

Nurture-Empower-Support: A Human-Centered Approach to Understand and Support ICU Families

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ABSTRACT

Family members have been shown to be integral to the well-being and recovery of patients in Intensive Care Units (ICUs). Watching a loved one fight a critical illness, however, can be a terrifying and life-altering experience. We present the results of a need-finding process aimed to investigate how interventions in the ICU can be designed to facilitate family member support in the ICU. We first delve into an in-depth 3-month ethnographic study to understand the complex ICU environment and to observe family-care team interactions. We then capture family experiences using journals and semi-structured interviews with a total of 23 family members. Based on these investigations, we propose NES (Nurture-Empower-Support), a three-stage framework to aid the creation of a holistic system that supports the dynamic needs of families in the ICU.

KEYWORDS

Intensive Care Unit, Human-Centered Design, Families, Nurses, Nurture, Empower, Support

INTRODUCTION

Intensive Care Units (ICUs) are areas of the hospital where seriously ill patients receive specialized care. ICUs cater to patients with life-threatening illnesses and injuries that require constant care and close monitoring from specialized equipment. ICUs distinguish themselves with a high staff-to-patient ratio and access to advanced technological equipment that is not routinely available elsewhere in the hospital.

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Since the shift to patient-centered care [5], family involvement in the ICU has been strongly encouraged [29]. Family members have been shown to play a critical role in the care of their loved ones [19] and have been identified as a vital source of information to the care team, as well as key emotional support to the patient [33]. Since patients in the ICU are usually unconscious or too ill to participate in their own care or express treatment preferences, the responsibility of making decisions often falls on their family members, profoundly affecting patient outcomes [28].

Watching a loved one fight a critical illness and being confronted with a complex clinical environment can be overwhelming and difficult to manage. Family members often struggle to make decisions [31] and experience anxiety, depression, and post-traumatic stress regardless of patient-outcome [1, 4, 8].

The ability to recognize and respond to the needs of family members in the ICU can substantially reduce the negative impacts of stress and increase their capacity to support the patient [7]. However, lack of time and a heavy workload can often reduce the care team's receptiveness to family needs. Although nurses, for example, have been shown to be aware of the various dimensions of family needs, this knowledge is not always translated into practice [7]. This discrepancy in perceived needs and varying personal interaction styles often hinder the development of a nurse-family relationship [25], and hence their ability to provide support. Clinicians have also reported family members' difficulty in accepting a poor prognosis, and understanding the complications of treatment to be major communication barriers [35]. Despite clinical guidelines in place to enhance family-centered care and mitigate friction in the support of ICU families [11], it has been shown that half the families experience inadequate communication and fail to comprehend diagnosis, prognosis, or treatment [2] despite high satisfaction with care [14].

In this paper, we explore how interventions in the ICU can be designed to mitigate the friction in providing care and support for family members. We seek to understand family experiences in the ICU through a 3-month ethnographic study in the ICU, one-to-one semi-structured interviews with family members, and analysis of experience journals. We then

classify family member needs under six distinct themes and formalize a three-stage framework called Nurture-Empower-Support (NES) to aid the design and development of appropriate interventions.

In summary, this paper highlights two key contributions to the field of HCI and Design for critical care:

- (1) Through our needfinding process, we reveal the progression of family member experiences and present six classes of needs for family members in the ICU.
- (2) We introduce NES, a three-stage framework for family-centered interventions in the ICU and discuss the implications of designing technology within it.

RELATED WORK

In order to better frame our investigation, we summarize related work in three different areas: families' needs in the ICU, existing ICU interventions, and related work in hospital inpatient, non-intensive, settings.

Exploring needs of families in the ICU

Existing literature documents the many needs that arise in the family when a patient is admitted to the ICU. These span from receiving information [13], communicating appropriately [2], and being provided with emotional support [9]. While information needs are classified among the most important needs of a family member [13, 30] these are often insufficiently met [2, 13, 30]. This is in part due to differences between the perceived importance of these needs by the family and the care team. Buckley et al., surveying nurses' knowledge of family needs, found that while the majority of respondents scored above 70% in their knowledge of family member needs, only 4.2% were able to rank these needs in order of importance [7]. Verhaeghes et al. found that needs are underestimated by the care team, and nurses underestimate their own role in satisfying these needs [30].

