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Perceived Met and Unmet Needs of Family Members of Patients in the Pediatric Intensive Care Unit

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Extensive research has been conducted over the years with a general focus on the family members of adult patients in the critical care setting. The resulting recognition of the profound impact that the family has on the patients' outcomes has led to greater focus on the direct assessment and identification of perceived met and unmet needs of family members. In contrast to the adult patients needs, this descriptive, exploratory pilot study consisted of 20 family members who had pediatric patients in the pediatric intensive care unit. Families completed a 2-part instrument: the Demographic Data Questionnaire and the Needs Met Inventory. Data were analyzed and reported the top 10 always met/usually met needs and the top 10 never met/sometimes met needs in order of importance during the first 24 to 36 hours after admission of the pediatric patient. The overall items under the subscale assurance ranked the highest as perceived needs always met/usually met. The overall items under the subscale support ranked the lowest as perceived needs never met/sometimes met.
Key words: *family members*, *pediatric intensive care unit*, *perceived met/usually met needs*, *perceived never met/sometimes met needs*

ILLNESS and hospitalization of a child in the pediatric intensive care unit (PICU) may have obvious detrimental physiological and psychological effects; however, an increasing amount of research is being conducted, which places emphasis on the effects encountered by family members.[1–3] The unexpected hospitalization of a child with a critical illness can be overwhelming and particularly stressful for parents and siblings. A life-threatening illness undoubtedly creates a perceived crisis for the child, but a true holistic approach to healthcare should include integration of the family members, as they may experience emotional turmoil as a natural response to crisis. During the past decade, studies have continually displayed the important role family members have in the overall well-being and progression of the illness of a child.[4–6] While a spectrum of effects is discovered through research, focus on the perceived needs of family members is needed to formulate evidence-based nursing interventions to address unmet needs of family members of hospitalized children.

The purpose of this study was to conduct a pilot study of 20 participants to identify and explore the perceived met or unmet needs of family members who had children hospitalized in the PICU. The Needs Met Inventory (NMI) was used to explore to what extent the family members judged the top 10 needs were being met or unmet 24 to 36 hours after admission of a child to the PICU. The NMI has established reliability and validity and has been used in numerous studies to measure met and unmet needs of adults in the ICU[1,7–10]; however, the instrument has not been used with pediatrics families; therefore, the pilot study

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was completed to establish use with family members who had children hospitalized in the PICU.

DEFINITION OF TERMS

1. *Perceived need*: A requirement of the family member that, if not met, becomes a demand that can produce distress.
2. *Family member*: Designated as any individual who is a significant part of the critical care pediatric patient's life and shares intimate and routine day-to-day living with that patient. May include parents, grandparents, siblings, and significant others to the critically ill pediatric patient.
3. *Critically ill pediatric patient*: For this study, a child admitted to the PICU due to life-threatening or potentially life-threatening alterations between 2 and 14 years of age.
4. *PICU*: Pediatric intensive care unit providing specialized care for critically ill pediatric patients.

UNDERLYING CONCEPTUAL FRAMEWORK

The underlying conceptual framework that guided this study was crisis and human needs theories. Because of the perceived crisis that often occurs when a family member becomes critically ill, Caplan[11] outlined 4 specific phases that culminate in the state of acute crisis: exposure to the stressor with anxiety ensuing; a previous problem-solving technique that does not relieve the stressor, which produces further anxiety; all internal and external resources are utilized to resolve the problem and relive the discomfort; and when resolution does not occur in the previous phases, anxiety reaches panic levels and major disorganization occurs. In addition to crisis events, Maslow's human needs suggest that 5 needs occur in hierarchal order: physiological, safety, love and belonging, self-esteem, and self-actualization. The first 3 needs may create situations in the PICU where the family may feel threatened and feel that their needs are not met. Maslow's theory postulates the idea that the needs of family members must be met to achieve progression to the highest level of functioning. Hence, it is crucial to promote family-centered care and identify, assess, and address those needs to avoid prolonged crisis events.[12–15]

