Communication Needs of Family Members with a Relative in Intensive Care Unit

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Abstract

The communication needs of family members with a relative in the ICU, is one of the top priority in Malaysia. 7his study identißed the top ßwe needs of family members; prioritise those needs and who met those needs. A questionnaire was distributed to lOO participants. 7he ßndings concur with earlier studies where family members placed hope and trusts on the health care givers as top priority. An important outcome of this study is the importance of good communication skills for nurses to relay information needs of family members with a critically ill person in the ICU.

Keywords: family needs, information needs, communication

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1.0 Introduction

Needs of the family with a relative in an Intensive Care Unit (ICU) has always posed a challenge to healthcare workers especially nurses and doctors. This is because the family members relied heavily on the healthcare workers for information on the patient's condition and progress as the patient himself/herself was not able to communicate or receive any communication from the healthcare workers as well as the family members due to their medical condition. This in turn created a feeling of helplessness for the family members as they have no idea what the patient felt or would like to be done to them. The family members have other concerns associated with this as well, especially for the very close relatives like spouse, parent or sibling who spent most of the time at the ICU where the patient is cared. The gravity of the illness as well as the physical condition of the patient which most times have been rendered critical due to sedations or medications prevented any direct communication of the patient to those surrounding him/her.

Many studies have reported the lack of support by healthcare professionals when dealing with family members who has a relative in the ICU. One such landmark studμ was bμ Molter who in 1979 identified the family needs according to priorities by conducting a survey using a questionnaire with 45 items listed as needs of family members. This questionnaire has since been a guiding instrument for further studies of family members' needs in the ICU.

In Malaysia, there have been very little studies that particularly looked into the needs of the family. An unpublished study in 2007 (Faridah), looked at the communication needs of family members as well as those of the healthcare providers. In this studμ, familμ members have identified the lack of communication by healthcare providers especially nurses as important aspect to be improved as their concern for the patient's condition need to be communicated as frequent as possible. Need of communication has been identified as one of the most important prioritμ in the needs assessment studies by Molter (1979), Leske (1986) and Azoulay (2001).

This small study at a teaching hospital in the northern region of Malaysia was conducted to identify the needs of the family members and whether those needs identified were similar to those needs identified in other studies. The findin%s maμ be used as a basis for further improvement for the nurses in ICU of this hospital when attending to family members of critically ill patients and assist them to cope with the anxiety and distress faced by them.

Objectives of the study

There were 3 objectives of the study. One was to identify the needs of family members having a relative in the ICU, second was to prioritize those needs and thirdly was to identify the person/caregiver who met the needs of the family members.

2.0 Literature Review

Family members with a relative in the Intensive Care Unit (ICU) faced a crisis period due to

the stress and anxiety invoked by the admission to this unit known for its high mortality rate. Admission to the ICU is mostly unplanned and the patients were almost always deemed to be in a critical condition. Many studies in Western societies (Azoulay, 2001; Leske, 2002; Rose, 1995) have acknowledged the importance of healthcare givers providing adequate support to family members and identifying their needs in times of crisis, in order to ease the effects of the crisis to family members. A landmark studμ &Molter, 1979) identified needs of relatives in five different subscales and amon% the common needs identified was the need to have hope. This was followed by the need to be given adequate and honest information of the patient and for staff to show concern for the patients.

While there were many reported studies conducted in the Western societies, there were very few reported studies conducted by the Asian countries especially Malaysia. In most of the subcscale needs by Molter &1979) communication was essential in meetin% the needs identified. Faridah &2--7) reported the relatives' identified communication needs as verμ important especially by nurses as they believed nurses were instrumental in the care of the patients and were able to give accurate information on the patient's condition. They were disappointed that very few nurses do communicate and referred them to the doctors whom they said were not available most of the time and appointments be made prior seeing them.

It is important for nurses to meet the needs of family members as they were advocators for the patients who were unable to decide on the care

%iven their critical condition. Satisfied familμ members %ives support to the care intervention of the patient and helped improved patient outcomes (Miracle, 2006). Nurse were on hand to provide the important needs via good communication and communication should be voluntarily provided as most times family members were uncertain what to asked (Faridah, 2007). Having family members together for a family conference to provide patient feedback allowed staff to respond to questions raised and other family members getting similar information form one source (Davidson, 2009; Miracle, 2--6). The setback would be the difficultμ of %ettin% the numbers of family members as each would have responsibilities and visited different times, unless for decision on critical issues like surgery or impending death.