When it comes to addressing this imbalance, most previous work put forward solutions that focus on integrating new processes into care-team workflows [7, 30], effectively focusing on the care team as the sole vehicle through which family members' needs may be satisfied. In this way, family members become passive receivers of support as they confront uncertainty and over-stimulation in the ICU. We believe that although many studies focused on surfacing the needs of family members in the ICU, less work analyzed family member experiences as a process [30], and the time-sensitive and interdependent nature of family member needs. We understand much less about how family members are actually addressing their needs in the ICU, and we need more work to clarify the experiences of family members and how these can shape interventions in the ICU.

Our work aims to identify how family member needs arise and change throughout their stay in the ICU so that they may be addressed and overcome. This will in turn enable families to know how to meet their own needs, rather than rely solely on the care team.

Interventions in the ICU

Although family needs in the ICU are identified as going beyond information seeking, the vast majority of interventions are based on providing some sort of static information to families upon entering the ICU, or when faced with a particular new procedure.

Interventions in the ICU typically attempt to overcome limitations of verbal communication with the use of information pamphlets [3, 21] or whiteboards that display relevant patient information [27], providing resources that patients and family members can reference as needed. The surge of these kinds of interventions might be linked to the inability to properly communicate by the family member upon entering a complex environment [9], as well as to the additional burden of interruptions by family on the care team [20].

While information pamphlets help deliver initial information and increase general comprehension in family members, families still seek more specific information [21] and follow-ups often fall back to verbal communication. Paul et al. concluded that there remains a need to further include patients and family members in the development of more useful information booklets [21]. The study also highlighted the need for more staff education about family member needs. Azoulay et al. also found that introducing a family information leaflet improved the exchange of information, yet the use of written information alone did not increase comprehension, and family members' satisfaction was not significantly associated with the delivery of the leaflet [3].

Although researchers have begun to explore better ways of ensuring family member needs are met in the ICU, much work remains to be done on how to leverage their contributions in the care process appropriately. Initial studies of technology-mediated aids envision improved collaboration through contextual and customizable mobile user interfaces [12]. Some hospitals today also provide patients and families with tablets through which they can access online portals and view patient records. However, usability and the relevance of features of such portals leaves a lot to be desired [34], and there is a need to include and support family members in the development of such interventions [9].

Family-centered Interventions beyond the ICU

While only limited work beyond the provision of static information (through pamphlets) has been done in the ICU, researchers are increasingly looking to leverage ubiquitous

technology such as mobile phones and tablets to deliver more effective family-centered interventions in a variety of inpatient settings. One such study elicited positive reactions from both patients and families on using mobile devices as information conduits to improve patient awareness and consequently patient satisfaction [22]. However, nurses expressed concern on the device's impact on their workflow, and further work must be done to explore controlled measures of comprehension and satisfaction. Similar interventions that make use of tablets [6] and in-room displays [32] to communicate and display dynamic data find the information "vague" [32], and the intervention itself to be not significantly better than the next best alternative, a whiteboard and a marker [6].

METHODS

To uncover opportunities for supporting family members in the ICU, we embarked on a study to analyze in depth the day-to-day operation of the ICU and uncover families' preferences, concerns, and desires. Although we ultimately focus on family needs, our investigation takes a holistic approach and looks at the ICU as a whole. Using Distributed Cognition [15] as a framework we aimed to understand the interplay of clinicians (doctors and nurses), families, environment, and the existing technology.

First, an ethnographic approach helped us understand how families navigate the complex ICU environment and interact with the care team. We then employed both experience journals and semi-structured interviews with family members who identified as the patient's primary caregiver,¹ to understand their experiences and how they viewed their role in the care of their loved one. We also explored how their perspectives changed throughout their stay in the ICU and how they adapted to caring and making decisions for their loved one, while supporting their family and personal needs outside the ICU. Our study was approved by the University's human protections board, and all participants agreed to participate.

The ICU Environment

Our study was conducted at UC San Diego Health's Jacobs Medical Center, a large teaching hospital in La Jolla, California. The ICU is located in a modern building with 12 dedicated beds and specializes in caring for both medical and surgical intensive care patients across neurosurgery, stroke care, general surgery, and oncology. The patient staff ratio in the ICU unit is 1:1 or 1:2 and a mix of registered nurses, hospital unit service coordinators, clinical care partners, respiratory therapists, pharmacists, and intensive care

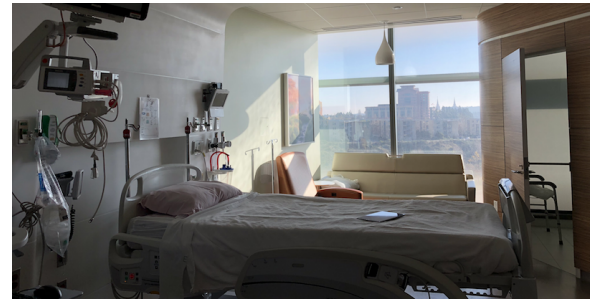


Figure 1: Intensive Care Unit Bed at the Local Hospital

physicians, take care of the patients. Figure 1 shows the typical environment of an ICU bed in the hospital where we performed this study.

