A Nursing Tool to Promote Patient- and Family-Centered Care in Adult Critical Care: The Family Care Assessment

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Abstract

Families of critical care patients experience stress that negatively impacts the family’s well-being and impedes the family’s ability to support the patient (Horn & Tesh, 2000). The patient- and family-centered care (PFCC) model emphasizes the importance of mutually beneficial partnerships among health care providers, patients and families, and one of the core components of PFCC is family participation (Institute for Patient and Family-Centered Care, 2010). Research indicates that involving families in providing care to critically ill patients is an effective way to meet family needs and reduce stress (Al Mutair, Plummer, O’Brien, & Clerehan, 2013). Additionally, evidence suggests that critical care nurses, families of critical care patients, and critical care patients themselves all support family participation in patient care (Garrouste-Orgeas et al, 2010). Critical care nurses are in a unique position to lead interventions to meet family needs by promoting family involvement in care. The Family Care Assessment is a tool that critical care nurses can use to assess the family’s desire to become active participants in patient care. I created this tool after conducting a review of the literature on nursing care of families of critical care patients which revealed a need for specific interventions to facilitate nurses in caring for families. The purpose of the Family Care Assessment is to facilitate a positive and productive relationship between the nurse and family, with the ultimate goal of supporting the family and improving patient care.
Family Needs In Critical Care

The admission of a family member to a critical care unit is an extremely stressful and often unexpected event. Family members of patients in critical care experience psychological distress in the form of anxiety, depression, and post-traumatic stress disorder (Davidson, Hopkins, Louis, & Iwashyna, 2013). The Society of Critical Care Medicine (2013) terms this group of mental health problems post-intensive care syndrome-family. Feelings of fear and grief are often compounded by disturbances in sleeping and eating patterns, as well as changes in family roles and responsibilities (Horn & Tesh, 2000). The stress of critical illness can disrupt the family system and nursing interventions to relieve stress and support family adaptation are needed.

To reduce family stress and support effective family coping, it is important to identify the needs of families. An instrument that has been used in numerous studies to examine family needs is the Critical Care Family Needs Inventory developed in a landmark study by Molter (1979). The questionnaire divides needs into five categories: assurance, information, proximity, comfort, and support. Assurance refers to the family’s need to be reassured of the health status of the patient and to feel confident that the patient is receiving the best care possible. The need for information refers to the need for increased knowledge of the patient’s problems. Proximity is defined as physical closeness to the patient. Comfort and support refer to emotional, psycho-spiritual, physical, environmental and sociocultural needs that can be met by healthcare providers, hospital chaplains, and friends.
Family needs can be met by allowing family members to become active participants in patient care (Al Mutair, Plummer, O’Brien, & Clerehan, 2013). A structured review of the literature on family needs and involvement in critical care revealed that families perceive the need for information about the patient’s condition and plan of care as especially important (Al Mutair et al, 2013). The process of learning how to help care for the patient provides an opportunity for the family to learn about the patient’s condition and therefore supports the family need for information. Involvement in care also supports the family need for maintaining close physical proximity to the patient. A repeated-measures study with 88 participants by Eldredge (2004) found that family members wanted to be physically close to patients and also wanted to be helpful, but they were not able to because the nurses assumed sole responsibility for care.

Studies indicate not only that families will benefit from being actively involved in patient care, but also that families have a desire to be involved in care. A qualitative study by Mitchell and Chaboyer (2010) determined that a common theme among family members of critical care patients was that they “grappled with conflicting feelings of helplessness and also a need to be involved and useful” (p. 157). Additionally, family members perceived that the act of helping provided an emotional connection and psychological benefit for both their relatives and themselves. A study to assess families’ opinions about family participation in patient care in critical care units by Garrouste-Orgeas et al (2010) surveyed 101 family members and determined that 97% indicated a desire to participate.
Patient- and Family-Centered Care

The patient- and family-centered care (PFCC) model recognizes the patient and the patient’s family as the unit of care rather than just the patient alone. This model of care “is grounded in mutually beneficial partnerships among health care providers, patients, and families” (Institute for Patient- and Family-Centered Care, 2010). During critical illness the role of the family is especially important because the family often becomes the patient’s voice when patients are sedated or unconscious. Family members can provide helpful information to health care professionals about the patient, and are often responsible for making decisions for the patient. Patient- and family-centered care is a holistic approach that acknowledges the emotional, social, and developmental support that families provide to patients to be a crucial component of health care.

