

# Family Resilience Technologies

Luddy School of Informatics, Computing, and Engineering

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# About me

1. I'm an Associate Professor and Chair of the the **Department of Human-Centered Computing**, where I study **Human-Computer Interaction**
2. I study how people & technology connect around healthcare
3. I work with patients and families (mostly in pediatrics) and I collaborate with them as participants to design next-generation technologies and to establish theoretical foundations for others to use in their own design work
4. **My methods:** interviews, observations, design workshops, and prototyping





# Context: Pediatric Cancer Caregiving



**Collaboration with  
Dr. Emily Mueller @  
Riley Hospital for  
Children**

Focus: extended  
hospital stays  
(AML/Osteosarcoma)





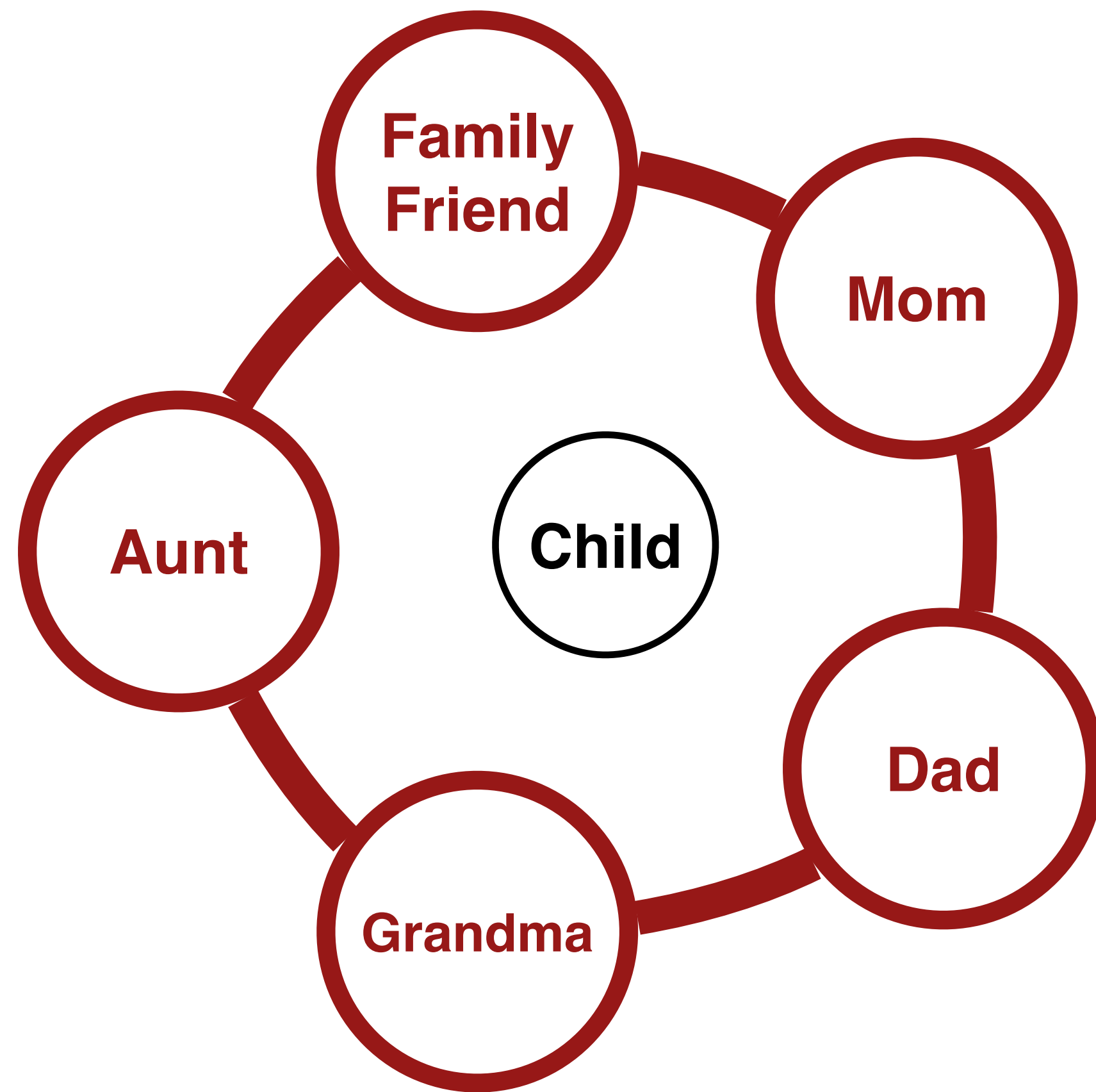
# My goal: bursting the ‘information bubble’

1. *Despite* better patient portals, the child’s hospital room is an **information bubble**
2. If you’re not there you’re not informed, or your information is delayed or compressed

Miller AD, Pollack AH, Pratt W. Bursting the Information Bubble: Identifying Opportunities for Pediatric Patient-Centered Technology. *AMIA Annu Symp Proc*. 2017;2016:894–903. Published 2017 Feb 10.



# Collaborative family care during hospitalization



How might technology support family members **in their collaboration with each other** during a child's hospital stay?





# How can technology give patients & families *caregiving superpowers*?

1. **Bridging distance**  
bringing other caregivers into the loop
2. Making it easier to share and find **information**
3. Supporting daily & weekly caregiving **rituals**





# Current grant: *Family Resilience Technologies*

1. **Family Resilience** is a strengths-based approach to meeting adversity
2. But it hasn't been applied to tech...yet!
3. How can collaboration technologies support and augment families' resilience during health crisis?



National Science Foundation Grant #2047432  
CAREER: Family Resilience Technologies:  
Augmenting Caregiving Coordination Systems  
for Health Crisis Response

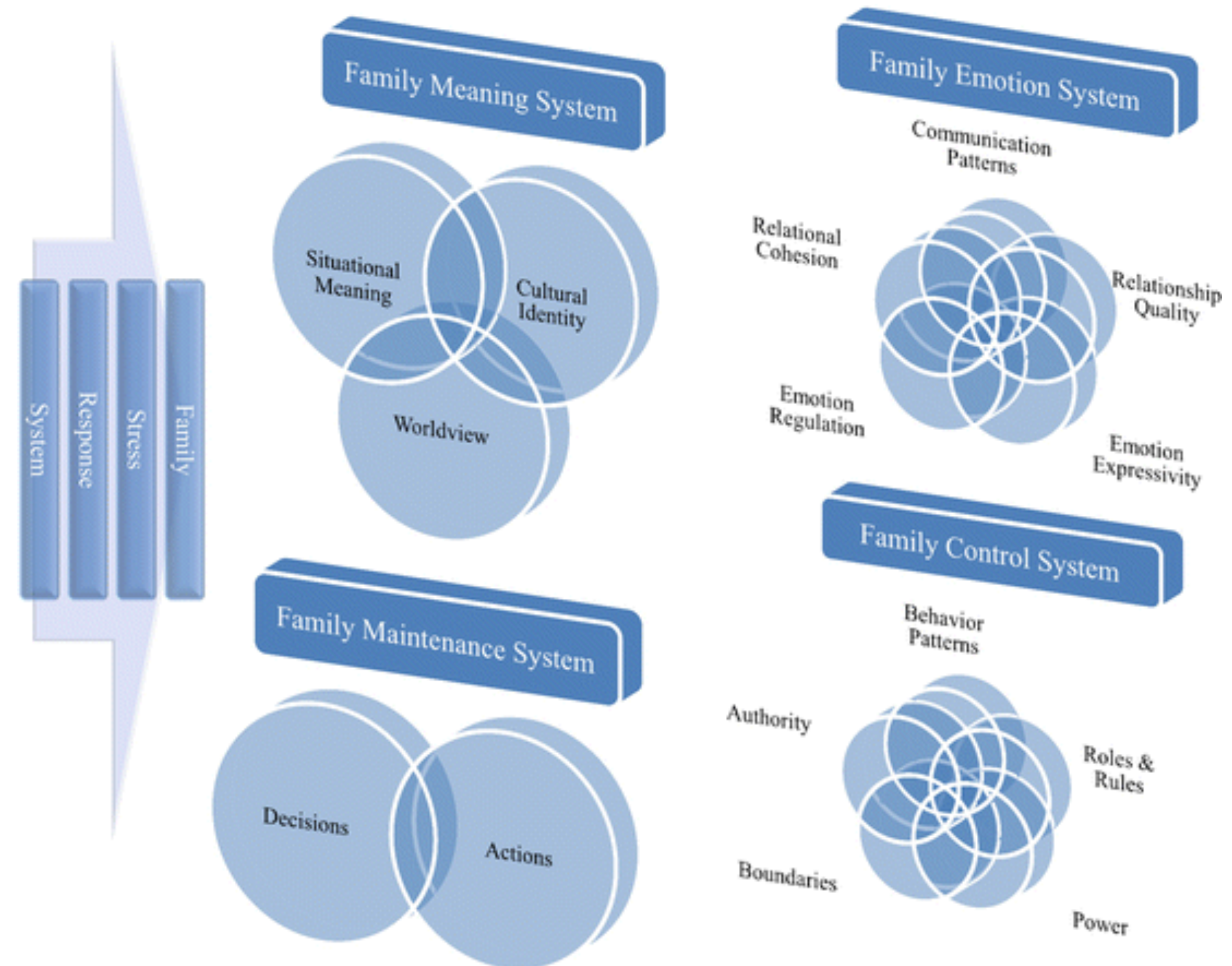




# Theory: Family Adaptive Systems

A model of **Family Resilience** in crisis situations, from the family sciences

Characterizes families' response to a crisis across 4 subsystems: **meaning, emotion, control, and maintenance**



