Designing Family-Centered Aids for the Intensive Care Unit

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ABSTRACT

Family member involvement has been shown to be key to the well-being and recovery of patients in an Intensive Care Unit (ICU), but they often find themselves overwhelmed and in an emotionally heightened state. ICU care teams, especially nurses, are typically considered to be in the best position to help and provide support to family members of patients. However, the heavy workload, lack of time, and personal interaction styles can make it difficult for them to be receptive to family member needs. To understand how current aids in the ICU are used and the challenges associated with them, we conducted 22 interviews with both family members and the care team. We also created prototypes of family-centered aids through a co-design session to reveal the opportunities that emerge for technology to facilitate family member support in the ICU without adding additional burdens on the care team.

KEYWORDS

Intensive Care Unit, Human-Centered Design, Families, Nurses, Co-Design

INTRODUCTION AND RELATED WORK

Intensive Care Units (ICUs) provide specialized care and close monitoring to patients with severe and life-threatening illnesses. Family members play a crucial role in the care of their loved ones [6] as they, among other things, provide emotional support for the patient and form an indispensable source of information for the care team. On the other hand the care team, especially nurses, due to their continuous interaction and constant bedside care, are best disposed to recognize and respond to the needs of ICU families and are often the primary source of both information and emotional support for families. However, varying personal interaction styles, a heavy workload, and lack of time can hinder nurses' ability to do so despite being aware of the various family needs [3]. Even with guidelines to enhance family-centered care and mitigate friction in the support of ICU families, half the families have been shown to experience inadequate communication [1].

Current interventions in the ICU primarily provide static information to families through information pamphlets [2] and whiteboards [10] to aid with comprehension and lower the burden on care team members [7]. While information pamphlets help deliver initial information and increase general comprehension in family members, families still seek more specific information [8] and often follow-ups fall back to verbal communication. Most of the research that uses inpatient technology-mediated aids like interactive reports that can be accessed through a mobile phone [9], or in-room displays [11], primarily focus on the patient and have not been studied in an ICU setting where family members and care givers are the main stakeholders in terms of information aids. Some ICUs provide patients and families with tablets through which they can access patient portals, like Epic's *MyChart Bedside*; these tools typically provide information on the care team, current medications, and lab results. While both family members and patients typically respond positively to the increased access to information, the usability and feature list of such portals leaves a lot to be desired [12], indicating a need to include family members in the development of family-centered interventions [4].

In this paper, we explore how additional technological aids can can mitigate friction in providing care and support for family members while working in harmony with the care team.

METHODOLOGY

We conducted a total of 22 semi-structured interviews with 18 family members (ages 28-73) and 4 care team members (ages 34-51) in the ICU of a large teaching hospital in San Diego, California. 16 of the family members were interviewed during their ICU stay and 2 family members were interviewed after the patient had been discharged. The 4 care-team members comprised of a nurse practitioner, a nurse manager, a charge nurse, and a primary/patient nurse. The interviews were conducted in the ICU and lasted 30-40 minutes each. Interviews with family members included a discussion of their ICU experience, the current aids they use, and the challenges faced. Interviews with the care team

Table 1: Total number of participants

	Family Members	Care Team
Interviews	18	4
Co-Design Session	2	

members focused on their work-flow, how they support family members, and the barriers encountered. We analyzed interview data using open coding and elements of grounded theory.

We also conducted a co-design session (see Fig. 1) with two other family members during their ICU stay and the previously interviewed care team members. The co-design session consisted of an open discussion of the challenges encountered while using current aids, and the characteristics of these aids that family members deemed important. We then used paper-prototyping to envision better systems that reflected these characteristics.

CURRENT FAMILY MEMBER AIDS

In this section we report on current aids that family members have access to in the ICU, and how they currently use them. Our goal is to broadly reveal barriers encountered by both care team members and family members in using these aids.

