



## An attempt to identify and understand the Psychological Factors of importance for families of ICU patients; 'Hope' still sustains as extremely important.

### Psychology

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### ABSTRACT

Admission to an Intensive Care Unit (ICU) is recognized as a situation of great emotional strife and uncertainty where fear of losing the patient and despondency reigns supreme. The effect of this phenomenon is felt severely by relatives when a family member is admitted to the intensive care unit due to a serious illness or a life-threatening condition. It also invokes feelings of anxiety, fear, frustration, dejectedness, hopelessness, mental exhaustion and in some cases misdirected anger in the patient relatives which could be psychologically damaging. Although, available literature has revealed that hope is crucial for relatives of ICU patients they have not been discussed well. The objective of this study was to explore, identify and understand the most important need of family members of patients in the intensive care unit (ICU) of Apollo Hospitals Bhubaneswar, and based on the findings and insights gleaned formulate plans and interventions to better respond to and satisfy families' needs for "Hope".

### KEYWORDS:

Psychological Factors, Intensive Care Unit, stressors, perception, anxiety, fear, hope, need.

### INTRODUCTION

The term 'intensive care' refers to the supportive care of a patient with advanced medical equipment; in order to save the patient's life itself evokes an emotional reaction for those who have any familiarity with the implications of having a loved one admitted to the ICU. Admission to the intensive care unit is "viewed as a crisis for both patients and their families" (Lee & Lau, 2003), whether the admission planned or unexpected and sudden. With the admission of a dear one in the ICU, immediate family experiences an upheaval and is often left feeling that a catastrophe is in their midst. Research has also indicated the admission to an intensive care unit by definition indicates "a life-threatening situation and can precipitate severe stress within a family" further emphasizing the sense of crisis within the family (Maxwell, Stuenkel, & Saylor, 2007). The sudden, unexpected and unfortunate turn of events throws the family into an emotional turmoil and the experience is often traumatic. The "stress evolving from such situation usually makes family members feel disorganized and helpless; as a result, they often show difficulty in mobilizing appropriate coping resources." (Lee & Lau, 2003). The uncertain prognosis and the critical condition of the patient may bring about complications for the patient's family, such as, psychological disruption, despair, fear, and anxiety and if this situation continues the relatives find themselves in a condition of physical and psychological exhaustion and disorientation, experiencing feelings of helplessness and desperation (Delva, Vanoost, & Bijttebier, et al., 2002). According to Pryzby, families are in a sense dysrhythmic' and may display erratic thinking following the admission of a loved one to an ICU. (Pryzby, 2005). These emotional responses if left unattended or unresolved affect the family's well-being adversely, and subsequently, the patient's health. Because the emotional turmoil that the relatives undergo may then lead to the expression of negative behavior directed towards other family members, the medical staffs and even the patient.

The whole of the family is greater than the sum of its parts (Bond, Draeger, Mandleco, & Donnelly, 2003) and any disorder in its parts will lead to the holistic disorder (Rabi Siahkali, Pourmemari, Khaleghdoust Mohammadi, Fereydoun, & Avazeh, 2010; Gavaghan & Carroll, 2002; Li et al., 2003). Family is defined as a social unit closely connected to the patient through love or legal ties or both. While the efforts of critical care providers focus on patients the family struggles to cope with the experience of having a loved one being seriously ill (Lookinland, 1995). Available literature also shows that family members experience levels of distress similar to that of the patient themselves (Kotkamp-Mothes, Slawinsky, Hinderman, & Strauss, 2005) and some believe that the family may experience

levels of distress greater than that of the patient, as the patient is often unaware of the situation and of his or her emotional state due to his or her medical condition or treatments. Nothing happens in isolation. System theory suggests that change in one part of a system may lead to change throughout the system. Extrapolating the system theory to a family would suggest that whatever illness strikes one family member all family members will be affected in some way.

Attending to a critically unstable patient being admitted to intensive care takes precedence over addressing the psychological turmoil experienced by their families. The staff's energy is directed towards saving the life and giving care to the patient and little time is left to help the family deal with this crisis. Lack of knowledge on how to deal with the families, time constraints and lack of understanding of what the family's needs are, result in the family's needs being ignored or forgotten, despite the staffs' best intentions. The focus of attention has always been on identifying the needs of the patient relatives from the staff point of view i.e. what the staff perceives as important for the family. Also, the studies available in the literature are limited in their scope or few in number that deals with the needs of a family member with a loved one in ICU.

