LIVED EXPERIENCE OF CRITICALLY ILL PATIENTS’ FAMILY MEMBERS DURING CARDIOPULMONARY RESUSCITATION

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**BACKGROUND**  During resuscitative efforts, patients’ family members are often barred from the patients’ rooms and may never have the opportunity to see their loved ones alive again. Recently, the need to ask family members to leave the room is being questioned. Little is known about families’ perceptions of cardiopulmonary resuscitation.

**OBJECTIVE**  To describe the experiences, thoughts, and perceptions of family members of critically ill patients during cardiopulmonary resuscitation in the intensive care unit.

**METHOD**  Six family members whose loved ones underwent cardiopulmonary resuscitation and survived consented to an audiotaped interview. During the interview, family members were asked to describe their experiences during the resuscitation. Interviews were transcribed and were analyzed for relevant themes by using Van Manen thematic analysis.

**RESULTS**  One major theme emerged: Should we go or should we stay? Additionally, 2 subthemes emerged: What is going on? and You do your job. A model, the family’s experience with cardiopulmonary resuscitation, was developed to reflect the research findings.

**CONCLUSIONS**  During the period of resuscitation, healthcare professionals neglect to recognize that patients’ family members are experiencing crisis along with the patients and that coping mechanisms are impaired. Moreover, the family members’ informational and proximity needs are often ignored during this time of crisis. Addressing these needs through appropriate nursing interventions will become increasingly important as patients’ family members begin to remain with their loved ones during cardiopulmonary resuscitation. (American Journal of Critical Care. 2004;13:416-420)

In many intensive care units, patients’ families are separated from the patients during resuscitation. In fact, only 3 hospitals in the United States have documented protocols allowing the presence of patients’ families during cardiopulmonary resuscitation (CPR) and invasive procedures.1-4 To date, few studies have been done on the benefits of family presence (ie, having patients’ family members present) during CPR, and little is known about how families experience cardiopulmonary resuscitation.

Most likely many factors contribute to barring patients’ family members from the room. Healthcare professionals are inclined to think that patients’ family members could not handle the seriousness of the situation or the performance of invasive procedures.1 Also, resuscitation efforts may be hindered by a family member who becomes disruptive or loses control of emotions, thus forcing the healthcare team to focus on the family member rather than on the patient. Likewise, members of the healthcare team fear losing objectivity if they perceive the patients as more than victims, a situation that would interfere with the staff’s coping mechanism of handling the situation. Practitioners fear that family members will search for medical mistakes, inappropriate comments made during CPR, and wrong decisions in treatment, potentially leading to malpractice suits.5,6

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Recently, nurses are questioning why patients’ family members must leave the room.\textsuperscript{4,7-9} Several professional organizations are attempting to better recognize the needs of patients’ family members during a crisis such as CPR.\textsuperscript{4,10} Additionally, nurses are asking whether patients’ family members can provide another aspect of care the healthcare team cannot, that is, caring support and presence.

\textbf{Family members struggle with the decision about whether to stay with their loved ones or leave.}

Little is known about families’ perceptions of cardiopulmonary resuscitation. Patients’ family members usually await the outcome of CPR away from the patients, where the families can only hope and pray for a positive outcome. According to Kosco and Warren,\textsuperscript{11} both patients and patients’ families are experiencing crisis; for example, a patient is fighting for life, and the patient’s family is waiting for an outcome and the potential loss of life.

\section*{Materials and Methods}

Healthcare professionals involved in CPR often do not identify and recognize the needs of the family members of a critically ill patient.\textsuperscript{11-13} The purpose of this qualitative study was to describe the experience of critically ill patients’ family members during CPR in the intensive care unit. The research question was as follows: What were the experiences of patients’ family members during the resuscitation of a loved one?

