CRII:SCH: Parent-2-Parent—Supporting Dyadic Caregiving Coordination in the Hospital

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200 YEARS

Overview

When a child is hospitalized, **within-family communication** and coping strategies of the parents, or dyad, are significant predictors of post-hospitalization health outcomes. In this grant, I am studying how technology can **support and augment the parenting dyad** during hospitalization, through a combination of rigorous qualitative investigations, parent-driven design sessions, and hospital-based pilot technology deployments.

Aim 1: Characterize current communication & coordination practices within parenting dyads

Modeling Dyads Through Interviews & Observations

Participants: Up to 30 parents of children currently hospitalized with a cancer diagnosis (30+ day hospitalizations)

Topics:

- Each parent's personal experiences of the hospital
  Stress levels; a "typical day"; perceived challenges
- Roles and shifting tasks
  Respective responsibilities; Change from 'normal'
- Communication within the dyad (with each other)
  Frequency; duration; medium; technology
- Communication with others in the 'caregiving circle'
  Grandparents; other children; other caregivers
- Concerns, barriers, & challenges
  Stressors; connectivity & availability; decision-making; parenting
- Technology use
  Communication strategies; scheduling & organization; ideal platform use
- Positive experiences
  Successful strategies, benefits of the experience

Analysis & Expected Outcomes: Iterative, inductive, thematic analysis using transcription, qualitative coding, grouping, & confirmation of themes across interviews, to produce a rich description of parents' current communication and coordination practices.

Validating Findings with Caregivers

Participants: Up to 100 parents from the hospital's patient engagement lists.

Topics: Validating themes relevant to practices, barriers, enablers, and insights from interviews and clinic observations, we will generate a survey to validate those themes in a larger pool of oncology parents and other primary caregivers, both those with a child currently undergoing treatment and those whose child has completed treatment lists.

Expected Outcomes: Validation of communication & coordination practices, and an indication of which design implications will have the greatest potential impact on parents and child patients.

Aim 2: Envision, demonstrate, and verify dyadic caregiving support technologies

Envisioning Connected Dyadic Caregiving Through Future Technology Workshops

Participants: Up to 20 parents who have or had a child hospitalized for extended time (3+ weeks)

Method: Participatory design using the *Future Technology Workshop* approach: half-day ideation sessions in which end-users generate their own early-stage or future-focused prototypes.

Steps:

- Brainstorming new dyadic collaboration and coordination practices
- Construcing low-tech futuristic prototypes that enable those practices, and proposing scenarios using the prototypes.
- Identifying (individually and then collaboratively) challenges and barriers they face carrying out everyday coordination tasks
- Returning to the prototypes to address these barriers.
- Converging on a set of design requirements

Expected Outcomes: Validation of communication & coordination practices, and an indication of which design implications will have the greatest potential impact on parents and child patients.

Demonstrating and Verifying Connected Dyadic Caregiving Through Technology Probes

Participants: Up to 30 parents with a hospitalized child

Method: Technology Probes We will deploy prototype apps for dyadic caregiving coordination in real use settings, observe use and working with participants to reflect on their use. We'll pick specific features & approaches based on results from the previous approaches, and likely leverage an open-source collaboration platform to speed development.

Examples of potential modules include: a module for collaborative note-taking, a module to encourage parents to initiate, record, and collaboratively process specific care-related conversations, or a module to allow annotation and linking to test results and other data in the EHR (although we will not directly integrate)

Expected Outcomes: Validation of the design implications and guidelines identified through interviews, observations, surveys, and workshops, as well as one or more artifacts that embody and reinforce those guidelines.

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