# Methods: Engaging with caregivers

1. **Formative interviews** — *explore caregiving coordination barriers & facilitators*
2. **Design-focused interviews/PD** — *identify technology opportunities*
3. **Card-sorting activities** — *validate barriers, opportunities, & FAS*
4. **Scenario-based user ‘thinkaloud’ tests** — *validate design approach*
5. **Q-methodology** — *looking for caregiver ‘types’ across caregiving stages*





# Findings so far...

## 1. Categories

1. Family Resilience in pediatric cancer caregiving
2. Family Resilience for technology / design implications

## 2. Time

1. Identifying caregiving tech opportunities **across the patient journey**

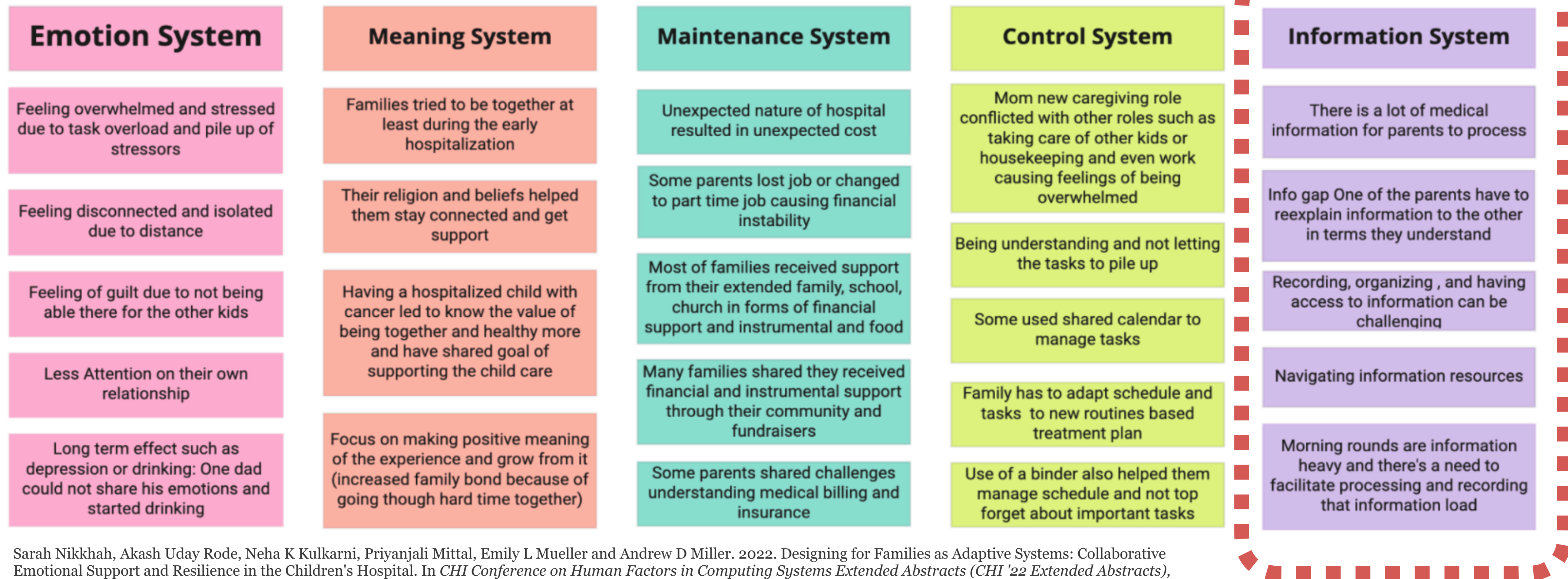
## 3. Categories over Time

## 4. Next: prototyping specific use cases



# Family Adaptive Systems

✓ applies to pediatric cancer



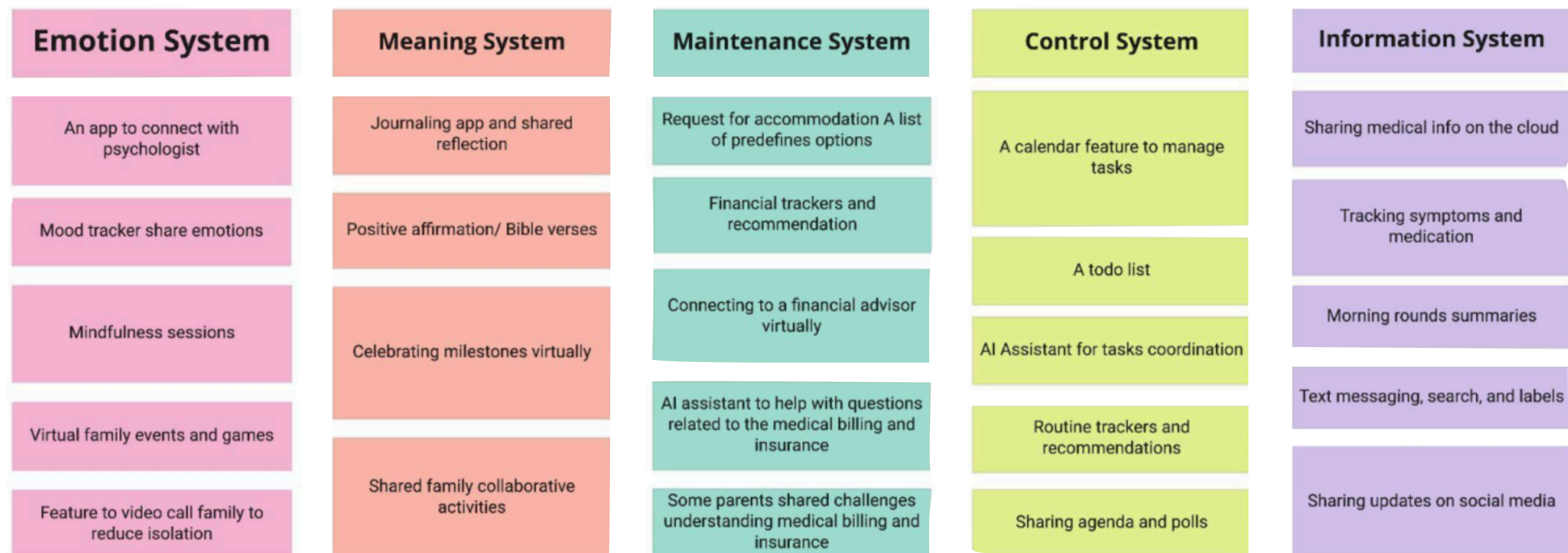
Sarah Nikkhah, Akash Uday Rode, Neha K Kulkarni, Priyanjali Mittal, Emily L Mueller and Andrew D Miller. 2022. Designing for Families as Adaptive Systems: Collaborative Emotional Support and Resilience in the Children's Hospital. In *CHI Conference on Human Factors in Computing Systems Extended Abstracts (CHI '22 Extended Abstracts)*, April 29-May 05, 2022, New Orleans, LA, USA. ACM, New York, NY, USA, 11 Pages. <https://doi.org/10.1145/3491101.3519787>