Design Ethnography at the ICU

Two researchers spent a total of 80 hours at the ICU over a period of 3 months. We observed physicians' and nurses' workflows and their interactions with various patients through the day to understand how information and emotional support was provided to family members. This was mainly done through shadowing physicians and the care team during their daily rounds, often held in the morning. At this particular ICU, rounds were nurse-led—meaning that the nurse, and not the physician, was leading the round. The two researchers also shadowed the charge nurse—who was in charge of the unit—as well as a patient-assigned nurse—who was the one responsible for up to two specific patients—through their entire shift.

We also observed family member characteristics and their conversations with the care team to gain insight on how they received and made sense of information. While a large part of these observations came from shadowing the care team, the researchers also spent 15 of the 80 hours at nurse stations adjacent to patient rooms to be able to better observe how different care providers interacted with a patient and their family throughout the day.

This ethnographic approach was purely observational - the researchers were silent observers and simply took notes, never asking any questions until the end of a session. Questions at the end of the session were directed towards the care team, often to be able to understand a medical procedure or a term that was used earlier. At the end of the session, the researcher documented their observations as field notes.

Experience Journals

Initiating dialogue with family members at such a stressful time in their lives can be challenging without trying to understand what they are going through. Cultural probes [10]

¹For the remainder of the paper we simply refer to them as the family member

allow researchers to familiarize themselves with the population they work with and reduce the chances of receiving guarded responses when compared to using traditional tools like surveys and questionnaires. Our cultural probe consisted of journals that family members could use to capture their experience in any way they felt appropriate (see Fig. 2). They were also given the option to send pictures or text messages to a phone number that would forward them to the researchers' email.

We distributed empty notebooks to be used as journals to 11 family members while they were in the ICU, 4 of who had never experienced being in an ICU before. They were between 29-71 years old and their loved one had been in the ICU for 2-19 days. There were no rules for what could go into the journals, and they were not mandated to use it. We encouraged them to write down the events of the day, capture their feelings, or even jot down questions they had about care plan or environment. We collected these journals when the patient was discharged from the ICU.

Of the 11 journals that were given out, we were able to collect 5 back from family members. This was due to unexpected transfers, discharge, or demise of the patients during which they failed to leave the journal behind. None of the family members used the phone number provided to them. When asked about it at the end of their stay they mentioned they were more comfortable with writing in the journal as they spent time in the patient room.

Semi-structured Interviews

To facilitate an in-depth understanding of family member experiences and perspectives, we additionally interviewed 18 family members who were between 28-73 years old.

Sixteen of these interviews were conducted in the ICU and typically lasted 30 - 40 minutes. Two of the interviews were with family members of ICU survivors, lasting 1-2 hours. Interviews used a semi-structured format and topics were kept consistent across participants. However, additional questions

were asked for clarification and to be able to adapt the interviews to individual experiences.

These topics included:

- (1) Prior experience in an ICU
- (2) Medical background, if any
- (3) Involvement in decision making and daily care plan
- (4) Information Sources
- (5) Interactions with the care team
- (6) Emotional state and family dynamics outside the ICU
- (7) Preferences/What matters most
- (8) Challenges faced

Interviews were recorded and then transcribed if family members allowed it. Ten family members refused to be recorded due to privacy concerns or religious beliefs. In that case, researchers took notes during the interview.

All ethnographic field notes, experience journals, and interviews were analyzed using an iterative, open coding approach by two researchers. We used grounded theory methods [26] to identify codes that emerged from the data collected across the three phases. The two researchers then integrated the resulting code and grouped them into a number of concepts that then describe the findings of our investigation.

We identify findings stemming from ethnographic field note entries with an E (for Ethnography), extracts from participants that used an experience journal with a J (for Journal), and quotes from participants that were interviewed with an I (for Interview).

FINDINGS: FAMILIES' JOURNEY IN THE ICU

In this section, we present our observations of family member experiences in the ICU. We first break their journey into three distinct stages that are typically navigated chronologically. We then present aspects of family member experiences that are spread across the three stages.

