

End of Life Care

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PRACTICE UPDATE

FAMILY PRESENCE IN RESUSCITATIVE AND TREATMENT PROCEDURES

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ONE FAMILY'S STORY

NASW would like to acknowledge the contribution of Marjorie Helm, an NASW member and social worker, to this practice update. Thank you for sharing your personal loss and experience. We hope your insight will inspire social workers to advocate for the practice of family presence in resuscitative and treatment procedures.

Trey was an active 11-year-old boy having fun at a friend's birthday party, when a tree limb fell in a strong wind and hit his head, causing a massive head injury. Immediately, Trey became unconscious and his nose began bleeding. His parents and 911 were called. Emergency medical technicians arrived and attempted to resuscitate Trey. His parents, Marjorie Helm and Chip Atkin, who are social workers, also arrived to attend to their only child.

Helm watched in a shocked, yet calm state, as emergency medical personnel worked to revive her son. Both parents made repeated attempts to get close to their son during treatment, but the emergency responders insisted there was not enough room. When Trey was airlifted to a trauma center, his parents were told they could not ride with him.

The separation from their son was excruciating for Trey's parents. Their instincts were to support and protect him. They had always been with him when he was injured and needed medical attention. Trey's parents drove to the trauma center where Trey continued to be treated, first in the emergency room, and subsequently in the operating room. Both parents pleaded to be with their son, even if he was unconscious. The separation continued, as emergency room personnel worked to save their son's life.

Finally, a hospital chaplain, who was called to support the family, requested that the parents spend a few minutes with Trey before he entered surgery. These precious minutes provided a physical and psychological connection for his parents. He went to surgery, and then to the trauma unit.

The doctor told Trey's parents he would probably not make it through the night. Helm and Atkin experienced support from the trauma unit staff, and were encouraged to be at Trey's bedside even as he continued to endure efforts to sustain his life. The trauma unit personnel were supportive and comfortable with the parents' presence.

"The trauma team made all of the difference in the world to us," Helm said. They encouraged us to touch and talk with Trey, even though he was unconscious. When one doctor did ask us to leave our child's side to do a procedure, it felt as though we were asked to leave our child when he was so close to death."

Less than 48 hours after the tree limb fell on Trey, he was declared brain dead. Trey became an organ donor with the consent of his parents.

Almost four years have passed since Trey's death, and his parents have reflected on the important practice of family presence while a loved one undergoes resuscitation or treatment procedures. Their positive and negative experiences reflect what has been found in research and practice on family presence in resuscitative and treatment procedures.

After her son's death, Helm says she and her husband talked about Trey's accident, death, and care during the traumatic two days. They debriefed with emergency responders to "know what their experience was with Trey and what happened. Some of the responders were reluctant to meet with us," Helm said. "We have talked with health care professionals and

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we continue to hear one theme: Family members cannot be counted on to be present in life-threatening situations. The staff need to take care of the child and cannot take care of the family.” Helm credits a local hospice for helping in their grief. She has become a hospice volunteer and bereavement parent support-group facilitator.

“I have talked with lots of parents who have been separated from their child in emergency treatment situations,” Helm said. “They feel excluded and helpless, like they are responsible. The parents tell me that to have been present with their child would have helped in their grief.”

WHAT IS FAMILY PRESENCE?

Whether from a patient and family, or a health care professional perspective, the presence of family members while a loved one undergoes resuscitation efforts or an invasive procedure seems difficult and unimaginable. Based on this reasoning, as well as on the anecdotal opinions that the invasive procedures and resuscitation effort would be too traumatic for relatives to watch and that the presence of relatives would interfere with staff performance (Rattrie, 2000), family members of critically ill or injured patients have usually been excluded from the resuscitation or treatment area. However, a growing body of research indicates that there are many benefits to family members being present during such efforts for the patient, family, and health care professionals involved in the patient’s care.

For some health care professionals, family presence (FP) is a standard practice; for others, it is an emerging procedure that requires training and understanding to help advocate for and implement in their health care setting.

RISKS AND CONCERNS ABOUT FAMILY PRESENCE

Although family members can usually be present during minor procedures, health care professionals have understandable reservations about FP in critical-care situations or during invasive procedures. Health service personnel are trained and consistently prepared to deliver physical care and carry out emergent procedures to individuals in life-threatening situations (Eichhorn, 1996). However, in this era of family-centered care, many health care professionals have also received sensitivity training for crisis situations.

When a practice such as FP is introduced, health care providers may approach the controversial issue with fear and skepticism:

- How will the family react during the active phase of resuscitation or treatment with the patient?
- Will the family become disruptive or emotional and require assistance from staff personnel who are trying to care for the patient?
- How will a family members’ reaction affect the provider’s performance?
- Will family members interfere in an effort to determine if everything is being done correctly?
- What are the litigation risks if something goes wrong (Eichhorn, 1996)?

