

Voices from the ICU: Perspectives on Humanization in Critical Care Settings

Gunchan Paul¹, Rubina K Mahajan², Parshotam L Gautam³, Gursabeen Kaur⁴, Sidakbir S Paul⁵, Birinder Paul⁶

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ABSTRACT

In the intensive care unit (ICU), relentless demands of immediate action, reliance on high-tech equipment, and weight of an overwhelming workload can obscure the patient's humanity. The impact of this dehumanization and humanization may be significant, hence the study aimed to understand experiences of ICU patients and their families and seek to understand the outcomes of such encounters during the course of ICU care. The study was based on inductive-grounded theory approach. After taking informed consent, the investigators invited the participants for the interview, in the vernacular language that was audio recorded and field notes were taken. Under the two main dimensions of humanization and dehumanization, the data yielded four main themes and eight sub-themes. The themes were communication, infrastructure, experience of care and patient autonomy. The dehumanizing behaviors contributed to patients feeling disregarded and undermined their sense of dignity and worth. To our understanding, this is the foremost barrier to a healthy patient–physician relationship. However, by prioritizing humanization in the ICU, healthcare professionals can create a more compassionate and supportive environment. Hence, it is essential to implement strategies that improve patient and family support in the ICU, such as providing regular updates on the patient's condition, offering emotional support through counseling services, and involving families in the care decision-making process. These measures can help alleviate the vulnerability experienced by patients and their families during such challenging times.

Keywords: Communication, Dehumanization, Experience of care, Families, Humanization, Infrastructure, Patient autonomy.

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HIGHLIGHTS

In the intense atmosphere of the intensive care unit (ICU), in relentless drive for saving lives, the medical professionals may overshadow crucial elements of holistic care, such as emotional support and personalized attention. Our experience of humanization and dehumanization in the ICU yielded four main themes that included communication, infrastructure, experience of care, and patient autonomy. To combat the profound impact of dehumanization, there's a pressing need for humanization in the ICU.

INTRODUCTION

In the ICU, every decision and action can have life-altering consequences. The constant monitoring, emergency interventions, and critical condition of patients create an atmosphere of urgency and stress.¹ Regardless of the primary reason for admission, the disease often compromises the dignity of the patient, making the restoration of health in a dignified and humane manner one of the most challenging aspects of healthcare delivery.²

Healthcare professionals in the ICU have been criticized for adopting an overly technical and mechanistic approach. This tendency toward clinical detachment, while sometimes a means of self-preservation in the emotionally charged ICU environment, can inadvertently erode the recognition of each patient's unique individuality.³ Humanization involves recognizing and honoring the humanity of patients and their families, acknowledging their individuality, emotions, and inherent worth. It means fostering connections, providing empathetic care, and ensuring that patients' rights are fulfilled during their journey through critical illness.⁴ It entails viewing patients not merely as medical cases, but as a person with distinctive needs and aspirations.

^{1–3}Department of Critical Care Medicine, Dayanand Medical College and Hospital, Ludhiana, Punjab, India

^{4,5}Department of Clinical Psychology, Dayanand Medical College and Hospital, Ludhiana, Punjab, India

⁶Department of Neurology, Dayanand Medical College and Hospital, Ludhiana, Punjab, India

Corresponding Author: Rubina K Mahajan, Department of Critical Care Medicine, Dayanand Medical College and Hospital, Ludhiana, Punjab, India, Phone: +91 9878645330, e-mail: humanismicu@gmail.com

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When these aspects of care are overlooked, this oversight can lead to dehumanization, i.e., stripping patients of their human qualities, where they are viewed as mere objects defined solely by their medical conditions.⁵

Depersonalization lies at the core of this dehumanizing process, further eroding patients' individuality. This reductionism not only diminishes the patients' sense of self but also undermines their inherent dignity and worth as human beings. In the ICU environment, patients and their families, already vulnerable and helpless, face a heightened risk of experiencing dehumanization.⁶

While numerous studies have explored this critical topic, there remains ample room for further investigation.⁷ Notably, there is dearth of research on this subject within the context of India. Thus, the aim of our study is to offer a comprehensive examination of the experiences of ICU patients and their families regarding the humanizing or dehumanizing treatment. Secondly, we seek to understand the impact and outcomes of such encounters during the ICU care. Through this study, we endeavor to shed light on the essential elements that shape the human experience within the confines of critical care, thereby paving the way for improved practices and outcomes in ICU settings.

