ORIGINAL ARTICLE

Family Needs in Intensive Care Unit: Study in East Java, Indonesia (Mix-Methods)

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ABSTRACT

Background: Patient care in the Intensive Care Unit (ICU), not only impact on patients but also affect the families. Waiting for patients who are being treated, especially in ICU, is a mandatory culture for the people of Indonesia, especially in East Java, which is predominantly inhabited by Madurese and Javanese people who have a high level of kinship.

Aim: To explore the Family Needs of Patients in ICU with the characteristics of a high kinship relationship.

Study Design: a Mix-Method approach, which is quantitative and qualitative. The study was conducted at 5 ICU hospitals in East Java, with the majority of patients coming from Madurese and Javanese.

Results: Results of this study indicate that the essential need perceived family is the assurance (mean±SD 3.43±0.26), followed by information needs (mean±SD=3.35±0.30), proximity (mean±SD 3.12±0.51), family support (mean±SD 3.01±0.39) and the least important was comfort (mean±SD 2.88±0.41). The study also found new family needs; these are spiritual needs and the involvement of patient care in the ICU.

Conclusion: Family needs listed from the most important are the needs of assurance, followed by the information needs, proximity, family support, and the least important is comfort. The study also concluded that there was a new theme that could be added in the CCFNI domain, namely spiritual needs

Keywords: Family needs, ICU, community bounding, spiritual, CCFNI

INTRODUCTION

Patient care in the Intensive Care Unit (ICU) not only has an impact on patients but also on the families who care for them (Fortunatti, 2014). Critical conditions and erratic conditions of patients can increase family stress levels and cause symptoms of depression, stress, and decreased quality of life (Cameron et al., 2016; Mendonca & Warren, 1998). This condition can reduce the vital role of the family as a source of support and decision-maker (Al-Mutair, Plummer, O'Brien, & Clerehan, 2013).

These problems can get worse with limited family visiting hours in the ICU due to family interaction is limited. Flexible ICU visiting hours have the potential to reduce delirium and anxiety symptoms among patients and to improve family members' satisfaction (Junior et al., 2018). Each hospital has a different ICU visiting room visit policy, but the majority of ICU policies have a limiting visit time policy. For example, in hospitals in France, visiting hours vary in 263 ICU rooms with 34 ICUs without visiting hours, 218 ICU have limited visiting hours (<4 hours a day), and only 11 have flexible visiting hours (Soury-Lavergne et al. 2011). The majority of ICU policies in Indonesia impose restrictions on visiting hours, including in the research hospitals. Generally, the patient's family waits in the waiting room near the ICU that can enter during visiting hours with limited time or only see patients from the windows opened during visiting hours. These restrictions can cause family needs to be close to family members may be unfulfilled.

As a country with a large population, Indonesia has 500 ethnic groups with the largest ethnic group, namely the Javanese ethnic group, including in East Java (Melalatoa, 1995). Besides the Javanese, the Maduranese is the other largest tribe in East Java. The two tribes have similarities because they have a high attachment or kinship among their members. Javanese society has the characteristics of a collectivist culture that prioritizes harmonious relations between community members and prioritizes meeting the desires of others (Wijayanti & Nurwianti, 2011). Our preliminary study revealed that this aspect of closeness is reflected in the culture of the community while waiting for families treated at the ICU, where many family members stay overnight in the hospital waiting room to wait for their family. The presence of a family in the ICU is crucial because the family acts as part of the support system and decision-maker (Koukouli, Lambraki, Sigala, Alevizaki, & Stavropoulou, 2018).

The family needs of patients in the ICU is essential because it can give the necessary information in providing comprehensive nursing care, increasing satisfaction, and increasing the ability of families in decision making. When the family needs met, the family will be able to carry out their role and avoid the adverse effects of hospitalization of patients in the ICU (Dorris & Warren, 1998; Molter, 1979; Nolen & Warren, 2014). This study aims to identify the family needs of patients treated at ICU in Indonesia, especially in the East Java region, using the Indonesian version of the Critical Care Family Needs Inventory Instrument (CCFNI).