To reduce psychosocial stressors experienced by family members of patients in the ICU a number of items have been identified as needs.

### These important needs as described in the literature are as follow:

**Information-** Studies on the needs of the families of critically ill patients during acute hospitalization period have identified information need as the most important need (Debarck, Dracup, Maisden, 1992). Family members have to be able to receive information about the patient's condition. Families may experience fear, surprise or revulsion at the sights, surroundings and smells surrounding the patient (Bartz, 1995), and need to have their anxieties relieved by such measures as discussing treatments having equipment use explained, discussing transfer plans and being notified at home if patient's condition changes (Linda, Wheeling, & West, 1984)

**Hope** - Rose (Rose, 1995) in her study of ICU stressors in families identified hope as the prime need in the initial period of uncertainty. Families' expressions of hope indicate increasing mastery over the feelings of vulnerability or uncertainty regarding the family member's critical care. Families are expected to make personal, financial medical, ethical and legal decisions when a family member is critically ill or injured (Bartz, 1995). Having hope, even a little, is

critically important, particularly when dealing with a new diagnosis and considering options. One may not be able to agree on or define what hope is, but one knows it when one sees, feels, and experiences hope. Hope is one of the most effective coping strategies and it is a resource that influences an individual's ability to cope with stressful, life-threatening situations. (Folkman, 1984) Hope helps family members to keep going and to manage care for the patient and for each other and is an essential psychological process in adapting to stressful situations (Verhaeghe, Van Zuuren, Defloor et al., 2007). The literature suggests that health professionals may hesitate to communicate hope because they believe that fostering hope in seriously ill patients encourages denial and fosters false reassurance (Northhouse, 1991).

**Communication-** West (Linda, Wheeling, & West, 1984) discussed the need to alleviate stress by reassuring the family that best possible care was being given and by talking with the family. Families want frequent and detailed communication from the physician. They want to know the patient's condition, plan of care diagnostic and treatment options and evidence of improvement or deterioration. They are more comfortable and less worried if they know the patient is receiving the best possible care (Bartz, 1995).

**Visitations-** Families need proximity to the patient. Every ICU has a visiting policy for frequency and number of people allowed per visit. Even when clearly communicated at the onset of critical care admission, the visiting policy often becomes unclear and frustrating (Bartz, 1995).

**Taking part in Patient Care -** Families want to provide some of the physical care for all members but this need is frequently not met. Allowing families to be helpful at the bed side is difficult for nurses because of concern that their activities would be interpreted as trying to get out of work (Riegel & Ehrenreich, 1989).

Although the experiences of families in the intensive care unit have been well documented in the research literature only a few studies have been found in the literature that actually deals with the needs of family members when someone they love is admitted to the intensive care unit. The aim of this study was to assess the perceived needs of the family members by having them identify what needs they perceived as extremely important and what needs were very important to them. Understanding the families' needs related to the intensive care stay, as they perceive them, would help in understanding how these needs can best be addressed by hospital staff and aid development of interventions based on the assessment of needs towards patients' and relatives', satisfaction. Families were also encouraged to offer suggestions and advice to meet their specific needs or concerns.

## METHOD

The study employs both qualitative and quantitative methods. The mixed method approach produces a more comprehensive understanding of the subject at hand and for the better understanding of all the variables at play. Existing studies do not employ qualitative methods that would provide a more nuanced understanding of the impact of intensive care on families. A quantitative approach to research can be conceptually limiting especially when the study has to explore matters of human subjectivity and emotions. So it was felt that a mixed method approach was better suited to explore the perspectives of family members and for offering guidelines to enable development of interventions that may assist healthcare professionals in providing meaningful support to families.

The setting for the study was the ICUs of Apollo Hospitals Bhubaneswar. The participants for the study consisted of close family members and other relatives involved in patient care and follow ups. The sample consisted of men and women ranging in the age group of 18 to 65.