METHODOLOGY

Study Location and Population

The study was performed in the ICU of a tertiary care hospital in North India. This ICU has an open visitation policy for the visitors and allows active participation of the family in the patient care. Family members were defined as any of the relatives and friends involved in patient care. Different family members were included for the same patient as experience may vary from person to person. The study included patients and their family members aged ≥ 18 years who had been in the ICU for more than 1 week. For each family member, age, gender, educational status, and relationship with the patient was recorded. Patients who had a major psychiatric condition were excluded from the study.

Study Design and Data Collection

The study was carried out using qualitative methodology. Based on inductive-grounded theory approach, in-depth interviews were conducted keeping focus on patients and their family member's perception on humanizing or dehumanizing behavior.⁸ Interviews were conducted in vernacular language; audio recording was done and field notes were also taken. Hypothetical, ideal, interpretative, or leading questions were asked in all forms.

Sample Size

The participants were selected by theoretical sampling, that is the individuals likely to provide the needed information were included. People with different sex, age, varying clinical and socio-demographic characteristics were taken. The data obtained from the first participant determined which new participants could be included until the saturation of the data. Hence, the sample size was governed by the spectrum of data needed to develop a theory, so it could not be determined before the data collection started.⁹ However, after a sample of 40, saturation of themes was achieved, therefore, the data collection was stopped thereafter.

Data Analysis

The data collected in the form of audio recordings underwent verbatim transcription and translation. Interviews along with the field notes were used to develop explanations, detect patterns, establish typologies, and identify categories.¹⁰ Analysis of audio tapes was done by a clinical psychologist along with two clinicians. After summarization of the data, a thematic framework was built. This included identifying initial themes or concepts, constructing a conceptual framework, labeling the data followed by sorting and synthesizing the data. This was followed by descriptive and associative analysis to develop an explanation.¹¹

Table 1: Demographic details of all the respondents

Characteristics	Patient (n = 13)	Family (n = 27)
Age in years, range	49 (25–48)	57 (28–60)
Gender, n (%)		
Female	7 (18%)	18 (45%)
Male	6 (15%)	9 (22%)
Type of ICU, n (%)		
Surgical	5 (12.5%)	10 (25%)
Medical	8 (20%)	17 (42.5%)
Place of residence		
Urban	6 (15%)	24 (60%)
Rural	7 (17.5%)	3 (7.5%)
Socioeconomic status		
Middle	6 (15%)	2 (5%)
Upper middle	4 (10%)	16 (40%)
Upper	3 (7.5%)	9 (22.5%)
Education level		
High school	3 (7.5%)	3 (7.5%)
Graduate	8 (20%)	10 (25%)
Post graduate	2 (5%)	14 (35%)
Family structure		
Joint		29 (72.5%)
Nuclear		11 (26.5%)
Relation to patient, n (%)		
Spouse/Partner		15 (37.5%)
Child		10 (25%)
Parent		8 (20%)
Grandparent		4 (10%)
Sibling		3 (7.5%)

RESULTS

In the present study, we evaluated the experiences of 40 respondents, with 13 being patients and 27 family members. The participants were within the age group of 25–60 years and 63% were females. Furthermore, 70% of the respondents lived in urban areas, while the remaining 30% were from rural regions. The majority of the participants were graduates (45%) belonging to upper middle socioeconomic status (50%) and had joint family structure (73%) (Table 1). According to the experiences and opinions of the respondents, the results were classified into two main dimensions of humanization and dehumanization, and the data yielded four main themes and eight sub-themes. The themes were communication, infrastructure, experience of care, and patient autonomy. Tables 2 and 3 summarize the codes under these themes.