Verbal Communication

Current Use: The information provided to family members in the ICU primarily occurs through face-to-face verbal communications with the care team. This occurs after the daily rounds in the morning (a scheduled discussion where the care team reviews clinical information and creates a care plan for the day) and throughout the day as care team members go in and out of the room. Care team members sometimes also draw pictorial representations of the correlations between different parts of the care plan on paper sheets in order to explain it better. When family members are not in the ICU, they often call the nurses for updates, especially in the morning to *"find out how the night went"*(P17).

Challenges: While care team members try to provide information they deem important, they acknowledged that they aren't sure how helpful it is since family members often don't ask for clarifications unless they are familiar and comfortable with them. Care team members also noted that while they try to be attentive to family member's needs, their focus is on the patient and they often simply don't have the bandwidth to do it consistently. They also mentioned that different members have different communication styles - some aren't too keen on talking and focus on patient-related tasks while others try to form lasting friendships with the family members. Family members expressed that the information they receive can be overwhelming and that they sometimes take notes or record conversations with the care team because *"it's a verbal thing and then they're gone"*(P10). However, while care-team members noted that this could be a valuable resource to family members, they expressed being uncomfortable with it. When they know a conversation is recorded, it can often be perceived as inimical and they become cautious about what they say and only give the family members information that is absolutely needed. This is especially common when the family member has previously been perceived as "difficult" by the care team. Care team members also mentioned that calls from family members in the morning could get in their way of attending to a patient or doing their routine tasks, and that family members get anxious when their call is not received.

Figure 1: Co-Design session in the ICU room. Shown are the space that is available to patients and family, and the placement of a few of the paper prototypes that we developed with the help of family members and the ICU care team.
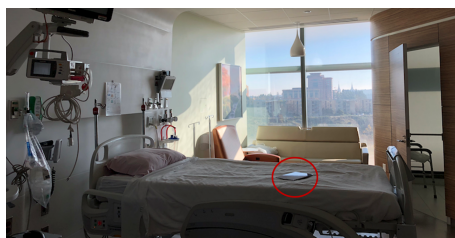
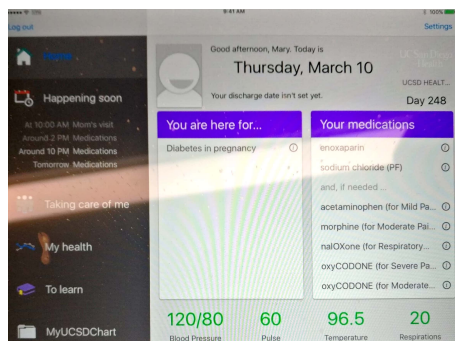**Figure 2: Intensive Care Unit patient room with the iPad given to families**

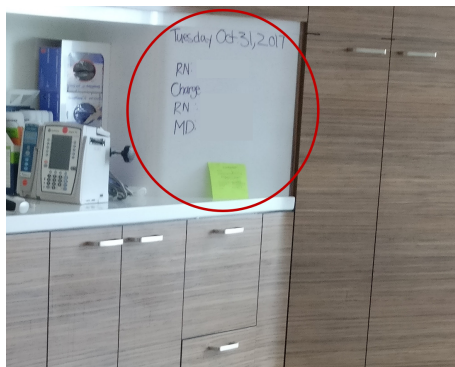
Figure 3: MyChart Bedside Interface

Figure 4: A whiteboard in an ICU room.

The Tablet Interface

Current Use: While not standard in every ICU, each room at the ICU in the hospital we worked with is provided with an iPad and an app developed by Epic named *MyChart Bedside* (see Figs. 2 and 3), through which family members can view portions of the patient's health records and lab results. Some family members thought that MyChart was *"generally a useful tool"*(P4) while others either did not use it or only used it as a *"backup to receiving information directly"*(P2). P15 also mentioned that while he did not use MyChart, his daughter would often access it remotely.