REVIEW OF LITERATURE

Theoretical basis for the research

To first establish an understanding of the importance family members bare on pediatric outcomes, a clear definition of the term *family* must be ascertained. *Family*, as defined by the *Oxford English Dictionary* is "a group of persons consisting of the parents and their children whether actually living together or not; in a wider sense, the unity formed by those who are nearly connected by blood and affinity."[1p(27)] Family is expanded to "anyone who is an integral part of the patient's normal lifestyle or whose collective homeostasis is modified by the patient's admission into a critical care setting".[1(p27)] Recognition of the significance of family role can be traced back to nursing pioneer Florence Nightingale's 1859 publication, *Notes on Nursing*, which denoted the great impact that the presence of family, friends, and visitors had on the ill Nightingale.[16]

The initial work toward perceived needs of family members was conducted by Molter[17] through organized interviews of 40 family members of patients who were critically ill. The family members ranked their needs according to importance using the Critical Care Family Needs Inventory (CCFNI), which is a 45-item Likert scale instrument with embedded subscales of assurance, support, information, proximity, and comfort. Ranked in ascending order, the top reported needs were as follows: to feel there is hope; to feel the hospital personnel care about the patient; to have the waiting room near the patient; to be

called at home about the patient's condition; to know the prognosis; to have questions answered honestly; to know specific facts about the patient's prognosis; to receive information about the patient once per day; to have explanations given in understandable terms; and to see the patient frequently.

Ward[3] completed a descriptive study, using a modified version of the CCFNI to identify the 10 most and least significant perceived needs of parents of infants within the neonatal intensive care unit (NICU) using a convenience sample of 52 parents of 53 critical infants in the NICU. Findings indicated that the 10 most important perceived needs were as follows: to know exactly what is being done for my infant; to see that the NICU staff provide comfort to my infant, such as giving my infant a pacifier, using blankets to support my infant's body, and talking softly to my infant; to know my infant is being treated medically; to have questions about my infant answered honestly; to be able to visit at any time; to be assured that the best care possible is being given to my infant; to know the expected outcome for my infant; to feel that the hospital personnel care about my infant; to know that my infant is being handled gently by healthcare providers; and to know the specific facts concerning my infant's progress. The 10 least important perceived needs were as follows: to have someone be concerned with my health; to have a bathroom near the waiting room; to have a pastor, clergy, or other person from my church visit; to have someone to help with transportation; to be allowed to have my infant's siblings visit; to receive help to respond to the reactions of my infant's siblings; to have another person with me when visiting NICU; to have comfortable furniture in the waiting room; to be able to talk to other parents whose infant is in the NICU or has had similar situations; and to have a support group of other families available.

A similar study was conducted by Scott[2] to identify the needs of parents of critically ill children in the PICU compared with those needs perceived by the nurses and to identify any discrepancies between the 2 groups. Again, a modified form of the CCFNI for pediatrics was used. Overall, the family members and the nurses identified similar perceived needs as significant. The top 10 highest-ranked needs were as follows: to feel that the hospital personnel care; to see their child frequently; to be called at home about changes in condition; to be assured that the best care is given; to know how their child is being treated medically; to visit at any time; to have questions answered honestly; to know the expected outcomes; to be recognized as important to their child's recovery; and to receive information once a day.

In summary, the family remains the most important social context to consider when determining interventions to positively influence children's outcomes. To facilitate family-centered pediatric care, the parental needs of the parents, siblings, and significant others must be accurately identified, prioritized, and incorporated into the plan of care. Anxiety from perceived unmet needs by the family members may prove to be detrimental to pediatric care through distrust of nurses, anger, dissatisfaction with care, disregard for treatment regimen, or even lawsuits.

METHODS

An exploratory, descriptive design using quantitative methodology was used to identify met and unmet needs of family members of critically ill children. Permission was obtained from the institution through internal review committee and nursing management, and data were collected through the use of structured interview schedules. The primary setting was a 12-bed pediatric unit in a large urban hospital trauma center. A convenience sample of 20 family members was selected with each meeting the following criteria.

1. The pediatric patient must be between 2 (24 months) years and 14 (168 months) years of age and must not have a chronic physical condition that requires frequent hospitalization in the PICU.

2. The admission to the unit must be subsequent to an acute injury or illness resulting in actual or potential physiological alterations that could be life threatening.
3. The family member participant must be 18 years or older; he or she may be a parent, significant relative, adult sibling, and any significant person who is important to the family function. The other family members must identify the family member completing the inventory as the most significant family person.
4. The family member must be willing to meet with the researcher and complete the Demographic Data Questionnaire and the NMI.