Humanization

- **Communication:** Both the patient and the attendant felt humanized when the nursing staff engaged in open, honest, and empathetic conversations. This helped create a safe environment where patients felt valued and understood. *Example: EF12 "They properly greet the patients with a gentle touch to show support. They call the patients respectfully by their names."*

Table 2: Description of the themes and sub-themes of the humanization dimension

Theme	Sub-theme	Codes
Communication	a. Verbal	EF11-Give positive reinforcement to the patient
		EF12-Talk to patient by calling out their names and interact fairly well on daily rounds
		EF5-Nursing staff is polite, patient, and empathetic
	b. Nonverbal (with patient)	EF1-Talk respectfully and encourage patient for well being
		EP2-Nursing staff always greets with a smile
		EF8-Common courtesy procedures performed, ask how is the patient doing, any pain or discomfort
	c. Verbal (with family)	EF9-Positive vibes when the doctor is around, does not feel like doctor patient relationship
		EF13-Explain the situation very well that they are doing their best, even if condition not improving and patient is critical
		EF16-Answer queries in detail, even if asked repeatedly they do explain
Experience of care	a. Physical care	EF3-Talk about the prognosis about the disease in each visit
		EF19-Nursing staff tries to help and solve the issues of the relatives, very co-operative
		EP3-Nurses are always around, never need to call them
		EP5-Care performed regularly and on time, no need to ask for it anytime
	b. Care plan	EF27-Take care of patient as their own family member
		EP2-No mocking or shaming of the patient
		EF7-Explain the procedure to be performed in detail
		EF23-Staff at bedside is very attentive and performs tasks diligently
	c. Emotional care	EP5, EP9-Adequate pain relief was given
		EP13, EP7-Mobilization of patient was done regularly
		EF10-All needs were met beyond expectations
		EF25-When I got emotional seeing the critical condition of my patient, nursing staff helped me to cope-up with the situation
Infrastructure	Environment	EF8-We can go out for some time; the nurses takes full care even when we are not around
		EF24-Nursing staff fully devoted to her work and is accessible
		EF14-Nurse is posted at our bedside they make extra effort to come and ask about his well being
		EF4-Never seen nurses, wards attendants sitting idle, chatting, laughing; always performing their chores professionally and with sincerity
		EF10-Open visitation policy was the most reliving and greatest act of kindness for the sick patient
Patient autonomy	Procedures	EF22-Procedures like tracheostomy or imaging for which patient has to be shifted are explained by staff and doctors in detail

Their gestures like attentive listening, maintaining eye contact, using a gentle tone, and respectful name calling contributed in making patients feel cared-for and respected. By giving clear instructions, and seeking confirmation of understanding about the procedures, they reinforced the patient's and the family members confidence in the healthcare system. It fostered a sense of control and involvement in the family members in the health journey of their patient. *Example: EP9 "For us our doctor is like our god, only they are the ones helping us out in this time of need and we are eternally grateful for it." EF16 "Some doctors inform us regarding the patient's condition themselves without even us enquiring regarding the same."*

- Infrastructure: The major code under this theme was open visitation policy for the family members. This allowed them to visit at times that suited them and provided patients with continuous emotional support. This helped reduce anxiety, and feelings of isolation experienced by the patients. *Example: EF10*

"The fact that I was allowed inside the ICU made my father super comfortable and I am grateful for that."

