

Needfinding plan

Focus

- Explore dynamics of family caregiving throughout surgical proceedings
- Press into the ways human interaction or lack thereof impacted patient's experience
- Probe the complex interplay between providing care and support for a patient but also caring for yourself

Stakeholders

We're trying to understand an issue that plays out at multiple scales. Right now, we're zooming into three key stakeholders:

1. Patients who have gone through surgery
2. Family members who provided support/given care
3. Doctors and hospital admin who interact with family members regularly

We'll then sketch out key intersection points between the stakeholders, and work to build out what each is thinking/feeling during it. Additionally, we'll do the *Recursive Why/How's* exercise on observations to dig into our observations.

We've found these people through friends, family, and our broader communities. We ended up interviewing 9 patients, 3 family caretakers, and a doctor.

Interview discussion guide

General hopes for our research: across patients, doctors, and caregivers, we're probing for *stories from in family-patient-doctor interactions*. Beyond just facts and logistic, we're listening and carefully maneuvering to expose the *frames* and overlaid *narratives* stakeholders tell themselves and others about their actions and interactions.

Interview Questions by Stakeholder:

- **Families who've had a member go through intense health issues that result in surgery**
 - **Patient.**
 - What was your role/what was required of you in the surgery process?

- Tell me about a time having your family around affected your hospital/treatment experience.
- What did you do with your family/friends in preparation for your procedure?
- What did you do with your family/friends immediately afterwards (on the order of a few days)?
- How did you communicate with your family/friends after your procedure?
- How did you prepare yourself ahead of time for the surgical procedure?
- **Family members**
 - **Present**
 - How did you feel when your family member was in the hospital?
 - What was your personal routine while your family member was in the hospital?
 - What did you feel was your role in your family member's recovery?
 - What did you think you were supposed to do as a caregiver?
 - Did you do those things?
 - Tell me about a time you think your presence improved/hurt your family member's experience.
 - How did you balance self-care/caring for your family member?
 - **Remote**
 - What role did you believe you should play in your friend/family member's procedure?
 - How did you connect with your friend/family member during that time?
 - What do effect do you think your support had on your friend/family member?
- **Doctors involved**
 - How does family involvement of a patient affect your work?
 - Can you think of a time when the presence of the patient's family/friends has affected your work?
 - What sorts of families feel make your life easier? Why? What types make it harder?
 - How might the education/understanding of the patient affect the procedure?
- **Hospital Admin**
 - What's the most challenging aspect of coordinating/managing families needs/requests/demands?
 - How would things be easier if the family wasn't doing X? In what ways is the family essential and super helpful?
 - Tell me a recent story of dealing with are the logistics of family visitors?
 - Tell me about a family feel make your life easier? Why? Tell me about a family that make it harder?

Stakeholders



Mr. S. K. Mann

Patient, 45

Mr. Mann wants to receive the best medical care possible while also feeling supported by his doctors and family.

Mr. Mann's surgical experience

Mr. Mann is in the hospital for an operation, accompanied by his close family and friends. He is nervous about the operation and overwhelmed by all of the information he is receiving and medical personnel he is meeting. Mr. Mann will be undergoing a procedure that involves general anesthesia. He will meet and be briskly briefed by his surgeon and anesthesiologist over the course of 20 minutes and then be whisked into the operating room for his surgery. When Mr. Mann comes out of the OR, he will be taken to a recovery room where he is dutifully watched and cared for by his family and friends until it is safe to take him home.

Mr. Mann's Surgical Challenges

Mr. Mann knows that he needs this procedure, but does not entirely understand why his body is betraying him or how it will be fixed. He does not know what information he needs and he does



not know how to determine who to trust, but he wants some indication that he is safe and in good hands. Mr. Mann does not feel humanized by his doctors and struggles to remember the information that they unload on him during their rushed briefing before his procedure. Mr. Mann wants to leave the hospital happy and healthy, but does not know if a doctor that does not seem to care about him as a person will provide quality care for his physical person.



The Carey Family

Family of someone undergoing surgery, Varying ages

The Carey Family wants to provide the best possible care for their recovering relative and is willing to undergo great personal sacrifice to do so.