The first phase of the study was a pilot study which lasted for two weeks. 30 patient relatives were part of this study. Intensive personal discussions lasting thirty minutes were held on a one on one basis with each individual stakeholder at a time convenient to them to arrive at an understanding regarding their perception on the items of the questionnaires. The responses recorded for analysis formed the basis for the development of the study instrument in phase II, keeping in view the need for linguistic clarity, cultural relevance, facilities available and the approach taken. The questionnaire for the relatives of the patient was adopted from the questionnaire used in the study conducted by Molter (Molter, 1979) and was shortened to 26 items from the 45 item instrument originally designed for relatives. The responses from the relatives on the administered questionnaires were collected on a 5 point scale. It formed the basis of the quantitative analysis undertaken where a. Score 1 denotes not important at all, b. Score 2 denotes slightly important, c. Score 3 denotes important. Score 4 denotes very important and e. Score 5 denotes extremely important.

**Phase III was the Pre-Intervention** data collection where a questionnaire consisting of 26 items was administered to 100 patient's relatives. In Phase IV the action plan was implemented which emerged from the responses gathered in Phase III. In phase V the impact of action plan implemented was studied.

## PERIOD OF DATA COLLECTION

- The data for the study was initially collected for the patients in the year 2012-13. This was the pre-Intervention data collection period.
- Interventions based on the findings of the study were administered in the year 2013-14 to the ICUs.
- The year 2014-15 was the post-intervention data collection year in which the same set of questionnaires were administered again to the patients.

## RESULTS OF PATIENT RELATIVE'S RESPONSES TO THE ADMINISTERED QUESTIONNAIRE IN THE PRE INTERVENTION PERIOD

Out of the twenty-six needs which were studied only one need was identified as extremely important by more than 50% of respondents. Another 12 needs were identified as very important.

The response of relatives is shown in table -1.

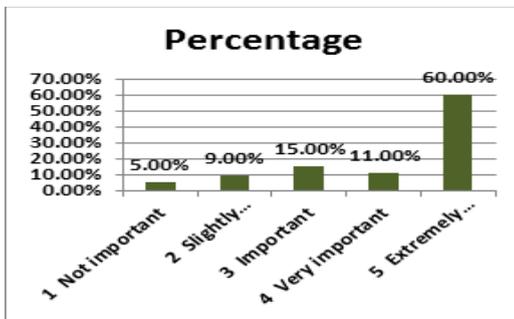
**Table 1: Distribution of needs of relatives/Patient's families, as per their responses:**

Score	Number of Items	Percentage (%)
1-Not important	01	3.85
2-Slightly important	05	19.23
3-Important	07	26.92
4-Very important	12	46.15
5-Extremely important	01	3.85
Total	26	100

### Need identified as extremely important.

In all the needs studied hope was identified as the most important need. 60.00 % of respondents identified this need to be extremely important. Hope has been identified as the most important need in earlier studies (Molter, 1979 & North house, 1991). Hope is important in everyday life. Whenever we find ourselves amidst a crisis, a few reassuring words is still hope and positivity in us. Similarly in the field of medicine those patients' relatives always look forward towards a hope and re-assurance from the doctor and nursing staff.

**Graph 1: Distribution of percentage scores of responses of patient relatives for Item number 1 i.e. "to feel there is hope:**



Though the majority of respondents identified this need as extremely important, significant difference was observed in the perception of this need according to categories of respondents. 63.04% of female relatives described this need as extremely important in comparison to 25% of male counterparts. No statistical significant differences were observed for this need in respect of the relation of relative to the patient and their age group.

The qualitative data that were recorded during the interactive sessions provided insights of the state of mind of the relatives and what constituted major source of psychological stress for them.

The wife of a patient said, "I am often afraid of what is going to happen. I wonder about the effects of the treatment and what further health problems to expect. I hope they will provide all the answers and provide sound guidance and information. That would help in instilling hope and inspire confidence in us."

In this regard, another participant wife said, "The staff is so cold they don't initiate discussions that clarify important details about my husband who is in ICU. We are in a hopeless situation, some consideration and empathy will give us strength why can't they understand that? We just need some kind and assuring words," she said.

The daughter of a patient said, "We just want the staff to pay attention and listen to us and create a sense of security, raise our spirits and strengthen hope in us. Receiving right and proper answers on patient's condition and treatment outcomes will put us in a good frame of mind that is necessary in these times of despair and crisis."

The son of a patient said, "I have been calling daily and few nurses gave out the details on the phone regarding my father's condition but lately they are not giving me any updates and one nurse was annoyed, spoke condescendingly and escalated the matter to the management."

Participants stressed the need for hope as the environment itself was very challenging. "It surprises me the way the Intensive Care team is behaving. Is it their arrogance or ignorance to keep families of critically ill patients at arm's length but they are forgetting. They don't realize that losing hope for the patient's recovery can be painful on the part of a family member," said a son of a patient summing up his disillusion.