# Family Adaptive Systems

✓ powerful for design

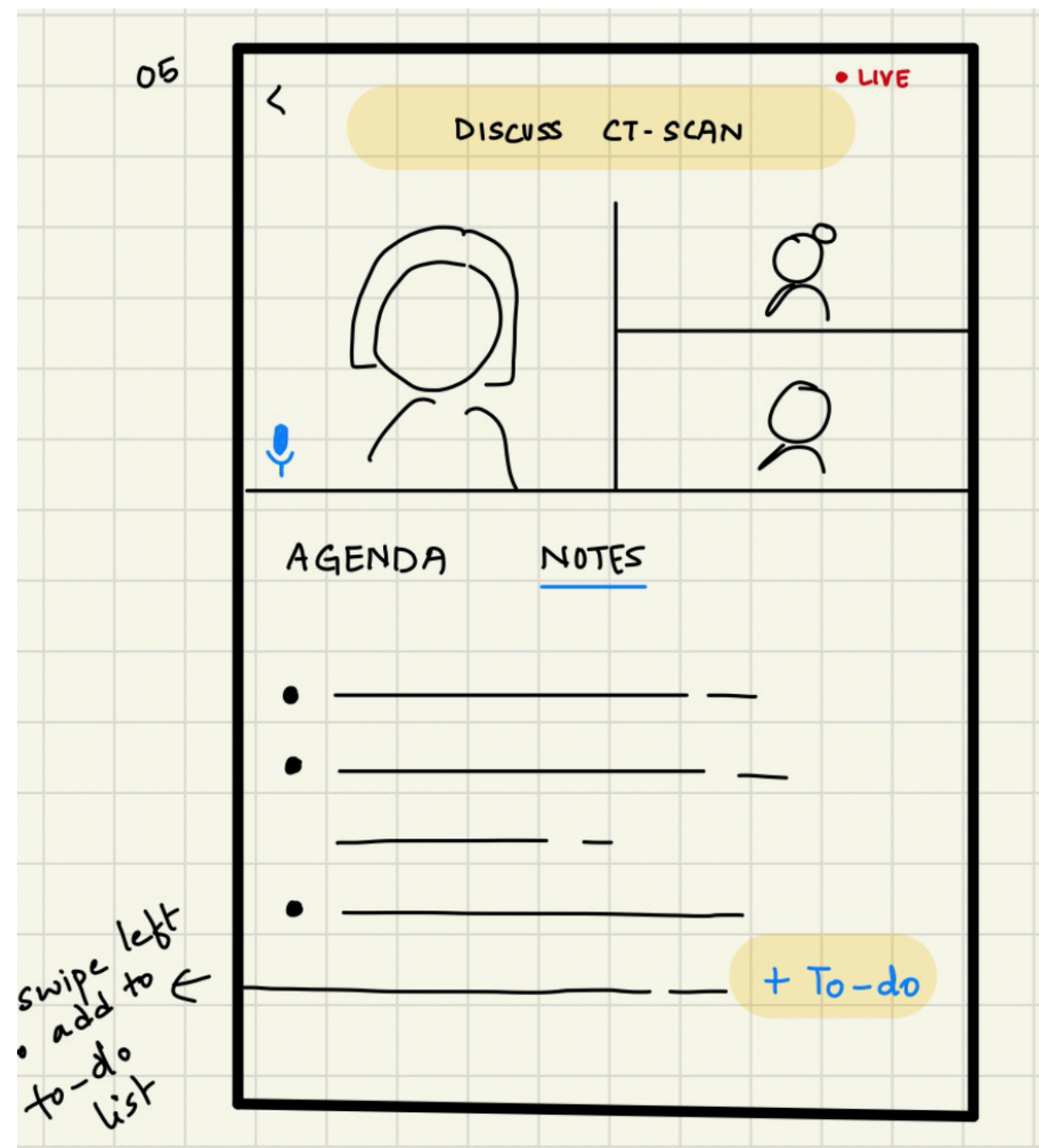


Under review, submitted to CSCW 2024

