The psychosocial needs of families during critical illness: comparison of nurses' and family members' perspectives

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KEY WORDS

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ABSTRACT

Objective
To explore the needs of relatives whose family member is unexpectedly admitted to an Intensive Care Unit and compare ranked need statements between family members and nurses.

Design
This is a descriptive study using the Critical Care Family Needs Inventory (CCFNI) to measure, rank and compare a series of need statements.

Setting
An Intensive Care Unit (ICU) in regional Victoria, Australia.

Subjects
A convenience sampling strategy was used to acquire a total of 58 participants; 25 family members of patients unexpectedly admitted to the ICU and 33 nurses.

Results
Comparative analysis of the data revealed that there were minor differences identified in the rank order of the need statements listed in the CCFNI amongst nurses and family members. A comparison with previous studies also identified minor differences in both the rank order of individual need statements and the five factor analysis categories previously established.

Conclusion
The CCFNI continues to be a good diagnostic tool in family needs assessment.

INTRODUCTION

The impact of an admission to an Intensive Care Unit (ICU) is often traumatic for the family members of the patient and may result in a crisis within the family. As these events do not occur regularly, individuals are overwhelmed by their experience of the ICU and often consider this encounter with a negative outcome such as death (Herman 1992). Critical illness frequently occurs without warning, pushing families beyond what is considered the 'normal' realm of coping and leading to the experience of trauma and crisis within the family (Daley 1984).

It is not unusual for each family member to be personally affected by his or her experience of critical care. Their own health and well-being may be affected by their emotional and psychological experiences of the intensive care environment and the impact can be directly related to the amount of support they receive in relation to these needs from staff in ICU.

It has previously been established (Davidson 2009; Hinkle et al 2009; Agard and Harder 2007; Eggenberger and Nelms 2007; Damboise and Cardin 2003; Delva et al 2002; Lee et al 2000; Hickey and Leske 1992; Koller 1991; Macey and Bowman 1991; Coutu-Wakulczyk and Chartier 1990; Forrester et al 1990; Chartier and Coutu-Wakulczyk 1989; Lynn-McHale and Bellinger 1988; O'Neill-Norris and Grove 1986) that families have some basic needs that must be met in order for them to cope better with the admission of their relative to ICU. These needs include (a) information, (b) reassurance, (c) support and (d) the ability to be near the patient (Damboise and Cardin 2003).

Over the years the issue of understanding family needs has received significant research attention in the nursing field, yet some four decades after Molter (1979) initially investigated this topic, the issue of understanding family needs still remains important. There are two dimensions to this: (1) family members' perception of needs when visiting ICU and (2) nurses' perception of family needs. This paper sets out to identify if the perception of family need held by nurses had changed over the years and whether the perception of need was representative of the current needs of family members visiting ICU.

METHOD

Data was collected over six months in a regional Victorian hospital. Family members of patients unexpectedly admitted to the ICU and nurses were interviewed. Unlike previous studies family members faced no restrictions on visiting hours.

Molter (1979) developed the Critical Care Family Needs Inventory (CCFNI) which utilised 45 need-based questions and focused on determining how family members felt about emotional and physical issues and the type of information they required to help them understand the care needs of their relative.

Previous studies have established readability (Macey and Bouman 1991; Gunning Fox Index = 9.0 = ninth grade reading level), reliability (Leske 1991; including internal consistency [Cronbach's (α) Alpha coefficient of 0.90] and test-retest reliability) and overall validity of the CCFNI. In addition, the CCFNI has been deemed as valid, reliable and readable in a number of cross cultural studies (Takman and Severinsson 2006; Lee and Lau 2003; Lee et al 2000; Bijttebier et al 2000; Coutu-Wakulczyk and Chartier 1990).

For the purpose of this study, changes suggested by O'Neil-Norris and Grove (1986) and Macey and Bouman (1991) were made to the CCFNI. In addition, 'To be told the truth even if it is distressing' was added. Previous research indicated that families wanted to 'feel the need for hope' but at the same time, they want questions answered honestly. This additional question was designed to determine if hope would remain a priority in the face of often distressing news.

Relatives of ICU patients were eligible to participate if the patient was unexpectedly admitted to the ICU and had been in ICU for at least 48 hours. For the purposes of the study 'relatives' were defined as those related by blood or marriage or were a friend of the patient, able to read to year nine level and aged over 18 years. There were no restrictions on participation of nurses working in ICU. Self administered information packs including the CCFNI, a Plain Language Statement, Demographic Questionnaire and Consent Form were provided to family members and nursing staff.