METHODS

This research was a descriptive study with a mixed-method type convergent design approach that is the collection and analysis of quantitative and qualitative data carried out simultaneously, then followed by integrated data analysis (Creswell, 2014). The study conducted at five hospitals in the East Java region of Indonesia that had intensive units from September to December 2018 that had passed the ethical test by the Medical Research Ethics Commission of

the Faculty of Dentistry, University of Jember No. 228 / UN25.8 / KEPK / DL / 2019.

The population of this study is the entire family of ICU patients in five hospitals in the East Java region of Indonesia. Quantitative study samples calculated using the G * power program, and 219 patients' families were obtained by convenience sampling technique by giving questionnaires to each respondent met the criteria. The inclusion criteria set are: families who have been waiting for patients for at least 18 hours of treatment, can read and write in Bahasa Indonesia. Qualitative data were obtained from 10 informants taken by purposive sampling technique at the five hospitals.

Quantitative data gained using the Indonesian version of the Critical Care Family Needs Inventory (CCFNI) instrument with 36 question items adapted from the original CCFNI Questionnaire from Molter (1979) and Leske (19) consisting of 45 question items (Wantiyah, A'la, Setioputro, & Siswoyo, 2018). The Indonesian version of the CCFNI questionnaire is the result of modification and adjustment to the Indonesian culture. It has been tested for validity with a CVI value of 0.87 to 0.93 and a reliability test with an alpha Cronbach value of 0.97 (Wantiyah et al., 2018). The Indonesian version of the CCVNI questionnaire consisted of 36 questions covering five domains with a Likert scale 1-4 (from not important (1) to very important (4), i.e., proximity (4 statements, score: 4-16), assurance (9 statements with score 9-36), support (9 statements with a score of 9-36), information (10 statements with a score of 10-40), and comfort (4, statement, score: 4-16).

Qualitative data was obtained by conducting in-depth structured interviews based on interview guidelines consisting of 10 open-ended questions developed from 5 domains of family needs, according to CCFNI.

Data analysis divided into three stages: a) quantitative data analysis with univariate analysis, b) qualitative data analysis with content analysis approaches, and c) integration of quantitative and qualitative data with joint displays approach (Fetters, Curry, & Creswell, 2013).

RESULTS

Quantitative results

Demographic: The results of the study regarding the demographic characteristics of the respondents showed in table 1 below. Table 1 showed that the majority of respondents were female (63.5%), with the highest level of education being Senior High School (SMA) which was 36.5%, with the majority of adults over, ranging from 26-35 years (26, 9%), the most ethnic Javanese and Madurese were 98.6%, with the majority Muslim religion.

Family Needs: Table 2 illustrates family needs, obtained an average value of 115.59 (±SD11.69). The most important need is the assurance (3.42±0.26), and the least important is comfort (3.21±1.87).

Table 3 shows the ten needs of the family that is considered the most important and the least important. Having the hope of healing included in the guarantee needs is the most important need (mean±SD: 3.86±0.38), while the need to be allowed to pour out feelings or cry (comfort domain) is considered the least important (mean±SD: 2.07±0.83).

Qualitative Results: Data on the characteristics of the participants in Table 4 shows that the majority of women are in the age range of 27-59 years, the majority is Muslim, have primary and secondary education levels and work as housewives.

This study produced seven themes, consisting of five themes according to the family needs domain according to CCFNI and two new themes, namely spiritual and involvement in patient care (Table 5).

Integrative results: The integration of qualitative and quantitative data analysis using the Joint Displays approach is presented.