Stage 1: The Initial Shock and Confusion

Family members experience a great deal of shock, confusion, and uncertainty when their loved one is brought into an ICU and are regularly faced with the fear of losing the patient. On recalling the transfer to the ICU, family members described feeling "very overwhelming" (J7), "helpless" (I7), and "frightful" (I13). At this stage, family members remain unaware of the extensive resources available to them as they "don't know what [they] don't have" (I6). For example, they "didn't know that family members were invited to join rounds" (I17), were often confused about the different specialties following the patient, and didn't know what they could bring into the ICU.

Why are we here?: Family members commented that there was "not a lot of information as to what was going on" (J7)

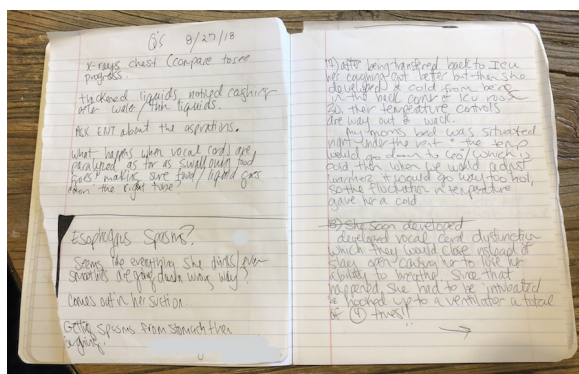


Figure 2: One of our Participant's Experience Journal

and they *"needed someone to help [them] understand what was happening..."* (J7). The simple fact of *"not knowing what's going on is scary"* (I13).

A foreign environment: Family members recalled viewing the ICU as *"foreign"* (I16) or *"hostile"* (I18), especially at first. The constant activity, the sense of urgency, the strange equipment, continuous noises, and bright lights, can all be hard to take in. Family members were unsure of *"what can I touch and what can't I?"* (I5), making them *"hesitant to do anything around the equipment because [they] might do the wrong thing"* (I15).

The flood of information: If a family member was present, the care team updated them on the treatment plan and prognosis, often multiple times during the day. However, in their emotionally heightened state, family members recalled being too overwhelmed to understand the specifics of their loved one's ailment. I16 mentioned that she really just needed to *"get a handle on what happened...I was faced with so much"*, and when the care team gave her more information, it was *"just too much"*.

Feeling out of place: Having multiple specialties following a patient is the rule in an ICU. Family members found this confusing and commented on the *"lack of communication about who is coming in and when"* (I9). Family members tended to see themselves as *"the extra person in the room"* (J5) and also recalled being *"kind of intimidated [by the care team]"* (I16). Reluctant to seek out information, I13 said she used to *"sit [in the room] and wait till they come in and talk to me"*. This initial unfamiliarity with the care team can make family members feel *"like an intruder at times"* (I17).

Maintaining vigil: Family members, especially at this early stage, tended to stay with the patient at all times: *"I've been here pretty much 24/7"* (I10). Everything else in their lives became unimportant, and simply leaving the room would bring about guilt: *"even a morning walk... I would feel guilty"* (I16). I14 affirmed that staying by his wife's bedside was his way of *"letting her know: 'I'm here'. I'm still here, since everything started"*.

Stage 2: Seeking Active Participation in the Care Process

With time, and increased awareness, the initial shock and confusion subsides: *"after you're there for longer than a week, you learn"* (I17). Feeling less overwhelmed, family members were more receptive to the information they received from the care team. They asked for more clarifications, and desired to be more involved in the care process, like I3: *"[I] want to be updated constantly and be involved in everything"*.

The importance, and difficulty, of asking questions: Family members acknowledged that the *"ability to ask questions*

and receive answers is critical...being in the ICU there's no time to be timid or shy" (I3). A complex care team meant that family members don't always know whom to direct questions to: *"You see a doctor in a white coat and don't realize that that guy's a cardiologist and you can't ask him the infectious disease questions"* (I17). Even when she knew exactly what to ask, I10 hesitated to do so: *"well on that screen, there's a whole bunch of numbers and I have not asked the respiratory therapist...I think it would be too time con-... well I just, I haven't"*.

Missing and conflicting information: Often family members *"aren't there when staff stop by, then a lot of information is lost"* (I4). Family members highlighted that if they were not around, they had no way of getting to know what happened during rounds or what the plan for the day was. The care team too, often miss family members when they are in the ICU. During an ethnography session doctors and residents mentioned wanting to talk to the patient's family but always seem to miss them. *"[Resident]: I always see him leaving from the corner of my eye and I'm like... ugh"* (E).

Families sensed that the care team knew more than they were saying. While they acknowledged that sometimes it might be *"better for nurses and doctors to kinda keep things to themselves..."* (I3), and they understood the reasons behind it, they expressed frustration: *"[but] I feel like there are some things that I kind of wish they would talk to me about"* (I3).