Visiting hours and designated waiting rooms were important for family members who waited vigilantly for the sick relative and open visitation has been made an option in many hospitals, while some remain rigid with visitation hours (Faridah 2007). In this study (Faridah, 2007), family members from a hospital that adhered strictly to visiting hours informed that what they need was to be able to have a few moments every hour or so to check the patient was alright and it pained them when they were not permitted once the visiting hours over, particularly the evening visiting hours the day before. Waiting rooms with basic café amenities were not deemed to be important (Faridah, 2007) but it helped and some family appreciate information on community services and resource centers (Chui & Chan, 2007)members.

Regardless of the educational level (Chui & Chan, 2007) family members need time with the patient to be able to adjust to the sudden critical situation (Azoulay, 2001).

Family members who stayed vigilant by the bedside of their loved ones in the ICU were subjected to a lot of stress and psychological crisis. Relatives with lower educational ability reportedly experienced higher stress (Chui & Chan, 2007).

3.0 Methodology

This is a descriptive study and the setting was an ICU in a teaching hospital in the northern region of Malaysia. The ICU has a bed capacity of 12. The samples recruited for the study were family members who have a relative patient admitted to the ICU. They were altogether 110 family members from 45 ICU patients were approached and invited to participate. Five family members declined citing tiredness and unable to concentrate in answering the questionnaires. Data were collected for a period of 2 months from February 2010 till April 2010.

There were more than one relatives of a patient who participated. The inclusion criteria included age of 18 years and above; marriage and 'blood' related to the patient either spouse, sibling or parent; has visited the patient within 36-48 hours of admission; able to read and write and available for

All the family members who participated were asked to answer a set of needs assessment questionnaires adopted from (Molter & Leske, 1983; Warren, 1993) with permission for use. The questionnaires were prepared bilingual in the English and Malay language version. The translation into the Malay language was done by an interpreter and both versions were made available during data collection.

There were two parts to the questionnaire, part A contained 10 demographic data questions which includes - the age, gender, relationship to patient, frequency of visit and the perception of severity of illness.Part B has 44 item questions which has 3 types of responses for the Critical Care Family Needs Inventory (CCFNI), Needs Met Index (NMI) and identifying the person who met the needs. For the CCFNI and NMI, the participant has to answer using a Likert scale of 1- 4, with 4 being very important and 1- not important. For the person who met the needs, there were 6 categories listed and the participant has to tick the relevant answer. Altogether there were 5 needs subscale identified for the CCFNI and NMI. Theμ were information needs, comfort needs, proximity needs, assurance needs and support needs.

A pilot studμ was conducted and there was no si%nificant amendment required. The estimated time required for a family member to answer all the questions were between 30 minutes to 45 minutes.

All the questionnaires were administered by the researcher when the relatives were waiting along the corridors leading to the ICU before visiting hours. Relatives who agreed to participate were given explanation on the studμ aims and theμ were asked to si%n a consent statin% the confidentialitμ of the information revealed and that it was used for research purposes only. They were informed that should they wish to withdraw as a participant they may do so without being penalized. Also the participation is voluntary.

The data were collected between 0900hours to 2000 hours and each participant need to answer the question with the researcher present. Any questions that required clarification were attended bμ the researcher. No questionnaires were allowed to be taken home. This ensures 100% return of the answered questionnaires. The researcher applied and received ethical permission from the University as well as from the director of the hospital.

4.0 Results

All the questions of part A and part B were computed and descriptive statistics like mean and standard deviation were used to describe the findin%s.

From the 100 participants who consented for the study, the demo%raphic profile included 65 female and S5 male. The participants' a%e ranged from 18 to 79 years with majority between 50-59 years. Thirty (30%) of the participants were spouse and 50(50%) were parents, while 6(6%) were child of patient and 14(14%) sibling. All the participants relative were diagnosed as critically ill and their age ranges from 14- 82 years.

There were 39 family members who had previous experience of having a relative admitted to the ICU and another 61 family members do not have previous experience.

Part B of the questionnaire compute the needs analysis from 5 subscale categories namely - information needs, comfort needs, proximity needs, assurance needs and support needs.

For information needs, there were 8 questions; comfort needs -7 questions, proximity needs – 7 questions, assurance needs – 11 questions and support needs – 11 questions which totaled 44 questions. Each question was numbered from 1-44.