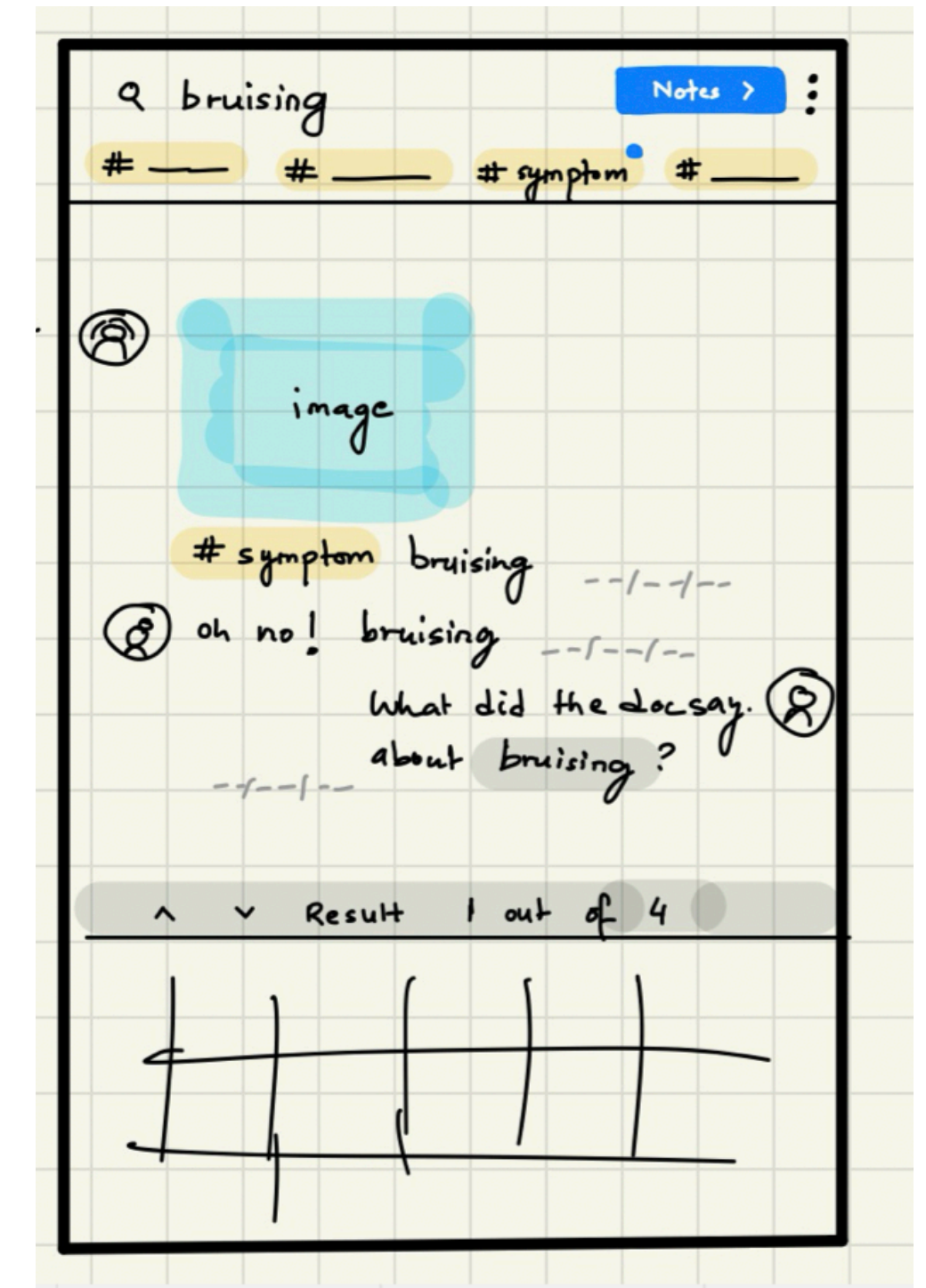




# Design explorations:

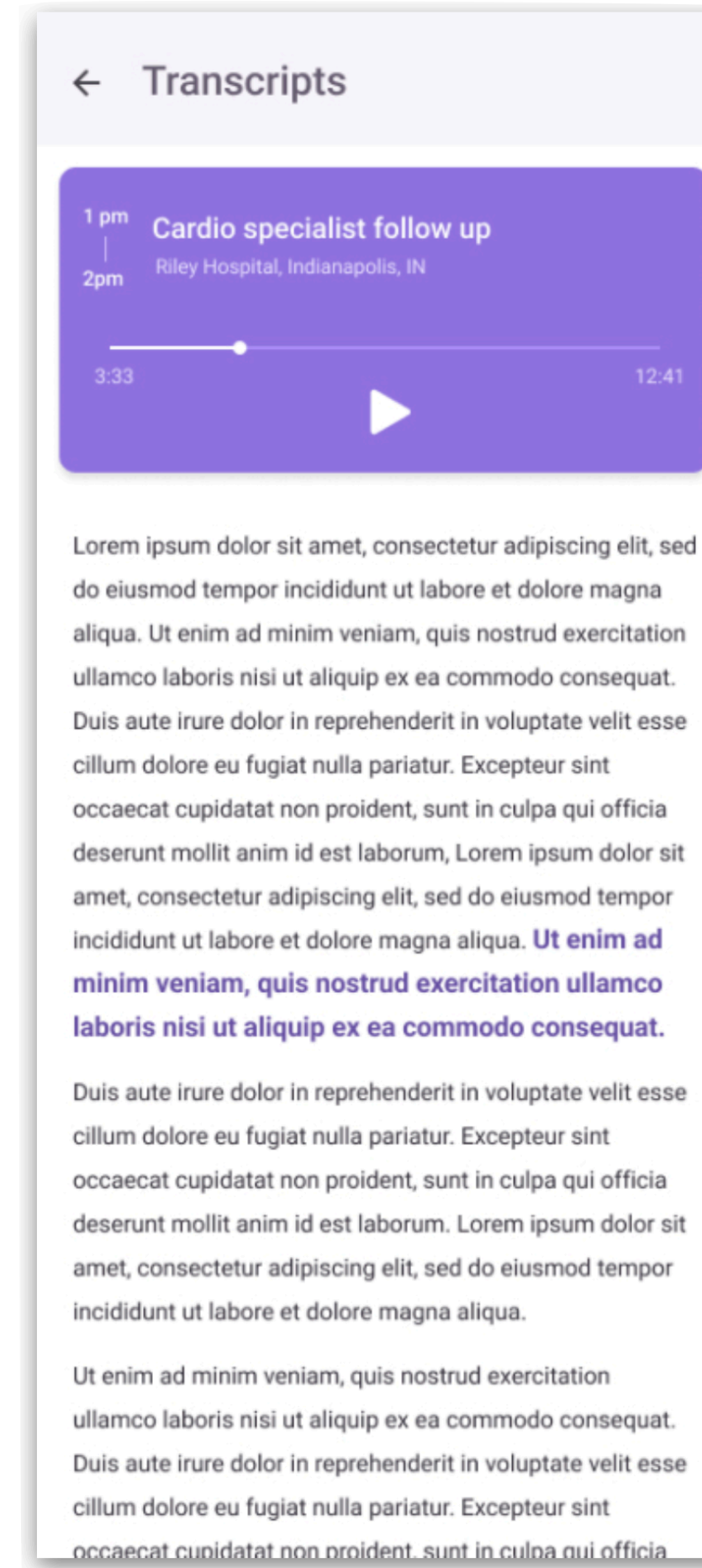
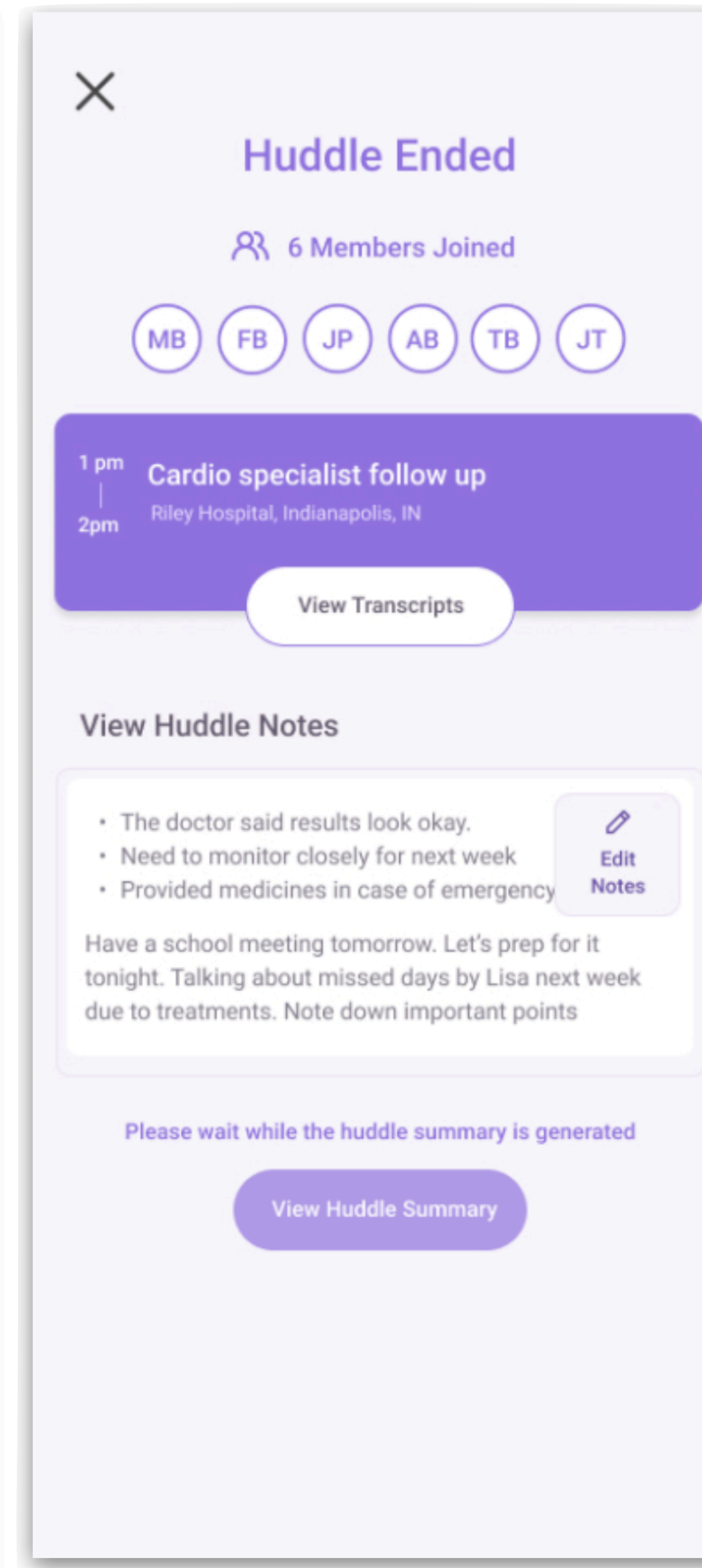
