

## REVIEW ARTICLE

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### THE ICU CARING FOR PATIENTS' RELATIVES: A REVIEW

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**ABSTRACT:** To study intensive care unit (ICU) patients' and relatives' satisfaction in regard to communication with medical staff (nurses and physicians), perceived support, environmental strain and their psychological distress. Patients and relatives were more satisfied with the communication than expected by the staff. The staff overestimated the patients and relatives' psychological distress. Relatives report more psychological distress symptoms post-ICU discharge compared to the patients. Medical staff is aware of psychological distress in ICU patients and relatives and effort to reduce this during ICU stay and afterwards should be implemented.

**KEYWORDS:** Communication, Patients, Relatives, Intensive care, Satisfaction, Psychological distress.

**INTRODUCTION:** An intensive care unit (ICU) is a ward where doctors, intensivists, brothers, sisters and most important the ward boys and ward aayas who have been specially trained in the high levels of care required by each pathological state, work together.

In the ICU, critically ill patients, who could not be safely cared for in general wards, are under constant control, day and night, and everything is done to ensure they receive the highest level of care possible.<sup>1,2</sup>

Commonly admitted through medicine department as Cerebro Vascular Accidents, Cardiac patients, COPD and Diabetes Mellitus, Hypertension and others, the accident and emergency (A&E) departments, or from the operating rooms after major surgery, obstetrics bad history, acute and chronic kidney disease these patients often require life-sustaining treatments, such as artificial ventilation, dialysis and cardiac resuscitation.

Intensive care comprises 1-2% of total hospital bed number in the India the average ICU in India has four to six beds, although units in larger hospitals, especially those receiving tertiary referrals, are bigger. Few units have more than 15 beds.

#### Caring for patients' relatives:

An important role of the ICU personnel is to assist families of patients during their stay in the ICU. As Bennett & Bion point out, the intensive care environment can be extremely distressing for both conscious patients and their relatives. The high mortality and morbidity of patients requires considerable psychological and emotional support, which is provided by the medical and nursing staff often in conjunction with professional<sup>3</sup>. Such support is difficult and time consuming and requires the involvement of all staff members and doctors attending the patient senior staff. Many relatives and friends wish to be close to critically ill patients at all times. Visiting periods are usually flexible and many units have a dedicated visitors' sitting room with basic amenities such as a television and toilet facilities. Often overnight accommodation can be provided in private rooms as back up rooms.

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### **Witnessed resuscitation:**

Witnessed resuscitation is widely not done in India. This is not the practice in India. Reason is the illiteracy of the relatives. Sometimes you have educated and co-operative relatives. The procedures are not tolerated by the relatives. Not only that they take out the different meaning out of the procedures. The role of the relatives at the time of resuscitation is important but it is far away from thinking in India.

### **Life-sustaining treatment decisions:**

Cardoso et al. evaluated Portuguese intensive care physicians in terms of 'do-not-resuscitate' decisions to withhold/withdraw treatment. DNR (Do Not Resuscitate) The investigators found that, in most of the responding cases, those decisions are made only by the medical group, with little input from the nurses(15%), patients (9%) or patients' relatives (11%), although most of respondents expressed a wish to involve them more in the process. In India and in our institute we usually inform the details of the patient's condition and outcome of the patients with the high level treatment. This is done verbally and the written consent for their decisions is also taken with the signature of the direct relatives with their address Sex, and religious beliefs of the respondents' influences the way in which these decisions are made.

### **Abuse and violence towards staff:**

The usual belief of the patient's relatives in India is our patients are not looked after in a disciplinary way or in a proper way; this is aimed to ascertain the frequency of abusive and violent behavior by patients and relatives towards intensive care staff. These abuses and complaints are many times relevant and genuine.<sup>1</sup> During the study period, verbal abuse of nurses, either by patients or relatives, occurred in our ICU in 58% of patients and nurses experience of physical abuse either by patients or relatives is less. Illness was the main perceived cause of offences by patients, whilst 'distress' (45%), alcohol (24%) and sociopathic behavior (27%) were the main causes amongst relatives. These acts are more common with the young patients dying and the young obstetrics patient mortality.