- Experience of care: This theme involved three sub themes namely: physical care, emotional care, and care plan. The physical care tasks such as bathing, dressing wounds, assisting with mobility, and administering medications were dealt with attentiveness and respect by the nurses, as a result of which patients felt dignified and cared for. *Example: EP5 "Mostly the staff is present nearby only. They look after everything." EF22 "Even if we are not around for an hour or half, we can easily move out for a bit without worries because the staff takes care of everything."*

The emotional support and motivational support provided by the staff helped the patients feel valued and less isolated, creating strong sense of connection and trust. *Example: EF3 "When we lost our patience, we were told that even though it will take time but all will be okay. Everything will be okay."*

Table 3: Description of the themes and sub-themes of the dehumanization dimension

Theme	Sub-theme	Codes
Communication	a. Verbal	EF15-Financial constrains could not be discussed with treating doctor EF2-Doctor was not available to discuss in detail the condition of the patient, would rush through rounds EF6-Hesitant to ask doctor directly about the progress of patient's condition EP8-Doctors who come for cross consultation never introduce themselves EP4-Doctor uses medical jargons and doesn't explain in layman terms EF7-Doctors guide about treatment but no personal involvement
	b. Nonverbal (with patient)	EP1-Emotionally not supportive EP11, EP8-Doctor take rush rounds and make fleeting eye contact EF17-So many forms and documents just asked to sign without giving complete information about what they are regarding EF20-Doctor does not have interest or know the patient as a person
Experience of care	a. Physical care	EF18-Sometimes attendants are asked to help while provide personal care and attendants relation with the patient is such that they may not be comfortable
	b. Care plan	EF26-Sometimes wake up the patient early morning to perform routine care EF22-Take sample at odd times even if patient resting, wake them up and take sample EP10-Rough handling, just to finish task without empathy
	c. Emotional care	EP16-Reasons for postponing surgery were not told EF21-Doctors do not interact much, only do so if asked directly
Infrastructure	a. Billing	EF17-Investigations were withheld till previous bills were cleared EF23-Navigating different systems is very difficult for the attendants
	b. Environment	EF1-Not enough or proper canteens and washrooms EF13-No waiting rooms at each floor, outside each ward EF19-Lot of botherations for family to repeatedly go to pharmacy and billing counters EF4-Location of ICU is through lot of corridors and stairs, cumbersome to locate as there are not adequate sign boards EF12-Forced to buy drugs from indoor pharmacy
Patient autonomy	Procedures	EP9-Do not ask for permission before examination, side change, physiotherapy

- Patient autonomy: Patients and family members felt humanized when they were informed and explained about the procedures to be performed, reducing anxiety, and fostering a sense of trust and security between the patient and the staff.

Dehumanization

- Communication: The patients and family members felt dehumanized due to the impersonal communication pattern of nurses and doctors. According to them, usage of technical jargon without explaining, made them feel excluded from their own care leading to confusion and sense of alienation. *Example: EF9 "The doctors should try to understand worries of the patient and his/her family members. They should explain things in layman language and be as honest as possible regarding where they are headed."*

Also, patients and family member felt it difficult to communicate on personal topics such as financial constraints, treatment plan, and social support with their treating physician. They found them to be always in a hurry, devoid of time, and empathy. *Example: EF4 "Since senior doctors only visit for 2 minutes we are often waiting for them but they sometimes don't talk to the patient directly."*

In terms of non-verbal communication, avoiding eye-contact or making fleeting eye-contact, discussing the treatment plan with the team but not addressing the patient made them feel

ignored or insignificant, as if they were not worthy of attention. *Example: EF23 "Doctor should spend some time talking to the patient instead of just discussing the patient among themselves."*

- Experience of care: Handling patients roughly during transfers, positioning, or care procedures, causing them discomfort or pain was reported under this category. Also, some family members did not feel comfortable being a part of the care because of their relationship with the patient. This caused distress and discomfort to the patient as well as the attendant. *Example: EF2 "Due to shortage of staff at night only one nurse was available and we had to help out but we felt like we might not know the proper way to support the patient in such a small space."*
- Infrastructure: Difficulty in navigating the corridors of a multispecialty hospital, cumbersome methods of payments, difficulty in accessing the key services such as canteens and washrooms increased the frustration and the anxiety of the family members. *Example: EF8 "The first time we came, we had to go up and down for almost half an hour to find the place. That was quite cumbersome."*
- Patient autonomy: Dehumanization was experienced by the patients when they felt that nurses delivered care in a mechanistic approach without consideration of patients sleep-wake schedule. Failure to communicate with the patient or family member about what was being done or why, made patients feel like passive objects rather than active participants in their

own care. Example: EF21 “The doctor was really rude to us and we felt as if we could not even ask about the health of our own family member. It was quite distressing for us.”