Table 1. Demographic information of the study participants for quantitative phase

Characteristics	n	%age
Gender		
Male	80	36,5
Female	139	63,5
Education		
No Education	8	3,7
Elementary School	46	21,0
Junior High School	38	17,4
Senior High School	80	36,5
University	47	21,5
Age (year)		
17-25	38	17,4
26-35	59	26,9
36-45	58	26,5
46-55	42	19,2
56-65	20	9,1
>65	2	0,9
Tribe		
Javanese	89	40,6
Maduranese	127	58,0
Chinese	3	1,4
Agama		
Islam	219	96,3
Christianity	6	2,7
Catholic	2	0,9
Waiting time (hours)		
18	30	13,7
24	116	53,0
48	18	8,2
≥72	55	25,1
Profession		
Do not work	99	45,2
Farmer	45	20,55
Civil servants	16	7,31
Private Sector	59	26,94

Table 2: Critical Care Family Needs (n: 219)

Domain	Mean (±SD)*	Sum of mean (±SD)
Assurance (9-36)	3,43 (± 0,26)	30,93 (±2,96)
Information Needs (10-40)	3,35 (±0,30)	33,54 (±3,67)
Proximity (4-16)	3,12 (±0,51)	12,47 (±2,21)
Family Support (9-36)	3,01 (± 0,39)	27,10 (±3,83)
Convenience (4-16)	2,88 (± 0,41)	11,55 (±1,98)
Total (36-144)	3,21 (± 1,87)	115,59 (11,69)

*note: range 1-4

Table 3: Ranking of family needs from the most important to the least important

Rank	No of item CCFNI	Pernyataan	Domain	Mean ±SD*
Most Important Family Needs				
1		Have hope for the patient's recovery	Assurance	**3,86 (**±0,38)
2	13	Obtaining assurance that patients get good care	Assurance	3,73 (±0,35)
3	34	Know the actual condition of the patient	Information	3,72 (±0,45)
4	31	Contact the family if there is a change in the patient's condition	Information	3,55 (±0,50)
5	32	Get information about the patient's condition at least once a day	Information	3,50 (±0,50)
6	12	Knowing how patients get treatment	Information	3,46 (±0,58)
7	9	Get support between families	Family Support	3,45 (±0,60)
8	1	Know the treatment goals and treatment actions provided	Assurance	3,43 (±0,60)
9	21	Get a guarantee from your healthcare provider that everything will be fine when you leave the hospital for a while	Assurance	3,43 (±0,57)
10	36	A waiting room is available near the intensive room	Convenience	3,39 (±0,59)
Unimportant Family Needs				
1	23	Allowed to cry	Convenience	**2,07 (**±0,83)
2	29	Discuss spiritual needs with religious leaders (eg clergy or priests)	Family Support	2,61 (±0,80)
3	24	Discuss with others about the problem at hand	Family Support	2,72 (±0,80)
4	17	Provided religious leaders (for example: kyai / priest) to assist	Family Support	2,85 (±0,82)
5	6	Can express every feeling that is felt	Convenience	2,96 (±0,75)
6	19	Visiting the patient in the intensive care unit (ICU / ICCU) with one of the relatives	Proximity	3,00 (±0,66)
7	4	There are health workers who can be contacted, when there are no families waiting at the hospital	Assurance	3,11(±0,69)
8	11	Knowing the hospital staff who care for the patients	Information	3,14(±0,53)
9	8	Knowing which hospital staff can provide information	Information	3,15 (±0,59)
10	2	Get an explanation of the situation / conditions in the intensive care room before entering ICU / ICCU for the first time	Information	3,18 (±0,71)

Table 4: Themes and Sub Concepts

Tema	Sub Concepts
Assurance	Caring of ICU Staffs to Patients and families
	Families Feel Unsafe
	Payments Made By Family
Information	Family Hope
	How to submit information
	How to get information
	Resources of information
	Time to Get Information
	The Importance of Information
	Family Perception
Proximity	Family Hope
	Family Perception
	Family Response to ICU Regulations
	Family barriers to being close to patients
	Ways To Be Close To Patients
Family Support	Family support
	Sources of Support
	Form of Support Obtained
	Meaning of Support for the Family
Convenience	Interaction with ICU Staffs
	Toilet facilities
	Lack of Facilities for Family Needs
	Things a family feels when waiting
	Family Hope
Spiritual	Needs a place of worship in waiting room
	Pray

