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Humanizing the ICU Patient: A Qualitative Exploration of Behaviors Experienced by Patients, Caregivers, and ICU Staff

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OBJECTIVES: To understand how patients and family members experience dehumanizing or humanizing treatment when in the ICU.

DESIGN: Qualitative study included web-based focus groups and open-ended surveys posted to ICU patient/family social media boards. Focus groups were audio recorded and transcribed. Social media responses were collected and organized by stakeholder group. Data underwent qualitative analysis.

SETTING: Remote focus groups and online surveys.

PATIENTS: ICU patient survivors, family members, and ICU teams.

INTERVENTIONS: Not available.

MEASUREMENTS AND MAIN RESULTS: Semi-structured questions and open-ended survey responses. We enrolled 40 patients/family members and 31 ICU team members. Focus groups and surveys revealed three primary themes orienting humanizing/dehumanizing ICU experiences: 1) communication, 2) outcomes, and 3) causes of dehumanization. Dehumanization occurred during "communication" exchanges when ICU team members talked "over" patients, made distressing remarks when patients were present, or failed to inform patients about ICU-related care. "Outcomes" of dehumanization were associated with patient loss of trust in the medical team, loss of motivation to participate in ICU recovery, feeling of distress, guilt, depression, and anxiety. Humanizing behaviors were associated with improved recovery, well-being, and trust. "Perceived causes" of dehumanizing behaviors were linked to patient, ICU team, and healthcare system factors.

CONCLUSIONS: Behaviors of ICU clinicians may cause patients and families to feel dehumanized when in the ICU. Negative behaviors are noticed by patients and families, possibly contributing to poor outcomes including mental health, recovery, and lack of trust in ICU teams. Supporting ICU clinicians may enable a more empathic environment and in turn more humanizing clinician-patient encounters.

KEY WORDS: communication; critical illness; intensive care unit; qualitative study; stakeholder perceptions

Dehumanization is viewing or treating another human being as less than human (1). When people are dehumanized, others view them or treat them as if they do not possess the same mental capabilities or agency that other human beings have (2). Dehumanization is often associated with disrespect—or a failure to honor another person's dignity or worth (3). Dehumanization can be strikingly overt (e.g., slavery or human rights violations) or it can be more subtle (e.g., bias, discrimination, indifference, or lack of empathy) (1). On the other hand, humanization refers to honoring the full identity, community, and dignity of another human being. When people are

humanized, others view or treat them as if they have the same mental richness and capabilities that other humans have (4, 5). Importantly, dehumanizing/humanizing behaviors may not be intentional and may be the unintended consequences of cultural norms and workplace structures.

Patients—especially ICU patients—find themselves in vulnerable states and are at risk of experiencing dehumanization (6–8). Members of the ICU team, sometimes busy and sometimes burnt out, may view or treat critically ill patients as less than fully human—albeit most of the time inadvertently. Some patients have reported feeling that they were treated as "objects" rather than as fully human—often because they could not communicate or advocate for themselves (7). Some patients reported that their medical teams have treated them with disrespect (9, 10). In comparison, many patients and family members have reported that their medical teams treated them as humans—and even elevated or honored their humanity by the personalized and compassionate treatment demonstrated (11, 12).

The negative impacts of dehumanization of ICU patients may be substantial and lasting. Several negative cognitive and emotional consequences have been noted including shame, guilt, sadness, anger, powerlessness, psychological distress, and withdrawal (13–15). Dehumanization and disrespect may be also associated with the provision of substandard medical care (16–19). Importantly, a climate in which dehumanization and disrespect is accepted at the highest levels may result in these behaviors being adopted among the wider ICU team (20, 21). The prevalence of emotional exhaustion and burnout experienced by many ICU staff may be linked to the often unintentional dehumanizing behaviors witnessed by patients/family members (2, 22). Humanization, too, may also be associated with outcomes such as improved communication and decreased psychologic morbidity among patients (23). Because the impact of dehumanization and humanization may be significant, it is imperative to understand how ICU patients are dehumanized and humanized—and to understand the root causes associated with such behaviors. The objective of this study was to capture a 360-degree view of how ICU patients are treated, including behaviors experienced, impact, and perceived causes of either humanizing or dehumanizing treatment, via engagement with ICU stakeholders. We herein define ICU stakeholders

as those groups or individuals who are employed in an ICU setting or who have been admitted to an ICU. This includes members of ICU teams (physicians, nurses, nurse practitioners, physical therapists, chaplains, and social workers), ICU patients, and their family members.

