

Online Supplement 1: Interview Guide

Humanization experiences

Think back on your time in the ICU. Think of how you were treated in the ICU. Can you share an example of when the ICU staff (or the people in the ICU) treated you as a person or as an individual or where you felt deeply respected or dignified?

What is the greatest act of kindness that you received in the ICU?

How were you treated in the ICU (not medically, but personally)?

Dehumanization experiences

Were there parts of the ICU experience where you felt less than human? (loss of respect, loss of dignity)

Dehumanization involves not treating someone like a human. It typically includes things such as violation of one's self, belittling, rudeness, acting as if you did not exist. Are there times when you felt dehumanized in the ICU?

Suffering of ICU patients falls into a few categories. Some suffering is experiencing symptoms such as shortness of breath or pain. Some suffering is experiencing confusion. But there is another aspect of suffering that is related to your sense of self. Can you share some examples?

Let's say you walked back in to the ICU as a peer supporter to help patients, what would you tell patients and family members?

What are key threats to worry about?

What are key things to do to preserve your dignity?

Who was your favorite person in the ICU? Why?

Who was your least favorite person in the ICU? Why?

When did you feel most alone or most abandoned?

Family experiences

How was your family treated? Were they ever treated as "less than human"?

Interventions

Imagine you are the administrator in charge of the ICU. You have infinite resources. What would you do differently for patients and families? How would you improve the experience for patients and families?

Do you have an idea of something that could work?

What could they have done better to treat you as a person rather than as a patient?

What can we do to better help patients like you in the future?

ARDS Foundation Post

Post 1: Hi ARDS Community. We would like to hear about behavior that you felt was dehumanizing when you, or your loved one, was in the ICU. When we say 'dehumanizing' we mean behavior that you felt failed to treat you like you were a person during your (or your loved ones) ICU stay.

Post 2: Hi ARDS Community. We would also like to hear about behavior that you felt was NOT dehumanizing when you, or your loved one, was in the ICU. When we say 'dehumanizing' we mean behavior that you felt failed to treat you like you were a person during your (or your loved ones) ICU stay. So when we say that, the actions or incidents that made you, or your loved one, feel like you were a person whom mattered who was also a patient in the ICU.

Supplemental Table 2. Baseline characteristics of participants

Participants	n	Gender, n
Patient survivors	28	(22 women, 6 men)
Family members of patients	11	(8 women, 3 men)
Clinicians (physicians, nurse practitioners, physician assistants)	8	(4 women, 4 men)
Nurses	3	(3 women)
Therapists (physical, occupational, respiratory)	11	(8 women, 3 men)
Chaplains	10	(7 women, 3 men)
Total	71	(52 women, 19 men)