Epicalc 2000 version 1.02 (Gilman and Myatt 1998) was used to calculate the difference between two

means, together with a 95% confidence interval, a t-statistic, and p-value. Ethics approval was granted by both the participating hospital Research and Ethics Committee (RAEC) and associated University RAEC.

FINDINGS

Seventy eight percent (25/32) of eligible families participated. There was an uneven gender spread (3 male, 22 females) and the relationship of family participants to the patient included spouses, mothers and friends. The age range of family participants was 34 - 71 years. Academic qualifications of family participants varied from primary school level to a post graduate university degree.

The participation rate for ICU nurses was 69% (33/48). Employment varied between full and part time and experience varied from clinical nurse specialists, associate and unit nurse managers to division one and two nurses. Years of experience in nursing ranged from four to 28 years, whilst experience in ICU nursing ranged from one to 22 years, with the majority of nurses having completed the ICU certificate[1].

Participants were asked to rank each question from the CCFNI on a Likert scale of one not important, two slightly important, three important and four very important. The means, standard deviations and difference of means between the nurses and family for the 43 questions in the CCFNI are shown in Table 1. The comparison of the ranked means is important as it demonstrates the compatibility of ranking in terms of importance across both groups.

[1] The ICU nursing certificate is a post-graduate diploma requiring 12 months intensive study in the area of critical care. There are no specific requirements for enrolling in the diploma, however 12 months experience post graduation is preferred.

Table 1: CCFNI Items, Means and Standard Deviations for Family and Nurses

Question	Family (n=25) Mean [S.D.]*	Nurses (N=33) Mean [S.D.]*	Difference in mean [95% C.I.]^	P Value
To know the expected outcome.	3.84 [.374]	3.64 [.549]	0.20 [-0.06, 0.46]	0.12
To have explanations of the environment before going into the critical care unit for the first time.	3.28 [.678]	3.27[.452]	0.01[-0.29, 0.31]	0.94
To talk to the doctor every day.	3.60 [.645]	3.21[.696]	0.39 [0.03, 0.75]	0.03
To have a specific person to call at the hospital when unable to visit.	3.04 [.978]	2.61 [.659]	0.43 [-0.00, 0.86]	0.05
To have questions answered honestly.	4.00 [.000]	4.00 [.000]	0.00 [0.00, 0.00]	1
To talk about feelings about what has happened.	3.12 [.881]	3.36 [.603]	0.24 [-0.15, 0.63]	0.22
To have good food available at the hospital.	3.16 [.943]	2.48 [.795]	0.68 [0.22, 1.14]	<0.01
To have directions as to what to do at the bedside.	3.00 [.866]	2.97 [.637]	0.03 [-0.37, 0.43]	0.87
To visit at any time.	3.88 [.440]	3.33 [.736]	0.55 [0.22, 0.88]	<0.01
To know which staff members could give what type of information.	3.28 [.792]	2.91 [.914]	0.37 [-0.09, 0.83]	0.11
To have friends nearby for support.	3.20 [.866]	3.21 [.696]	0.01 [-0.40, 0.42]	0.96
To know why things were done for the patient.	3.72 [.542]	3.70 [.467]	0.02 [-0.25, 0.29]	0.88
To feel there is hope.	3.80 [.408]	3.13 [.806]	0.67 [0.32, 1.02]	<0.01
To be told the truth even if it is distressing.	3.68 [.690]	3.82 [.465]	0.14 [-0.16, 0.44]	0.36
To know about the types of staff members taking care of the patient.	2.88 [1.054]	2.67 [.692]	0.21 [-0.25, 0.67]	0.36
To know how the patient is being treated medically.	3.64 [.569]	3.52 [.566]	0.12 [-0.18, 0.42]	0.42
To be assured that the best care possible is being given to the patient.	3.80 [.577]	3.91 [.292]	0.11 [-0.12, 0.34]	0.34
To have a place to be alone while in the hospital.	2.60 [1.118]	2.82 [.882]	0.22 [-0.31, 0.75]	0.4
To know exactly what is being done for the patient.	3.72 [.458]	3.64 [.549]	0.08 [-0.19, 0.35]	0.55
To have comfortable furniture in the waiting room.	2.68 [.802]	2.79 [.600]	0.11 [-0.26, 0.48]	0.55

Table 1: CCFNI Items, Means and Standard Deviations for Family and Nurses, *continued...*

