Canadian Journal of Nursing Research, 1995, Vol. 27, No. 4, 83-87

Brief

The Meaning of Critical Illness to Families

Patricia A. Rose

La maladie grave crée des tensions chez les malades et leur famille. Pourtant, les réactions de la famille varient et le fait d'avoir un être cher au service de soins intensifs peut ne pas entraîner de crise dans toutes les familles. L'objectif de la présente étude est d'examiner et de décrire le sens que les familles donnent à une situation liée au service de soins intensifs. On a conduit des entrevues en profondeur mais non structurées avec dix-huit membres de huit familles qui ont un malade en service de soins intensifs. On a analysé les entrevues qualitativement et celles-ci ont révélé cinq catégories de sens que cette situation avait pour les familles : *c'était l'un ou l'autre, tout va bien, monter les étages, c'est comme si j'étais sur des montagnes russes,* et *il n'y a aucun espoir.* Les huit familles étaient unanimes à décrire une période d'incertitude durant laquelle elles ne savaient pas si le malade survivrait. Ensuite, la trajectoire que prenait la maladie grave suivait l'une des deux voies : positive ou négative. Les conclusions de l'étude intéresseront les infirmières qui veulent mieux comprendre les effets de la maladie grave sur la famille.

Critical illness creates stress in patients and their families. However, families' reactions vary and suggest that having a loved one in an intensive care unit (ICU) may not be a crisis for all families. The purpose of this study was to explore and describe the meanings that families ascribe to an ICU experience. In-depth unstructured interviews took place with 18 family members from eight families of ICU patients. Interviews were analyzed qualitatively and revealed five categories of meanings that the ICU experience had for families: "it could go either way," "everything is good," "going upstairs," "like living on a roller-coaster," and "there is no hope." All eight families described an initial period of uncertainty during which they were unsure whether the patient would survive. The subsequent trajectory of critical illness followed one of two paths: positive or negative. The results of this study are of interest to nurses who seek to broaden their understanding of the impact of critical illness on the family.

Critical illness creates stress in patients and their families (Halm, 1992; Koller, 1991; Lynn-McHale & Smith, 1991). It is not clear that the experience of all families can be labelled as the crisis of critical illness (Kleiber et al., 1994; Reeder, 1991). Observations made in clinical practice raised the question of how families determine the nature of their

Patricia A. Rose N., M.Sc.(A), is Nurse Clinician Teacher at the Royal Victoria Hospital and a lecturer in the School of Nursing at McGill University, Montreal.

experience in an intensive care unit (ICU). Some families were seen to react calmly to situations that the staff viewed as a crisis, whereas others seemed to have difficulty coping with situations that contained few elements of uncertainty. This prompted consideration of how families appraise the ICU experience. The purpose of this study was to describe and explore the process that families use in assigning meaning when a family member is in the ICU.

Methods

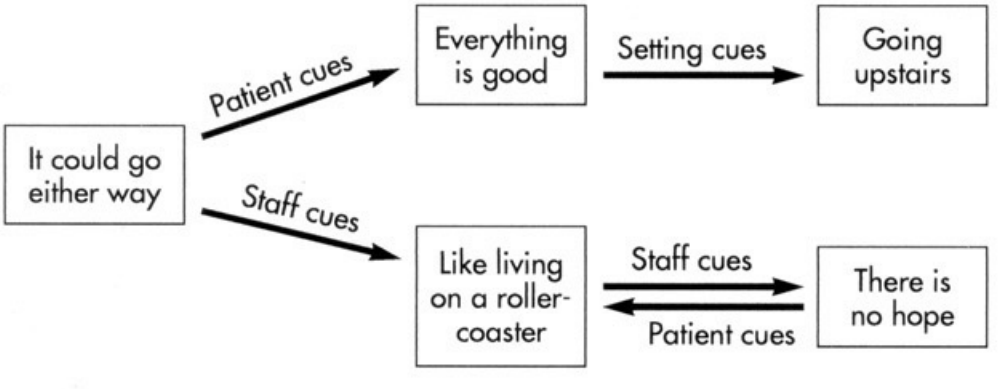
A qualitative design was chosen for the study. Eight families of patients in a surgical ICU participated. During in-depth unstructured interviews, a total of 18 family members talked about their ICU experience. Interviews took place over a period of time varying from one to eight weeks.

Data were analyzed qualitatively. The unit of analysis was a specific instance that included either a statement by the family that described their appraisal of their situation, or references to the cues that were used during that appraisal process.

Findings

Families described five meanings that the ICU experience had for them (Figure 1). In all cases this meaning changed over time, as the result of a cue that the family perceived as an indicator of a change in their situation. The cues used by families to assess their situation consisted of stimuli received from the patient, the staff, and the setting.