Supplemental Table 3. Dehumanizing and humanizing behaviors

Dehumanization		Humanization	
Behaviors	Example quotes	Behaviors	Example quotes
<ul style="list-style-type: none"> Talking “over” the patient and not “to” the patient Not introducing themselves or explaining what they are doing or what is happening or why (often when the patient was assumed to be unaware) 	<p>“A lot of those discussions . . . would happen in my room between physicians and my parents. It was like I wasn’t in the room . . . I was out of my coma . . . but I wasn’t included . . . I kind of felt like a fly on the wall as people were talking about what was going to happen to me.” (Patient)</p>	<ul style="list-style-type: none"> Talking “to” the patient and not “over” Introducing themselves and explaining what they are doing and why (even when the patient was assumed to be unaware) 	<p>“Each night [one nurse] would tell me who he was, and tell me what he was about to do . . . I couldn’t respond . . . I was chemically paralyzed. I looked like I was in a coma. To him, he didn’t know if I could hear him or not, yet he acted like I did . . . He would say, ‘Hey, Mr. Smith, this is Jim. I’m gonna bathe you now, I’m gonna do this.’ He would talk to me like I was responding to him.” (Patient)</p>
<ul style="list-style-type: none"> Not learning about or acknowledging the patient as a person outside of the hospital 	<p>“[A patient asked to be repositioned] and the nurse [stood] right at the door and [called] for help from other nurses and [said], ‘[Room] 36 needs turning.’ The [patient’s] family member [was] sitting right there . . . but [the patient was] referred to by [her] room number.” (Chaplain)</p>	<ul style="list-style-type: none"> Learning about the patient as a person outside of the hospital 	<p>“I brought a photograph of my wife . . . [of her] holding my two kids, and I can’t tell you how many of the staff spent time talking about that . . . It provides a different link with the . . . staff . . . that goes beyond, ‘They’re just a patient’” (Family member)</p>
<ul style="list-style-type: none"> Not allowing family presence 	<p>“[I was] abruptly moved to [another floor] . . . It was like 11 pm. They told my family that they had to leave because visiting hours were long over. So even though they moved my room in the middle of the night to a place where I was unfamiliar with . . . the only constant I had - my family - was forced to leave. And this contributed to the delirium that I experienced shortly thereafter.” (Patient)</p>	<ul style="list-style-type: none"> Allowing family presence 	<p>“My son was only 18 when he contracted ARDS. He did have a 14-year-old sister, which the hospital did allow my daughter complete access to him in his room. She could stay as long as she needed or wanted, and could sleep in the room in a chair with him . . . They were very close, and I think that helped with his recovery, actually.” (Family member)</p>
<ul style="list-style-type: none"> Ignoring or minimizing the patient’s suffering (including a lack of empathy, compassion, or caring) 	<p>“[When they decided to withdraw life support on my husband, the nurse and the respiratory therapist], sat and watched through the window after they unhooked him, watched him wake up, watched him gasping for air, watched him suffocate to death—and did nothing. Absolutely nothing. No attempt at making him comfortable, nothing. It didn’t even phase them. He was nothing to them, just a body taking up a bed—a bed that that I learned later was desperately needed as the ICU was full that day.” (Family member)</p>	<ul style="list-style-type: none"> Compassionately addressing suffering Providing a personalized environment (e.g. favorite music or items from home) 	<p>“We had a cystic fibrosis transplant patient who had just come to the end. [Her medical team] knew she was gonna die, and she knew she was gonna die. She . . . loved horses . . . They surprised her . . . They took her downstairs, and someone had brought a couple of horses down to the area right outside the hospital, and brought her out there on her vent to pet the horses . . . This was really stunning and made pretty much everyone cry.” (Physician)</p>
<ul style="list-style-type: none"> Using distressing, dismissive, or offensive language (often when the patient was assumed to be unaware) 	<p>A patient overheard two doctors outside her door talking about who her pulmonologist was going to be. One doctor asked the other, “Who is [the patient’s] pulmonologist going to be?” The other one answered, ‘Dr. So-and-so.’ Then the other doctor said, ‘Oh geez [not Dr. So-and-so] . . . We can tell [that patient] goodbye.’ That really upset me.” (Patient)</p>	<ul style="list-style-type: none"> Using empathic and encouraging language 	<p>“A real focus should be made on using as positive language as possible. I think that when [a patient is] in that vulnerable state, it really is like you just feel completely helpless. You’re completely reliant on the people around you—nurses, doctors, your family—to help you. When you’re hearing treatment plans and things like that, procedures, in a negative context, it doesn’t really take very much to put you in a state of complete panic . . . What’s going to happen to me? That sort of thing. It can be</p>
<ul style="list-style-type: none"> Blaming, mocking, or getting angry at the patient (e.g. for 	<p>“[The nurses] insisted I walk to the bathroom 3 days after waking from my coma and I collapsed and had a [bowel movement] all over myself and everything else. They yelled at me because it</p>		