\section*{Setting and Participants}

The study was done in the coronary care unit in a 700-bed urban community hospital in northeastern Ohio. Participants were adult family members (>18 years old) of patients who received cardiopulmonary resuscitation. The family members were near the patients when cardiac arrest occurred. Family members whose loved ones survived were approached and were asked to participate in the study within 24 hours of the resuscitation. Written consent was obtained from all participants before the interviews.

\section*{Human Rights Protection}

The institutional review boards of Kent State University and the study institution approved the research protocol. Permission to conduct the study was also received from the hospital administration and the nursing department.

\section*{Procedure}

All participants were interviewed within 24 hours of the resuscitation. Each interview was conducted in a private place agreed upon by the participant and the investigator. Participants were asked to describe the events that had occurred during the resuscitation. The following open-ended questions were asked if they were not addressed in the description of the event.

1. I understand your loved one had cardiopulmonary resuscitation. Where were you when this event happened?
2. Did the healthcare team allow you in the room during the resuscitation? If not, where were you asked to wait?
3. What feelings and emotions did you experience during resuscitation of your loved one?
4. Who was available to support you during the resuscitation of your loved one?
5. Did a member of the healthcare team provide updates during the resuscitation?

\section*{Data Analysis}

Data for analysis included audiotaped interviews and field notes. Audiotapes were transcribed and were analyzed by using the thematic analysis of Van Manen.\textsuperscript{14}

\section*{Results}

One major theme emerged (see Figure): Should we go or should we stay? This theme consists of 3 phases: pre-jives (a premonition that something is amiss), here and now, and breaking the rules. Additionally, 2 subthemes emerged: What is going on? and You do your job.

\textbf{Family members were permitted to “break the visiting rules” but only after patients were stabilized.}

\section*{Should We Go or Should We Stay?}

Participants mentioned struggling with the decision about whether to stay with their loved ones or go home and take care of other needs. This struggle evolved over a period of 3 phases: pre-jives, here and now, and breaking the rules. Within the here-and-now phase, 2 subthemes emerged: What is going on? and You do your job. Families wanted to know what was going on. Additionally, they realized that their hands were tied and placed a tremendous amount of trust in the healthcare team. Essentially, they said to the team, you do your job, meaning resuscitate the patient and provide care.
In the pre-jives phase, family members recognized subtle changes or specific signs that indicated something was wrong with their loved one and reported the changes or signs to the healthcare team. Once satisfied with the interventions of the healthcare team, the family members then decided it was a safe time to leave the patient’s room.

The here-and-now phase is the crisis phase: crisis for both patients and their family members. The family members either negotiate with the healthcare team to stay in the room during CPR, or they accept that they cannot be present and leave the room. In contrast, the healthcare team controls the situation and assumes responsibility for making all the decisions in caring for the patient.

What Is Going On? During the here-and-now phase, families wanted to know what was going on. Families had many questions about what was happening to their loved ones. A majority expected to receive answers.

You Do Your Job. The healthcare team was entrusted to resuscitate the patient and, once successful, to care for the patient.

Breaking-the-Rules Phase

After a patient’s condition was stabilized, his or her family members moved into the breaking-the-rules phase. For most participants, this phase meant maintaining vigilance at the hospital and waiting to receive information about what was going on and what was going to happen next. Generally, family members were permitted to break the rules, both formal and informal, to be with their loved one, but only after the patient’s condition was stabilized. The formal rules included such things as the regulations posted in the institution about the permissible hours for visiting patients. The informal rules were the discretionary rules that individual nurses made about family visiting.

Discussion

Previous research indicated that patients’ family members are more able to cope with the patients’ illnesses when the needs of the family members are met. The ability of family members in this study to effectively cope with a loved one’s illness was impaired. Leske and Hupcey both determined that patients’
family members feel a need to be close to and protect the patients when threatened by the permanent loss of their loved ones; hence, family members have a need for vigilance, particularly during a critical illness. This need for vigilance is even more pronounced during CPR as families await a final outcome, and it continues after resuscitation if a deterioration in the patient’s condition occurs. Leske also determined that informational needs are important for patients’ families. In fact, Leske stated that a major fear of family members is that healthcare providers will withhold information about the families’ loved ones.