Table 5

Domain	Mean (±SD)*	Pernyataan
Assurance	3,43 (±0,26)	*".. that support is more important for me than a doctor or nurse because he knows more about the condition of the patient, not the family."* (P.6; P.7) *"... Take full care of the nurses and pay full attention to the nurses and you can rest ...."* (P.8) *"... we always think negatively if anything happens ... because we are responsible for it ...we feel worried because the curtain is always closed."* (P.6) *"Wow, if my mom is inside, but I am outside, it makes me insecure.."* (P.6) *"On the other hand, it's a benefit for the patient, because they are fully cared for, and the nurses are fully cared for as well as the nurses and my dad can rest ..."* (P.8)
Information	3,35 (±0,30)	*"..it's important because I have to know the details of my family's health status.."* (P.6) *"...because I want to know the true information of the patient.."* (P.5) *" I want that ... the right of the patient's family to know the condition of the patient like how… " (P.8)*
Proximity	3,12 (±0,51)	*"..I want to be able to come in at any time to visit.."* (P.4) *"If I wait for my father here, I just want to be allowed to enter at any time, that's it… "* (P.4) *"... I want to accompany me here at any time allowed to enter, maybe 2 hours. I want to be close to the patient ..."* (P.4) *" I want to accompany the patient inside so as not alone, and I feel sorry if alone in the "* (P.7) *".. limited time makes us uncomfortable to be close to patients.."* (P.6) *"I always pray for patients all the time and I still in the hospital to stay close"* (P.8) *"as much as possible, I stay here whenever the nurse calls me, so I can immediately come in a quick way whatever is needed fastly right "* (P.8)
Family Support	3,01 (± 0,39)	*"Support from my siblings from my children from the family that I always get" (P.8; P.5; P.6)* *"The biggest support from the family is asking how my father is, and they support through prayer, they pray for my father" (P.8)* *".. there must be friends chatting. if there are no friends, the atmosphere becomes saturated .." (P.3)* *"... in my opinion, support and prayer are important to me ..." (P.5)* *"Because the most important support is the support of those closest to you" (P.5)*
Convenience	2,88 (± 0,41)	*"... it's comfortable, and the nurse is not snapping ..." (P.1)* *"In the waiting room, there is no room for prayer ..." (P.6)* *"I was silent in this waiting room which was okay, it was very comfortable, as long as the patient was well cared for" (P.1)* *"... I feel uncomfortable because there is no bathroom ..." (P.6)*
Spirituality		"*I think prayer is important because I believe it can help my mother to be recovered*" (P.6) "*I usually pray for make me feel comfort and peace*" (P.1) "*I never forget to pray because God gave my father's illness and if I leave god, it might make my father getting worst*" (P.8)

DISCUSSION

Family needs in intensive care are often the lowest priority in patient care in the intensive care room because care is more focused on patients who are in critical condition and require close monitoring (Dorris & Warren, 1998). Patients' family members are personally affected by the experience of nurses in doing critical care. Each family member's health and well-being may be affected by whether his or her needs are met and by the actions of the health care team (Davidson, 2009).

Assurance: Previous studies regarding the family needs of patients in the ICU place collateral as the priority need (Al-Mutair et al., 2013; Dharmalingam, Kamaluddin, & Hassan, 2016; Fortunatti & Felipe, 2014; Jacob et al., 2016; Munyiginya & Brysiewicz, 2014; Ozbayir, Tasdemir, & Ozseker, 2014; Saputra & Utami, 2015). In this research, the need for hope of healing is the most important of the ten aspects of guarantee needs so that the family needs to strengthen the belief that the family members who are sick get the best quality of care.

"... we always think negatively if anything happens ... because we are responsible for it ..." (P.6)

"... Take full care of the nurses and pay full attention to the nurses and you can rest ...." (P.8)

The hope of healing the patient is shown by the family with psychological responses such as anxiety, worry, and fear, as expressed by participants.

"... in this ICU, I was worried that I was afraid of something happening, so I was worried ..." (P.6)

Needs have hope for healing patients included in the five items of guarantee needs on the list of the ten most important needs (Bandari et al. (2015). Most of the problems faced by families are a sense of uncertainty that causes a high demand for collateral. These uncertainties lead to the response of family anxiety to the patient's health status (Liew et al. (2018).