The Institute for Patient and Family-Centered Care (2010) identifies four core concepts essential for PFCC: respect and dignity, information sharing, participation, and collaboration. Respect and dignity are promoted when members of the health care team listen to and honor patient and family preferences. The family’s culture, knowledge, beliefs, and values should be taken into account when planning care. Information sharing between the family and health care provider should be complete, timely, and accurate so that families can be participate in care and decision making. Patients and families should be supported to participate in care and decision making at the level they desire. Collaboration is supported when patients and families are included in an institution-wide basis. Interventions that
facilitate family participation in patient care tasks support the key tenets of patient- and family-centered care.

**The Role of Critical Care Nurses in Caring for the Family**

Critical care nurses are in a unique position to meet family needs and facilitate family involvement in care. Nurses provide most of the bedside care for patients, and accordingly spend the most time with patients and families. Nurses also play an important role in providing information about biomedical, psychological, and sociological aspects of disease and by acting as translators of information between physicians and patients (Slatore et al, 2012). Family members of critical care patients themselves identify nurses as the best resource for meeting their needs (Al-Mutair, Plummer, O’Brien, & Clerehan, 2013).

Critical care nurses recognize families as important partners in patient care. Research indicates that critical care nurses value family presence and the information that family members provide, and find it frustrating when patients do not have family at the bedside (Engström & Söderberg, 2007). Caring for the family can be a time consuming task, yet nurses believe that they have a responsibility to care for the family when the nursing of the patient allows it (Ågård & Maindal, 2009).

Critical care nurses need specific tools and strategies to help them care for families. A descriptive correlational study by Buckley & Andrews (2011) concluded that while nurses demonstrated knowledge of the needs of relatives, there was no significant statistical relationship found between knowledge scores and self-reported practice. These results indicate that knowledge is not necessarily
translated into clinical practice. Nursing interventions that operationalize the patient- and family-centered care model in adult critical care are needed in order for nurses to provide optimal care for patients and families.

**The Family Care Assessment**

The Family Care Assessment is a questionnaire for families of patients in critical care that gathers information about the family’s desire for involvement in a variety of patient care tasks. The family indicates from a list of patient care tasks which they want to learn about and participate in. Completing the tool not only provides an opportunity for the family to express their desire for involvement in care, it also allows them to select tasks they feel comfortable completing. The patient care tasks included in the Family Care Assessment are divided into three categories: activities of daily living, comfort measures, and mobility.

The nurse and family should complete the Family Care Assessment together at the beginning of each shift. The patient must also be included in this process when possible. In the left-hand column the nurse indicates which patient care tasks are appropriate for the family to be involved with given the patient’s medical condition and plan of care. For example, the nurse would not indicate that range of motion exercises were appropriate for a patient with multiple fractures. In the right-hand column the family indicates from the same list of tasks which they would like to learn about and help with. The nurse should include the family in tasks marked by both nurse and family. When completing the Family Care Assessment with the family, the nurse should provide education about how each task can benefit the patient and the rationale behind including it in the patient’s care. Information
sharing and collaboration take place when the nurse and family complete this tool together.

The activities of daily living tasks included in the Family Care Assessment are full bath, face wash, eye wash, mouth care, shampoo hair, comb hair, face shave, and lotion application. These tasks are some of the most practical for family members to be involved in. Unlike technical nursing skills such as performing a dressing change or tracheostomy suctioning, the activities of daily living are routinely completed outside the hospital setting and familiar to the public. These activities promote hygiene and preserve the patient’s dignity. Protecting dignity, a core concept of patient- and family-centered care, involves seeing the patient as a unique person and supporting patient appearance (Hall & Høy, 2012). Involvement in care activities to promote hygiene and preserve dignity can provide comfort to family members because it is a way for them to respect and acknowledge the patient’s individuality and preferences.