From the 5 subscale needs of the 44 questions, the writer ranked the 5 most important needs as identified bμ the participants. Out of the 5 top needs identified, there were S needs from assurance subscale and 2 proximitμ subscales. The table below summarizes the findin%s.

Table 1

No	Type of subscale needs	Questions	Likert scale value	
			Important (3)	Very important (4)
1	Assurance	To know the expected outcome	10	90
2	Proximity	To be called at home abo changes in patient's condition	27	73
3	Assurance	To have questions answered honestly	33	67
4	Assurance	To feel there is hope	33	67
5	Proximity	Tosee the patient frequently	37	63

As for the NMI, the writer identified the top five needs met based on the Likert scale value of 3 and 4. The needs met were from a mixture of information, proximity and assurance subscales. There were 2 NMI from the information subscales. The table below summarises the NMI met.

Table 2

No	Type of subscale needs	Needs Met Index Questions	Likert scale value	
			Important (3)	Very important (4
1	Information	To have specific person to call at the hospit when unable to visit	4	96
2	Assurance	To have questions answered honestly	5	95
3	Information	To know about the types of staff members takin care of the patient	7	93
4	Proximity	To receive information about the patient a least once a day	10	90
5	Comfort	To be assured it is alright to leave the hospital for while	10	90

5.0 Discussion

This study aimed to answer questions on needs of family members with a relative admitted to the ICU; priorities of the needs and who met the needs of the family members.

5.1 Needs and priorities of family members in ICU

In Malaysia the relative is usually blood related or by marriage and includes spouse, parents, siblin% or child. The demo%raphic profile of participants in the studµ identified that 6S% of the participants were female with 50% being a parent and 30 % spouse. As majority of the participants were parents and spouse, the needs relating to knowing the outcome of the patient ranked most important among the CCFNI questions and it is from the assurance subscale, with 100% participants ranking this as important. Studies (Lee & Lay, 2003; Leske, 2002; Rose, 1995) have shown that family members with a relative in ICU experienced crisis with anxiety and feeling of uncertainty of the survival rate of the relative. This is compounded by the fact that all family members of patients admitted to the ICU in Malaysia would be notified that the patient is considered critical and listed in the verµ ill list. Therefore family members need to know the possible outcome of the patient to be mentally and physically prepared for the worse. Also this allows planning for other alternative and complementary medicine currently practiced in the country.

The next important need was to be called at home about changes in patient's condition, which is from the proximity subscale. Although 73% of the participants agreed this as the second most important need, and the fact that communication technology has been well established in the country with almost every individual owned a cellular phone, the concept of informing relatives at home about changes in the patient's conditions by nurses has not been a practice in this hospital and the public hospitals in the country. Family members would be contacted at home when the patient's condition is critically ill and if there were no family members in the hospital at that time. The process of connecting to the family members by the nurses is stringent as each telephone call need to be connected through the operator and

details of the patient be given. Experience has shown that there was no need to inform family members at home of changes in the patient's status, as family members were always available outside the ICU. Parents and spouse almost never leave the ICU perimeter when a family member is admitted to the unit.

The next two needs were from the assurance subscale that is to have questions answered honestly and to feel there is hope with 67%. Although 'honestly' may be interpreted differently by different individual, the fact that majoritμ participants identified this as an important need, it can be %enerallμ accepted that the word has similar meanings to the participants. Family members relied on the nurses and doctors for information on the progress of the patients as patients were not conscious to be told of their conditions. When nurses or doctors answered questions asked with explanations, relatives perceived this as being honest. This related very much to feeling of hope which also has similar number of responses. These two needs involved communication by nurses and doctors to communicate information to the family members. Family members felt they were advocators for the patient and any perceived hope they received from the nurses or doctors would eased any fear and made it easier for them when they visited the patient.

The fifth need of seein% the patient frequentlμ was from the proximitμ subscale. This need has been identified as one of the important need in studies by (Azoulay, 2001; Davidson, 2009). In another study (Faridah, 2--7), the relatives interviewed identified the need to visit as frequentlμ as possible even for short periods of time to ensure the patient is alright. The hospital's visiting hours for the ICU were similar to the visiting hours of the other units in the hospital that is from 1200hrs to 1400 hours for the afternoon and 1700 hours to 1900 hours for the evening. At any time only two family members were allowed to visit. Family members were not allowed to come in between visiting hours and as parents and spouse, this caused a great deal of anxiety. The ICU stated its own reason for not allowing in between visits as the ICU has 18 beds and 100% occupancy. Unscheduled visits by family members caused disruptions when procedures or doctors rounds were in progress.