METHODS

Participants

We recruited ICU patient survivors, family members of ICU survivors and nonsurvivors, ICU nurses, physicians, nurse practitioners, occupational therapists, physical therapists, respiratory therapists, and chaplains for a qualitative study comprised of stakeholder focus groups, and open-ended responses to an open-ended survey posted on the acute respiratory distress syndrome (ARDS) Foundation Facebook Page during the period of October 2017–October 2018. Patients and family members were recruited via the ARDS Foundation. Healthcare team members were recruited via the ARDS Foundation, the Society of Critical Care Medicine Discovery Research Network Patient and Family Engagement Workgroup, Northwell Health, and Mayo Clinic. Inclusion criteria were English speaking, age greater than or equal to 18 years old, and experiences related to ICU patients greater than or equal to 18 years old. There were no exclusion criteria. The study was approved by the Northwell Health Institutional Board of Review. Informed consent was obtained from focus group participants. Survey respondents provided a waiver of documentation.

Data Collection

Qualitative data collection consisted of two parts. In part 1, focus groups were held for each of the following ICU stakeholder groups: 1) ICU patient survivors, 2) family members of ICU survivors, 3) family members of ICU nonsurvivors, 4) ICU nurses, 5) physicians, 6) nurse practitioners, 7) occupational, physical therapists, and respiratory therapists, and 8) chaplains. Focus groups were conducted remotely using web-based video conferencing. Focus groups lasted approximately 1 hour each, were conducted using guided interview scripts, and were moderated by investigators with training in focus group moderation (M.E.W.,

N.H). Focus group participants were asked to describe ICU-based situations in which they experienced or observed patients or family members being treated in both humanized ways (e.g., with kindness, or in ways that accommodated individuals' unique needs and wishes) or dehumanized ways (e.g., treated in a rough manner, referred by only their room number), and the causes and consequences of these behaviors as it related to patient care and outcomes. All focus group sessions were audio recorded. Focus group audio recordings were de-identified and transcribed verbatim. Part 2 consisted of administration of an open-ended survey using an asynchronous social media platform. The surveys were posted to the public patient/family Facebook page of the ARDS Foundation, and included two open-ended questions regarding dehumanizing and humanizing ICU experiences (**Supplemental Table 1**, http://links.lww.com/CCX/A691). Surveys were open 2 for weeks for participants to respond.

Data Analysis

Focus group transcriptions and written responses from the Facebook postings were read by three members of the study team. Analysis included a deductive approach using a priori codes based on our specific focus group and online survey questions related to humanizing and dehumanizing experiences in the ICU. We also applied an inductive approach. This allowed us to develop new codes based on the unique experiences of our participants as they emerged during our readings of the transcripts and survey responses. The study team met weekly both in person or by phone, to discuss findings and develop our qualitative codebook. All transcripts and open-ended survey responses were uploaded to NVivo 12 (QSR International, Doncaster, VIC, Australia) and coded using this codebook. Initially, the first four out of eight transcripts were coded independently by two investigators (M.J.B., M.E.W.), after which we tested inter-rater reliability between the two coders. The percent agreement was 99%, with a kappa statistic of 0.72, indicating substantial inter-rater reliability (24), allowing the remaining four transcripts and Facebook posts to be coded by one coder.

Institutional Review Board Statement

Approval for this study was granted by Northwell Health's Human Research Protection Office in The Feinstein Institutes for Medical Research (Institutional Review Board Number 17-0945).