The need for aspects of collateral that is felt to be the least important is knowing health workers who can be contacted when no family is waiting at the hospital. Most loyal families wait for patients and do not leave the hospital until the patient returns or moves room.

"... stay here whenever the nurse calls me can immediately come quickly whatever is needed so I can be fast too right" (P.8)

Information: The need for information describes the family's need to obtain information about the patient's condition and get the answers needed when the family wants to know the patient's condition (Damghi et al., 2008; Liew et al., 2018). In this study, information needs become the second priority requirement with the highest item, namely the need to know the actual condition of the patient. The family wants to get detailed information in every situation that occurs in patients in the ICU because the family cannot see the patient's condition directly

"... it's important that you have to know the details of the family, the health of the patient must know the details ..." (P.6; P.8)
"... because I want to know the actual state of the patient ..." (P.6)

The importance of information for families by the culture of Indonesian society with Javanese majority ethnic groups who have a caring attitude and care for others (Wijayanti & Nurwianti, 2011). Al-Mutair et al., 2014; Fortunatti & Felipe, 2014 place information as a priority after the need for assurance aspects, while Jacob et al. (2016) place information needs on the actual condition of patients as the most important needs.

Proximity Need: The need for closeness is included in the three highest priorities. Families always want to be close to patients and can continue to monitor the development of their loved ones. The desire of families to close with the patients encourages them to stay in the hospital patiently.
"..... I will never be far away" ".... as much as possible I stay here whenever the nurse calls me can immediately come quickly whatever is needed papi I can be fast too right " (P.8)

In Indonesia as a country with strong family bonds, being involved in caring for a family member during illness is part of the Indonesian culture (Effendy, Vernooij-Dassen, et al., 2015; Effendy, Vissers, Tejawinata, Vernooij-Dassen, & Engels, 2015; Goodwin & Giles, 2003). Such a strong family bond implies that family members protect each other and demand and provide loyalty throughout life (Goodwin & Giles, 2003). in addition to strong ties, Indonesian society has high kinship characteristics, characterized by the desire to always get together with their social environment, especially family members (Wijayanti & Nurwianti, 2011).
The need for closeness increases because of the limitation of visiting hours, even though the family is aware that the visiting clock rules are for the good of the patient.
"... on the other hand, it is a benefit for the sufferer because they are fully cared for by the nurses, and the nurses are fully cared for and can rest ..." (P.8)

Closeness with patients can make a family calm, even though they can only see patients briefly (McKiernan & McCarthy, 2010).

Family Support: In ICU, the family needs support for themselves to cope with these problems. The priority support needs are support among family members.
"*Because of the most important support of the people closest*" (P.5)
"*The support from my siblings from my children from my family is certain*" (P8; P5; P6)

The need for support is based on the existence of Javanese culture that feels itself is not an alliance of individuals, but rather a unity of form "one for all and all for one" (Herusatoto, 2008). The proverbial "*mangan ora mangan sing penting kumpul*" which reflects culture, always wants to get together with their social environment (Melalatoa, 1995). Based on the strength of the characters and virtues that stand out in the Javanese, it can be said that the Javanese are a tribe that likes to gather and live in a society based on an attitude of fairness, cooperation, and sharing (Wijayanti & Nurwianti, 2011).

Other sources of support needed are from nurses and doctors:
"Yes, once, the young nurse said it wasn't time yet to realize, mom ... so patient .." (P.10)
"... that support is more important to me than a doctor or nurse ..." (P.10)

Other sources of support come from nursing staff through effective communication and interpersonal relationships that can provide emotional support (McKiernan & McCarthy, 2010).

The aspect of support that is not a priority is support from other parties, namely religious leaders. The family is more comfortable to accompany the patient directly through the doá approach because mentoring by clergy indicates that the patient's condition is deteriorating and will die.