In addition to preserving the patient’s dignity, the activities of daily living patient care tasks also help prevent complications that can occur in the critical care setting. Keeping the patient’s skin clean, protecting the skin from excessive moisture, and the use of lotion to hydrate dry skin are important interventions to prevent skin breakdown and the development of pressure ulcers (National Guideline Clearinghouse, 2009). The nurse can educate family members about the dangers of pressure ulcers and how to assess the patient’s skin for signs of breakdown during bathing. Oral care not only prevents dental caries but for patients on a ventilator routine oral care also reduces the risk of ventilator associated
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Pneumonia (National Guideline Clearinghouse, 2011). Educating families about these health risks and teaching them about the benefits of hygiene can help them feel that they are able to make a meaningful contribution to protecting the patient’s health.

The comfort section of the Family Care Assessment includes the following patient care tasks: presence, touch, and music. The Family Care Assessment can be used by the family to indicate a desire to be present at the bedside, and nurses can support presence by educating the family about the policies and procedures on the unit regarding family visitation. Families may be intimidated by medical technology and afraid to touch the patient, however touch can be therapeutic for the patient. The physiologic properties of touch for the critical care patient include lower systolic and diastolic blood pressure and respiratory rate, improved sleep, and decreased pain (Papathanassoglou & Mpouzika, 2012). Similarly, families may not be aware that hearing is often the last sense to leave when patients are sedated. The nurse should educate the family that playing music can decrease stress and anxiety in critical care patients (Dijkstra, Gamel, van der Bijl, Bots, & Kesecioglu, 2009).

Completing the Family Care Assessment with the nurse will help families realize that presence, touch, and music are permissible and beneficial to the patient.

The mobility section of the tool includes the following tasks: application of antithrombotic stockings, help the patient turn in bed, range of motion exercises, and help the patient get out of bed. Intensive Care Unit (ICU)-acquired weakness is a condition that is characterized by acute neuromuscular impairment and associated with risk factors such as inflammation, ventilator dependence, and immobility.
Early progressive mobility is important for reducing the risks of immobility because ICU-acquired weakness is associated with long term consequences such as prolonged mechanical ventilation, increased length of hospital stay, self care deficits, and poor quality of life (Vasilevskis et al, 2010) (Banerjee, Girard, & Pandharipande, 2011). Progressive mobility is a series of planned movements in a sequential manner beginning at a patient’s current mobility status with a goal of returning to baseline (Vollman, 2010). This process involves elevation of the head of the bed, manual turning, passive and active range of motion exercises, continuous lateral rotation therapy, movement against gravity, upright/leg-down position, chair position, dangling, and ambulation (Vollman, 2010). Including the family in efforts to promote early mobility will be helpful to the nursing staff because multiple people are required to get critical care patients out of bed safely. When circumstances prevent a patient from moving or getting out of bed, the family can support the immobile patient by applying antithrombotic stockings to promote circulation.

The 'Nurse comments' and 'Family comments' sections of the Family Care Assessment are a space for the nurse and family to include additional relevant information. This section was created to facilitate more individualized and culturally sensitive care. For example, the family can use this section to indicate the patient’s favorite music or TV station so that when they are gone the nurse will know what the patient prefers to listen to. The nurse may wish to write specific instructions for the family in this section such as, “To reduce risk of aspiration remember not to
lower the head of the bed when completing patient care.” This section of the tool facilitates open communication between nurse and family.

**Implementation of the Family Care Assessment**

Implementation of the Family Care Assessment will be efficient and cost effective. The first step is training the nursing staff how to use the tool. This can be accomplished in a one hour in-service training session. An important focus of the training should be educating the nursing staff about the benefits and importance of patient- and family-centered care in adult critical care. Nurses will appreciate the value of spending extra time to complete the Family Care Assessment with families if they understand how it will be beneficial to patients and families.