Instrumentation

The instrument packet contained 2 questionnaires. The first questionnaire was Demographic Data Questionnaire for family members and consisted of the following 10 items: (1) age of the pediatric patient; (2) diagnosis of the pediatric patient; (3) gender of the pediatric patient; (4) gender of the family member; (5) relationship of the family member with the pediatric patient; (6) age of the family member; (7) previous hospital experience of the family member; (8) highest educational level of the family member; (9) employment of the family member; and (10) perceived condition of the pediatric patient.

The second questionnaire, the NMI, was a 45-item, self-administered questionnaire consisting of the same questions used on the CCFNI. Permission was obtained from Leske[14] to adapt the CCFNI. The NMI has been used by numerous researchers and has established reliability and validity. The questionnaire includes 5 subscales: support, comfort, information, proximity, and assurance. The NMI consists of a 4-point Likert scale in the following format: 1 (*never met*), 2 (*sometimes met*), 3 (*usually met*), and 4 (*always met*). The NMI differs from the CCFNI in which the researchers asked the family members to rank how well the perceived needs were met or unmet rather than to rank the importance of the need statement.

Data collection procedure

After approval had been received from the administration of the institution, the investigator in the PICU waiting room contacted family members who met the criteria. Verbal and written explanations regarding the purpose of the study were provided. Participants were informed of the risks and benefits, time required, procedure, measures to ensure confidentiality and anonymity, and voluntary involvement as the status. Participants were advised that they could withdraw from the study at any time. A copy of the letter of explanation in the form of a cover letter was provided to each family member when written consent to participate in the study was obtained. The Demographic Data Questionnaire and the NMI were then explained and administered to the eligible family members at 24 to 36 hours after admission of the children to the PICU. Data collection for the quantitative study took place over a 6-month interval.

FINDINGS

Data were analyzed using descriptive statistics. The mean age of the pediatric patients was 46 months (approximately 4 years; SD = 17.02). Eight of the children had never been in the PICU prior to this admission. Eleven of the children were admitted with severe respiratory illnesses, 2 with complications from surgery, 4 with febrile seizures, 2 with dehydration, and 1 with injuries from an automobile accident. The pediatric participant gender was 14 females and 6 males.

The relationship of the family member to the pediatric patient was as follows: 13 mothers, 3 grandmothers, 2 aunts, 1 father, and 1 significant other. The ages ranged from 18 to 49 years, with a mean of 28.6 years (SD = 9.8). Twelve of the family members were employed full-time, 6 part-time, and 2 were unemployed but searching for employment.

Table 1. Met needs

Top 10 needs always met/usually met according to Needs Met Inventory	Mean	SD
1. To know what things were done for the child (I)	4.00	0.00
2. To have questions answered honestly (A)	3.90	0.32
3. To have directions as to what do to at the bedside (S)	3.90	0.32
4. To have explanations given that were understandable (A)	3.90	0.32
5. To have felt the hospital personnel cared about the child (A)	3.90	0.32
6. To have seen the patient frequently (P)	3.90	0.32
7. To have the waiting room near the child (P)	3.90	0.32
8. To know the prognosis (A)	3.80	0.42
9. To talk the doctor every day (I)	3.80	0.42
10. To have felt there was hope (A)	3.80	0.42

Abbreviations: A, assurance subscale item; I, information subscale item; P, proximity subscale item; S, support subscale item.

Thirteen of the family members had completed high school, 2 had obtained general educational development, 4 had graduate college degrees, and 1 completed 11th grade. Twelve of the family members had at least 1 or more children at home. Interestingly, only 1 of the family participants perceived the child in critical or grave condition while in the PICU. Hours of visitation in the PICU ranged from 8 to 24 ($M = 16.9$, SD $= 4.8$). Eleven of the family members stayed at the hospital 24 hours per day.

Data were analyzed to indicate the top 10 always met/usually met needs in order of importance during the first 24 to 36 hours after the admission of the child to the PICU. Frequency distribution and mean scores were calculated and are shown in Table 1.

Data were analyzed on the NMI to indicate the top 10 never met/sometimes met needs during the first 24 to 36 hours after the admission of the patient to the PICU. Frequency distribution and mean scores were calculated and are shown in Table 2.