### **When the patient dies:**

The reasons for eventual dissatisfaction among families of patients who died in the ICU, in terms of the assistance offered during the patient's stay in the hospital and the information received from the medical staff<sup>4</sup>. This survey found that the relatives of patients who died were most dissatisfied with the care received according to a) the type of death; this is sudden death vs. death preceded by a gradual deterioration in the patient's status, and b) the manner in which the relatives were notified of the death. We stressed the need for improvement, especially in communicating information to the relatives of these patients. For an excellent ICUs' functioning, communication skills and organizational procedures become key issues

**MATERIAL AND METHOD:** A questioner was prepared for the patients relatives and patients.<sup>5</sup> Total 25 questions were decided with marking. Results were checked on five scale regime as follows -- Degree of satisfaction and distress were measured on a five-point 0-5 distress, 6-10 dissatisfied, 11-15, 60% satisfied, 16-25 satisfied above 85%.

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### Questionnaire: ----- out of 25 marks

S. No	Question	Marks
1	You came on your own to this ICU or referred by somebody?	1 mark
2	How did you get the information about the hospital? 1. Patients 2. News Paper 3. Doctors 4. Your knowledge	4 mark
3	How are the doctors and staff of ICU? 1. Regular 2. Irregular 3. Smiling 4. Serious	4 mark
4	Do you get information about your patient's condition at regular intervals? 1. 4 hourly 2. 6 hourly 3. 12 hourly 4. 24 hourly	1 mark
5	Who talks with you? 1. Doctor 2. Staff 3. Ward boy 4. Clerk	1 mark
6	Do you feel restricted hrs for visit required? Yes or No	1 mark
7	Do you feel 24 hrs. for visit required? Yes or No	1 mark
8	Will you give your consent for some procedures as Intubation, Ventilator, Tracheostomy, Central line? Yes or No	1 mark
9	Will you be ready for Do not Resuscitate procedure? Yes or No	2 mark
10	Would you like to donate Body or organs or eyes if there is brain death? Yes or No	2 mark
11	Are you satisfied with the treatment? Yes or No	1 mark
12	Are you satisfied with the treatment given to you by staff? Yes or No	1 mark
13	Will you accept the death of your patient even if you know he is serious? Yes or No	2 mark
14	How are the arrangements for the relative's relaxations? Good or bad	1 mark
15	What grading you will give to ICU? A, B, C, D,	2 mark

Total no. of patients were 636. Out of that 419 were male and 217 were females. Ratio of Male: Female 2: 1, 65.88% male and 34.11 % female. Total no of relatives were present with patients were 1545. Out of that 1048 were male and 497 were females 67.83 % male 32.16% female.

Type	Male	Female
Patients 636	419 (65.88%)	217 (34.11 %)
Relatives 1545	1048 (67.83 %)	497 (32.16 %)

Table no. 1: Sex distribution

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Total no of patients who answered questionnaire was 424. Out of that 319 were male and 105 were females. Ratio of Male: Female 3:1, 75.23% male and 24.76% female. Total no of relatives who answered the questionnaire were present with patients 948. Out of that 639 were male and 309 were females 67.40% male 32.58% female.

Type	Male	Female
Patients424	319	105
Relatives948	639	309

**TableNo.2:Sexdistributionoutofanswered**

**RESULT:** From the answers in the questionnaire following results were obtained. 424 patients answered the questioner out of that 319 male. In males 27/319 were distress (8.46%) 56/319 were dissatisfied (17.55%), 163/319 were 60 % satisfied (51.09%), 73/319 were 85 % satisfied (22.88%). Relatives were 948 who answered the questionnaire. Out of that 639 were male. In Males 58/639 were distress (9.07%) 60/639 were dissatisfied (9.38%), 428/639 were 60% satisfied (66.97%), 93/639 were 85% satisfied (14.55%).

Type	0-5 Distress	6-10 dissatisfied	11-15 60% satisfied	16-25 85%satisfied
Patients	27	56	163	73
Relatives	58	60	428	93

**Table No. 3: Degree of satisfaction and Distress: ---- Male**

From the answers in the questionnaire following results were obtained. 424 patients answered the questioner out of that 105 were females. In females 06/105 were distress (5.71%) 18/105 were dissatisfied (17.14%), 53/105 were 60% satisfied (50.47%), 28/105 were 85% satisfied (26.66%). Relatives were 948 who answered the questionnaire. Out of that 309 were females. In females 22/309 were distress (7.11%) 38/309 were dissatisfied (12.29%), 175/309 were 60% satisfied (56, 63%), 74/309 were 85% satisfied (23.94 %).