After training the nursing staff, the second component of implementation is making the tool available to families. The Family Care Assessment can be laminated and placed in the patient’s room. The advantage of a laminated version of the form is that it can be changed and updated when the patient’s condition changes or when the nursing staff changes. Keeping the form visible in the room may prompt the nurse and family to remember to use it. It should be the nurse’s responsibility to ask the family if they would like to complete the Family Care Assessment. The laminated forms can be sanitized and re-used when new patients are admitted.

**Expected Outcomes of the Family Care Assessment**

Implementation of the Family Care Assessment will be beneficial for families of critical care patients, patients themselves, and critical care nurses. One of the crucial positive outcomes for families is reduced stress. Use of the Family Care Assessment will help meet family needs. The Family Care Assessment supports the
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Family need for information about the patient’s condition because knowledge is increased when the family partners with the nurse to learn about patient care tasks. Assurance that the patient is receiving quality care is supported when families understand the rationale behind why patient care tasks are beneficial to the patient. The Family Care Assessment supports the family need for proximity to the patient because the family is invited to be at the bedside providing care. Finally, the act of helping the patient has been shown to reduce stress and provide comfort to families (Al Mutair, Plummer, O’Brien, & Clerehan, 2013).

The Family Care Assessment will increase the number of families that become involved in patient care because it will serve as an invitation for families to participate in care. Garrouste-Orgeas et al (2010) found that 97% of family members surveyed indicated a desire to participate in care, however only 13.8% spontaneously provided patient care or asked the critical care staff to help them participate in patient care. These results suggest that though there is a desire for involvement in care, families may not actively pursue this role without being prompted by critical care staff. Filling out the the tool helps families to explore their own desired level of involvement in patient care. Discussing the Family Care Assessment with the nurse can also help the family learn new ways to support the patient they had not previously known about.

The Family Care Assessment will have a positive impact on patient health outcomes. The Family Care Assessment will help create an environment that supports the patient- and family-centered care model. Implementation of a patient- and family-centered model of care has resulted in positive patient outcomes such as
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reducing restraint use, total hours on the ventilator, and length of stay (Damboise & Cardin, 2003). The Family Care Assessment will lead to collaboration between the nursing staff and the family which will lead to more information sharing and therefore increased personalization of care for the patient. By reducing family stress, the Family Care Assessment will strengthen the family system. According to the principles of patient- and family-centered care, the patient exists within the structure of the family and the family needs should be met to protect health of the family and the integrity of the family system (Institute for Patient- and Family-Centered Care, 2010). Maintaining family integrity will benefit the patient because it will allow the family to care for the patient. Participating in patient care in the hospital will equip the family with practical skills that can be used to care for the patient after discharge.

The Family Care Assessment promotes culturally sensitive care for patients and families by allowing families to indicate their preferences regarding participation. A number of factors, including family culture, may influence family preferences for participation in patient care tasks. Completing the Family Care Assessment allows family members to choose patient care activities they want to help with and to opt out of participating in tasks that they feel are inappropriate. A descriptive qualitative study to identify the perceived needs of Saudi families of members of critical care patients in relation to their culture determined that family involvement in care is highly culturally appreciated and expected in varying degrees from different family members (Al-Mutair, Plummer, Clerehan, & O’Brien, 2013).
The Family Care Assessment allows family members to identify patient care tasks that are appropriate in the context of their family and culture.

