or wants to but doesn’t know it’s okay to ask

FEELS

- Understands the pain of ambiguous little incremental losses caregivers experience throughout the journey
- Feels happy that doctors are amazing people but notices that they sometimes miss the more human aspects of interaction
- Felt upset by feeling like a low person on the totem pole as a social worker, not respected
- Feels incredibly grateful that the current doctors respect and value her opinion and seek it out

Barriers to Implementation

Once we had found the need for grief acknowledgement and support and cemented that as our solution, the Honor Project, solved the need, it was necessary to investigate how to get clinics onboard to adopt it and barriers they might have to being amenable to such an idea.

Through our interviews and research we found 4 main categories which stood in the way of easy implementation of the Honor Project. These were imperative to understand as we knew we would have to be sensitive to them when presenting the Honor Project, it was important to not turn anyone off by touching these hotspots.

Logistics & Time Constraints

"Time constraints are the number one issue to implementation of something like this, hard to come up with time for something that's not clinical."

"I didn't know how it was going to fit into my schedule, I was worried, but we make time for it and now that it's in my routine it works and is very integral."

Emotionless Medical Stigma

"Caring that deeply for a patient keeps one from being objective and it really makes it tons harder to deliver shitty news."

"We protect ourselves from overly empathizing, because if you do that, it would be very hard."

'Built for This' Ideology

"I think if you are an emotional person and it gets to you, you leave oncology, because you know, you can't handle it, it's not a bad thing."

Sentiment that you either have it in you to deal with the emotional toll of oncology or you do not

Physician Failure Mentality

"Sometimes there is a mentality that physicians don't want to accept that they can't do anything more, they don't want to admit defeat, this can lead to an attitude of death meaning failure, if that's the case then how could you possibly get together and talk about the patient's who have died?"

"I feel...like a failure [when I have to inform them that their loved one died]..."

Define & Ideate

With our goal of getting the Honor Project into more clinics we needed to define who exactly we would be targeting in our efforts. While there are a wide variety of individuals who can benefit from the program, from the physicians and nurses to the administrative staff and clinical trial researchers, it was important to narrow our focus on who to design our implementation materials for. We wanted to have the highest chance of the program being adopted so we needed to define the various users and see their relationships in order to understand who might be best to take on implementation and therefore who we should target in our dissemination materials and efforts.

After defining our users we ideated ways we could spread the information about and impact of the Honor Project, made prototypes, and tested them with individuals we had previously interviewed.

Points of View - Prototype - Testing

Defining Users

When looking through the users we created Points of View for we came to the conclusion that it would be best to create our materials on the Honor Project around the neuro-oncologist physician as they often set the tone when it comes to the emotional opennes of a clinic. From our interviews we learned that it is imperative to get the chiefs of the departments to sign off on and support such programs for the highest probability of team members attending so we felt it would be smartest to design our presentation of the Honor Project in a manner that neuro-oncologists could see themselves reflected in the experiences we represented.

Hardworking, well meaning neuro-oncology physician

Needs community acknowledgement that they have human emotions like everyone else

Because otherwise they will remain closed off as they believe the medical culture assumes that to be a good doctor they have to be emotionless and stern

Dedicated & worn out oncology nurse overwhelmed by suppressed and unprocessed grief

Needs to feel worthy of the grieving process

Because the medical culture pressures her to suppress the human need to grieve in order to maintain good judgement and be a "good nurse"

Invested & experienced neuro-oncology social worker, committed to efficiency and impact

Needs guidance and support to accept brain cancer as a terminal illness and still maintain positivity

Because without this, the emotional burden of trying to 'save' his patients will burn him out

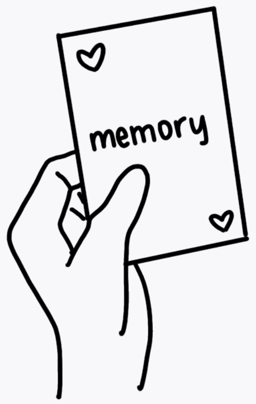
Ideation

Now came the part of the project when we asked, what could we make that would get the Honor Project out into the world?

Idea generation in most Human-Centered Design projects is focused on coming up with a brand new, out of the box concept to serve a need. While we also were focused on creative concepts our design problem was in regards to spreading an existing solution rather than coming up with a new solution altogether.