"It is a big and reputed hospital and after coming here we were hoping a pleasant experience and the staff would be helpful. Even though we were not well versed in English language they would listen to our countless questions and give us thoughtful answers that would instill hope in us. They would make you feel like everything's going to be ok," said another patient relative.

"I thought I took right decision to come here for treatment but the

taciturn nature of staff here is only adding to my confusion. Clear, comprehensible information and emotional support were lacking as was the environment and that would make us feel reassured by and confident in them."

**Need identified as very important.**

Twelve needs were identified as very important.

**Item 2** - To feel that hospital personally cares for the patient; this need was identified as extremely important by 15% whereas another 46% ranked it very important.

**Item 3** - To have a waiting room near the patient; this need was identified as extremely important by 14% whereas another 37% ranked it very important.

**Item 4 & 5** - To know the diagnosis and prognosis; to know the diagnosis and prognosis were identified as extremely important by 29% of relatives. The need to know diagnosis was rated very important by another 38% whereas 25% rated knowing the prognosis as very important

**Item 6** - To have questions answered honestly; this need was identified as extremely important by 23% of respondents. Another 29% rated it as very important.

**Item 7** - To receive information about patient once a day; this need was identified as extremely important by 24% of respondents and another 31% rated as very important.

**Item 8** - To know specific facts concerning the patient progress; this need was identified as extremely important by 26% of respondents but another 28% rated it as most important.

**Item 9** - To have explanations in the term you understand; 25% of male respondents identified this need to be more important in comparison to only 18.48% females.

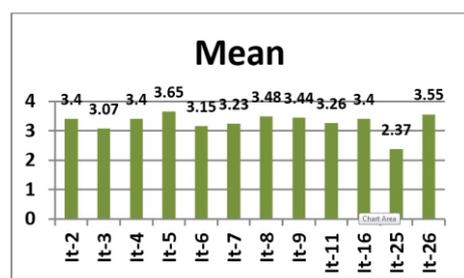
**Item 11** - To be assured that best possible care is being given to the patient; this need was identified as extremely important by 20% of respondents and another 31% ranked it as very important

**Item 16** - To have cordial staff in ICU who even answers your telephone calls; this need was identified as extremely important by 31% of respondents while 25% rated it as very important.

**Item 25** - To have a place of worship nearby; this need was identified as an extremely important need by 13% of respondents. Another 21% rated it as very important.

**Item 26** - To have a telephone connection nearby; this need was identified as an extremely important need by 28.00% of respondents. Another 33.00% rated it as very important.

**Graph 2: Needs identified as very important for the Patient Relatives**



**ACTION PLAN IMPLEMENTATION DIRECTED TOWARDS THE ITEM WHICH SCORED HEAVILY ON THE SCALE OF IMPORTANCE:**

From the patient's relative's point of view 'hope' held an extremely important place. Since hope held a critical importance the devised action plan focused on instilling hope and keeping it alive. To this end, the inducted doctors and nurses were educated on the importance of imparting hope to the patient and the patient relatives and also taught to exude hope in their approach to patients or patient treatment. Management post this finding started involving patient relatives whenever there was a change in medication or in care plan or improvement in patient's health condition. It was done through the family meetings. Management detailed a policy on End of life care concept that is built on equal parts hope and medical knowledge. Non-salvageable patients were treated under the concept of End Of Life Care (EOLC) as long as with a glimmer of hope that they could be revived. This would make the relatives feel that the hospital cares for the patient.

The 12 other items which were rated as very important by the patient relatives were discussed in-depth and interventions were formulated and implemented to reinforce the mechanism that delivered the reassuring effect that the patient relatives look forward to as agents of hope and would help the patient relatives to remain in a positive frame of mind. This would enable them to control their emotional reactions better and manage the conditions better because they believe that the power of hope was reinforced if they remained positive and upbeat about the critical situation.

**Results of Patient's relatives' responses to the administered questionnaire pre and post the intervention period; a comparative analysis**

In the post-intervention period, focus was given to the extremely important and very important needs of patient relatives in order to understand the efficacy of action plan implementation to work on and strengthen the psychological need so as to have a positive impact on patient relatives in bringing down the stress. To assess the efficacy of action plan implemented, by analyzing the change in the perceptions of the patients' relatives, post-intervention data collection was initiated by administering the same questionnaire.