The Family Care Assessment will also promote the formation of a positive and productive relationship between the nurse and family. Evidence suggests that communication with nursing staff is improved when family members are involved in providing care (Mitchell & Chaboyer, 2010). Offering families the option to complete the Family Care Assessment will demonstrate to the family that the nurse cares about their preferences and well-being. Results from a study that implemented a short family assessment called the ‘15-minute family interview’ indicated that brief interactions can be valuable for the establishment of deeper and more productive relationships between the nurse and family (Silva, Moules, Silva, & Bousso, 2013). Completing the Family Care Assessment with the nurse is a brief interaction that can improve the family’s relationship with the nurse and the overall hospital experience. The relationship between family members and nursing staff is important because families that perceive positive family-centered relationships with the health care team experience higher levels of satisfaction with the care and report higher levels of psychologic well-being (Van Riper, 2001).

Implementation of the Family Care Assessment has the potential for important financial implications. Customer service is an important component of quality health care, and has a major impact on hospital finances due to the value based purchasing system of reimbursement currently used by the Centers for Medicare and Medicaid Services. Poor communication was found to be the largest source of dissatisfaction with hospital care among bereaved relatives of ICU patients.
in a multidisciplinary study by Cuthbertson, Margetts, & Streat (2000). Increased frequency of communication with the health care team is associated with increased family satisfaction (Jacobowski, Girard, Mulder, & Ely, 2010). Implementing the Family Care Assessment may increase the family’s satisfaction with the hospital experience by improving communication with the nursing staff. By improving family support and equipping the family to be involved in patient care, the Family Care Assessment may improve family’s ability to care for the patient after discharge and could therefore impact re-admission rates. Research is needed to determine the actual outcomes of implementing the Family Care Assessment.

Summary

The Family Care Assessment is a tool to assess family preferences regarding participation in patient care. When families become involved in providing patient care the experience of helping the patient contributes to decreasing family stress. Increased communication between the nurse and family leads to important information being shared about the patient, resulting in increased individualization of care. Family members involved in care perceive more respect, support and collaboration from the health care team than families not involved in care (Mitchell, Chaboyer, Burmeister, & Foster, 2009). The Family Care Assessment will facilitate a partnership between families and the health care team that will increase family satisfaction with the hospital experience. Patient outcomes have been shown to improve when patient- and family-centered care strategies are implemented in critical care. The Family Care Assessment is a nursing intervention that supports the
core concepts of patient- and family-centered care and will have a direct impact on the quality of care provided to patients and families.
Family Care Assessment

The purpose of the Family Care Assessment is to give family members a chance to help with patient care. In the left-hand column the nurse chooses activities that the family can help with that are appropriate for the patient. In the right-hand column the family chooses activities they would like to learn about and help with. The nurse will include the family in activities marked by both nurse and family.

Patient: __________________________________________________________

Family member(s): ________________________________________________

Nurse: __________________________________________________________

Activities of Daily Living

These activities promote hygiene and can help prevent problems such as skin breakdown. Ask your nurse for more information.

<table>
<thead>
<tr>
<th>Activities of Daily Living</th>
<th>To be completed by the nurse: Please choose the activities that are appropriate for family participation.</th>
<th>To be completed by the family: Please choose the activities you would like to participate in.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Full bath</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Face wash</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Eye wash</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mouth care</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Shampoo hair</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Comb hair</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Face shave</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lotion application</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
**Comfort**

These activities provide comfort and other benefits for patients in critical care. Ask your nurse for more information.

<table>
<thead>
<tr>
<th>To be completed by the nurse:</th>
<th>To be completed by the family:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Please choose the activities that are appropriate for family participation.</td>
<td>Please choose the activities you would like to participate in.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Presence</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Touch</td>
<td></td>
</tr>
<tr>
<td>Music</td>
<td></td>
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</tbody>
</table>

**Mobility**

These activities help prevent problems that can happen as a result of being in bed for long periods of time. Ask your nurse for more information.

<table>
<thead>
<tr>
<th>To be completed by the nurse:</th>
<th>To be completed by the family:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Please choose the activities that are appropriate for family participation.</td>
<td>Please choose the activities you would like to participate in.</td>
</tr>
</tbody>
</table>

| Application of antithrombotic stockings | |
| Help the patient turn in bed | |
| Range of motion exercises | |
| Help the patient get out of bed | |

Nurse comments:

Family comments:
References


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