The Carey Family's Hospital Experience

The Carey Family accompanied their loved one to the hospital and sat in a room with them while medical professionals hustled in and out of the room to perform tests and provide brusque explanations of what was about to happen to the person who taught them how to ride a bike and cried at their graduations. The Careys ask as many questions as they can and try to remember the instructions the doctors give them for how to take care of their loved one after the procedure is over. They are moved to the waiting room and sit in silence for hours while they wait for news as to whether one of the most important people in their lives has survived. Once the procedure is over, they sit with their recovering loved one, and eventually bring them home. When home, they do everything in their power to keep their loved one comfortable and healthy.

The Carey Family's Challenges

In order to provide the love and support for their family member, the Careys must put their lives on hold. Family caregivers struggle to learn all the information they need to ensure that they are providing the best care possible. They spend hours talking to doctors & nurses, researching online, and reaching out to their broader community for tips and tricks on how to keep their lives running smoothly. Many family members spend so much time thinking about their loved one that they often forget to take care of themselves.



Dr. Noe

Surgeon

Dr. Noe wants to provide the best possible care for their patient both inside and outside the hospital.

Dr. Noe's Hospital Experience

Dr. Noe is taking care of many different patients, and has an allotted amount of time she can give them all in order to keep things running smoothly at the hospital. Her primary goal is to provide the best medical care for the patient's 'plumbing.' During her visit with patient X, she has 10 minutes to prepare them for the OR. She quickly runs through the list of things she thinks the patient should know, and asks for any questions. The patient's family tries their best to think of all the things they need to have answered, but are intimidated by Dr. Noe's tight schedule and focus on her documentation.

Dr. Noe's Challenges

Dr. Noe struggles to find the balance of efficiency, excellent care, and human connection. Given her primary goals of medical excellence and her tight timeline, Dr. Noe often has to sacrifice connecting with her patients on a more human level. This can create rifts of trust between her and her patients, and she just hopes they follow her instructions during their recovery.

Observations

Doctor's compressed briefings to patients and family prove pivotal to recovery success, yet are often poorly remembered, miscommunication riddled, or un-attended by crucial caretakers.

- **SUMMARY:** Doctors have 10 minutes before surgery to brief patient, yet patients are most nervous there, and often don't form questions until after doctor leaves.
- **QUOTES:**
 - "As a patient you feel intimidated about requesting time. You know the doctor is on a schedule. You end up thinking of all your questions afterward. That's why they say to write down the questions you want to ask before seeing your doctor."
 - "It makes us [doctors] much more nervous when the patient comes alone. There will be no one there to help them comply with our instructions. [...] It's the least ideal scenario."
 - "I didn't remember anything the doctor told me before my surgery"
- **INTERPRETATION:** Because the danger of operation is *immediate, unknown, and foreign*, few patients or caregivers are calm or very level headed when info is dispersed, instead imagining horrific, worst-case scenarios from unreliable sources (TV, scary second-hand stories). On top of that, It goes against our most basic survival instincts: *here, strange doctor I know nothing about, hurt me. This will help me. (what!?!?!)*
- **RESULTING NEEDS:**
 - To have irrational yet deeply compelling fears and imaginings recognized.
 - To have faith in their doctor's ability to do what's best for them.
 - To be in a place where you can hear and understand the doctor completely.
- **HMWs:**
 - How might we synchronize the patient's questions with the doctor's availability?
 - How might we disseminate information from doctors to patients with complete clarity and retention?
 - How might we make it cool to ask embarrassing/"stupid" questions?
 - How might we create a perfect memory of the doctors' briefings for the patients and family caretakers?
 - How might we create a time & space where the patient/caregivers can hear and understand what the doctor is saying?

- How might we create a space in which we recognize irrational (yet deeply compelling) fears and imaginings?

Part A. Doctors must often choose medical excellence/efficiency over human connection.

- **SUMMARY:** Typically with only 10 minutes between meeting a patient and having to attend to the next medical procedure, doctor's interactions felt curt and often distant to many of our interviewees. In a situation where patients are already likely to shrink back into their own beliefs, this added impersonality caused many patients not to follow doctor's orders.
- **QUOTES:**
 - "[People tell the medical staff that] 'we're lacking the personal touch'" -Valerie, hospital staff
 - "[The most recent] doctor was more patient and understanding, so she was more receptive [to taking the medication she'd been neglecting]."
 - "They're too busy to check in on me" - Patient
 - "The doctors are so focused on documentation they're not looking at me."
 - "When one case is finished, the next case is expected to be able to start in the operating room within 15-20 minutes. In that short window of time, that is when you go out to speak to the patients[...] For such little time to explain the procedure and the risks on the anesthesia [it is difficult]"
- **INTERPRETATION:**
 - Doctors are emotionally taxed. They're trained to be distant: treat bodies as a "plumbing". After long hours and many patients, doctors become normalized to death & tragedy; being continuously thrust against people's most messy parts (physically and emotionally) is routine. To surgical patients in a place of extreme vulnerability and pain, however, having their lives in this stranger's hands is terrifying, and even the most empathetic doctors encounter distrust.
- **RESULTING NEEDS:**
 - To generate reciprocal empathy/understanding for doctors
 - To make doctors less like strangers
 - Give patients confidence in their doctors.
- **HMWs:**
 - How might we make the medical interaction between doctor and patient feel more like a caring exchange?
 - How might we eliminate the need for human connection?
 - How might we make doctors seem like superman?
 - How might we make documentation feel like a waste of time?
 - How might we make the doctors and patients as close as good friends?