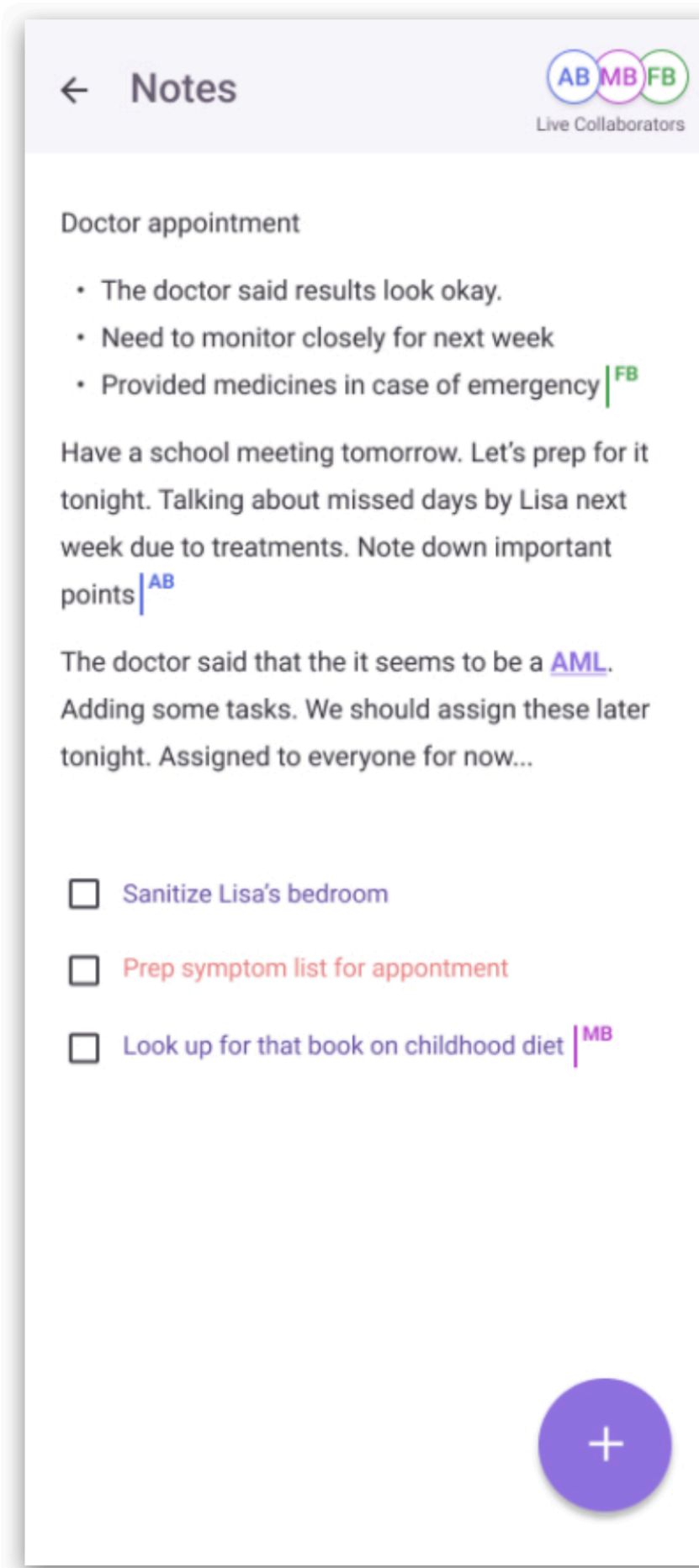
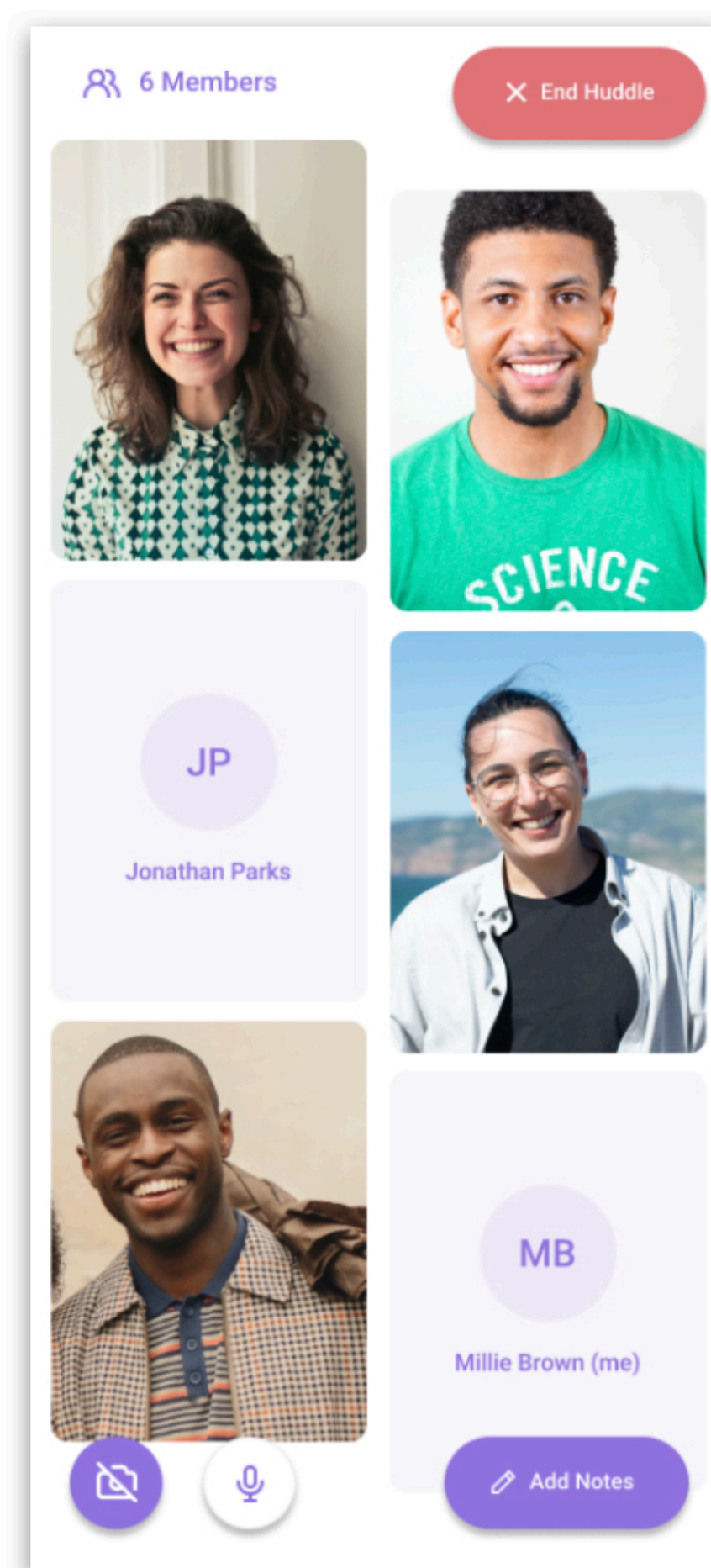
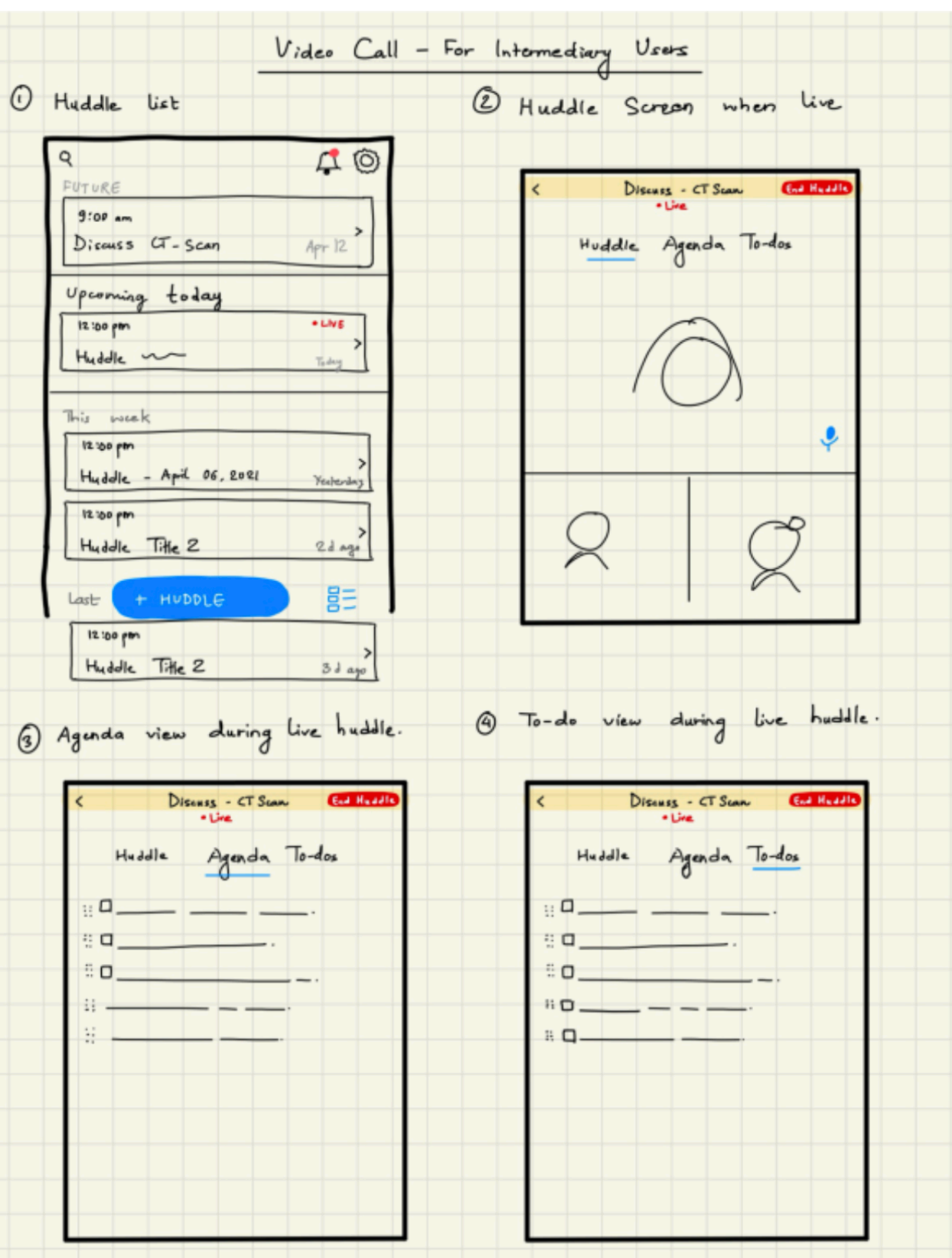