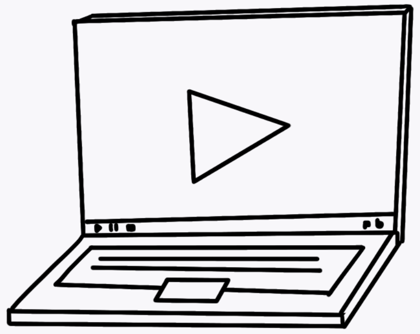
Reflecting on Human-Centered Design at this juncture helped me reaffirm my belief that it is a tool that can be used in a wide variety of ways. A tool such as HCD is a framework, and frameworks can be applied as directed step by step or in a winding, reconfigured pattern. I found great value in using HCD to solve the problem of spreading an existing solution and in this way our ideate phase was not focused on generating solutions to help medical staff healthily process grief but how to convince team members it was important and convey the impact that the Honor Project could have on them and their colleagues.

Honor Project Card Deck

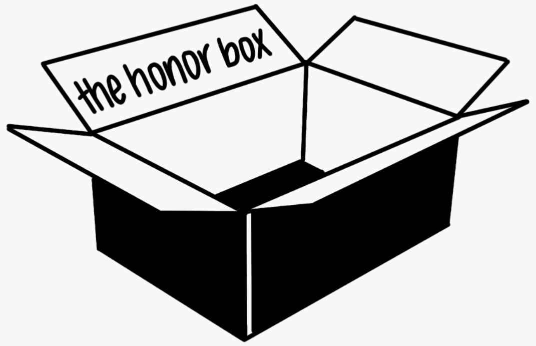


Honor Project 'Recipe'

Honor Project Video



Honor Project Kits

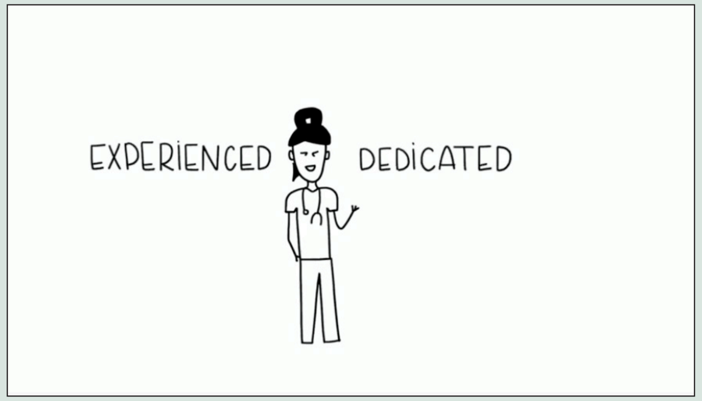


Concept Development

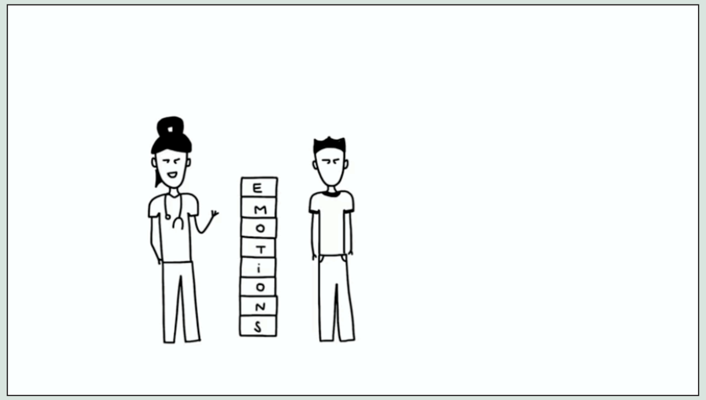
After ideation and checking in with our co-designer Rosemary, we landed on a video, with my partner Kaitlyn's wonderful visuals, as the concept that would be most effective in getting the Honor Project out into the world and implemented.

The hope behind the video was to exemplify an emotionally relevant story which medical staff could relate to and see then see the potential that The Honor Project could have on their lives and subsequently the experiences of their team members.

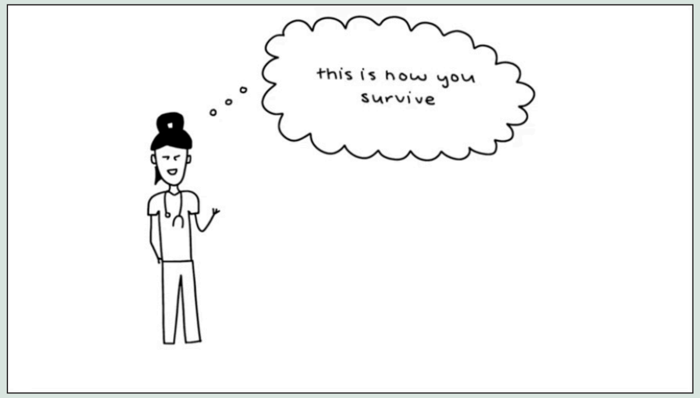
Several iterations of our storyline and script later, we created a prototype of the video itself. We tried to include as many points about the benefits of The Honor Project as well as touch on the barriers to implementation and buy in.