RESULTS

We evaluated the experiences of 71 ICU stakeholders (28 patient survivors, eight family members of ICU survivors, four family members of patients who died in the ICU, eight physicians/nurse practitioners, three nurses, 11 therapists, and 10 chaplains (**Supplemental Table 2**, http://links.lww.com/CCX/A691). These participants worked at, or received patient care at, 48 ICUs in the United States and Canada. Overall, 73% of participants were women. Among the 71 participants, 45 participated in the focus groups and 26 participated in the message boards (**Table 1**).

Dehumanizing and Humanizing Behaviors

Participants identified several behaviors of the medical team which they perceived to be either dehumanizing or humanizing (**Supplemental Fig. 1**, http://links.lww.com/CCX/A692 and **Supplemental Table 3**, http://links.lww.com/CCX/A691).

Communication. Patients were dehumanized when medical teams talked over them, rather than to them—often when the patients were assumed to be sedated or unaware. In comparison, team members at other times would always introduce themselves to the patient and explain what was happening, even when the patient was assumed to be sedated or unaware. It was also perceived to be dehumanizing when team members did not learn about the patient as a person or did not refer to the patient as a person (e.g., referred to the patient by a room number or diagnosis). This was in comparison to medical teams who learned personal information about the patient and often included photographs of the patient's pre-hospital life. Dehumanization occurred when medical teams said distressing, dismissive, or offensive remarks, including mocking patients or blaming them for their own illness or for soiling themselves. Patients reported that they could overhear the chatter in their ICU rooms where clinicians would say distressing remarks when the clinicians assumed the patients could not hear. Patients were humanized when team members said encouraging and empathic comments in the patient's presence. Participants also reported dehumanization when they were not adequately prepared for ICU or post-ICU events such as

TABLE 1.
Demographics of 33 Participants Who Attended the Focus Groups

Participant Characteristics	Patient Survivor (*n* = 8)	Caregivers (Patient Information) (*n* = 5)	ICU Health Team Member (*n* = 20)
Age, *n* (%)			
18–40 yr old	2 (25.0)	3 (60.0)	12 (60.0)
41–60 yr old	5 (62.5)	1 (20.0)	6 (30.0)
61–80 yr old	1 (12.5)	1 (20.0)	2 (10.0)
Gender, *n* (%)			
Female	5 (62.5)	2 (40.0)	16 (80.0)
Race/ethnicity, *n* (%)			
White	8 (100.0)	5 (100.0)	16 (84.0)
Black/African-American	0	0	1 (5.0)
Asian	0	0	2 (10.5)
Other	0	0	0
How many years of experience do you have working in the ICU? *n* (%)			
1–5 yr	X	X	13 (65.0)
6–10 yr	X	X	1 (5.0)
11–15 yr	X	X	5 (25.0)
15+ yr	X	X	1 (5.0)
What is your profession? *n* (%)			
Nurse	X	X	2 (10.0)
Physician	X	X	3 (15.0)
Advance practice provider (nurse practitioner or physician assistant)	X	X	2 (10.0)
Physical therapist	X	X	3 (15.0)
Occupational therapist	X	X	3 (15.0)
Respiratory therapist	X	X	1 (5.0)
Chaplain	X	X	6 (30.0)
What was the reason patient was admitted? *n* (%)			
Acute respiratory distress syndrome	4 (50.0)	2 (40.0)	X
Sepsis	3 (37.5)	0	X
Other respiratory condition	1 (12.5)	3 (60.0)	X
Was the patient intubated?, *n* (%)			X
Yes	7 (87.5)	5 (100.0)	X
I don't remember	1 (12.5)	0	X
Length of patient in the hospital? *n* (%)			X
1–2 wk	2 (25.0)	1 (20.0)	X

The X's represent that the question does not apply to the specific category of participants (e.g., "what was the reason patient was admitted?" does not apply to the clinicians).

what the recovery process looked like and the possibility of experiencing difficulties such as post-traumatic stress disorder. In comparison, humanization occurred when care team members took the time to explain ICU events and the expected recovery to patients and family members.

Family Involvement. It was perceived as dehumanizing when the patient's family (their core support system) was not allowed to be with them in their hospital room, especially at night or at times of transition. In comparison, humanization occurred when family members were allowed and accommodated.