1. **Family Huddles:** a mobile app that supports live voice/video meetings where family members can share updates, keep track of tasks. Huddles can be viewed or reviewed after the fact.
2. **Enhanced Messaging:** a chat-based app that uses AI to help sort & store relevant information shared during conversation, supports to-do lists & calendars



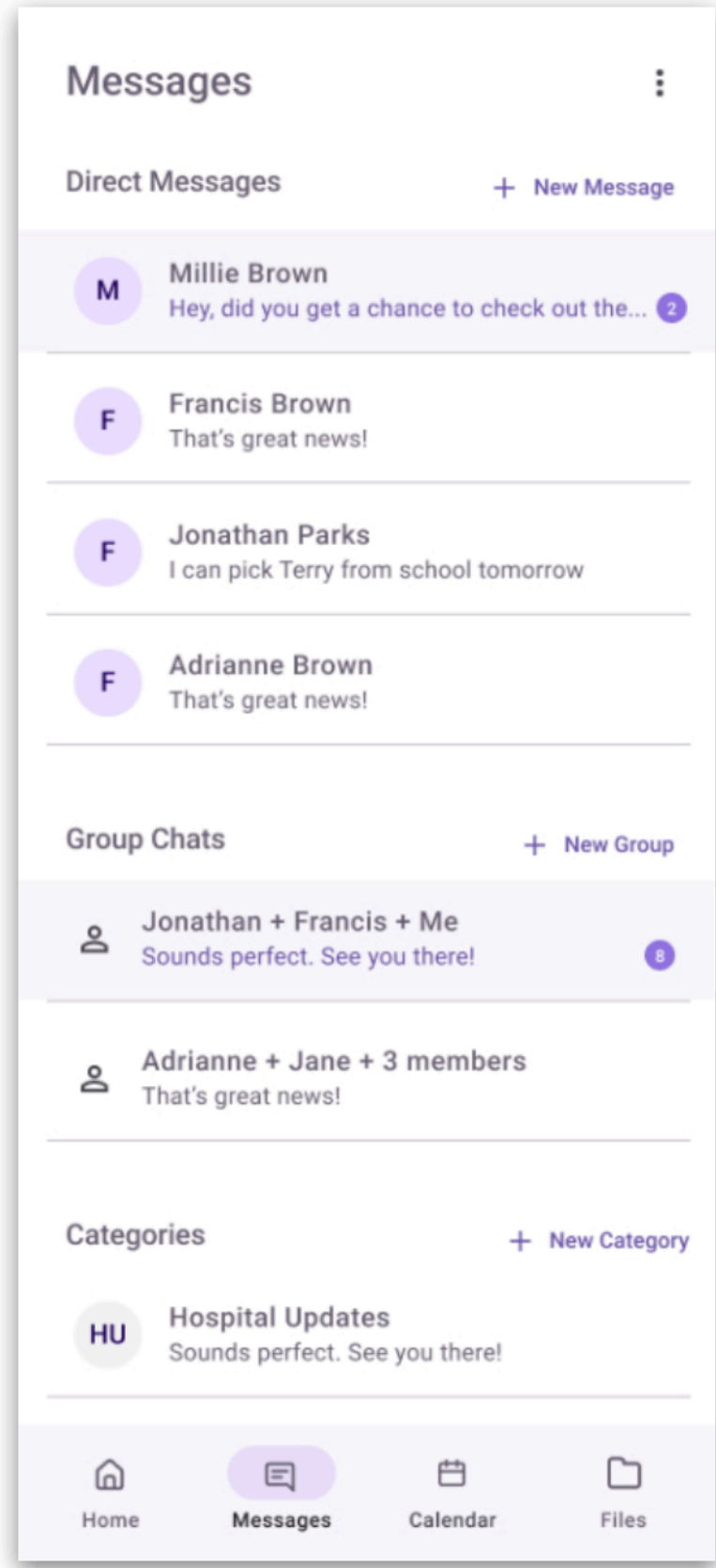
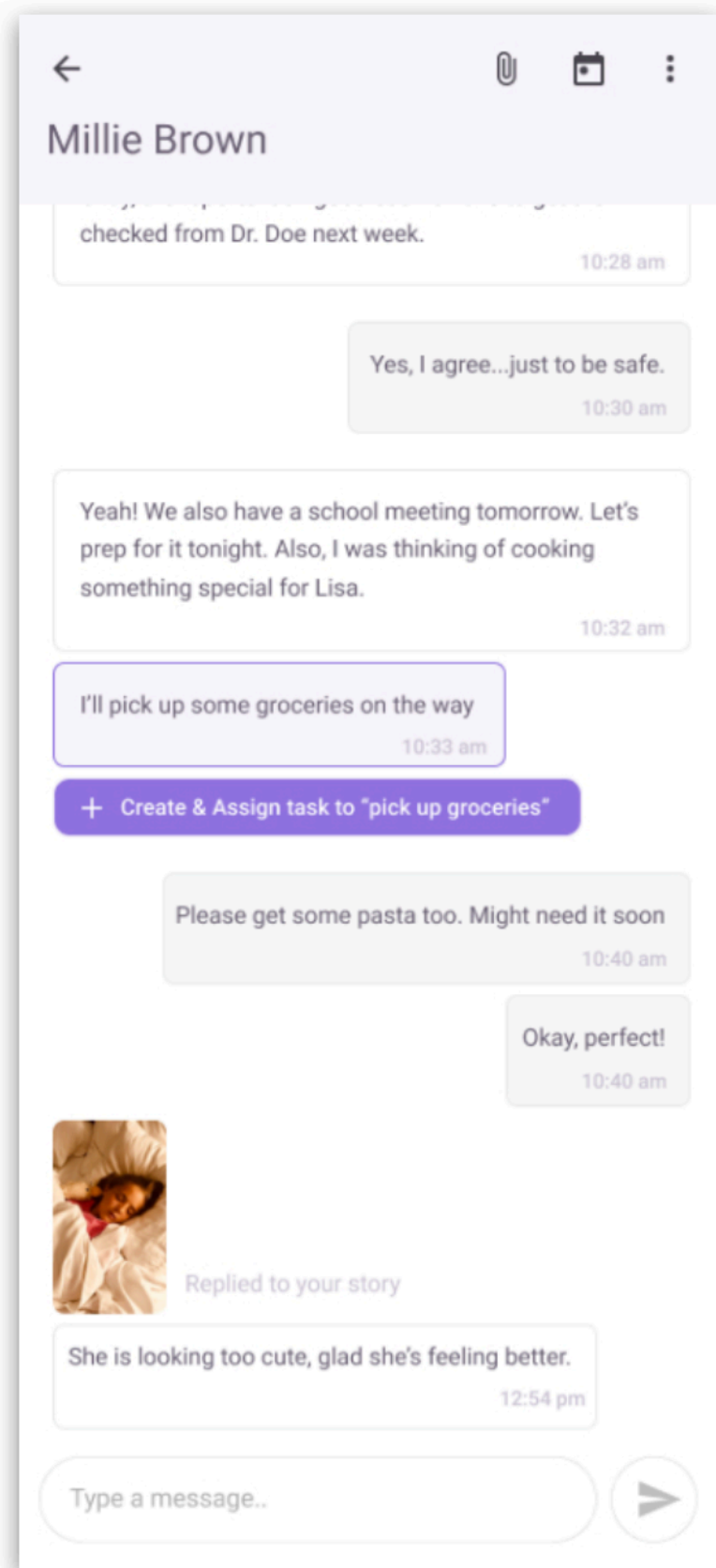
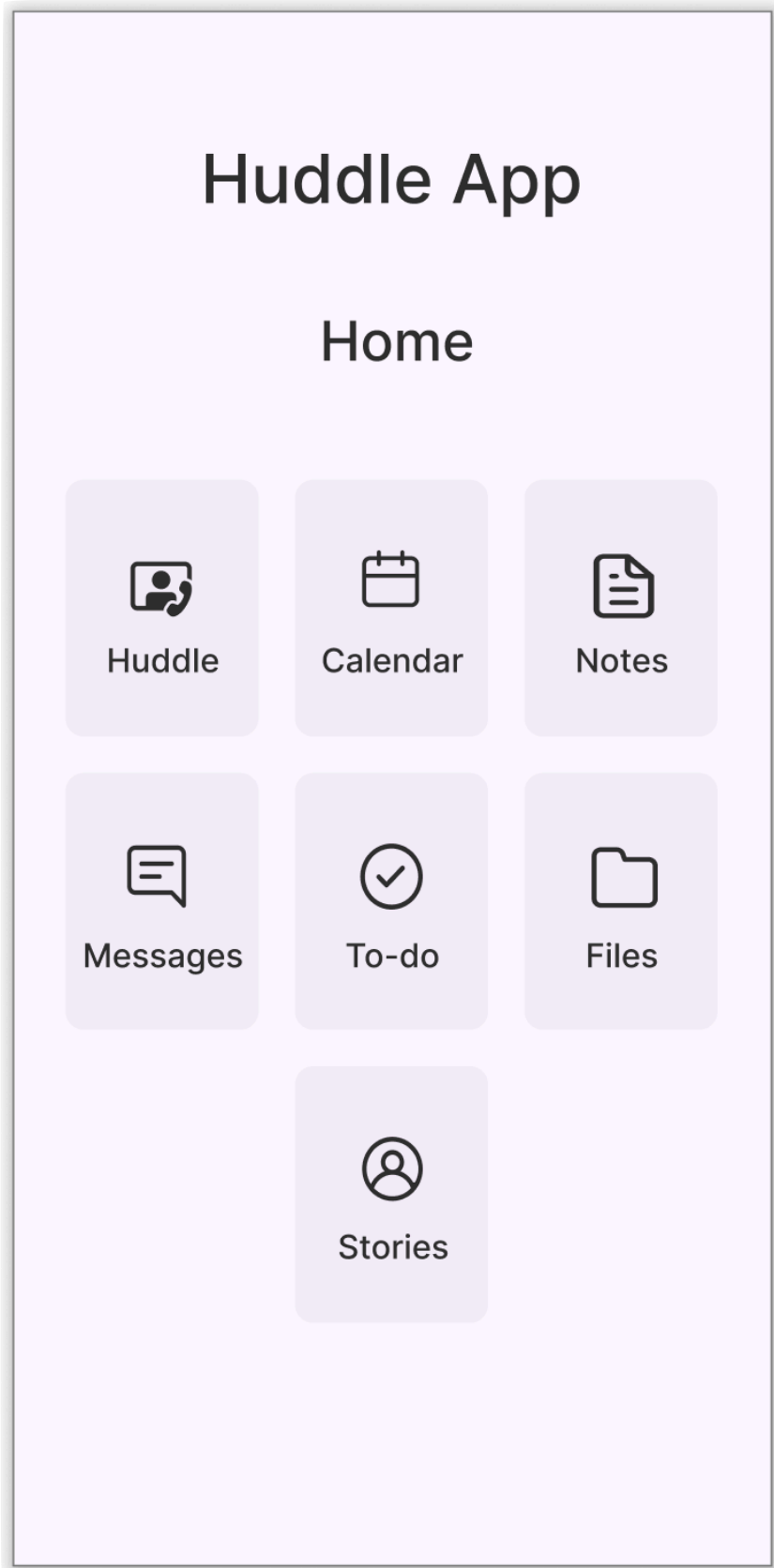
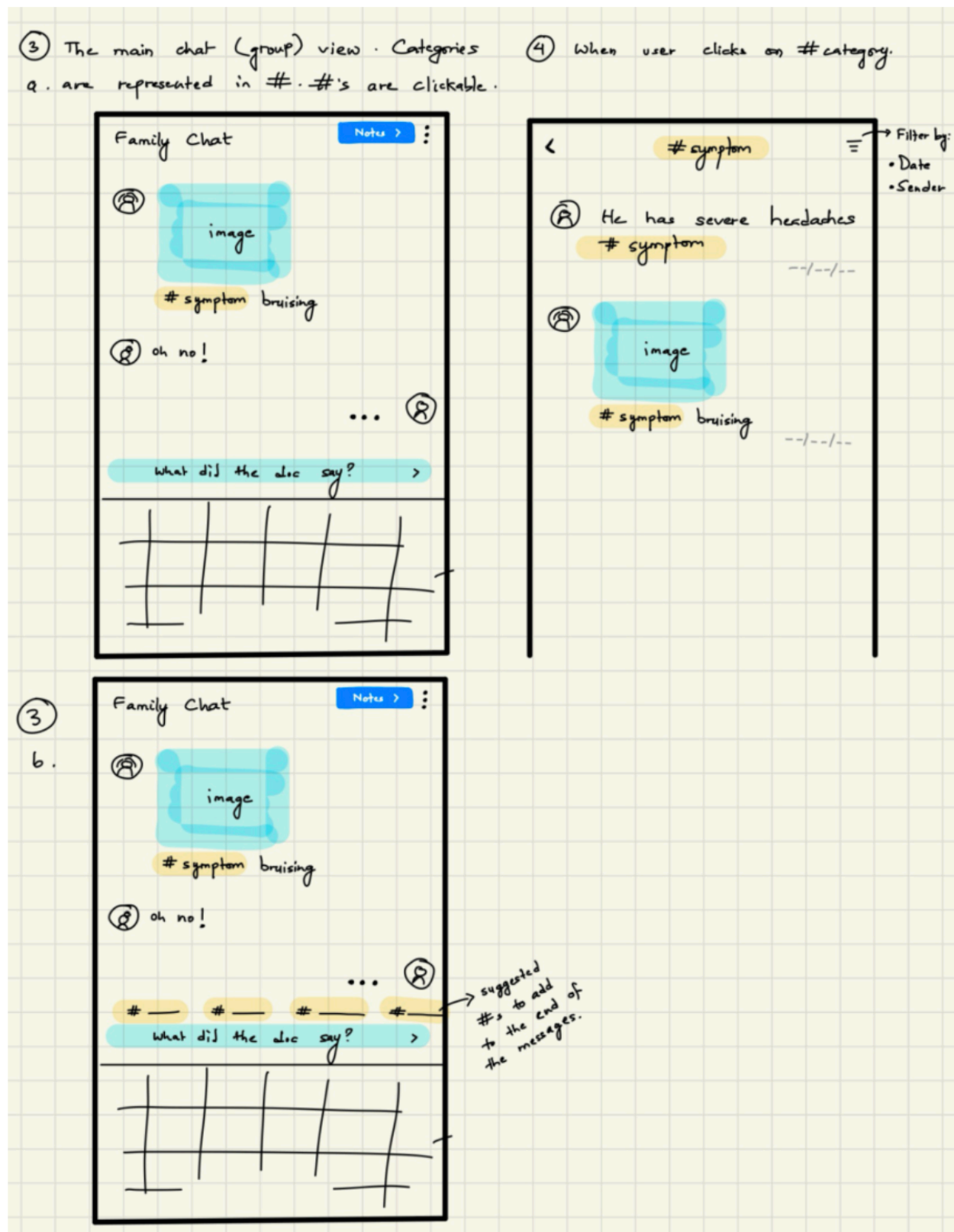