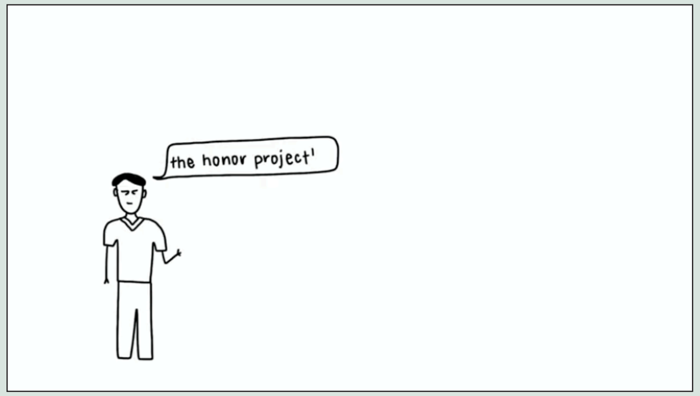
Meet Emily. Emily is an experienced and dedicated neuro-oncologist. Although she loved her work, she often felt worn out by the inevitability of death.



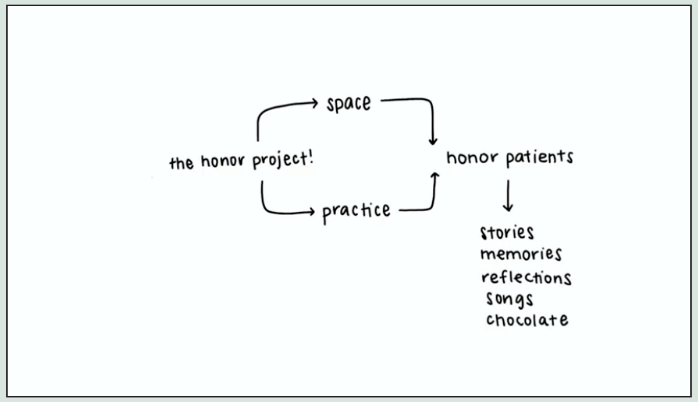
Over the years, she found herself desensitized to death, building up a wall between herself and her patients. This is what successful physicians do, she told herself.



This is how you maintain sound judgement and remain professional. This is how you survive.

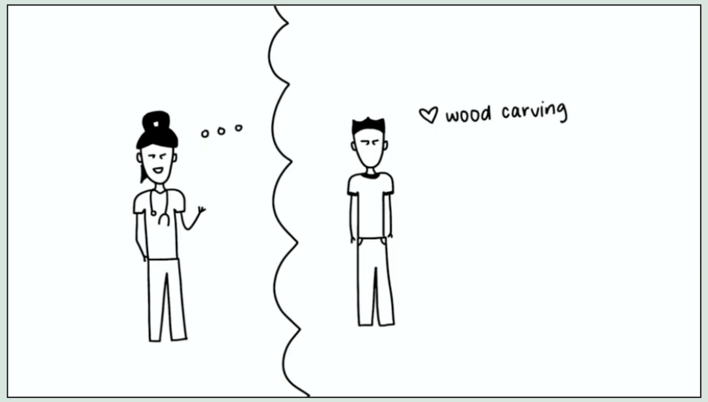


Until one day, her chief introduced the Honor Project.

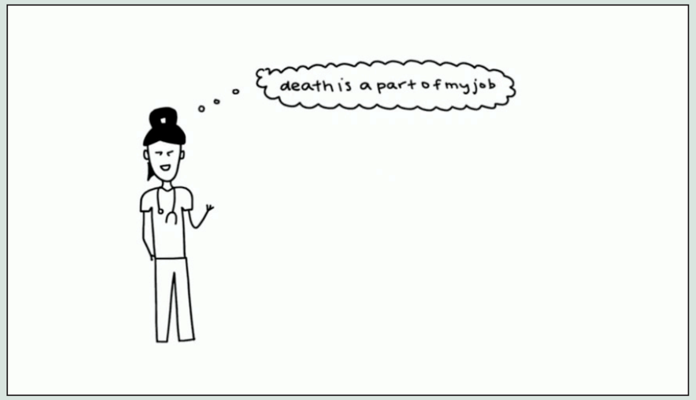


The Honor Project is a space and a practice where the entire multidisciplinary team gathered together each month to honor the patients who had died and support one another. Sharing stories, memories, reflections, songs, and chocolate.