Table 2. Unmet needs

Top 10 needs never met/sometimes met according to the Needs Met Inventory	Mean	SD
1. To have a pastor visit (S)	2.20	1.32
2. To talk about the possibility of the child's death (S)	2.70	1.12
3. To have talked to the same nurse every day (P)	2.70	0.90
4. To have comfortable furniture in the waiting room (C)	2.70	0.68
5. To be alone at any time (S)	2.90	0.99
6. To talk about negative feelings such as guilt or anger (S)	2.90	1.21
7. To have been told about chaplain services (S)	3.00	1.56
8. To have someone help with financial problems (S)	3.00	1.11
9. To have another person with the relative when visiting pediatric intensive care unit (S)	3.10	0. 87
10. To have been told about someone to help with family problems (S)	3.10	1.21

Abbreviations: C, comfort subscale item; P, proximity subscale item; S, support subscale item.

Subscales

Support

Of the 15 items under the subscale support, only 1 item, to have directions as to what to do at the bedside, scored highest under always met/usually met on the NMI.

Never met/sometimes met needs under support items were as follows: to have a pastor visit; to talk about the possibility of the child's death; to be alone at any time; to talk about negative feelings such as guilt or anger; to have been told about the chaplain services; to have someone to help with financial problems; to have another person with the relative when visiting the PICU; and to have been told about someone to help with family problems. Eight of the items listed under the support subscale were noted as never met/sometimes met. The mean score for subscale support on the NMI was 3.05.

Information

Of the 8 items under subscale information on the NMI, to know what was being done to the patient and to talk to the doctor every day scored highest under always met/usually met needs. None of the 8 items under the subscale information were listed in the top 10 needs of never met/sometimes met on the NMI. The mean score for subscale information was 3.64.

Proximity

Of the 9 items under subscale proximity on the NMI, to have seen the patient frequently and to have the waiting room near the patient scored highest under always met/usually met needs. Never met/sometimes met need was to have talked to the same nurse every day. The mean score for subscale proximity was 3.55.

Assurance

Of the 7 items under subscale assurance on the NMI, to have questions answered honestly, to have explanations given that were understandable, to have felt that the hospital personnel cared about the family member, to know the prognosis, and to have felt that there was hope scored highest under always met/usually met. None of the 7 items were listed in the top 10 needs of never met/sometimes met on the NMI. The mean score for subscale assurance was 3.84.

Table 3. Comparison of the mean scores and standard deviation for each subscale on the Needs Met Inventory

	Mean	SD
Support	3.05 (5)	1.04
Information	3.64 (2)	0.53
Proximity	3.55 (3)	0.72
Assurance	3.84 (1)	0.37
Comfort	3.40 (4)	0.72

Comfort

Of the 6 items under subscale comfort on the NMI, none were listed in the top 10 as always met/usually met. Never met/sometimes met need was to have comfortable furniture in the waiting room. The mean score for subscale comfort was 3.40 (Table 3).

Family members who completed the open-ended questions ($n = 4$) perceived the following needs that were not found on the NMI instrument: (1) to provide a Spanish-speaking interpreter for better flow of communications on the night shift; (2) to provide more nursing assistants for routine care; (3) need more comfortable furniture in the waiting room; and (4) need to keep snacks for patients continuously. Family members also made positive comments ($n = 3$) such as the following: (1) great medical center with up-to-date technology; (2) nurses are really kind and caring; and (3) doctors seemed to really know what they are doing.

DISCUSSION

The purpose of the research study was to conduct a pilot study of 20 family member participants who had children in the PICU. The

NMI was used to describe, explore, and rank the top 10 items under always met/usually met needs and never met/sometimes met needs of family members. When all 45-need statements were considered on the NMI, assurance had the highest mean responses, with information, proximity, comfort, and support following in rank order.

NEEDS OF THE FAMILY MEMBERS

Support

Family members ranked items under subscale support as the lowest mean on the NMI. The 15 subscale items under support were as follows: to have explanations of the environment; to talk about negative feelings such as guilt or anger; to have directions as to what to do at the bedside; to have friends nearby for support; to have a place to be alone while in the hospital; to have help with financial problems; to have a pastor visit; to talk about the possibility of death; to have another person with the relative when visiting; to have someone concerned with the relative's health; to have been encouraged to cry; to have been told about other people who could help with problems; to have been alone at any time; to have someone to help with family problems; and to have information about chaplain services. Only 1 of the needs was found in the top 10 of always met/usually met needs, which was to have directions as to what do to at the bedside.