DISCUSSION

The apparent chaos of ICUs is often a reflection of the intense, life-saving efforts of a dedicated medical team working in highly dynamic environment. The medical staff is attuned to this high-stakes, fast-paced environment. However, the emotional toll on patients and their families can be overwhelming. They feel lost, and helpless as they witness their loved ones in critical condition.¹²

Understanding and addressing the patient’s and family’s experiences contributing to humanization or dehumanization context are necessary for delivering high-quality care and improving outcomes. This interview-based study was conducted in the ICU of a tertiary care hospital. From the findings of our study, we found four major themes of concern.

The first being communication, both verbal and non-verbal, which was also a major theme in the study of Basile et al.¹² Effective communication is not just a skill but a fundamental component of ethical and humane care.¹³ When the staff and doctors engaged in open, clear, comprehensive, and respectful communication, it made the patients and their family members feel cared and respected. This helped built their trust in the practitioner and alleviated fear and anxiety experienced in the vulnerable situations. Our findings are supported by the studies that highlight the importance of verbal and non-verbal communication in building effective interpersonal relationships with the patient.^{14,15}

Importance of communication can be understood by time or instances when it was not offered, like when interactions were small or unsatisfactory. For instance, excessive use of medical jargon specifically in country like India where majority belongs to rural background, as in our study, is a major hindrance. Other examples of non-verbal dehumanizing behaviors include dismissive body language, such as crossing arms or avoiding physical contact, failing to provide reassuring touch, using a condescending tone of voice when speaking to patient or caregivers and speaking in language which they were unable to comprehend. These dehumanizing behaviors can contribute to patients feeling disregarded and undermine their sense of dignity and worth.¹⁶ To our understanding, this is the foremost barrier to a healthy patient–physician relationship. Our findings are supported by the study of Adams et al. where the authors emphasized that the dehumanized behavior of the doctors leads to decrease in patient satisfaction and reduces their treatment compliance.¹⁷

The second major theme was experience of care, which is a critical component of nursing that directly impacts patient outcomes and overall well-being. When the staff responded to the care in a respectful, individualized, and compassionate manner, the patients felt satisfied. Seeing their relative receive compassionate care also increases the trust of the caregivers in medical team.¹⁸ On the other end, handling patients roughly during transfers or positioning, causing discomfort or pain were examples of dehumanizing behaviors. Contrary to the findings of the previous studies, in our study some relatives reported feeling uncomfortable and embarrassed in assisting in the care of their patient.¹⁹

The next theme was infrastructure that significantly contributed to humanizing or dehumanizing experience. The design, layout, facilities, and overall environment played a crucial role in promoting well-being, comfort and dignity for patients, families, and staff.²⁰

Our findings indicated a dissatisfaction among the participants due overcrowded hospital wards and common areas, constant noise from medical equipment, difficulties in navigating the hospital and finding departments, or locating amenities like washroom and canteens. This added to the stress and anxiety of being in a stressful environment and is supported by the findings of Hughes et al. where authors identified various barriers posed by infrastructure in providing effective care.²¹ In the present study as most of the participants belonged to rural background, they might have had difficulty in utilizing modern technological services such as electronic health records, patient portals or navigating apps.