This isn't for me, Emily thought. She was built for oncology.



The very next day, she received news that a long time patient suddenly died. His love of wood carving and kind demeanor reminded her of her own father.



She took a deep breath, and reminded herself that dealing with death was a part of her job.... continues to THE END.

Testing & Feedback

We showed our video prototype to the UCSF staff members we had interviewed as well as a few other medical providers we knew from the Brain Tumor Network and elsewhere. The feedback we recieved was very valuable as we wanted to ensure the video would land well with healthcare staff and sound accurate medical language wise.

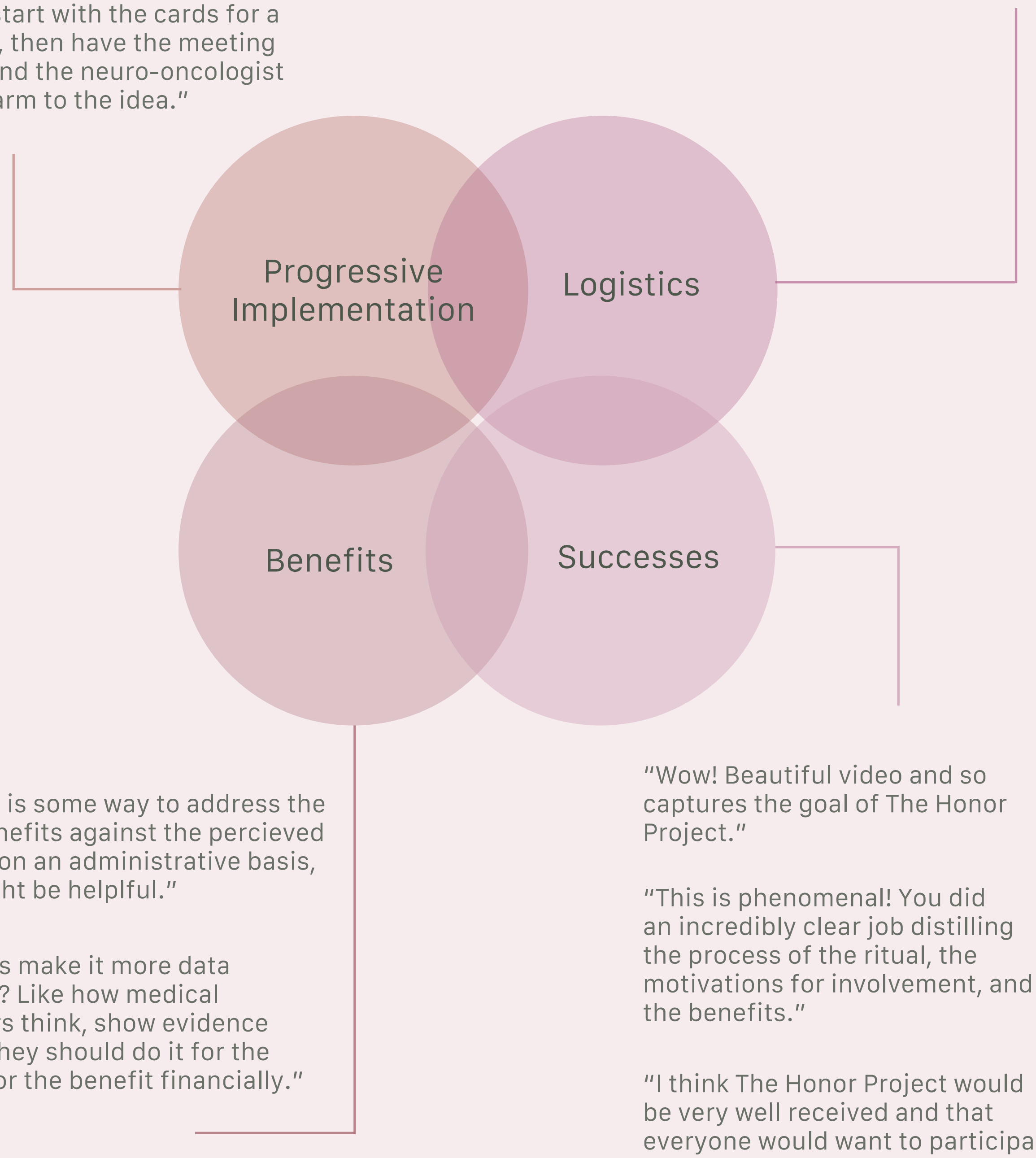
We knew a short video would be most effective and because of that there was no way to fit every point we wanted to make about The Honor Project into it. The goal of the video was to touch people and take them through the emotional journey of an individual experiencing grief and The Honor Project benefits. With the feedback on addressing costs, data, and logistics we came to the conclusion that an accompanying document would be the best place for this information.