Taking part in daily rounds: Family members overwhelmingly stated *"rounds were most helpful in getting information"* (I1) since they *"get to hear what everyone [on the care team] says...the summary and plan...[so] I know what's coming"* (I10). Listening in on rounds empowered family members: *"up until the time we were joining rounds, we had come to be known as a difficult family...I had lots of questions and there were challenging aspects to his care and decisions that were very difficult...it empowered us...I could have all of our questions answered...it didn't solve everything, but it certainly made a huge deal to us in terms of understanding what the trends were, what concerns the doctors had..."* (I17).

Interpreting medical jargon: The most cited barrier to understanding the information received was in being able to interpret medical terms. I17 described it as the care team having *"their own language..."*. I7 admitted that he *"wouldn't have a clue how to interpret information without a doctor around"*. Family members acknowledged that the only way they really learn is by *"getting my input from people who really know what's going on"* (I3). Family members also mentioned that they looked up information on the Internet when they did not understand something, sometimes spending the night researching online simply so they could *"hold a conversation [with a doctor]"* (I16).

Caring for the patient: As the initial shock of being in the ICU wears off, family members begin engaging in the care of their loved one. Due to the nature of the ICU, patients are often unconscious or delirious for majority of their stay. Family members stressed the importance of maintaining verbal communication during this time: *"having people come in talk to him, touch him...You can't explain it but I just knew it was something that needed to be done"* (I16). Family members also said that prayers and *"music was really helpful, we could have playlists on Pandora that we chose for him. The noises in the ICU are just unbelievable, all the alarms and beeps...so anything that can drown out the terrible sounds and that would soothe the person..."* (I17).

Stage 3: Finding a Place in the Care Team

This stage was not one that many families were able to achieve. Some of them due to the limited time in the ICU, others because they never reached an emotional state that would allow them to be an effective partner in the care process. Our work aims to better support families towards reaching this third stage. The few families that reached this stage said that they became more confident as they learned to cope with the stress of the situation, navigate their way around the ICU, and understand how they could be of value to the care team: *"It took me a while [but] I felt like I was just as much a valued member of the care team when I got more confidence"* (I17).

Ongoing and Dynamic Events

Here we present dynamic aspects of family member experiences that are a constant or could occur at anytime during their ICU stay.

The Emotional Distress: The psychological toll of having a loved one critically ill is present every step of the way, regardless of the stage. I14 revealed, *"sometimes it's hard to digest because you want things to go forward but some days it feels like it's going backwards"*. I16 recalled that there were many instances in the ICU where she found it hard to *"grasp what was going on...I kept looking at him like 'he had a flu!' and fast forward a week and he's in a coma?!"*. In her journal, J5 wrote *"feeling discouraged today. he is so frail...hard hard hard...I know it's a matter of time but still very difficult for me to see such weakness"*.

Dealing with ICU delirium: Family members are often unprepared to deal with ICU delirium, a form of mental impairment that can occur in critically ill patients. ICU delirium can present itself at any stage of a patient's ICU stay and can make them anxious and aggressive. Family members reported that the patient would be *"psychotic and go crazy and hallucinate about things"* (I17). Watching their loved one become delirious can *"get very intense"* (I15), especially when

it is unexpected. Being aware of it beforehand, however, can help family members prepare for it. I13, for instance, went to a support group when her husband was in the ICU: *"they tell you that he's gonna have hallucinations, he's going to be delirious. So that kind of helped me and my kids prepare for what we were going to experience"*.

Making Medical Decisions: Family members felt the immense pressure of having to make medical decisions on behalf of the patient, mentioning that they *"hope this is the right thing to do"* (I16). End-of-life discussions with the care team can be especially difficult. In one of these discussions, I16 recalled that a doctor had just told her that she *"needed to make arrangements"...I got really mad. I screamed - chewed him out. And then there was nothing I could do except sit there and watch [the patient]"*. These discussions often involve multiple doctors and family members, with family members needing to make decisions before fully coming to terms with them. I17 recalled one specific instance: *"I felt that we were being pressured to not go with kidney dialysis...the doctor said 'he may have a couple of days maybe a week left, and if you put him on kidney dialysis he may be on it for the rest of his life. You have to start thinking about his quality of life - would he want to live like this?'... and I'm feeling like 'oh my god oh my god'...I said, we don't want to give up yet..."*.

FINDINGS: THE SIX CLASSES OF NEEDS

After analyzing the experiences that emerged from family members in the previous section through our need-finding process, we were able to define six distinct classes of needs.