Type	0-5 Distress	6-10 Dissatisfied	11-15 60% satisfied	16-25 85 %satisfied
Patients	06	18	53	28
Relatives	22	38	175	74

**Table No. 4: Degree of satisfaction and Distress: ---- Female**

### DISCUSSION:

#### 24-Hour ICU Visiting Hours?

Several views are there for this issue. From relatives' side it is a must as our patient is serious. Safety is the major problem in the night inspite of the security. In our institute this is more or less true. Physical assault to staff. On top of it, if outcome of their beloved one is bad then the disturbed mood, anger and aggressive reaction of relatives are dangerous. All hospitals have or should have a well-managed and accessible security system for the needful.

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Quality of Acuity and care of the patients is definitely questionable. CPR, DC Shocks are the procedures not seen by the relatives. They label it as crude methods and label it responsible for the death. In our 25 bedded ICU Unit some or other procedure or emergency resuscitation is going on, should family members be included in the procedure. We are not against it. But there should be a way to ask them to be aside in emergency procedures. In spite of the restricted time in the morning hrs. the relatives take a chance in the name of the doctors, for giving medicines, diet prescribed. These hrs. they go on as per the wish of the security or clerk or staff. Certain cultural or religious practices will make it more difficult.

VIP patients and VIP visitors are also difficult to manage. Visitation hour rules should be made mandatory for the VIP patients' relatives to prevent any unrest and distress among the others Also these rules to be liberalized for patients nearing death.

No thought is given to patient's privacy and care. Why should relatives be allowed to see central line insertion? ICU admissions are more after 7.00 p m. Working is hampered as the presence of relatives is there and it is more disturbing.

Answering the calls from outside about the health status of the patients, receiving calls of specialists for condition of patients, moving with doctors for rounds is a difficult task.

**Limited visiting hours:** Limited visiting hours are strictly followed up in engineering companies. We are not allowed to enter in the factory<sup>3,6,7</sup>. Some places have rule! Their relatives follow the discipline. Why not in the hospital is difficult to answer.

Possibly the relatives feel it is their last visit with the patient. Their mentality of meeting the patient when they come even at odd hours is difficult to analyze. Either it is the patient who has to remember it if possible or it is one of the work of the day. ICU's with nosocomial antibiotic resistance bacteria, invasive procedures, and brain-injured patients who are extremely sensitive to stimulation (which can result in life-threatening elevated intracranial pressures) have no need for rules according to administrators. I believe there has to be common sense guidelines.

Limit the number of people

No children unless someone is dying.

No food.

No cell phones.

We had to change our policy from open visitation to restricted visitation due to family members. Our visitors have a sense of entitlement and what the nurse needs to do for them and their loved one. We believe in updating families but are not here to teach nursing to fifteen different family members and explain what medicine we are giving when we are simply flushing a line. Food, drinks, cell phones we feel like it makes our job 10 times harder, the family members get ICU psychosis and begin to hyper-focus on the monitor, the ventilator, IV Lines running slowly. We make exceptions for the terminal and children<sup>7,8</sup>.

We don't go to work with someone else and tell them how to do their job, then why is it ok for nurses to be subjected to this. Relatives come and advice how the staff should work? It is a safety issue. Things get out of hand to fast, it should be to benefit the patient if a family member stays, you can't let one family member stay and not another, they all have an excuse.

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I think it depends on the individual care of the patient as the person that is in ICU may find it comfortable having a family member or friend spending the night as they would not have to bother the nurses for every little thing. Some are not satisfied with only a window for visitation which- that if someone missed due to work or necessity- would be unable to see the patient

We believe that if visitors are causing any trouble at all, they should be evacuated- at least temporarily. Still I feel that most times frequent visitation is in the best interest of the patient. If the family members can't abide by rules, then this should be the grounds for limiting their visitation. However, there are 2 sides of the coin. We have set times for visiting, three 30 minute sessions, and one hour long session in the ICU.

Hospitals and their staff are visiting caretakers in their patients' lives. They will never have the same advocacy for their patients as loving family members. Family members of patient respond well to explanation, especially when they see staff trying their best to provide the best care for their patient.

We think the policy should depend on what the patient is in the ICU for. Basically we think it needs to depend on the patient and the family behavior.

God Bless everyone who works in the health care field!