# Design explorations: Family Huddle





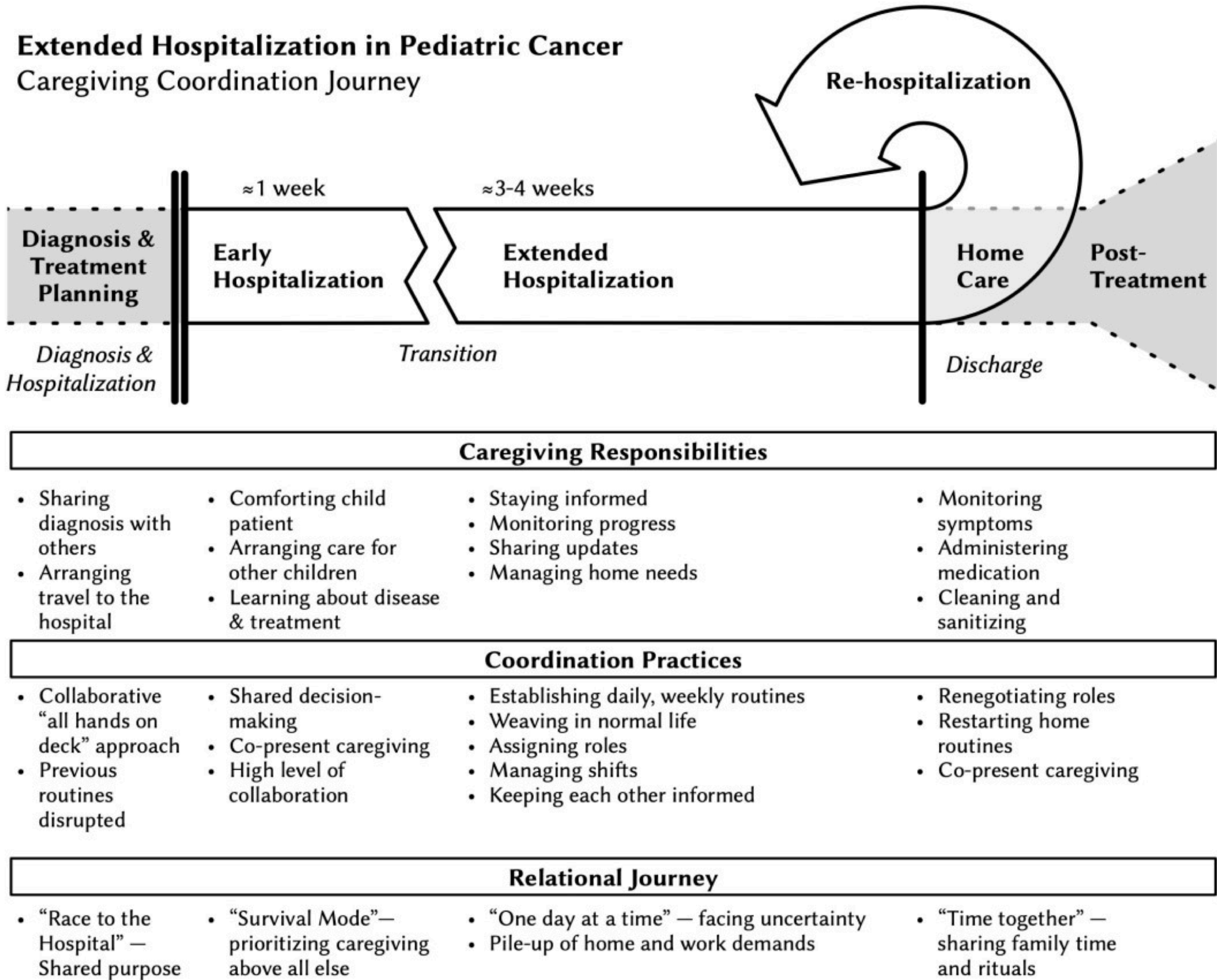
# Design explorations: Messaging



# Caregiving Coordination Journeys

- ✓ Caregiving coordination responsibilities, practices & the relational journey vary systematically across the patient journey
- ✓ Technology support needs also change depending on the stage