It is important to remember that the questionnaire was administered to the same category of patients' relatives and not the same set of relatives. The study was conducted over a protracted period of three years which is a long enough period to expect that the exact same relatives who responded to the questionnaire in Phase III to continue till Phase V. But what was similar and remained unchanged were feelings of anxiety, depression, hopelessness, despair, fear, exhaustion and desperation that trigger emotional peril for both individual family members affected by the patient's intensive care stay and for the family as a whole that formed the part of the study in the Phase-III.

**Table 2: Comparative response value for the item identified as extremely important in pre and post intervention period**

Score	Parameter	Number of Item( s)		Percentage (%)	
		Pre	Post	Pre	Post
5- Extremely important	To feel there is hope(Item No.1)	01	01	60	66

Upon analyzing the responses to the administered questionnaires in this period of study, it was revealed that the sole item "Hope" which was responded as extremely important by the patient relatives at 60% in the pre-intervention period went by 6 percentage points to 66% in the post-intervention period. This result further reinforces the importance of hope for the patients those are critically ill. It also goes on to highlight no matter how many interventions are devised at targeted interventions undertaken to meet family needs for fostering and sustaining hope; it is never enough. It also suggests that hope is a dynamic concept a no matter what plans of care are implements

satisfy the family needs of critical patients there are some needs that go unmet and gain prominence. Also, the meaning and importance of hope depends on the life situation and personal philosophy of each individual (*Fitzgerald Miller, 2007*) and it is impossible to cater and satisfy each individuals perception of hope. The study findings also reveal that these unmet needs continue to be present despite dozens of studies that identified unmet needs of family members of patients in the ICU and practice recommendations suggesting ways to meet the unmet needs of family members. It also indicates that the multiple needs of family members of patients in the ICU ranging from communication, information, visitation, vigilance, assurance, and hope are intertwined and it has to be a concerted and all-encompassing effort to address these needs.

For the patient relatives who patiently wait for a glimmer of positive news amidst all the crisis hope is a symbol of optimism. They not only clamour for information related to their family member they also want overall enhanced communication with the healthcare team. And they want it to be honest, reliable and truthful. So it is important for the staff to do the fine act of balancing when they communicate with the family members when a patient has bleak prognosis or in the case of terminally ill or unsalvageable patients. The onus shall lie on the medical team or the primary Consultant to employ discretion and walk the tightrope between communicating the news and avoiding false hope. The study also indicated not only the perceived vital nature of 'hope' but also emphasised on the need to deliver quality communication that addresses the concerns of family members. Communication shouldn't be only information but potential implications of hospitalization that should assist patient families in planning ahead for the ICU stay.

Twelve needs were identified as very important for the patient relatives in the pre-intervention period while in the post-intervention period 7 items of the 12 were identified as very important and other 5 were responded as important items by the relatives. The analysis of the post-intervention results suggests that the intervention based on the assessment of needs had yielded perceptible positives indicating the efficacy of the action plan. Since there were positive takeaways from the results the needs weren't taken for further discussion.

**CONCLUSION**

The study was undertaken to determine the perceived important and immediate needs of families with relatives in the ICUs of Apollo Hospital, Bhubaneswar. The study design combined both the qualitative and quantitative methods to explore the needs of families of patients in the intensive care unit which is an important area for continued exploration. The goal was to better understand not only psychosocial stressors experienced by family members of patients in the ICU but to identify those needs which are currently unmet and formulate interventions or make referrals to meet those unmet needs. The information gleaned from the assessment data aided the formulation of suitable interventions which were implemented in the subsequent phases. Later, the impact of the interventions was assessed to evaluate their efficacy in meeting the families' extremely important and very important needs. The study also provided deeper knowledge about the need for holding hope in patients' families, particularly families of patients in the ICU. Hopefully, the information gathered from this study will provide the underlying assessment data necessary to formulate multi-pronged plans of care and interventions to meet family needs. This study also provides insights that attempting to learn from the families themselves about their perceived needs and how they believe these needs can best be met can help in developing an effective delivery mechanism that maintains and strengthen hope. The tools that were employed to understand and analyze the needs of the patients' relatives could serve as a guide for better management of family needs while simultaneously fine-tuning the existing coping mechanism and developing new mechanisms of sustaining hope.

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