"The unique thing about grieving for me as a physician is that I usually have to grieve alone."

"Needs to be a slow implementation, people will not buy into it right away, maybe have phases, start with the cards for a while etc, then have the meeting portion and the neuro-oncologist slowly warm to the idea."

"I still do think there could be value addressing how this might be prioritized or accomplished in a busy health care world."

"No one has time in this field, so maybe don't mention how long it takes."



"If there is some way to address the staff benefits against the percieved "costs" on an administrative basis, that might be helplful."

"Perhaps make it more data focused? Like how medical providers think, show evidence of why they should do it for the patient or the benefit financially."

"Wow! Beautiful video and so captures the goal of The Honor Project."

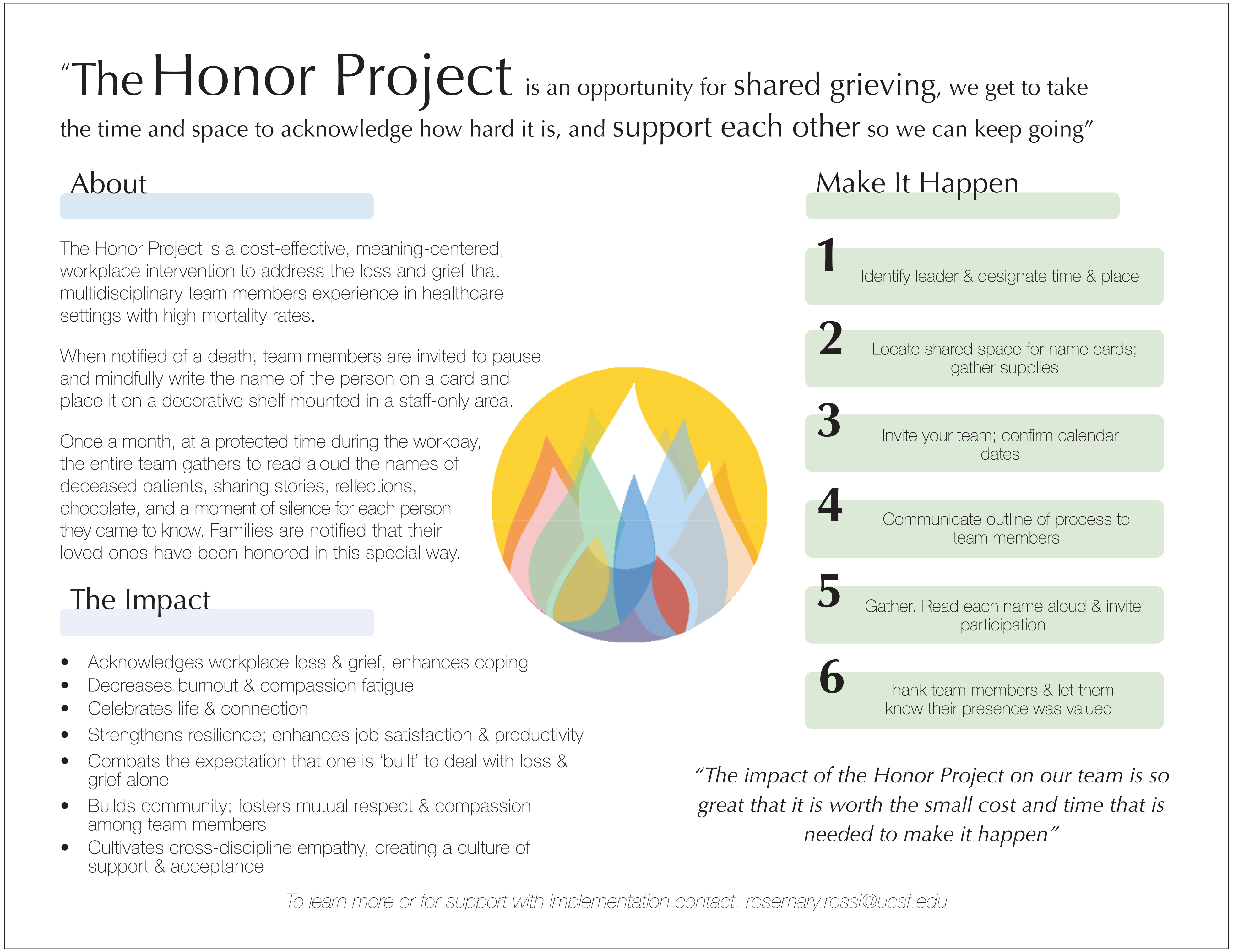
"This is phenomenal! You did an incredibly clear job distilling the process of the ritual, the motivations for involvement, and the benefits."