Challenges: Many family members found MyChart *"Unhelpful because it only shows blood-work [and lab results]"*(P1) and that it required *"too many clicks to find results/information"*(P7). Family members found that it was *"easy to jump to conclusions"*(P4) since the information was hard to interpret and wished there was some indication to tell them what to focus on. The care team too found that family members would often misunderstand the information they see and read articles on the internet that do not fully apply to the care of their loved one. They also noted that some family members gravitate towards numbers and lab values, often focusing on just one number without fully understanding them.

Whiteboards in the Room

Current Use: The rooms in the ICU were equipped with whiteboards (Fig. 4) that the care team members could use to write down care plan goals and contact information. Family members found it useful to know the care plan goals to help them understand what they should look forward to. P13 mentioned that the ICU her husband was admitted in previously *"had a glass board and I loved it...If I had a question and I was sitting there I could go jot it on the board and it would be addressed when the doctors came in...they would also put little notes down there"*(P13).

Challenges: Family members noted that the whiteboard was often not updated and hence tended to not pay too much attention to it.

ICU diaries and Care Pages

Current Use: ICU diaries are diaries written by family members and nurses for ICU patients to read afterwards to understand what happened to them. While not directly aimed at family members, the diaries have the potential to positively impact them[5]. CarePages (http://www.carepages.com), was a website that allowed family members to upload their stories or photos when they were hospitalized to keep friends and family updated. While none of our participants were aware of it, we found brochures for it at the hospital. At the time of our study, this particular website was closed.

Challenges: While family members noticed the diary in the ICU room, they were not aware of what it was or if they could use it. When asked about it P15 exclaimed *"Oh! I didn't know there was anything in there, I have always wondered what it is"*.
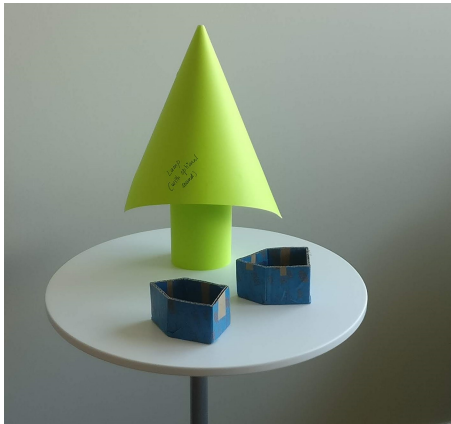
Figure 5: An image of a co-design artifact: Unobtrusive alerts with a smart lamp.
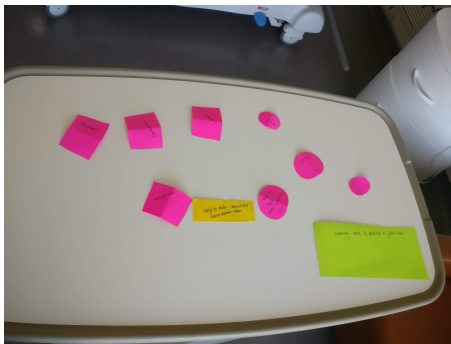

Figure 6: Prototype with movable parts to enable care team members to visually represent the care process.

DESIGNING FAMILY AIDS FOR THE ICU

Our co-design session included creating paper prototypes that reflected the characteristics for family-centered aids in the ICU that both the family members and the care team members deemed important. Here we introduce the major characteristics and how these have been embedded in a range of different paper prototypes (Figs. 5, 6, 7, 8).

Alerts that don't demand immediate attention and can be engaged with when ready: Given that using sound for notifications would likely add to the number of alarms and noises already present in the ICU, our participants envisioned an unobtrusive alert system—a *lamp* (Fig. 5)—that would slowly light up to prompt family members to engage with the system. Family members also envisioned using the lamp to encourage them to meditate or reflect on their day and help them cope with stress.