Of the 15 subscale items, 8 were listed in the top 10 needs as never met/sometimes met. These items were as follows: to have a pastor visit; to talk about the possibility of the child's death; to be alone at any time; to talk about negative feelings such as guilt or anger; to have been told about chaplain services; to have someone help with financial problems; to have another person with the relative when visiting PICU; and to have been told about someone to help with family problems.

The findings for this pilot study may suggest that family members are dealing with negative feelings such as guilt and anger, and the need to discuss these feelings is imperative. Pediatric nurses can be attentive to such negative feelings and offer support by listening to or seeking outside assistance from hospital chaplains, pastors, or counselors. Literature may be provided regarding these services to the family members so that they have this knowledge. Support can be offered by discussing the environment of the unit and methods to communicate if the child is unable to communicate because of ventilation. When children are critically ill, family members may wish to discuss the possibility of death. Because family members' perceptions of bereavement experiences around the death and immediately after the death could affect bereavement outcomes, early detection of unmet needs by nursing staff is an important nursing responsibility.

Families facing death of a pediatric patient are at potential risk for physical and psychological health problems. Although it is unrealistic to expect pediatric nurses to address every aspect of family members' needs when death of a child occurs, stressors associated with bereavement experiences of a child may be reduced if appropriate and timely interventions are provided. Family members require opportunities to talk about the child with hospital staff, understandable explanations, and the opportunity to be present at the time of death if that should occur.

Information

Family members ranked items under subscale information as the second highest mean on the NMI suggesting the need to have information provided about the child. The 8 subscale items under information were as follows: to talk to the doctor every day; to have a specific person to call at the hospital when unable to visit; to have known which staff member could give what type of information; to know what things were done for the patient; to have known the types of staff members taking care of the patient; to have known how the patient was being treated medically; to have known exactly what was

being done to the patient; and to have helped with the patient's physical care. Two information items listed in the top 10 as met were as follows: to know what things were done for the child and to talk to the doctor every day. None of the above items were found in the top 10 needs never met/sometimes met regarding information. Computer and information technology systems have provided a means for the public to receive information immediately, thus producing a more informed society and family members who are more knowledgeable to ask better questions and elicit more information. Because the pediatric units are highly technical areas, nurses and families may be more readily aware of the need to provide information before entering into the PICU. Pediatric nurses must maintain competencies, continuing education credits for licensure, Pediatric Advanced Life Support and Neonatal Life Support certification, as well as certification to operative and interpret data from specific equipment in the PICU.

Proximity

Family members ranked proximity needs as the third highest mean score. The 9 subscale items listed under proximity were as follows: to have visiting hours changed for special conditions; to have visited at any time; to have talked to the same nurse every day; to have visiting hours start on time; to have been told about transfer plans when they were being made; to have been called at home about changes; to have received information once a day; to have seen the patient frequently; and to have the waiting room near the patient. Two items, to have seen the patient frequently and to have the waiting room near the child, were ranked in the top 10 needs always met/usually met. One item, to have talked to the same nurse every day, was ranked in the top 10 items as never met/sometimes met.

Most units are beginning to relax visiting times and allow parents or significant others to remain in the room as much as possible. Frequent visitations have become the norm in many of the PICUs so that the child can remain attached to the family. Families seem to like and enjoy this idea; however, critically ill or immunosuppressed children may not enjoy this luxury as much as others. The idea of talking to the same nurse every day is problematic as nurses tend to work 12-hour shift, earn days off, or may be assigned to other patients to accommodate the workflow and integrity of the unit. A good response to these changes might be for the nurse to introduce the newly assigned nurse to the family members.