Convenience: The need for comfort is a need that is felt to be the least important. Comfort is not a priority, so families do not pay attention to their personal needs because they are more focused on healing and handling patients
"*In this waiting room, it's okay like this ... yes, it's nice if the waiting room ... it's already comfortable"* (P.1, P.3, P.6). "
"... as long as the patient is managed "(P.1)

Indonesia, especially Java, has a "nrimo" culture and a collectivist culture that prioritizes meeting the wants/needs of others (Melalatoa, 1995; Wijayanti & Nurwianti, 2011). Azoulay et al., (2001), as relatives were more concerned about the patient's condition as opposed to their own needs. Other studies also find comfort to be the least important or not a priority (E. Azoulay et al., 2001; Cameron et al., 2016; Jacob et al., 2016).

The characteristics of the patient's family in this study indicate that some or 5 out of 10 partisans have low education, namely not in school and primary education, so the family is not demanding. Research by Damghi et al. (2008) shows that families with low levels of education do not require and accept what they are.

Even though the family conveyed that the comfort aspect was less important, the waiting room availability item was the most important thing, and the item allowed to cry was the least important item from the comfort aspect. Families assume that improving hospital facilities can certainly improve family comforts, such as adequate waiting rooms with facilities for places of worship, bathrooms, and toilets.
"... it's uncomfortable, so there's no bathroom ..." (P.3; P.7; P.9)
"*There is no room in the waiting room for worship for prayer ..."* (P.6)

Meneguin et al. (2018) state that there is no direct relationship between comfort and the family needs of patients.

Spiritual Need: This research found a new aspect that was explored qualitatively and was felt important for families in Indonesia, namely the spiritual needs that do not yet exist in the CCFNI instrument. Families convey the very important thing when waiting for patients in the ICU is to pray and the need for additional facilities for religious activities, because it can help the patient's recovery and make the family calm.
"*I consider prayer important because I believe it can help to heal umi*" (P.6)
"*Every day, I recite the Koran for healing umi, so I assume that the progress of healing Umi comes from Allah ..."* (P.6)

"*If my worship never leaves, yes, because the papi's disease comes from God, so I am afraid that if I leave God, my condition will get worse*" (P.8)
"*If I pray it will be cool then*" (P.1)

The characteristics of Indonesia, with the majority of Muslims, are known as religious communities and have high spiritual needs. Indonesia is a country that is based on its constitution on law and influenced by religious values. Moreover, considering that most people have a religion, some expressions and manifestations of religiosity and spirituality should appear in their daily practices. (Vigar, Himawan, & Pearls, 2016).

The characteristics of the participants, mostly Madurese, are known as religious communities. Madura has been widely recognized as part of the diversity of Indonesian Muslims. They hold fast to the traditions or teachings of Islam in slapping the reality of their social and cultural life (Adib, 2009) in (Rahmasari, Jannah, & Puspitadewi, 2014).

Religiosity represented the source of power that came through comfort, hope, and meaningfulness (Koenig, 2009). They are essential tools used when coping with life's stresses and illness (Cole and Pargament, 1999; Dein and Stygal 1997) (Naewbood, Sorajjakool, & Triamchaisri, 2012). Koenig explained that religiosity represented the source of power that came through comfort, hope, and meaningfulness (Koenig, 2009). Gall, Kristjansson, Charbonneau, & Florack (2009) concluded that spirituality and religiosity gave individual guidance on how to behave and assess a situation, what action should be taken, as well as decide what coping strategy would be used to address the situation.

The findings of this study have similarities of the needs identified and showed consistent results with studies done in the west (Azoulay, 2001; Leske, 2002; Sturdivant & Warren, 2009) and those in Taiwan (Liaw, Chen, & Yin, 2004). The top priority for the needs of assessment varies with different groups of population and background. Still, the findings are consistent with other previous studies indicating the requirements of assurance, proximity, and information subscales. Consistently through the role of nurses in meeting those needs remain a critical factor, and nurses need to continuously identify strategies to best meet the needs of family members in times of crisis (Hashim & Hussin, 2012).

CONCLUSION

Family needs listed from the most important are the needs of assurance, followed by the information needs, proximity, family support, and the least important is comfort. The study also concluded that there was a new theme that could be added in the CCFNI domain, namely spiritual needs. Therefore, even though the CCFNI questionnaire had been adapted to Indonesian culture, it still needed to be developed.

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