Question	Family (n=25) Mean [S.D.]*	Nurses (N=33) Mean [S.D.]*	Difference in mean [95% C.I.]^	P Value
To feel accepted by hospital staff.	3.60 [.500]	3.21 [.781]	0.39 [0.03, 0.75]	0.03
To have someone to help with financial problems.	2.84 [.898]	3.18 [.769]	0.34 [-0.10, 0.78]	0.12
To have a telephone near the waiting room.	3.00 [.978]	3.27 [.674]	0.27 [-0.16, 0.70]	0.21
To talk about the possibility of death.	3.52 [.918]	3.61 [.556]	0.09 [-0.30, 0.48]	0.64
To have another person with you when visiting the critical care unit.	2.84 [1.068]	2.73 [.876]	0.11 [-0.40, 0.62]	0.66
To have someone be concerned with your health.	2.56 [1.003]	2.88 [.781]	0.32 [-0.15, 0.79]	0.17
To be assured it is alright to leave the hospital for awhile.	2.96 [1.060]	3.42 [.708]	0.46 [-0.01, 0.93]	0.05
To talk to the nurse caring for my relative everyday.	3.68 [.557]	3.61 [.556]	0.07 [-0.23, 0.37]	0.63
To be encouraged to express emotions.	2.68 [.998]	3.12 [.600]	0.44 [0.02, 0.86]	0.04
To have a bathroom near the waiting room.	3.00 [.913]	3.00 [.661]	0.00 [-0.41, 0.41]	1
To be alone at any time.	2.12 [1.013]	2.58 [.936]	0.46 [-0.06, 0.98]	0.07
To be advised of support services who can help with problems.	3.52 [.653]	3.42 [.663]	0.10 [-0.25, 0.45]	0.56
To have explanations given that are understandable.	3.80 [.500]	3.82 [.392]	0.02 [-0.21, 0.25]	0.86
To have visiting hours start on time.	3.13 [1.076]	2.94 [.892]	0.19 [-0.33, 0.71]	0.46
To be told about pastoral services.	2.28 [.936]	2.88 [.857]	0.60 [0.13, 1.07]	0.01
To help with the patient's physical care.	3.24 [.723]	2.64 [.699]	0.60 [0.22, 0.98]	<0.01
To be told about transfer plans while they are being made.	3.60 [.500]	3.27 [.761]	0.33 [-0.02, 0.68]	0.06
To be called at home about changes in the patient's condition.	3.80 [.408]	3.73 [.517]	0.07 [-0.18, 0.32]	0.57
To receive information about the patient at least once a day.	3.64 [.569]	3.70 [.467]	0.06 [-0.21, 0.33]	0.66
To feel that the hospital personnel care about the patient.	3.88 [.332]	3.82 [.392]	0.06 [-0.14, 0.26]	0.54
To know specific facts concerning the patient's progress.	3.88 [.332]	3.64 [.603]	0.24 [-0.03, 0.51]	0.07
To see the patient frequently.	3.84 [.374]	3.48 [.619]	0.36 [0.08, 0.64]	0.01
To have the waiting room near the patient.	3.24 [1.052]	3.30 [.684]	0.06 [-0.40, 0.52]	0.79

*Standard Deviation
^95% Confidence Intervals

Table 2: Five Most important CCFNI Items needs as identified by Family Members and Nurses

Question	Description	FAM Mean	NUR Mean
5	To have questions answered honestly.	4.00	4.00
9	To visit at any time.	3.88	----
40	To feel that the hospital personnel care about the patient.	3.88	3.82
41	To know specific facts concerning the patient's progress.	3.88	----
1	To know the expected outcome.	3.84	----
42	To see the patient frequently.	3.84	----
17	To be assured that the best care possible is being given to the patient.	----	3.91
14	To be told the truth even if it is distressing.	----	3.82
33	To have explanations given that are understandable	----	3.82

The five needs identified as being of the highest importance to nurses and family are shown in Table 2.

Families ranked 77% and nurses ranked 70% of the total need statements either important (3.00) or very important (4.00). The majority of the lower ranked needs by family are those that pertain to family members own personal requirements (see Table 3) and show that families prefer the ICU staffs' attention focused on the patient's care.

Table 3: Five Least Important CCFNI Items Needs as Identified by Family Members and Nurses

Question	Description	FAM Mean	NUR Mean
31	To be alone at any time.	2.12	2.58
35	To be told about pastoral services.	2.28	----
26	To have someone be concerned with your health	2.56	----
20	To have comfortable furniture in the waiting room.	2.68	----
29	To be encouraged to express emotions.	2.68	----
7	To have good food available at the hospital.	----	2.48
4	To have a specific person to call at the hospital when unable to visit.	----	2.61
36	To help with the patient's physical care.	----	2.64
15	To know about the types of staff members taking care of the patient.	----	2.67