- How might we make patients feel like their doctors trust *them* and their intelligence? feel like heroes united by a quest? teammates fighting for a championship?

Part B. Miscommunication between patients and doctors leads to rifts in trust and unsafe actions.

- QUOTES:

- "I feel like the doctor is keeping secrets from me"
- "Patients behave like: 'I don't believe what they're saying, so I'm not going to do what they tell me to do'" - Doctor
- When the hospital staff neglected to refill Sally's IV, her blood began to drain up into the bag, and she had to carry the IV with her to find a nurse.
- When family doesn't know what's going on, they often believe the doctor isn't providing good care.
- VB didn't know she had to keep taking her pain meds so almost had to be readmitted.
- VB said she had 4 stairs in her house, but actually meant 4 flights of stairs. Her physical therapy was misguided.

- **INTERPRETATION:** Why *wouldn't* you trust your doctor? We found a few salient reasons. First, doctor/hospital environment is alien and separate from patient's world. While a patient will nod their head wearing a gown, back at home the doctor's instructions don't stick because they never spoke to their own presuppositions and perspectives, or to how their instructions would affect their day to day life. Additionally, during their hospital stay, the doctor doesn't communicate with me as much as I want.

- RESULTING NEEDS:

- To have medical information and instruction framed and made relevant to patient's daily life, in which different obligations change the way instructions feel and are remembered.
- To be kept updated, even if just to know that the doctors are still working on me.

- HMWs:

- How might we help a patient feel 'in the loop' on their care?
- How might we distill the doctor's orders into 140 characters?
- How might we make a patient feel like everything a doctor says is completely true?
- How might we bring the doctor into the patient's world?

People who've gone through a certain recovery become experts in recovery methods.

- **SUMMARY:** In the case of someone who breaks their jaw, the recovery process involves 8 weeks of having a jaw wired shut. Figuring out how to eat and get enough calories becomes a hard problem to solve. After having gone through the process, you are an expert at the solving those problems (problems which most people don't know how to solve).
- **INTERPRETATION:**
 - Patients have unique needs not captured in general caretaking advice or common experience ("I hate blended squash, so I need a better solution for me and my broken jaw.")
- **RESULTING NEEDS:**
 - To find personal solutions to unique and lonely conditions.
 - Be aware of many solutions in order to find a good fit.
 - To recover as quickly and painlessly as possible.
- **HMWs:**
 - How might we make recovery seem like a video game?
 - How might we make the recovery process seem like something the patient has done before?
 - How might we utilize the experience of patients who have undergone the recovery process to help patients still recovering?
 - How might we give the patient a personal recovery coach?
 - How might we create a magic pill that will give the patient the knowledge to recover in the best possible way?

Caregivers willing to sacrifice personal needs for their loved ones can still fall short of providing the necessary care.

- **SUMMARY:** Caregivers don't know what they don't know. VB and her husband did not know that VB needed to keep taking her pain medication but he knew what equipment VB needed to return to full mobility (because hospital staff told him). Gale's husband did not know how to keep up with Gale's nutritional needs, though he knew exactly which meds to administer (because he'd been told by the doc).
- **QUOTES:**