"I think The Honor Project would be very well received and that everyone would want to participate in my department if one of our head doctors and I showed this video and brought the program to our team."

Implementation Guide

To ensure that the message of our video led to action and implementation of the Honor Project at other clinics we created an Implementation Guide to further spell out the steps and aspects of the program.

We made sure to clearly spell out the benefits of the Honor Project as well as distinctly show how to make this program happen. There had been a worry expressed in our testing of the video that the administrative and logistical aspect should be mentioned in some form which we addressed through a quote on cost and time.



"The Honor Project is an opportunity for shared grieving, we get to take the time and space to acknowledge how hard it is, and support each other so we can keep going"

About

The Honor Project is a cost-effective, meaning-centered, workplace intervention to address the loss and grief that multidisciplinary team members experience in healthcare settings with high mortality rates.

When notified of a death, team members are invited to pause and mindfully write the name of the person on a card and place it on a decorative shelf mounted in a staff-only area.

Once a month, at a protected time during the workday, the entire team gathers to read aloud the names of deceased patients, sharing stories, reflections, chocolate, and a moment of silence for each person they came to know. Families are notified that their loved ones have been honored in this special way.

The Impact

- Acknowledges workplace loss & grief, enhances coping
- Decreases burnout & compassion fatigue
- Celebrates life & connection
- Strengthens resilience; enhances job satisfaction & productivity
- Combats the expectation that one is 'built' to deal with loss & grief alone
- Builds community; fosters mutual respect & compassion among team members
- Cultivates cross-discipline empathy, creating a culture of support & acceptance

Make It Happen

1 Identify leader & designate time & place

2 Locate shared space for name cards; gather supplies

3 Invite your team; confirm calendar dates

4 Communicate outline of process to team members

5 Gather. Read each name aloud & invite participation

6 Thank team members & let them know their presence was valued

"The impact of the Honor Project on our team is so great that it is worth the small cost and time that is needed to make it happen"