Compassionate Care. Dehumanization occurred when the patient's suffering was not assessed, recognized, acknowledged, or attended to. This was in comparison to instances where the team not only attended to routine suffering, but also identified and provided highly personalized ways of improving patient well-being (such as honoring dying wishes). In addition, patients felt dehumanized when care team members touched them without explanation or in a rough manner (e.g., using very cold water to bathe or moving their bodies without notification, warning, or explanation). Appropriate touch such as holding a patient's hand was felt to be very humanizing. Also, dehumanization occurred when the patient's appearance (e.g., eyeglasses, hair) or basic hygiene (e.g., oral care) was neglected. In comparison, humanization occurred when oral care, hair care, and other hygiene practices (shaving legs, etc.) were performed. Participants reported dehumanization when the patient's privacy, modesty, or sleeping schedules were not respected—often when the medical team's schedule or agenda took priority. In comparison, humanization occurred when care team members respected modesty, privacy, and sleeping schedules. Finally, dehumanization occurred when the patients felt like they were not allowed to exercise control—even over simple items such as the timing of medication administration or when their personal cares occurred. In comparison, many patients reported that one of the most humanizing aspects of critical care occurred when the medical team allowed them to participate and exercise some control over these simple activities.

Consequences of Dehumanizing and Humanizing Behaviors

Patient participants reported feeling devalued and feeling as though they were a bother to the medical team (Supplemental Fig. 1, http://links.lww.com/CCX/A692 and Supplemental Table 2, http://links.lww.com/CCX/A691) because of dehumanizing behaviors. One family member described that she felt that, to the medical team, her husband was "just a body taking up a bed"

and not an actual person. In addition, when patients were dehumanized, they felt a loss of trust in the medical team and a loss of patient/family motivation to participate in the recovery plan. When ICU events were not explained to patients, patients also reported experiencing confusion, disorientation, and delirium. This, in turn, was associated with increased distress, fear, panic, and anxiety. When patients are dehumanized, there may be a lower likelihood that clinicians will advocate for certain treatments resulting in potentially suboptimal medical treatment and neglect. Family members also reported experiencing guilt, depression, and anxiety when they felt the patient was being dehumanized.

On the other hand, humanizing behaviors were associated with improved physical recovery including faster strength recovery, earlier extubation, and improved speech (Supplemental Fig. 1, http://links.lww.com/CCX/A692 and Supplemental Table 3, http://links.lww.com/CCX/A691). Patients also had increased emotional and mental well-being and less distress. They had a better comprehension of reality, less delusions, and less delirium. There was increased trust in the medical team, improved patient/physician relationship, and increased engagement and sense of purpose. In addition to patient outcomes, humanization was associated with several medical team outcomes such as increased empathy, increased motivation to help the patient, spending more time with the patient, valuing the patient as a person, developing personalized care plans, and better understanding of goals of care. In addition, clinicians reported that when patients where humanized, the clinicians also felt more humanized themselves and found more joy in participating inpatient care.

Potential Causes of Dehumanizing Behaviors

The causes of dehumanization as reported by ICU healthcare team members, patients and families were grouped into three types (Supplemental Fig. 1. http://links.lww.com/CCX/A692 and **Supplemental Table 4**, http://links.lww.com/CCX/A691).

Patient/Family Causes. Participants suggested that potential causes of dehumanizing behaviors included patients appearing ill or medicalized (i.e., with "lines and tubes" attached to them) patients having impaired cognition (often due to sedation or illness), language

barriers, being perceived to be difficult or having exceptional needs, being perceived to be the cause of their own illness (e.g., drug overdose or repeated missed dialysis sessions), and when there was no family advocate present at the bedside.

ICU Healthcare Team Causes. ICU healthcare team potential causes suggested by participants included situations in which the medical team used dehumanization or detachment as a coping mechanism for their own distress, focused on task completion, lacked situational awareness of the patient's suffering or situation, had significant other time constraints, received no training or modeling of humanization behaviors, and had no personal experiences of being an ICU patient or family member.