Asynchronous communication with the right care team member: Since family members often did not know who could best answer their questions, a *question board* (Fig. 7) was prototyped to allow care team members who came into the room to answer questions. They would be able to see both a list of questions assigned to them and a list of unassigned questions that family members were unsure of whom to direct to. The care team member could either answer the question verbally or leave a note on a *digital scratch pad* attached to the *question board*. They could also assign a question to another person from the unassigned list if they knew who could answer it.

Aiding sensemaking by encouraging reflection and providing visual take-aways: Family members emphasized that being able to capture conversations with the care team was imperative to helping them understand the information received at their own pace. We prototyped a *notepad* with a thin screen attached on the top that showed the name of the care team member that just entered the room, and what their role in the care was. The *notepad* allowed them to take down their own notes while also automatically transcribing the conversation. When done, they envisioned to be able to review the notes, highlight and save sections of the conversation, send these to another family member, or automatically assign a question to the care-team member on the *question board*. Our participants also envisioned a way for the care team to represent the care process pictorially using a touch screen through a prototype (Fig. 6) that had different blocks to mark treatment procedures and relevant biomarkers that the care team could use to move around and make links (by dragging their finger between blocks). This allowed for a visual representation of the conversation that family members could save and go back to when needed.

Personal observations and suggestions for the care team: Since family members knew best their loved ones, they could provide useful observations for the care team. Our participants prototyped two systems that allowed family members to provide their input. One consisted of a small *screen above the patient's bed* (Fig. 8) that could be used to suggest actions nurses could take in the absence of the family member. For example, family members would say "if [patient] is anxious, play [playlist]",
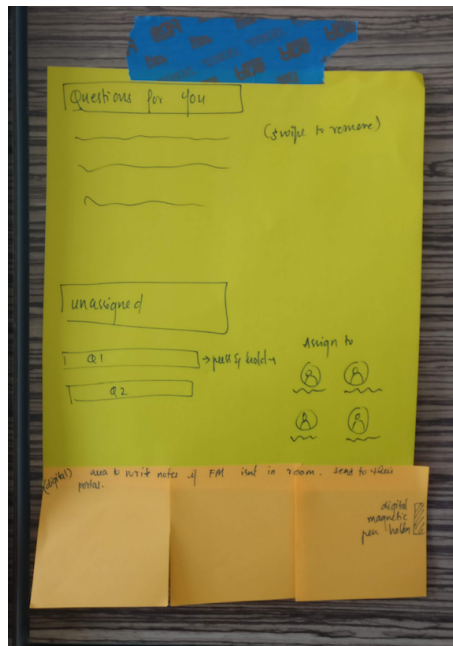
Figure 7: Question board prototype with a digital scratch pad at the bottom.
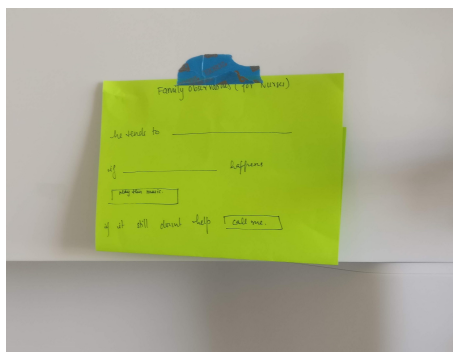

Figure 8: Prototyped small screen to put above the patients' bed.

which could then be activated by the touch of a button. The other prototype was a screen outside the room that showed family observations of patient behavior that could be viewed by the care team during the daily rounds. Not only could the information be helpful for the care team, it also served to provide structure to a family member's role during rounds.

CONCLUSION AND FUTURE WORK

Family members play an integral role in the care and recovery of their loved one, however, unaddressed needs and a lack of aids prevent their full engagement, especially in the Intensive Care Unit. In this paper, we investigated how current aids support families in the ICU and explored potential solutions that would better address their day-to-day needs. Our prototypes provided an initial direction for how technology could better engage family members throughout their stay in the ICU. We plan on continuing to design and deploy more comprehensive family-centered aids and evaluate their performance in the ICU.

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