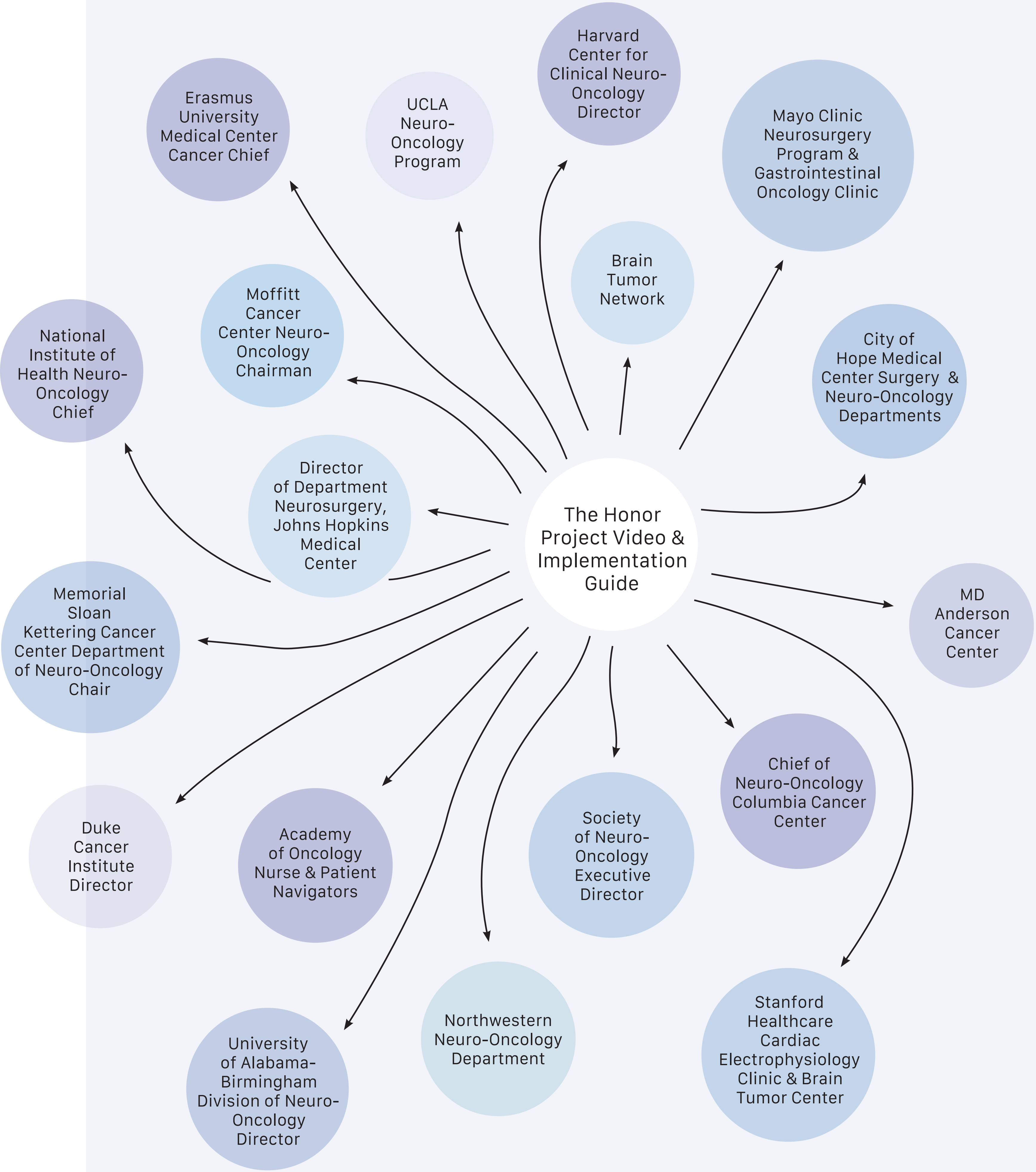
To learn more or for support with implementation contact: rosemary.rossi@ucsf.edu

Sharing the Materials

After creating our materials and a website, *thehonorproject.org*, for them to live, we gathered the names and contact information of the directors of the top neuro-oncology, brain tumor, and neurosurgery clinics and centers across the country.

Dr. Susan Chang, the director of the UCSF Division of Neuro-Oncology, kindly sent our materials out as we agreed that they would have the most success landing and garnering responses if they came from a respected individual in the community.

Along with our materials we created a short survey which was included in the emails. The aim of the survey was to create a place for questions, suggestions, feedback, and to ask if individuals were interested in implementing The Honor Project with their healthcare team. We wanted to make sure we had a way to track the success of our materials.



The Honor Project Video & Implementation Guide

Erasmus University Medical Center Cancer Chief

UCLA Neuro-Oncology Program

Harvard Center for Clinical Neuro-Oncology Director

Mayo Clinic Neurosurgery Program & Gastrointestinal Oncology Clinic

Brain Tumor Network

Moffitt Cancer Center Neuro-Oncology Chairman

National Institute of Health Neuro-Oncology Chief

City of Hope Medical Center Surgery & Neuro-Oncology Departments

Director of Department Neurosurgery, Johns Hopkins Medical Center

Memorial Sloan Kettering Cancer Center Department of Neuro-Oncology Chair

MD Anderson Cancer Center

Chief of Neuro-Oncology Columbia Cancer Center

Duke Cancer Institute Director

Academy of Oncology Nurse & Patient Navigators

Society of Neuro-Oncology Executive Director

University of Alabama-Birmingham Division of Neuro-Oncology Director

Northwestern Neuro-Oncology Department

Stanford Healthcare Cardiac Electrophysiology Clinic & Brain Tumor Center

"We could be the guinea pigs at Mayo Clinic, we could start it and then share two months later how it has affected us and how it has made a difference in our day to day life, and get more buy in from the whole department."

"My colleague is in cardiology and has lost 30 patients this year due to Covid. The psychological burden these physicians face is immense and unaddressed. Passing your video along. Love the concept and thought of this."