Healthcare System Causes. Healthcare system-related factors that might cause dehumanizing behaviors included a culture of dehumanization, wherein certain aspects of dehumanized care are normalized such as referring to a patient by their room number instead of their name; fragmented care, wherein shift changes prevent meaningful engagement with patients over time; protocols that do not account for humanizing behaviors, such as cardiopulmonary resuscitation protocols; and hospital schedules that often do not fit individual patient needs or are disruptive such as body-washing in the middle of the night.

DISCUSSION

Our work has captured a range of experiences of dehumanizing/humanizing behaviors as described by patient survivors, family members of survivors and nonsurvivors, nurses, and multidisciplinary ICU staff. The dehumanizing behaviors identified by the stakeholder participants were often perceived to be unintentional (i.e., without purposeful malice). Medical team members were also perceived to be unaware that their behavior or practices were dehumanizing to patients and their families. One of the most referenced examples of this in our study, among the dehumanizing behaviors (**Table 2**), was when clinicians entered the patient's ICU room and incorrectly assumed that because the patient's eyes were closed or because they could not communicate back that the patient was also unaware of what was happening. Often, in this setting clinicians would fail to introduce themselves when they walked in the room, failed to explain to the patient what was happening, or do things to the patient, such as examining them, turning them, or changing their ventilator settings, without telling them what they were doing. From the patient's perspective, when an unknown person walked into the room and started touching them or doing things to them without any explanation, this was often distressing—especially when the patient had no ability to communicate their distress to the person in the room. One patient summed this up when she said, "All I could do was scream inside and cry since I couldn't talk." Preliminary investigation of interventions to communicate to ICU patients about what is happening have been associated with improved outcomes such as less sedation utilization, shorter duration of mechanical ventilation, and less delirium (25, 26).

Family presence was viewed widely to be a source of humanization for patients. Families served as a source of advocacy for patients when they could not advocate for themselves, were a link to the patient's life and personality outside of the hospital, and were an irreplaceable support system for the patients. Family presence was crucial at times of transition such as during nighttime or during arrival to a new unit with a new care team and environment. Unfortunately, only a minority of ICUs in the United States have unrestricted family visitation policies (27). This is despite a growing body evidence that open visitation and family presence is associated with improvements in anxiety, agitation, length of ICU stay, satisfaction, and end-of-life care (28–31). On the contrary, when families (or even patients themselves) were considered to be exceptionally needy or overbearing—this led certain medical staff to distance themselves and potentially dehumanize patients.

Among many other potential factors, the suboptimal well-being of ICU team members was felt to play a causative role in dehumanizing behaviors. Thus, efforts to reduce dehumanization of ICU patients will not be successful without consideration of the well-being, distress, and burnout of the multidisciplinary ICU team members. Burnout, one component of which is depersonalization, affects many ICU physicians and nurses (32). High workload, high patient to staff ratios, and perceived moral distress may all contribute to ICU team members treating patients as "objects" rather than human beings in need of compassionate care (22).