Assurance

Family members ranked subscale items on assurance as highest mean of this pilot study. The 7 items listed under assurance were as follows: to have known the prognosis; to have questions answered honestly; to have felt that there is hope; to have been assured that the best care possible was being given; to have been given explanations that were understandable; to have felt that the hospital personnel cared about the family member; and to have known specific facts concerning the patient's progress. Five of the eight items were listed in the top 10 needs always met/usually met that were to have questions answered honestly; to have explanations given that were understandable; to have felt the hospital personnel cared about the child; to know the prognosis; and to have felt that there was hope. None of the items under assurance were listed in the top 10 needs never met/sometimes met. In this pilot study, the pediatric nurses were performing exceptionally well in providing assurance to the families.

Comfort

Families ranked subscale items on comfort as the fourth highest mean with 6 items listed under comfort, which were as follows: to have good food available at the hospital; to have comfortable furniture in the waiting room; to have felt accepted by the hospital staff; to have a telephone near the waiting room; to have been assured that it was alright to leave the hospital; and to have a bathroom near the

waiting room. None of the items were listed in the top 10 needs always met/usually met and only 1 was listed in the 10 needs never met/sometimes met and that was the item regarding having comfortable furniture in the waiting room.

During the busy day of the pediatric intensive care, nurses may not be attuned to the fact that family members need to feel that it is all right to leave the hospital for a while. Reassuring the family members that they can be called if needed may be one way of assisting with this issue. Listening to the family with empathy may be one method of making the family comfortable with the hospital staff. Providing snacks in the waiting room may assist with the long-time notion that hospital food is not very appetizing and also provide food for those who do not have extra money for snacks in this time of economical recession. Although the hospital food may not seem as desirable as eating at home or at a restaurant, many may need this break for a few minutes of time to themselves.

Comfort issues have been addressed more recently in that many waiting rooms have extra phones, more bathrooms, and new and comfortable furniture. Many units have reclining chairs that are suitable for sleeping along with pillows and blankets. All have television sets with remote control access.

In summary, the interesting finding that assurance needs provided the highest mean from the NMI may be attributed to the caring aspect of pediatric nurses who are faced with assisting young lives to return to more optimal levels of functioning. Pediatric nurses tended to provide assurance that the pediatric patients were receiving the best possible care that could be offered. Families desired nurses to explain prognoses, answered questions honestly, instill hope for the best outcomes, and provide assurance that the best possible care was being offered by discussion using understandable terms. Family members hope for the best possible outcome for their young children and desire that positive assurance.

IMPLICATIONS

The goal of this pilot study was to determine whether the NMI could be successfully used to identify family members' perception of needs as always met/usually met and never met/sometimes met on a 4-point Likert scale. Because patient advocacy is the cornerstone of nursing and the family is a major part of pediatric patients care, the pediatric nurses must be aware of and address perceived met and unmet needs of the family members.

Findings from this initial pilot study may be considered a first step in addressing never met/sometimes met needs identified by the family members and provide fertile ground for future studies. The unmet needs may surface as the focus of nursing assessment of patients and family members to perpetuate the idea of total care. Certainly those never met/sometimes met needs may be addressed and plans implemented to assist in meeting those needs. Nurses can continue to provide assurance, information, proximity, comfort, and support, which will ultimately lead to more satisfactory outcomes as family members' participation and decision making regarding the care of their child.

Given the complexity of variables that influence perceived needs as met or unmet, additional research should be conducted to continue to address the use of the NMI with pediatric patients, as well as other diverse units such as pediatric cardiovascular recovery. As nurses more readily identify these unmet needs, family members will become involved in an egalitarian interaction that expands giving and receiving by both nurses and family members.

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Erratum

The Effect of Nurse Champions on Compliance With Keystone Intensive Care Unit Sepsis-Screening Protocol: Erratum

In the article that appeared on page 251 of Vol 31, No. 3, the following acknowledgment was omitted:

The author thanks Dr Morris A. Magnan (formerly of Oakland University) and Dr Mary Ellen Powers (Northern Michigan University) for their expert input for this article, which was submitted in partial fulfillment of the author's doctorate of nursing practice from Oakland University in Rochester, Michigan. The author also thanks Marquette General Health Systems ICU staff nurses for their dedication and State of Michigan Department of Labor and Economic Growth for grant funding.

This error has been noted in the online version of the article, which is available at www.ccnq.com.

Reference

Campbell J. The effect of nurse champions on compliance with keystone intensive care unit sepsis-screening protocol. *Crit Care Nurs Q.* 2008;31(3):251–269.