1. The need for emotional support — Family members emphasized the overall need for emotional support and reassurance and said that it was especially crucial in the beginning as they tried to cope with the overwhelming situation. Nurses were observed consoling distressed family members on numerous occasions, saying: *"I know it's hard, we're going to try and fix things so they're better"* (E). Family members recognized and appreciated being treated with empathy and often recalled the staff as being *"fantastic across the board - they were warm and loving"* (I13). Family members also tended to understand care team constraints, but expressed the need to have someone they could lean on: *"I know everyone was busy...would have been nice to have someone with us"* (J7).

2. The need for enhanced awareness — Family members expressed that having more information about the ICU when their loved one was transferred would have been very valuable. They wished for an orientation video or *"an ICU for dummies kind of thing"* (I17) that informed newcomers of what the ICU was, what the equipment did, what to expect from the care team, and what resources were available to

them. For instance, family members were only aware they could join rounds when someone invited them: I17 said *"we had been in the ICU for a couple weeks. I didn't know that family members were invited to join, but because I knew some of the doctors, they allowed me to join"* and commented that there needs to be a standard way of letting family members know *"this is what the ICU is like...there are rounds, you are welcome to come to join, you shouldn't ask a lot of questions, these people are busy"*.

3. The need to build relationships — Building relationships with the care team enables family members to ask questions and allows the care team to better involve the family member in the care process. We observed many family members form friendships with the care team and referred to the care team, notably the nurses, as family. This bond enabled nurses to more openly explain procedures and patient prognosis at a level closer than others on the care team. They were also able to support and console family members, providing them with necessary hope and reassurance.

4. The need to support sensemaking — Sensemaking, or being able to sustain a motivated effort to understand connections (among people, places, or events) in order to anticipate trajectories and act effectively [16], can be difficult in the ICU. Feelings of fear, frustration, and loss of control were common among family members as they tried to source and interpret the information they needed, especially since the patients themselves were unable to be part of their own care. Family members voiced their need to receive and make sense of *"nitty gritty details...like numbers and raw results"* (I3). When possible, family members described the ability to finally track and make sense of complex information as *"very empowering, like when you have a Fitbit or so..."* (I17).

5. The need to be part of the care process — Family members *"want to believe that I am an active part [of the care]"* (I14) and that they are positively contributing to the well being and recovery of their loved ones. However, they expressed that establishing themselves in the ICU and feeling like they had an active role in the care process was challenging and took time.

6. The need to care for themselves — We observed that in the initial stage, family members focused solely on supporting the patient, often at the expense of their own well-being. Only once family members became grounded they were able to view their experiences from a more rational perspective, thus enabling them to practice self-care. After commenting on her initial difficulty in leaving the ICU for a break, J5 mentioned that she finally went for a walk with a friend and got a haircut: *"just something different for myself - something not connected to the hospital"*, highlighting the emphasis

of *"normal people doing normal things"* in promoting better self-care.

A STAGE-BASED APPROACH

As illustrated in the previous section, our findings point to six *classes of needs* that family members presented while in the ICU. To support these needs, interventions in the ICU must be able to: (1) provide emotional support, (2) enhance awareness, (3) aid building relationships, (4) promote sense-making, (5) support participation in the care process, and (6) encourage self-care. In this section, we propose a stage-based framework to guide the design of family-centered aids with a focus on supporting the changing needs of families across the different stages of their ICU experience.

Concurrency and Prepotency of Needs

All family members, regardless of how long they have been in the ICU, or whether they have been in a similar position before or not, require direct or indirect support for all six classes of needs simultaneously. We refer to this as the *concurrency of needs*.

In addition, the classes of needs identified are inherently interdependent and often support or hinder each other. However, we noticed certain classes of needs could dominate, and failure to address them reduces the family member's receptiveness to aids that support other classes of needs. For example, failure to provide successful emotional support could leave a family member in a heightened emotional state. This then hinders their sensemaking ability, which in turn, hampers the ability to be an active participant in their loved ones care. We refer to this as the *prepotency of needs*, a concept most notably used in Maslow's hierarchy of needs [18]. It is therefore imperative that a support system designed for family members not only supports all six classes of needs, but also prioritizes the most prepotent one to ensure proper family member receptiveness to all the aids provided.