TABLE 2.
Consequences of Dehumanizing Behaviors

Consequences of Dehumanizing Behaviors	Example Quotes
Patient/family felt devalued by (or a bother to) the ICU team	"I got the 'You can move yourself' comments, and I already was so scared to bother [the medical staff] that I never asked for help unless I really needed it. So I stopped asking for help moving until I had slid so far down [the bed] that my knees were bent up my waist." (Patient)
Patient/family lost trust in the ICU team Patient/family lost motivation to participate in recovery plan	"All I wanted to do at that point was to leave the hospital, and I did. I left the hospital. I came home. I did not go to—they wanted me to go to a rehab, but I wouldn't go there. I just wanted to come home and take care of myself." (Patient)
Patient became disoriented (misinterpreted reality)	"The [doctor's] conversation was just so casual around, 'Well, she's gotta go to rehab,'…I'm sure it sounded perfectly normal to [the doctors], but to [the patient]…she went to sleep one day and woke up a month later and didn't know exactly what was going on. Her mind is reorienting, and she thought that she had had some sort of a drug overdose…and that she was going in drug rehab. That's an example of the kind of language that led to this misunderstanding of her situation. It was extremely anxiety-producing." (Family member)
Patient experienced distress (fear, panic, anxiety)	"I was 31 weeks pregnant when I woke up [from my coma] and being tied up not knowing what's going on, I became paranoid thinking that the hospital was trying to take my baby, like I was kidnapped…[My medical team] automatically assumed that I knew what was going on, why I was there and everything that happened. And I honestly didn't know anything. All I knew was that I opened my eyes and now I'm in a hospital bed tied down, staples across my pregnant belly from the emergency surgery of a ruptured appendix. I remember being so terrified…It's still a battle, physically and mentally." (Patient)
Loss of encouragement and support	"I'm haunted by the fact that we were told repeatedly and dismissively that my mom couldn't hear us when she was in a coma. It wasn't till I joined this [support] group that I realized many people knew what was going on around them while they were on the vent [or in a coma]. I think about what we said in her presence that might have been terrifying to her. I think about what I would have said to her had I known she possibly could have heard me…My mom died after 19 days with ARDS, so I'll never know." (Family member)
Loss of patient advocacy Suboptimal medical treatment (neglect)	"I had a patient that was…very delirious, hadn't been gotten up in days. Nursing didn't even really know his name. He had some bleeding going on that no one had noticed… [He was] not getting as much attention as should be given, because he wasn't really talking for himself." (Therapist)
Family guilt, depression, or anxiety	One family member recalled when she was trying to help her sister who was agitated on the ventilator,…"One of the doctors had come in and looked at me and looked at how agitated [my sister] was and said to me, 'She's really sick, and you're really agitating her. You need to step out.' I went outside and cried." (Family member)

Our work has several implications. First, ICU clinicians and team members should be aware that patients and families (and other stakeholders) can feel dehumanized. The medical team may often be unaware that dehumanizing behaviors are occurring, and these specific examples may increase awareness and change behaviors. Second, solutions to reduce dehumanization and increase humanization should be explored—with specific attention given to addressing the root causes of dehumanizing behaviors including clinician well-being a culture promoting empathy. This will be difficult as there is a tension between the clinicians need to detach themselves enough to be able to perform invasive procedures, and the recognition of the patient as a human with sensitivity to pain. Third, further investigation should be given to measure the impact of dehumanizing behaviors on patient, family, and ICU team outcomes. This too will be challenging as there will need to be an objective measure of dehumanizing behaviors. Efforts to increase humanizing behaviors must be balanced to provide compassionate patient care while supporting clinician psychologic well-being.

LIMITATIONS

We note four limitations to our study. 1) Our work is limited to experiences within the U.S. and Canadian healthcare systems, which may differ from perspectives in other countries with different workflow pressures and social norms. 2) There is selection bias in the participants who chose to engage in these focus groups and surveys. Specifically, we note the larger proportion of female and Caucasian participants, and the fact that we were only able to recruit three ICU nurses into the study. However, our future work will involve exploring humanizing and dehumanizing behaviors among underrepresented populations. 3) We also note the risk for recall bias, particularly among some ICU patients and family members whose ICU admissions may have occurred several years prior to their participation in the focus groups. Finally, 4) we also note as a limitation the fact that we only posted the online surveys for a 2-week period, limiting the number of responses we received. Nevertheless, our work provides a 360-degree view of ICU care, including patient, family member, clinician, and chaplain perspectives, and represents the largest qualitative study to evaluate dehumanizing and humanizing behaviors of ICU patients.

CONCLUSIONS

This qualitative data suggests that ICU patients experience dehumanization in a variety of ways, often because of unintentional behaviors of ICU team members. Humanizing behaviors were viewed as being associated with a wide range of positive outcomes including improved patient, family, and ICU team effects. However, while our work adds to the data about dehumanizing behavior experiences, measurement tools must still be developed, and the root causes must be further investigated before effective interventions can be developed and implemented. This will include supporting ICU clinicians directly to enable a more empathic environment, and in turn, more humanizing clinician-patient encounters.

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