soiling themselves or for causing their own illness)	pulled out all my tubes!" (Patient) "I had nurses who would honestly make fun of my anxiety." (Patient)		catastrophic to hear any sort of negative type of language to describe that." (Patient)
<ul style="list-style-type: none"> • Touching the patient roughly or without explanation (e.g. during bathing or repositioning) 	"[One of my nurses] was showing a trainee how to give me a [sponge] bath. Pour cold water—told her it didn't matter. All I could do is scream inside and cry since I couldn't talk. I've never been treated so harshly as I was that day. . . Still haunts and upsets [me] to this very day!" (Patient)	<ul style="list-style-type: none"> • Using appropriate physical touch (e.g. holding a hand) and notifying/explaining to the patient before other physical touch (e.g. repositioning) 	"Some of our most rewarding [physical therapy] sessions . . . are when a patient starts to get up for the first time and we encourage a family member or a spouse, 'When's the last time you gave them a hug?' Too often we keep family members, you know, 'You have to stay off to the side. We need you over here. We need you out of the way.' They lose that compassion and that touch with the patient . . . It's an incredibly powerful thing when they can start to hug and touch each other again." (Physical therapist)
<ul style="list-style-type: none"> • Neglecting hygiene or usual appearance (e.g. oral care, hair, dentures, eye glasses, etc.) 	<p>"Often, I will find patients with their mouths so caked up with dead skin and whatever else that they wouldn't be able to talk even if they wanted to, because their mouth is in such horrible condition." (Occupational therapist)</p> <p>"The nurses didn't touch my hair and it was a giant revolting mat after a month. My sister sat and sprayed detangler and combed it through strand by strand and braided it. The nurses wanted to cut it off." (Patient)</p>	<ul style="list-style-type: none"> • Attending to hygiene and usual appearance) 	"And I thank God to this very day the two teams who were so amazingly dedicated to her. They would even put lipstick and braid my wife's hair while induced [in a coma]." (Family member)
<ul style="list-style-type: none"> • Disregarding the patient's privacy and modesty 	"My privacy wasn't protected. I know that after I got off the vent, still in the ICU though, I was on a bedpan, and in walks a male cousin that I hadn't seen in like four or five years. I'm pretty sure I looked a mess. I know that he didn't care, but I did." (Patient)	<ul style="list-style-type: none"> • Respecting privacy and modesty 	"I make sure to first tell [patients] what I'm going to do and also tell them how I'm gonna keep them modest. I say, "I'm gonna put this blanket over your pelvis, and then I'm gonna look under your gown so I can see your incision . . ." (Therapist)
<ul style="list-style-type: none"> • Interrupting the patient's sleep or schedule 	"If that was a normal person walking around, you wouldn't just barge in their room and be like, 'Sorry, this is the only time I have to talk to you.' It would be like, 'Oh, let me look for a good opportunity to interact with you and respect your time' . . . Right now, [the patient is] resting, and we should really respect that, because we would respect that in a different setting. If that was my mom resting, I wouldn't go in and just wake her up willy-nilly to talk to her about something." (Therapist)	<ul style="list-style-type: none"> • Respecting the patient's sleep and schedule 	"I'm really passionate about . . . identifying patient schedules—so if . . . they're resting or they're doing something, it's giving them the privacy of having that." (Therapist)
<ul style="list-style-type: none"> • Preventing the patient from exercising control or participation 	"How often do you walk into a room and the patient wants to get up to the chair . . . and our immediate reaction is, 'You can't get out of bed.' Just something simple like [that]. We give [patients] zero control about anything . . . If we could just give some of that back, and give them that little bit of feeling of control, I think that would make a huge difference." (Nurse Practitioner)	<ul style="list-style-type: none"> • Finding ways to allow the patient to exercise control and participation 	"I asked [my nurses] every other day to wash my hair . . . all these other little things that helped me . . .to feel like I had some of my independence back and some control." (Patient)

<ul style="list-style-type: none">• Not preparing the patient for ICU or post-ICU events	“[Nobody prepared me about] PTSD . . . Prepping us that way, mentally, emotionally—this is what you may experience. Then once, when it does happen, you’re not overwhelmed by it. You’re not taken aback by it.” (Patient)	<ul style="list-style-type: none">• Preparing the patient for ICU or post-ICU events	“It was really great that the nurse did give me that printout [and explained to me what to expect]. (Family member)
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Online Supplemental Table 2: Potential causes of dehumanizing behaviors