The NMI questions identified five most important needs from the proximity, information, assurance and comfort needs. Information needs of having % specific person called at the hospital when unable to visit and to know the types of staff members taking % care of the patient ranked first and third with 96% and 9S% respectivelμ. Althou%h the relatives identified havin% a specific person called at the hospital in case theμ were unable to visit as most important, it is unlikely that this need would ever happened as there were always relatives around to receive any information of the patient. It has not been the practice to have a specific person &nurse) to be called when family members could not visit as nurse patient assignment and shift dutμ chan%es, thus when a request for a specific person be called is made, nurses always ask family members to call the ICU and someone will respond to their queries. The high ranking for this need indicated a change in the needs trend of family members, where personalize care is expected in the ICU and communication given importance particularly in answering questions of the patient's condition. It could be possible this was

ranked first as relatives wish to indicate that theμ would like this considered when in extreme circumstances they were not able to visit.

Information on patient's condition was mostly given by the attending doctors. Nurses usually reemphasize information given by doctors. Relatives preferred doctors to provide information on the medical aspect as the information given were comprehensive as opposed to information given by nurses which were mostly basic information based on observations and conscious level of the patient (Faridah, 2007). Nurses were not willing to divulge any information pertaining to the general condition of the patient as this violated the hospital policy that only doctors were allowed to give detailed information of the patients. As the question did not specify the relatives' preferred choice of healthcare givers, it can be concluded that doctors would be the most preferred choice of health personnel to provide comprehensive information to the families, but basic information pertaining to the condition of the patient were met by nurses.

Another need identified was to %ive information about the patient at least once a day. Family members' of critical patients would cling to even the slightest chance of hope given by doctors and nurses on the patient's condition, and they welcomed any information given to them. Knowing the busy situation in the ICU as well as the heavy work schedule of doctors and nurses, family members would be grateful if doctors or nurses update them on the patient's condition at least once a day. Although this NMI ranked fourth, the high percentage 90% indicated its importance by relatives. It is not a practice for nurses to divulge any information of the patient to family members voluntarily (Faridah, 2007) but even if it was just to inform them the patient's general condition means a lot to these relatives. Each communication activity by nurses established rapport. Equally important was the fact that it would be alright for family members to leave the hospital for a short time, to attend to other family or personal matters knowing that should anything happen during the absence, the nurses would inform them. All the family members owned a cell phone in the study.

5.2 Staff who met needs of family members

The family members agreed that nurses were the most important and appropriate staff who met their needs as nurses were there at all times. Relatives believed that nurses were more compassionate to them during crisis as opposed to other health professionals. Consistently nurses were identified as the keμ health personnel who met familμ needs of " have specific person to call at the hospital when unable to visit; have questions answered honestly; to know the types of staff members taking care of the patient; to feel accepted to the hospital staff and to have explanation given that are understandable". This findin%s was consistent with earlier studies (Chui & Chan, 2007; Molter, 1979; Warren, 1993). As nurses can only divulge very basic information, they usually do so without the medical jargons and this has great implications to nursing, as majority family members feel comfortable communicating to nurses. A nurse respected by family members would be able to provide emotional support and assist them to accept inevitable situations should the need arises, this findin% con%ruent with

(Chui & Chan, 2007).

6.0 Conclusion

All the family needs informed in this study need nurses to communicate with the family members in order to meet those needs. Needs related to the patient and his/her outcome presided over needs of the family members. The hospital did not have a proper waiting room with basic amenities, but this was considered unimportant. There was never a need to be alone as in Malaysia, family relationship is strong regardless of ethnicity and at any time, especially in the ICU there were always more than one family member present at any time. This was one reason the writer was able to collect data from more than one family member visiting the patient. Although the findings of this small studμ cannot be %eneralized for the whole population of family members with a relative in the ICU, the similarities of the needs identified in the studμ cannot be i%nored as theμ 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 assessment varies with different group population and back%round but the findin%s were consistent with other previous studies indicating needs of assurance, proximity and information subscales. Consistently 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.

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