"This video is super well-done, and I love the concept of The Honor Project. I would be happy to learn more about this. I will also include others in our City of Hope neuro-oncology team who may be interested as well."

Responses

While we continue to receive responses and track the impact of our materials and efforts we have heard from several individuals who are interested in implementing The Honor Project with their healthcare team.

So far, the Honor Project has been implemented at *MD Anderson Cancer Center* and is in the process of being implemented at the *National Institute of Health*, *Miami Cancer Institute*, *Dana-Farber Cancer Institute*, and the *Duke Cancer Institute*.

We look forward to seeing the reach and impact of the program and continuing to hear how The Honor Project and grief acknowledgement and support practices transform individual and team experiences in medical spaces.

04 Reflection & Acknowledgements

Design In Healthcare

Throughout this process I came to understand Human-Centered Design (HCD) even more than I had before. It is a tool with a unique ability to reach human experience and feeling that is rarely expressed in day to day life and in other design processes. This was clear to me through the responses we got on our video and even simply on the quotes we gathered throughout our interviews. There is a raw beauty in the attentive and acceptive listening of HCD that allows for individuals to express themselves safely and trust that the designer is in it as an act of service and not with a goal of production or self-aggrandizement. Especially when discussing topics as heavy and personal as a brain cancer diagnosis I learned that the interview portion of the process is one of the most critical and impactful stages that requires preparation and personal reflection. It is imperative to consider one's own situated identity when asking questions about others and to reflect on the effect of one's presence overall.

As for HCD as a tool in medicine, the most important insight I gathered is that healthcare *is* Human-Centered Design. Diagnosing is empathy and problem solving, treating is ideation, and prototyping. Because of these similarities, HCD can be a perfect tool to help fill in the gaps to make healthcare better.

Since medical professionals have such expertise curing and helping people, the analytical and technical aspects of the experience and environment can be concentrated on to an extent that misses the human element of healthcare. This is where I find Human-Centered Design to fit perfectly into the medical space, to bridge the scientific and the technical with the emotional. When we think about going to the doctor so many of us have fears about asking questions, sounding uneducated, not wanting to doubt the expert, these are all emotional aspects to the experience of healthcare and physician-patient relationship that we have no structure for. While the medical field clearly does an excellent job treating people, Human-Centered Design can help provide tools and frameworks to make the feeling aspect of the experience more comfortable for all involved.

Co-Design

One of the most impactful aspects of this project with UCSF and the work I did last semester with the Brain Tumor Network was the opportunity I had to co-design with professionals in the healthcare field.

What I've gathered most from this process is that Human-Centered Design should be empowering, not extractive. In the end you as a designer are creating something for a user. You will move on to your next project but the user will continue to engage with your creation. This fact makes it imperative that users feel ownership over the tool and that their thoughts, concerns, and preferences have been taken into account. It is possible to take a user's feedback into account during the testing stage but the next level of excellent design is bringing them along through the entire design process, teaching them why you're doing what you're doing, and how to employ HCD in their own lives. This will leave them with the tools and the confidence to use your creation and alter and spread it further if they desire, so that it can live on and they can thrive after you have left.

While co-design is an imperative and fulfilling practice it can sometimes be difficult, as are all collaborative efforts. One effect of doing a design project working to spread a solution to a need that someone else made, as we did with The Honor Project, was a fear that we were going to do something that our co-designer disagreed with or felt encroached on her creation. It was sometimes difficult to know when we could make decisions without passing them by our co-designer or to figure out where our roles began and ended.

Despite this it was incredibly fulfilling to work with our co-design partners on both The Honor Project and Brain Tumor Network portions of our project. We created close, trusting relationships and felt that the work we did together was mutually beneficial.

Acknowledgements

I would like to thank my partner on this project, Kaitlyn Paulsen, for her incredible work ethic, genius insights, positivity, and humor. This project would not be what it is without her and I am very grateful that I had the opportunity to work on an impactful topic with such an exceptional designer and friend.

A large thanks goes to Fred Leichter my Human-Centered Design major sponsor, thesis reader, and mentor. Fred’s unwavering support and teaching has guided me through my college career and opened my mind to topics and possibilites that inspire me and positively impact the world. My gratitude goes to Fred for opening so many doors for me and for being an incredible mentor and friend.

Additionally, I sincerely appreciate all the invaluable guidance, insight, and support from my co-designers, advisors, colleagues, family, and friends who made my Human-Centered Design major and this thesis possible:

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Contact: a.zimsmith1@gmail.com