Definitions

Family- A person or persons with an established and supportive relationship with the patient. Each health care institution may have policies that define family further due to legal and ethical considerations.

Family Presence- The practice of family members’ presence during a loved one’s resuscitation or treatment procedure (Rattrie, 2000).

Resuscitation- The act of reviving a person and returning them to consciousness (Wordnet Dictionary, 2003). Other terms for resuscitation include cardiac resuscitation, cardiopulmonary resuscitation, and CPR.

Treatment Procedure- Medical care by procedures or applications that are intended to relieve illness or injury (Wordnet Dictionary, 2003).

Family Support Person- This role is usually a health care professional, such as a social worker, chaplain, nurse, or child-life specialist, with no direct patient care responsibility, and is specifically assigned to initiate interventions, assist the family, provide emotional and psychosocial support, and be a shoulder to lean upon in FP situations (Columbus Children’s Hospital, 2004). A family-support person guides the family through the experience with support, information, and understanding.

BENEFITS OF FAMILY PRESENCE

For families witnessing the resuscitation or a treatment procedure, the benefits include:

1. Feeling that they provided comfort and protection to the loved one who was in pain, afraid, vulnerable, or defenseless;
2. Understanding what was happening with their loved one;
3. Knowing every possible intervention was being provided for their loved one;
4. Reducing their fear and anxiety and helping them realize the reality of the situation;
5. Lessening their helplessness; and
6. Helping in their grief following the death from failed resuscitations (Meyers, 2000).

Families also found that their presence reminded health care providers of the person, and not just the patient, to whom they were delivering care. “For families of dying patients, FP also provided the chance to say goodbye to their loved one and have some closure on a shared life” (Meyers et al., 2000).

For health care professionals, the benefits of FP include:

1. Helping meet families’ emotional and spiritual needs;
2. Families knowing everything was done for their loved one;
3. Appreciating the care delivered to the patient;
4. Being able to educate families on what care was being provided to a patient;
5. Families providing support and assistance to the patient and, in turn, the staff felt this helped them;
6. Acting more professional in the presence of family; and
7. Seeing the patient in terms of a person whose dignity, privacy, and need for pain management were important.

IS FP FOR EVERYONE?

Each health care team or institution considering or practicing FP has important decisions and policies to make. FP may be offered to family members, but they should always have the option to decline and to have those wishes respected. Some institutions have developed a screening tool to evaluate who may be eligible to be offered FP. There may be circumstances in which FP is not appropriate, such as when someone is under the influence of drugs or alcohol, and cannot endure or understand the practice of FP.

THE ROLE OF THE SOCIAL WORKER

Social workers, acting as the family-support person or the family facilitator in health care scenarios in which families witness resuscitations or treatment procedures, embody a significant role and function. This role continues across the continuum of care and includes meeting the family upon arrival, maintaining contact and presence throughout the procedure or resuscitation, and, if appropriate, providing bereavement follow-up care. Specific activities may include:

- Preparing family members for the patient visit by informing them of the patient’s appearance, procedures to be performed, value of the support or helping role, such as talking and touching the patient (if appropriate), bedside time restrictions, and instances when it may be appropriate to be escorted from the room (Meyers et al., 2000);
- Providing emotional and psychosocial support;
- Acting as a liaison with the medical staff and family, which can include advocacy for the family being present or leaving when the family is ready to depart (Columbus Children’s Hospital, 2004).

In a study of FP during resuscitation attempts,

- 97 percent of family members would choose to witness it again;
- 76 percent believed their grieving was made easier;
- 67 percent thought their presence benefited the patient; and
- 100 percent felt confident that everything possible had been done to save their family member (Knazik et al., 2003).

NASW AND FAMILY PRESENCE

NASW has supported the practice of family presence in a number of ways:

- NASW promoted family presence in the *Bereavement Guidelines for Social Workers in Emergency Departments Guidelines* and chapter trainings.
- NASW has also participated in the Ambulatory Pediatric Association's National Consensus Conference on Family Presence During Cardiopulmonary Resuscitation (CPR) and Procedures in September, 2003. The conference objective was to develop and publish consensus guidelines useful for defining policy about family presence during pediatric procedures and CPR. The article is in the last stages of approval, before publication submission.

NEW BENEFIT FOR NASW MEMBERS

FREE Online Courses

Understanding Cancer:

The Social Worker's Role — 2.0 FREE CEUs

Funded by an unrestricted educational grant from Bristol-Myers Squibb Company.

Understanding End of Life Care:

The Social Worker's Role — 2.0 FREE CEUs

Funded by an unrestricted educational grant from Soros Foundation's Project on Death in America.

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