Nurture-Empower-Support

To support the above described six classes of needs, we introduce the *Nurture-Empower-Support* (NES) framework. NES is inspired by existing psycho-social models [17, 18, 23, 24]. Specifically, according to Slaikeu [24], crisis is defined as a *"temporary state of upset and disorganization, characterized chiefly by an individual's inability to cope with a particular situation using customary methods of problem-solving, and by the potential for a radically positive or negative outcome"*. When confronted with a sudden emotionally charged event, the event overwhelms normal coping and the person is unable to effectively utilize previously learned coping behaviors and reduce stress[24]. To alleviate the immediate pressure

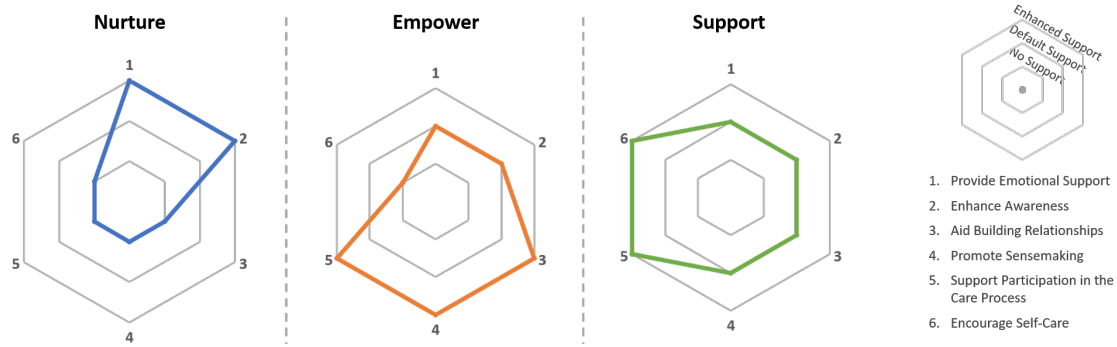


Figure 3: NES framework depicting prioritization of prepotent needs. The three concentric hexagons represent No Support, Default Support, and Enhanced Support respectively (from inside to outside). The 6 numbered vertexes represent support for the 6 classes of needs. Default supports only builds up once the prepotent needs of the previous stage have been met.

and restore the individual to a pre-crisis level of functioning, Puryear introduces Crisis Theory [23]. We believe that this theory provides a foundational model through which interventions for families in the ICU can be framed. Although other models such as Maslow’s hierarchy of needs [18] or stage-based information models like the one by Li et al. [17], could better support the stages we uncovered in our work, we believe that a framework modeled around Crisis Theory allows for flexibility and support, while being mindful of both the concurrency and prepotency of needs.

Our NES framework aims to enable family members to both achieve emotional stability as well as be active participants in the care process. It consists of three stages, each defined and driven by an intent: *Nurture*, *Empower*, and *Support*. Each stage is characterized by three varying levels of support across the six classes of needs: *no support*, *default support*, and *enhanced support*. At each stage, family members receive enhanced support for the most prepotent or dominant needs. If family members’ receptiveness to aids for a certain class of need is hindered until these prepotent needs are met, it receives no support in that particular stage. All other classes of needs are supported at a default level.

Below we describe the three stages of NES, highlighting in parenthesis what classes of needs are addressed in every stage—e.g. (1) for need #1, emotional support. Figure 3 illustrates how the NES Framework dynamically supports the six needs. Note how default support builds up in the three stages and is only available when prepotent needs in previous stages are met.

Stage 1: Nurture

Initial experiences of family members in the ICU are marked by emotional conflict, overwhelming stress and anxiety, and maladaptive coping strategies. *Nurture* aims to calm family members and reduce stress to a level that is conducive to emotional stability by providing emotional support (1) and

enhancing awareness (2). Emotional support builds necessary resilience in family members by providing reassurance and allowing them to recognize and express latent feelings. Awareness of the patient’s illness, the prognosis, and their surroundings further help establish a comfortable environment and reduce the initial shock and confusion family members face in the ICU. Alleviating this initial tension is crucial for family members to begin addressing information needs and participating in the care process.

Stage 2: Empower

Once the initial stage of overwhelming emotion subsides, family members begin foraging for information and knowledge. *Empower* aims to help family members to build relationships with the care team (3), receive and interpret relevant information (4), and begin participating in the care process (5). Establishing a bond and being more comfortable with the care team allows family members to receive more information, ask clarifying questions, and participate in rounds. Cultivating sensemaking abilities at this stage is crucial for family members to be able to interpret the information they are receiving and thus build the confidence required to be able to take on an active role in the care process.

Stage 3: Support

The previous two stages aim to move family members closer to an equilibrium where they are no longer in a state of acute emotional distress, are equipped to interpret the information they receive, and begin taking a more active role in the care process of their loved one. The *Support* stage strives to maintain this equilibrium while encouraging self-care (6), something most family members tend to neglect while in the ICU. They also continue to receive enhanced support for participating in the care process (5) since it is an ongoing effort. The *Support* stage, characterized by the concurrent support of all six classes of needs, lasts until the end of a family member’s ICU stay.