Nurses ranked the need 'to help with the patient's physical care' as a less important need than the family (mean dif = 0.60 [95% C.I. 0.22, 0.98], P <0.01). The family have a need, which is identified by nurses 'to have questions answered honestly' (mean dif = 0.00 [95% C.I. 0.00, 0.00] P = 1). Families also need 'to visit the patient at any time' (mean dif = 0.55 [95% C.I. 0.22, 0.88], P<0.01) and 'to know the expected outcome' (mean dif = 0.20 [95% C.I. -0.06, 0.46], P=0.12). Families also ranked the need 'to feel there is hope' as more important than the nurses ranking for this item (mean dif = 0.67 [95% C.I. 0.32, 1.02], P<0.001). The interesting point was the family group did not rank 'to be told the truth even if it is distressing' with as high importance as the nurses, however the difference was not statistically significant (mean dif = 0.14 [95% C.I. -0.16, 0.44], P=0.36).

Previously established factor analysis of the CCFNI produced five clusters of need including the need for information, assurance and anxiety reduction, proximity and accessibility, support and comfort. Demographic data were used to identify subgroups for the nurses and the families. Both 'spouse' and 'parent' groups ranked the factors in the same order as that identified by the full family group.

The nurses group was subdivided based on their experience in nursing and critical care. Nurses, who had less than five years ICU experience were the only subgroup to rank the factors in the same order as the overall nursing group, however the overall nursing group did not rank all of the factors in the same order as the family group. The closest ordering was achieved by nurses with less than five years experience in ICU and nurses with over five years experience in clinical nursing, demonstrating that more years experience does not necessarily result in a greater understanding of family needs.

DISCUSSION

Despite advances in medical technology and the increased inclusion of families in ICU care, the results of our study are similar to the results found in previous studies (Davidson 2009; Hinkle et al 2009; Eggenberger and Nelms 2007; Damboise and Cardin 2003; Delva 2002; Bijttebier 2000; Lopez-Fagin 1995; Davis-Martin 1994; Koller 1991; Macey and Bouman 1991; Coutu-Wakulczyk 1990; Forrester 1990; Chartier 1989; Lynn-McHale 1988; Leske 1986; O'Neill-Norris 1986; Daley 1984; Molter 1979). Breakdown of family needs into categories illustrate

a change over time, however, from an emphasis on the need 'to feel there is hope' to a need 'to have questions answered honestly'. This may be attributed to the change in family participation in the ICU environment, resulting in the family being more aware of the expected outcomes for the patient. Families are also able to monitor more closely the care provided to the patient, which increases understanding of the patient's treatment and prognosis. This supports the previously established need for information. It reinforces the need to provide family members with up to date and accurate information relating to the patient at regular times.

Other studies (Leske 1986; O'Neill-Norris and Grove, 1986; Molter 1979) which highlight the family's need 'to feel that the hospital personnel care about the patient' and 'to know the expected outcomes' show similar findings to the current study. Both of these needs we would expect to remain constant over time given the nature of the critical care environment. The family members also ranked 'to have the waiting room near the patient' and 'to be called at home about changes in the patient's condition' lower than those from previous studies, again highlighting more recent changes in family visiting policies.

Given the current interactive role between nurses and family members, nurses often explain procedures to the family as they are carrying them out. Subsequently the previously identified need 'to know why things were done for the patient' has reduced in its importance. A simple brochure written in terms that family members can understand could address a lot of the needs assessed as important in the current and previous literature. An overview of the ICU and what can be expected when a family member is admitted including contact details for the unit can provide a valuable resource for family members to reflect on as they often do not take in all the information initially provided and are often too overwhelmed to ask for clarification. Providing people with permission to ask questions frequently, to assist with basic patient care and to visit or contact the unit at any time can assist nursing staff with meeting a significant amount of family members needs.

There are two limitations of this study. First, the number of participants in our study is smaller than some of the other studies and second, all of the participants were sourced from the same hospital which may limit the generalisability of these results. These are minor limitations and the results of this study provide contemporary support to previous work. Whilst this study may be seen as a replication it is important that instruments such as the CCFNI are evaluated from time to time to ensure they maintain relevance. This study highlights the fact that the CCFNI continues to be a good diagnostic tool in family needs assessment in the intensive care environment.

CONCLUSION

This study focused on replicating previous studies (Daley 1984; Molter 1979) using the CCFNI with the results illustrating only minor changes in the ranking order of needs of family members and nurses between 1979 and 2003. However, our results did show a significant change for families from the need 'to feel there is hope' to a need 'to have questions answered honestly'. This supports the use of the CCFNI as a valid research tool with current participants. It further highlights the importance of the need for information provision and communication between family members and ICU staff. The use of a brochure encouraging family participation and providing contact details for key ICU staff and a brief description of their role will be a valuable resource for family members to reflect on during the relatives' ICU admission.

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