We see positive, but mostly the negative families as stated they will break every rule, use cell phones, over stimulate the patient, get upset at you for not giving them a warm welcome. The truth is family when anxious and scared passes that negative energy on to the patient. The longer the family stays most of the time 24/7 in our unit, the less they are taking care of themselves and the anxiety Safety and Quality of care have been compromised in the 24 hour visitation.<sup>6,9,10</sup>

Visiting hinders healing, in some cases, family often think and feel as if we should be at the bedside every minute of the day. The slightest touch or sound wakes them, there are studies to back up the constant sleep of a vented patient helps them to get off the vent a full two days earlier.

Nurses talk on personal calls all the time on cell phones or regular phones.

24hrs visitation is not the best thing for me or the patients as we can see. Most of the time the families are not very helpful when it comes to care. They are very helpful in telling you what you should be doing. They break every rule there is to break even after being told no cell phones. They talk down to you like you are some kind of servant to them and not a professional taking care of their loved one. They take too much of our attention away from patient care. We can't even get our charting done or get the other patient some medication.

During the visitation hours' the staff should involve the relatives in basic care like combing hair, oral cleansing, side changes, physiotherapy of limbs which helps in emotional bonding of the whole team. During this time, the staff should be at the patient's bedside to gain confidence of the patients attendants. No sitting at the counter, gossiping, talking on cell phones, resting in the room should be allowed for the staff<sup>6</sup>.

Staff safety is first, so if staff safety is a legitimate concern for a unit that is considering its visitation policy, We would expect the policy to be structured to address that concern first and foremost.

What's wrong with visitors seeing everything we do for the patient, as long as the patient or his surrogate decision maker consents to that?

Shielding loved ones from the realities of the patient's illness lead to unrealistic expectations and delayed decision-making abilities.

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Some nurses, we must admit, oppose open visitation for no other valid reason other than because they themselves are stressed by the added communication requirements, or uncomfortable having others observe their care.<sup>3</sup> The presence of visitors creates additional work and distraction for them. Other nurses are more easily able to welcome family members onto the team, and see their presence as an opportunity for communication, teaching, establishing relationships, etc.

It's not only that relatives and attendants only abuse and show aggression, they appreciate and help when they see the doctors and nurses working dedicatedly on their patient irrespective of the patient's condition.<sup>11</sup>

For a fairly extensive 2 year research study on open ICU visiting hours, check out the 2006 article in *Circulation*, Vol. 113, Issue 7, by Fumagalli et al titled "Reduced cardiocirculatory complications with unrestrictive visiting policy in an intensive care unit: results from a pilot, randomized trial", PMID #16490836.

A quote from a JAMA article to be particularly thought-provoking. In an editorial on the subject of open visiting hours, Berwick and Kotagal write "In an effort to stabilize the details of ICU operations, health care institutions and professionals neglect the plausible assertion that they are the visitors in patients' lives, not the other way around". (Berwick, D. M. and Kotagal, M., "Restricted visiting hours in ICUs: time to change", *JAMA* 2004, Vol. 292, issue 6, PMID#15304472).

When we do bedside procedures that frankly most families don't want to witness, or that would require a sterile field, we always ask the families to step outside the room for a while...and explained why. No one has ever refused.

In emergent situations, we "tell" the family they need to step outside the room, explaining we need all the space in the room for equipment and people who are caring for their loved ones. Also, explain that we cannot give the best care if we have to worry about family members.

If you spend a little time teaching family members about the disease that has their loved ones in ICU, and allow them to provide minor care, you will find they will be your best allies.<sup>7</sup> They will feel you have given your best care and done all you can...even if the patient expires.

The Nursing Executive Center has published a Practice Brief titled, "The Family as Patient Care Partner." It is an excellent resource based on evidence based practice in partnering families for best patient outcomes.

Patient centered care approach. This concept has both positive and negative consequences, as one would expect. We do limit 2 visitors at a time and 1 overnight. I feel the visitation should be at the nurses' discretion in some cases such as: fresh post-op, suicide attempts, behavioral health problems and neurology patients, infection control issues, for example. We have some problems with families not following the "rules", mostly more than 2 in the room, bringing sick people to visit, bringing children, also, and some visitors are very critical and demanding of the nursing staff. We have other equally sick patients to care for. Some on the other hand are very appreciative and helpful. I am certain in most cases the support does aid in a healing environment for the patient. As long as visitors do not interfere with care and promote the wellbeing of the patient, there is an opportunity for this to work in most cases.