Extended Hospitalization in Pediatric Cancer  
Caregiving Coordination Journey



Sarah Nikkhah, Swaroop John, Krishna Supradeep Yalamarti, Emily L. Mueller, and Andrew D. Miller. 2022. Family Care Coordination in the Children's Hospital: Phases and Cycles in the Pediatric Cancer Caregiving Journey. Proc. ACM Hum.-Comput. Interact. 6, CSCW2, Article 296 (November 2022), 30 pages. <https://doi.org/10.1145/3555187>



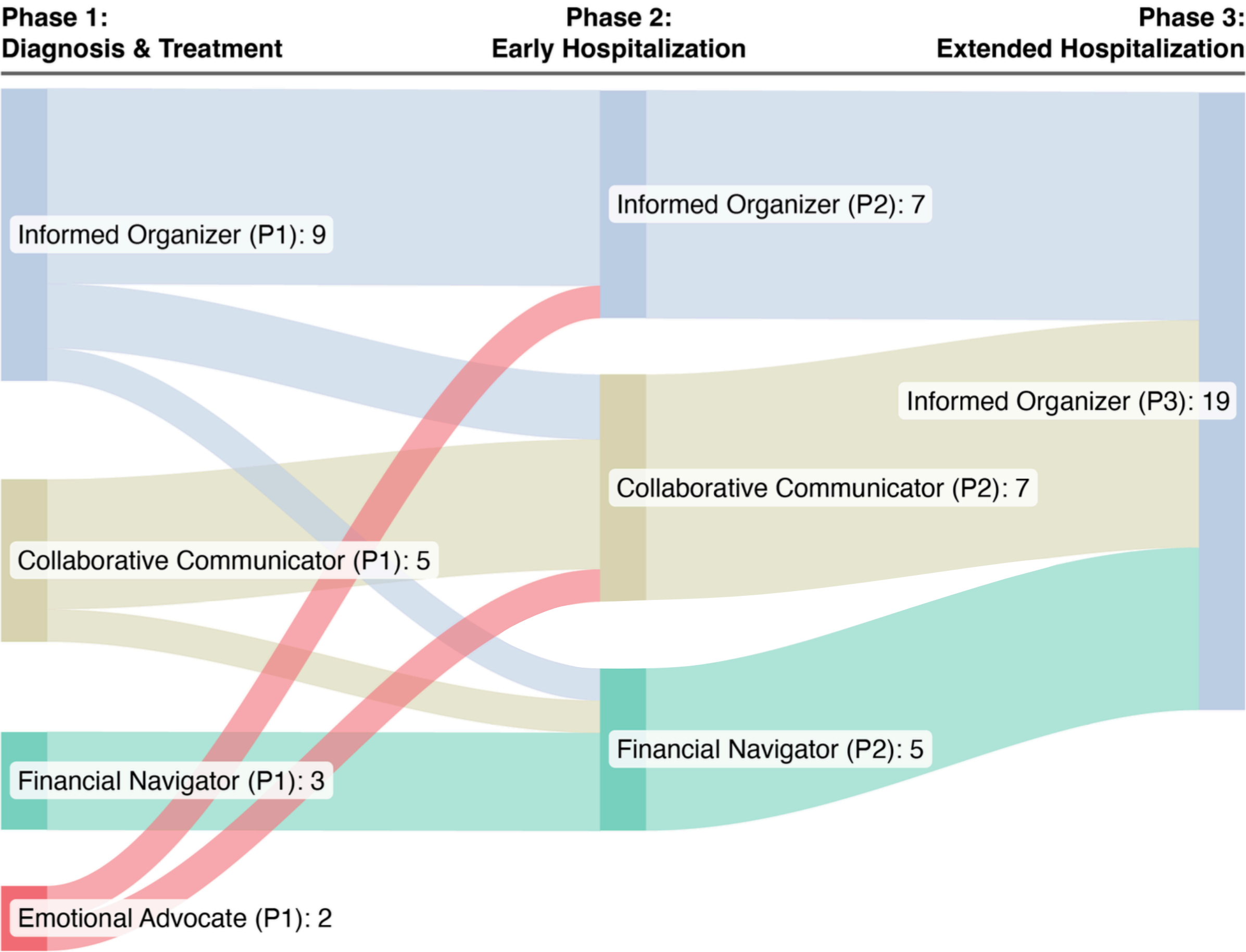


# Ongoing work: Systems, Features, & Stages

- ✓ Some systems are more important at specific stages
- ✓ Not all caregivers prioritize the same things

Least Helpful	Sort the cards according to what features you would find the most helpful					Most Helpful
-3	-2	-1	0	1	2	3
<div>A comprehensive digital platform should be developed to assist families in managing their finances, particularly in relation to medical bills. This platform could provide tools and recommendations to help families understand their medical bills and budget around unexpected medical expenses.</div> <div>Communicating the complexities of the crisis to all family members, including young children, is a significant challenge, often leading to feelings of being overwhelmed and misunderstood.</div>	<div>An integrated system that listens to our calls and sets schedules automatically could be highly effective, provided it ensures maximum privacy and data protection.</div> <div>A well-developed tool that listens and gauges our feelings could be beneficial, especially during times when we feel like we're hanging on by a thread.</div> <div>A multi-device connected software that can manage tasks, remind about appointments, and ensure data privacy would enhance the control and management system.</div>	<div>A feature that recommends shared family collaborative activities, such as game nights, can enhance family bonding and provide emotional support during treatment.</div> <div>Balancing the demands of caregiving with other responsibilities, such as work and caring for other children, presents a significant challenge in maintaining order during a crisis.</div> <div>A system that helps track tasks agreed by others and allows primary caregivers to check progress could be beneficial in managing family responsibilities.</div> <div>An integrated platform that allows family members to share information, games, and calendars can help keep everyone connected and updated would be useful.</div>	<div>A digital journal for reflecting on our mental health could be beneficial, but it needs to be developed better to truly support our needs.</div> <div>Having a feature that allows for searching and filtering financial resources, such as fundraisers, can greatly assist in understanding and managing financial aspects of medical care.</div> <div>Having an AI or virtual assistant to filter and share pertinent medical information with the right group of people can be very useful, but it should be specific to the needs of each family member.</div> <div>A collaborative tracker for symptoms and medicines would simplify the process of monitoring a child's health status and treatment.</div> <div>Managing and processing the overwhelming amount of medical information, while dealing with the learning curve about the illness, poses a significant challenge during a child's hospitalization.</div> <div>A social media-like platform specifically for caregivers could facilitate the exchange of ideas and experiences, providing invaluable support and advice.</div> <div>Unexpected medical situations and hospital visits can disrupt family plans and cause emotional distress.</div>	<div>AI tools that can track finances and generate a detailed list of hospital charges, insurance payments, and personal expenses can significantly ease the burden of managing finances during a medical crisis.</div> <div>A comprehensive app that integrates lab results, discharge instructions, medication lists, and a shareable calendar would significantly streamline the management of medical information.</div> <div>A tool that prepares us to understand and manage mental changes, cognitive issues, and school-related challenges could be immensely helpful.</div> <div>The system should include a list of predefined options to support accommodation requests, particularly for families who have to travel long distances for medical treatment.</div>	<div>An integrated application that syncs medical data and family calendars across devices would streamline the management of appointments and tasks.</div> <div>Sending random positive affirmations throughout the day can help caregivers achieve mindfulness and maintain a positive outlook.</div> <div>The idea of setting milestones in the treatment process and celebrating virtually is appealing, but it needs to be personalized and meaningful to our unique journey.</div>	<div>Balancing the financial stability of the family while ensuring the child's needs are met is a significant challenge.</div> <div>A shared platform for family communication, where we can discuss everything and keep everyone in the loop through boards and group texts, would keep us connected and informed.</div>

Submitted to CHI 2024





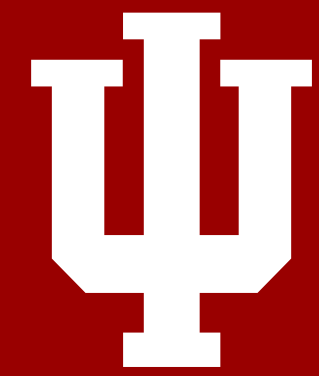
# Towards Family Resilience Technologies

1. Bridging distance
2. Reaffirming shared beliefs
3. Encouraging emotional expression

**But more research is needed!**







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