DISCUSSION

In this section, we discuss the implications of developing technological interventions under NES and identify opportunities for future research to expand the framework.

At a general level, the NES framework encourages designers (and developers) to take a holistic approach in developing interventions by calling attention to the importance of the evolution of needs through the family member journey in the ICU. NES does not attempt to completely satisfy a certain need before moving onto the next stage; instead, it strives for *sufficiency*—a need is provided with enhanced support up until the point it is no longer prepotent, after which a default level of support is provided. This allows for eventually supporting the concurrency of the six classes of needs in the *Support* stage.

Through the six classes of needs, NES also supports the design of future interventions by helping identify the gaps in current systems. Importantly, NES can be adapted to any number and combination of aids and does not dictate *what* interventions must be introduced into the ICU. Rather, NES guides the *design goals* to accomplish and *when* they can be introduced in order to create an effective support system for family members in the ICU.

For example, if we were to design a family-centered health informatics system, NES would help recognize the various features required. It would also acknowledge that introducing complex information at once can be overwhelming. Hence, the *Nurture* stage could prioritize providing awareness of the complex equipment used to care for the patient and their capabilities. The *Empower* stage could offer supplemental aids that provide understanding of medical terms, clear definition of personnel roles, and highlight relevant details to help family members interpret the information they receive. The *Support* stage might additionally allow family members to add their own observations into patients records, helping them be an active part of the care team. At the same time, NES would also recognize that interventions that encourage self-care (like meditation or self-reflection) might not be effective while the family member is in an emotionally heightened state and suggest that they be added in the *Support* stage once family members have learned to cope with their situation and are more receptive to it.

The framework does not specify how long a specific stage lasts. We observed that some family members felt overwhelmed throughout their stay, whereas a few resilient family members, especially those with prior experience in an ICU, moved towards Stage 3 faster. NES aims to encourage and empower family members to effectively and promptly transition towards Stage 3. However, it does not mandate how transitions between stages occur. Armed with the knowledge

of how the six classes of needs evolve, designers could make transitions across the stages context-aware. For example, as family members recover from the initial shock, they might start to engage more frequently and ask more specific questions to an interactive ICU family-centered system. Such behavioral changes could be monitored, and their realization would, for instance, trigger a transition to the next stage.

The progressive and uni-directional nature of the framework has been designed by taking into consideration how drastic and unexpected events that would be problematic in previous stages do not push family members back onto previous stages. Once a stage is reached, family members only go forward. For example, if the condition of the patient deteriorates drastically, family members might find themselves acutely anxious again. Nonetheless, we observed that family members experiencing these events did not go back to the initial state of shock and confusion (Stage 1) since they were now acclimatized to the ICU environment and the situation itself. Comparably, although ICU delirium can occur unexpectedly in patients, family members can be provided with support for ICU delirium (like providing awareness of the phenomenon and coping strategies) without additional emotional aids like those in Stage 1. While our current observations support the single direction of NES, more work needs to be done to better understand unexpected events and the best way to incorporate targeted aids to create a more robust framework.

The NES framework provides a way of framing the complexities of family member experiences in the ICU and can be easily extended to reflect findings from future research in the area. For example, we envision the framework to be extended to include behavioral triggers that could guide transitions across stages, as well as support for other stages (like post-ICU family needs). Finally, we believe that the outcomes of additional longitudinal studies focused on the whole family (as opposed to the primary caregiver only), as well as the care team members, would also create opportunities to extend the NES framework.

CONCLUSION

Family members play an integral part in the care and recovery of their loved one, and supporting their participation in the ICU is an important step towards increasing clinical-outcomes and improving family-centered care. However, un-addressed needs impede their full engagement and current interventions for family members do not consider how family needs change across the ICU experience.

In this paper, we gain an in-depth understanding of their challenges and experiences through ethnography, experience journals, and semi-structured interviews. This allowed us to formulate six classes of needs that family member

experience, and reveal two characteristics of these needs—concurrency and prepotency—that have implications in the design of family-centered aids in the ICU. Finally, we introduce a stage-based framework—Nurture-Empower-Support (NES)—that encourages integration of the entire ICU experience of family members in the development of new technological interventions. With better insights into the nature of family experiences and needs in the ICU, the NES framework empowers HCI researchers, designers, and developers to explore new approaches to create effective family-centered aids that considers family members as key participants in the recovery of their loved one in the ICU.

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