As Chesla and Stannard noted, nurses take specific actions that prevent family members from being with the families’ loved ones, such as strict visitation and avoidance of patients’ family members. In my study, family members were kept from their loved ones during the time of CPR, just when both families and patients are extremely vulnerable. Koller and Warren also noted that families in crisis need reassurance and informational support to cope effectively. However, during this period of CPR, families in my study were barred from the patients’ rooms and forced to wait in another room.

I found that families struggled with the question of should we go or should we stay. The amount of information the healthcare team provides seals this decision. Usually during CPR, a patient’s family is kept at bay until someone takes the time to explain what is going on. By controlling the families during CPR, the healthcare team denied them the ability to watch out for the families’ loved ones and provide protection. When a patient’s condition stabilized, the nursing staff shared information with the patient’s family. Families feared that the healthcare providers would withhold information; unfortunately, families needed this information to determine what would happen next and whether they should go or stay.

Families fear that healthcare providers will withhold information about their loved ones.

Limitations

Family members of critically ill patients have a high degree of vulnerability that markedly increases with the need for CPR. Family members whose loved ones died during CPR were not asked to participate in this study because I anticipated that interviews would be excessively burdensome for them. If family presence during CPR is to become a reality, the opinions and feelings of family members from both successful and unsuccessful resuscitation attempts become equally important in determining policy and procedure related to family presence.

Survival rates for patients who had CPR were low, so finding potential subjects for the study was difficult. Excluding family members whose loved ones died during CPR resulted in a markedly low number of participants eligible for the study when the number of attempted resuscitations that occurred during a 6-month period is considered. Essentially, before a policy in support of family presence is implemented, a study with more participants is necessary to more fully understand the thoughts and feelings of family members of critically ill patients during CPR.

Implications

The purpose of this study was to understand the lived experience of family members of critically ill patients during cardiopulmonary resuscitation. Once healthcare professionals better understand the experience of patients’ families during CPR and the experience of the healthcare providers, we can link these experiences to determine appropriate interventions. The results of early studies suggest that family presence may be one such intervention.

Another intervention may be to provide a family liaison. Several institutions have attempted to better meet the needs of patients’ families by providing a family liaison. Hodovanic et al described their volunteer program to aid the family members of patients in the intensive care unit. Kahn describes their volunteer program, an advocate meets with patients’ family members to meet the needs of patients’ families by providing a family liaison. Several institutions have attempted to better meet the needs of patients’ families by providing a family liaison. Washington described a program instituted to target the informational needs of patients’ families. In this program, an advocate meets with patients’ family members on a daily basis to provide information, explanations, and reassurance.

Conclusion

Throughout the experience of having a loved one undergo CPR, families seek information and proximity; these needs have been well defined by numerous studies during the past 2 decades. Entwined within the concepts of information and proximity is the notion of you do your job. That is, patients’ family members place an enormous amount of trust in the healthcare team. They expect the team to do its job in resuscitating patients and to provide care after resuscitation. In most instances, a patient’s family has no choice but to trust the healthcare professional. My results indicate that the healthcare team controls the situation during CPR.
Patients’ families lose autonomy and do not gain ground when they attempt to negotiate their way into the resuscitation room. By controlling a patient’s family during CPR, the members of the healthcare team deny the family the ability to watch out for the family’s loved one and provide protection. When families are not provided information during resuscitation, they cannot determine what is going on. Families are in crisis and need reassurance and informational support to cope effectively.

Further research is needed on the perceptions of patient’s family members during CPR. Once healthcare professionals understand the perceptions and needs of patient’s families, appropriate interventions, such as family presence or the use of a critical care liaison, can be implemented and evaluated. As a result, patients’ families and healthcare providers can provide patients in distress with a unique aspect of care: a caring presence and support.

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REFERENCES
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