Figure 1
The Meaning of Critical Illness



All eight families described an initial period of uncertainty during which they were unsure whether the patient would survive. During this time families verbalized their feelings of hope, anxiety, and uncertainty. They talked of how "it could go either way." Throughout this initial period families sought indicators that their situation was improving. To this end, they monitored the patient's appearance and talked with staff.

In describing what this uncertain time was like, families clearly outlined when that period ended and what caused it to end. The subsequent trajectory of critical illness followed one of two paths. Families who obtained positive cues from the patient went on to "everything is good" while families who received negative cues from staff proceeded to "like living on a roller-coaster."

Path 1

Everything is good. For four families, a change in the meaning of the situation began with a cue from the patient. Verbal and non-verbal patient behaviours were interpreted as signs of improvement and effected a change to "everything is good." During this phase families looked to equipment in the ICU setting to confirm that the patient was getting better. Families for whom the ICU experience took on a meaning of "everything is good" had short, uneventful stays in the ICU before being transferred "upstairs."

Going upstairs. All families who experienced "everything is good" continued on an upward trajectory to "going upstairs." For these families, an alteration in their situation was prompted by a change in setting.

Path 2

Like living on a roller-coaster. After experiencing "it could go either way," four families progressed to a situation that was more negative – one which they described as "like living on a roller-coaster." These families outlined how verbal and non-verbal behaviours of staff had altered the meaning of the situation. Families described the constant ups and downs in both the patient's condition and their own experience. Over and over, they emphasized how they coped by taking one day at a time.

There is no hope. All families who described their situation as "like living on a roller-coaster" experienced a transition to "there is no hope." This occurred after families were told by the staff that there was little

chance that the patient would survive. Families became discouraged and talked of the patient's imminent death. Once there was no hope, families no longer relied on staff cues to evaluate their situation. Instead, they focused on the mental status of the patient. Families were able to detail the bad clinical picture of the patient but, at the same time, watched for a sign from the patient that the situation was not as bleak as it appeared.

Discussion

This study suggests that the ICU experience has five meanings for families. It also outlines the variety of cues families use to determine that meaning. Descriptions of these cues and meanings will help nurses to understand the day-to-day experience of families. Families' perceptions of their situation are not always congruent with the staff's evaluation of the situation. This discrepancy in perceptions creates difficulties when nurses judge families as reacting inappropriately to the patient's condition. It may be that families do not respond to the physical, objective environment but rather to the environment as it has meaning for them. Staff, on the other hand, may assess the patient's condition on the basis of objective information that is interpreted in light of their expert knowledge and experience. Nurses need to increase their awareness of the subjective nature of the process by which families assign meaning to their situation. Future research should be directed at exploring the relationship between families' and nurses' perceptions of the ICU experience and at describing ways in which discrepancies in these perceptions can be diminished.

It appears that all families who experience "like living on a roller-coaster" proceed to a situation wherein "there is no hope." This finding would seem to preclude families from experiencing "everything is good" after they have spent a period of time "living on a roller-coaster." Given the size and characteristics of the study sample, conclusions must be drawn cautiously. There is a need to examine the ICU experience of families from a larger, more varied group.

The findings of this study suggest that staff cues carry mostly negative connotations while patient cues are viewed as positive. Knowing that patient and staff cues play different roles in families' perceptions will enable nurses to pay closer attention to the implications of their own behaviour, as well as that of patients. The exact nature of the role that patient and staff cues play requires further exploration.

References

Halm, M.A. (1992). Support and reassurance needs: Strategies for practice. *Critical Care Nursing Clinics of North America, 4*(4), 633-642.

Kleiber, C., Halm, M., Titler, M., Montgomery, L.A., Johnson, S.K., Nicholson, A., Craft, M., Buckwalter, K., & Mcgivern, K. (1994). Emotional responses of family members during critical care hospitalization. *American Journal of Critical Care, 3*(1), 70-76.

Koller, P.A. (1991). Family needs and coping strategies during illness crisis. *AACN Clinical Issues in Critical Care Nursing, 2*(2), 338-345.

Lynn-McHale, D.J., & Smith, A. (1991). Comprehensive assessment of families of the critically ill. *AACN Clinical Issues in Critical Care Nursing, 2*(2), 195-209.

Reeder, J.M. (1991). Family perception: A key to intervention. *AACN Clinical Issues in Critical Care Nursing, 2*(2), 188-194.

Acknowledgement

The author would like to acknowledge the invaluable assistance of Laurie Gottlieb, N., Ph.D., Director of the School of Nursing and Associate Dean of Medicine, McGill University, in all phases of this study.