- “Greg had a very rigorous little Excel chart that he kept and he made sure that I took my pain medications *exactly* every 4 hours, even if that meant getting me up at night.”
- “He was very good about the meds, he wasn’t particularly good about the food. Because, one, I couldn’t eat, but two, he doesn’t do things with food. So even if he’d had a list of ‘blend a banana with yogurt and warm it up,’ that would’ve been helpful.”
- **INTERPRETATIONS:**
 - Greg wants to get his wife home as soon as possible. The hospital is uncomfortable, and home seems like a safe haven where he can watch over the recovery of his loved one. He’s so anxious to get Gale out, he forgets to think about asking hospital staff for help. He doesn’t realize that there is more to helping Gale recover than just trying really hard. There are bits of information he needs to know before he can be the all-star caretaker he wants to be.
- **RESULTING NEEDS:**
 - To be educated on how to care for loved one.
 - For patients/caretakers to feel safe, comfortable, and in control.
- **HMWs:**
 - How might we give caregivers PhDs in patient care?
 - How might we compensate caregivers for their time and energy?
 - How might we ensure that family caregivers know everything they need to know before taking their loved ones home?
 - How might we make the hospital feel a place where seeking knowledge is encouraged?

Because caregiver exhaustion typically goes unexpressed to the patient, patients make poor advocates for caregiver self-care.

- **SUMMARY:** While the kidney transplant recipient felt proud of his logistical preparation and intentional breaks given to family, family members in reality dealt with internal exhaustion from less basic, but still important emotional/social needs.
- **STORY:**
 - **Hospital Birthday:** For example, Mr. Kidney’s daughter struggled internally with spending her birthday sitting in a hospital room.
- **INTERPRETATIONS:**
 - Why does caregiver exhaustion typically go unexpressed? They don’t want to make the patient feel bad/a burden, but instead to to recover faster. Or just don’t want to look/feel selfish (After all, their own needs pale in comparison (in the

caretaker's opinion)). Similarly, the patient's aren't thinking about the caregiver's needs because they themselves are completely out of it.

- **RESULTING NEEDS:**
 - To be appreciated
 - To be supported while they care for their loved ones.
- **HMWs:**
 - How might we get rid of caregiver exhaustion?
 - How might we make family caregivers feel like the most important people in the world?
 - How might we make self-care readily accessible for caregivers in a hospital setting?
 - How might we allow for patients to show their appreciation for their family caretakers?

Having family nearby will reduce the suffering involved with getting treatment at a hospital.

- **QUOTES:**
 - "When you have people watching out for you, you seem to recover faster and the staff seems to treat you better" - Kim
 - The best experiences at hospitals involve families
 - "There was no family to look out for me or protect me" - Sally
 - Births were the best experiences at hospitals
 - When Mike's father got experimental heart surgery and survived, everyone was extremely joyful to see him.
 - [Literature](#) about the role of family during a patient's hospital experience.
- **INTERPRETATION:**
 - Having family around makes us feel comfortable and loved. This allows for our bodies to relax and focus on healing. Family also helps up stay distracted from our current woes. Together, a family is self-sustaining, sharing each other's burdens to ensure a happier whole.
- **RESULTING NEEDS:**
 - To be carefree during recovery.
 - To feel deeply cared for.
- **HMWs:**
 - How might we make the hospital staff feel like family to the patient, and vice versa?
 - How might we give patients the feeling of a warm holiday, surrounded by loved ones, when they are actually alone in a hospital?

Medical distrust, which often lingers long after the initial procedure, stems mostly acutely from experiences of isolation.

- **STORIES:**

- Mike had a traumatic, isolating experience as a child and even now hates going to the hospital. This distrust of hospitals currently gets in the way of him getting potential health risks checked out.
- Sally's worst experience was with being left alone writhing in pain during her episode with appendicitis.

- **INTERPRETATIONS:**

- A single bad experience can forever taint one's perception of hospitals. The resulting distrust can prove to be dangerous for patients. The feeling of isolation in a hospital is extremely terrifying for people. Alone in a world you don't understand, and worried for your own health. It's like being thrown in a dungeon. There are a lot of unknowns, and being isolated allows for your imagination to run wild.

- **RESULTING NEEDS:**

- To be sure you're being cared for.
- To have faith in those you've put in charge of your health.

- **HMWs:**

- How might we help patients recover from bad medical experiences?
- How might we give patients good medical experiences to counter the bad ones?
- How might we keep patients from ever feeling isolated in a hospital?

Favorite HMWS

How might we use the wealth of knowledge from those who've gone through recovery before – recovery experts – to benefit current recoverers?

How might we allow for caretakers to take care of themselves while taking care of their loved one?

How might we make patients and doctors feel like heroes, united by a quest?

How might we create a perfect memory of the doctors' briefings for the patient/caretakers?

How might we help patients feel surrounded by family when in the hospital alone? ← Give patients a guardian angel?