Open visitation policy was considered as the most humanizing behavior as the presence of family under distressing circumstance provided increased comfort and resilience, that helped accelerate healing process. Our findings echo with those who have advocated the benefits of unrestricted visitation hours and highlighted that presence of caregivers provided comfort to the patients in unfamiliar circumstances.^{22,23}

Lastly, patient autonomy also affected the participants. Here, the major codes reported were lack of explanation before doing procedures or reasons for cancelling or postponement of the procedure. In a study conducted by Lee and Lin, the findings revealed positive relationship between perceived patient autonomy and their satisfaction with the care to patient–physician relationship.^{24,25}

According to our results, it is difficult to define the percentage of humanizing or dehumanizing experiences as the respondents felt valued and dignified in one aspect and dehumanized in some other instance. However, the overall impression among participants was that dehumanizing behaviors were often unintentional, and medical team members were unaware that this was detrimental to patients and their families. A mixed method study in future could quantify their experience and our study may serve as an addition to literature in building such scores. Box 1 depicts few suggestions from our results to improve the humanizing experience of the patients and their families. Box 2 mentions the probable causes of dehumanization from the experience gathered from our patients.

We have noted a few limitations in our work. This study highlights the experience of patients admitted to a single institute and hence, a particular type of patients only may have been

Box 1: Suggested ways to a more humanizing experience for the most vulnerable ones

- Introduce yourselves to patients and make a small talk to know the patient beyond their illness
- Minimize the effects of altered consciousness and impaired mobility by promoting physiotherapy and mobilization
- Psychoeducation about the procedure and the treatment plan to lessen anxiety²⁶
- Give the patients choice over the meals, incorporating activities from their daily lives such as reading newspaper or book, allowing them to keep their personal things with them in ICU settings to enhance their sense of freedom and overall well-being
- Patient-centered design for hospitals with clear way-finding systems and logical department placements, so that they can navigate independently and safely²⁷
- Easy access to key services to reduce frustration and anxiety
- Regular training sessions and workshops focusing on body language, empathy, patient-centered care, and effective communication for medical team members

Box 2: Probable causes of de-humanizing experience

- Loss of identity
- Loss of ability to communicate
- Loss of ability to advocate for one's self
- Loss of control
- Loss of respect
- Loss of privacy/modesty
- Purposeful shaming/mockery

included and the experience may differ from other hospitals having different work culture. Secondly, there may have been selection bias, as only family members of survivors were interviewed, whereas the experience of the non-survivors may have been different. Lastly, there is a possibility of having recall bias by the participants or not expressing fully as they were being recorded. Thus, this may influence the generalizability of results.

CONCLUSION

The role of clinicians is to relieve unnecessary suffering. Validating the feelings and desires of the patient and caregivers is crucial in the healing process as it generates a sense of autonomy and empowerment. To increase awareness among medical team members about their behavior and its impact, implementing regular training sessions and workshops that focus on body language, empathy, patient-centered care, and effective communication can be highly effective. Additionally, incorporating patient perspectives and experiences into medical education and curriculum can also lead to greater understanding of the potential harm caused by dehumanizing behaviors.²⁸ Finally, encouraging open discussions and feedback within the team, as well as providing opportunities for shadowing and observing patient experiences, can help medical professionals better understand the impact of their behaviors and practices on patients and their families. Hence, addressing not only the physical aspects but also the emotional and psychological well-being of the patient is crucial for the holistic care of the patient.

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Ethical Approval

Institutional Ethical Committee approval was sought. Privacy of participation and confidentiality of the data was guaranteed by coding the transcripts using numbers and not including any participant identifiers on the transcripts. Each interview was identified by letter E (experience) and further subcategorized as P for patient and F for family member and were sequentially numbered.

ORCID

Gunchan Paul  <https://orcid.org/0000-0002-3834-9852>

Rubina K Mahajan  <https://orcid.org/0000-0001-9933-5342>

Parshotam L Gautam  <https://orcid.org/0000-0002-7615-4781>

Gursabeen Kaur  <https://orcid.org/0009-0009-2476-5685>

Sidakbir S Paul  <https://orcid.org/0009-0009-5338-7943>

Birinder Paul  <https://orcid.org/0000-0001-6039-4740>

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