Potential causes of dehumanizing behaviors	Example quotes
Patient factors	
<ul style="list-style-type: none"> • Medicalized and ill appearance 	<p>"[ICU patients are] lined up. They have all these drips connected to them. They become a patient, not a person. It's always a little shocking to me when family members will bring in pictures of what they look in their everyday life, or a reminder in some way of who they were before they came to ICU . . . and stayed here for weeks and weeks. I think those reminders are surprising, and that is because they have ceased to be real people outside of that bed to the people taking care of them." (Physician)</p>
<ul style="list-style-type: none"> • Impaired cognition (sedated or not interactive) 	<p>"I would definitely say it shouldn't be different, but I do think it is . . . different when you're going into your patient's room and they're intubated and sedated versus your patient that just got extubated the day before and is oriented." (Nurse)</p>
<ul style="list-style-type: none"> • Language barrier (does not speak English) 	<p>"Our policy is . . . to use interpreters anytime we deal with [patients who don't speak English]. But, in practice, that can be nearly impossible. We see some dehumanizing there, where patients aren't cared for as well because they're not respected because they don't speak English as their preferred language." (Chaplain)</p>
<ul style="list-style-type: none"> • Perceived to be difficult or have exceptional needs 	<p>"I've seen dehumanization in . . . patients who are a little bit more, I guess lack for a better word, needy . . . Maybe they're a little more difficult to deal with. I'm thinking of a few different circumstances where the patients were so distressed in their own situation that they just constantly were berating the staff, the nurses, constantly banging on the bed every five minutes, which over an eight month period, can really wear on the emotions of the staff and cause them—not cause them but have that result of, they start to treat this patient in dehumanizing ways out of frustration." (Chaplain)</p>
<ul style="list-style-type: none"> • Perceived to be the cause of their own illness 	<p>"When patients . . . come in repeatedly with the same issue [with missed dialysis or drug overdose or alcohol intoxication] . . . I think those patients particularly seem to be brought down to one disease process . . . more often than others because . . . of their frequent use of the medical system . . . perhaps . . . our bias in terms of if they don't accept the help . . . [and they don't] do and what we want them to do." (Nurse)</p>
<ul style="list-style-type: none"> • Absence of family advocate at bedside 	<p>"I think we respond differently to people who have family at the bedside compared to those who don't, whether it's a reminder that there's someone there who cares . . . deeply and is invested outside of, obviously, the patient themselves, or if it's just a reminder of humanity, who they are, the ability to communicate better with the ICU team." (Physician)</p>
ICU team factors	
<ul style="list-style-type: none"> • Coping mechanism for the ICU team's own distress 	<p>"As [team members] in the ICU, we see people die and suffer all the time. I think that sometimes a coping mechanism . . . is to dehumanize the patient. It doesn't hurt as much to take care of them and to see them suffer and die if you don't see them as a person. I think that's very unfortunate, but I think that that's the reality. That's something that happens a lot." (Therapist)</p>
<ul style="list-style-type: none"> • Focus on task completion 	<p>"Sometimes we get so task-oriented . . . We're focused on what it is that we need to get done to care for the patient, but we're forgetting that the patient is somebody's mom, somebody's dad, brother, sister." (Therapist)</p>
<ul style="list-style-type: none"> • Lack of situational awareness (of the patient's suffering or situation) 	<p>"I walked into a room and had a whole history and physical with the patient, and then maybe 4 minutes into it, the nurse told me the patient was on the bedpan. I had absolutely no idea that the patient was on the bedpan, and I was completely mortified that I had just come in, and they were pooping while we were having a conversation." (Physician)</p>
<ul style="list-style-type: none"> • Time constraints 	<p>"I've had experiences where . . . there's not an immediate response back to me [from the patient] and the flow of the conversation isn't normal, maybe they're just delayed . . . Then I immediately assume, 'Well, okay, I don't have time to engage in this conversation. It's gonna take way too long to go slowly.' Or maybe they can't talk, but they can write on a piece of paper. It's too time-consuming to do that. I have my tasks that I need to get done, and I'm gonna forgo really trying to go the extra step to reach into their soul and communicate with them and allow them to express themselves however they're able to in that moment in time." (Therapist)</p>
<ul style="list-style-type: none"> • No training in or modelling of humanized care 	<p>"I had never really thought about [humanizing patients by talking to them while they were sedated on a ventilator] . . . until I saw it being modeled—and that changed my practice." (Physician)</p>
<ul style="list-style-type: none"> • No personal experiences of being an ICU patient or family member 	<p>"[I am an attending ICU physician and] it took me being in the hospital with my pregnant wife [as a patient], and a set of really difficult [clinical] circumstances, for me to realize how important it was for me to really want to be in [my wife's hospital room] 24/7." (Physician)</p>
Healthcare system factors	
<ul style="list-style-type: none"> • Computers, electronic medical records, focus on documentation 	<p>"Computers and medical records definitely takes away from the bedside care of the patient. It takes away time from actually having a human interaction with the patient. You are reading about the patient on the computer versus spending talking to them in person. We don't even ask the patient if what's in the medical record is accurate." (Nurse)</p>

<ul style="list-style-type: none"> • Aspects of dehumanized care are normalized 	<p>“The ICU is a really normal setting for us ‘cause we work here every day, but for the patient it is . . . really scary, and they don’t know who all these people are walking into the room. I think we take that for granted, that this is such a normal setting for us, and it’s not for most [patients].” (Therapist)</p>
<ul style="list-style-type: none"> • Fragmented care (e.g. shift changes) leads to less engagement 	<p>“Especially the house staff who are rotating . . . they are an intern, or the on-call resident, or even the fellow . . . They are less engaged in what’s going on.” (Physician)</p>
<ul style="list-style-type: none"> • Protocols do not allow for human behaviors (e.g. CPR protocol) 	<p>“[After we stopped CPR], the patient died, and no one had held his hand the entire time. No one had talked to the patient the entire time. It was mostly just talking above and beyond the patient, but yet here is the patient’s final moments in life, and there was no—what I might term—meaningful, compassionate touch or meaningful, compassionate language spoken to the patient . . . We were just so focused on [the protocol of performing CPR] . . . that we completely lost . . . Mr. Jones in [all of this].” (Physician)</p>
<ul style="list-style-type: none"> • Hospital schedules do not always fit individual patient needs. 	<p>“We put [patients] into the mold of this preset system . . . ‘Well, do you wanna take your Ambien at 8:00, or 9:00 p.m.? Well, I’m sorry. Pharmacy profiled it at 8:00, because that’s how the system is set up, and that’s how it works’ . . . [the system doesn’t always fit into the patient’s] needs.” (Nurse practitioner)</p>