There is a term called ICU PSYCHOSIS which the patient develops after few days of stay in ICU because of the environmental factors and the patients disease process itself. This can be managed by behavioral therapy, music, reassurance and taking patient out on trolley or wheel chair.

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We do close the unit to visitors at shift change and when our team makes walking rounds through the unit. We do encourage families to go home and sleep at night as being a critical care unit we as nursing staff are doing frequent assessments. We do ask that only 1 family member stay at bedside and ask that it be a person that could sign a consent form if an invasive procedure need be done. This has seemed to work well for us. Families feel more involved in their loved ones care.

Family is a critical link when it comes to providing holistic, comprehensive care.

### **Attitudes to life after the hospital experience:**

Having a relative, partner or close friend in an intensive care unit (ICU) has a huge impact not only on patients, who may be unconscious or sedated at the time, but also on their relatives, whose lives may suddenly be turned upside down as they wait by the patient's bedside, not knowing whether they will live or die. This is an extremely traumatic situation that everyone deals with differently and which affects people in many different ways. Many people said the ICU experience had made them realize what was really important to them and put life into perspective. Having lived in the uncertainty of not knowing whether the ill person would survive or be brain damaged, disabled or paralyzed if they did, had made small, trivial things in life seem unimportant compared to what they'd been through. Some felt they were now more relaxed about minor, every day concerns that might previously have bothered them. Many people said their experience of having a relative or close friend in ICU had made them value life more and they now wanted to enjoy it, live it to the full and make the most of everyday.<sup>12,13</sup> Others said, instead of putting off the things they enjoy, they'd realized the importance of doing them now because no one knew what the future held. One woman noted that, when her husband had died suddenly and unexpectedly several years ago, she'd decided she had to make the most of life and every day. After her partner's recent critical illness, this perspective had been reinforced. One man said that, although he and his wife were enjoying making the most of their life together, people around them had often found their new way of living difficult to accept. Many people said they'd become less materialistic and had realized not only how precious life was but so too were the people in their lives.<sup>2,11</sup> Some said the ICU experience had made them value or be more grateful for their family, partner, children or friends. Others said they'd become more family orientated, and yet others that they'd renewed relationships with siblings that had drifted over the years, especially if they'd had children. Several said they'd grown closer to their partners, and one man explained that he'd grown closer to his partner and her family and it had made him see how relatives can support one another. You could be supportive and caring. You grew closer to your relatives because they spent so much time together when they were visiting their near ones in ICU.

Many people said they'd re-evaluated their lives. One man said he and his wife had decided to move to the country and spend more time with their children and grandchildren. Several said they'd made or were planning to make changes in terms of work, some wanting to work less or in less stressful jobs or environments. Some feel to live somewhere quieter and spend more time with their wife, children and grandchildren. Some people said that having a relative or close friend critically ill in ICU had changed them as people, a few saying they were now more open about their feelings. Some felt they'd become more patient, others that they were less bothered by minor problems. One woman said that, since her brother's accident, he'd become more grateful and now valued his life more and the people in it. One woman said she and her husband had both become more relaxed since his illness. Some people had made changes, such as stopping smoking or eating healthier, either to



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improve their own physical health or because they'd wanted to help the ill person in making these changes.<sup>14</sup> For some, the ICU experience had strengthened their spiritual beliefs, which had helped them accept or understand what had happened. Some people said that, when the ill person had first started improving, they'd wanted to make changes to the way they'd lived but, with time, had 'gone back to normal'. Others felt that their experience hadn't led them to making any changes and, after the ill person had started recovering, they just wanted to get back to normal. Yet others said that, although they would have liked to resume their former life, they couldn't because the ill person hadn't completely recovered and now needed a lot of care. One woman said that, after her best friend had been discharged from hospital, she'd become her carer and hadn't had time to think about whether the ICU experience had changed her attitudes to life. Her friend's health was worse than before her illness and this often left her close friend feeling depressed. Another said it was too soon to tell how her son's accident had affected her attitude to life because he was still recovering from his accident and still needed her support. Several people, whose relative's health was now worse than before their illness or accident, had had to make many changes to their daily lives and this had often been difficult or stressful. One man said he'd become his wife's full-time care taker and this had been extremely difficult because they had very little support (see 'Emotional impact on family and friends').

Hospital experience of the patients and relatives can be made more comfortable and less distressing by just being more considerate and compassionate with their feelings of insecurity about life and death of the patient.

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