THE PSYCHOSOCIAL NEEDS OF NEXT OF KIN OF VENTILATED PATIENTS ADMITTED TO INTENSIVE CARE UNIT, HOSPITAL UNIVERSITI SAINS MALAYSIA

By

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LIST OF SYMBOLS

ANOVA – Analysis of variance

CCFNI – Critical care family need inventory

CCFNI-M – Critical care family need inventory -Malay version

EFA – Exploratory factor analysis

ICU- Intensive care unit

KMO – Kaiser Mayer Olkin

M- Mean

P-value - probability

PCA – Principal component analysis

r – Correlation coefficient

SD – standard deviation

HUSM – Hospital University Sains Malaysia

N - number

CCU – Critical care unit

SPSS – Statistical analysis software package

MRICR – Malaysian registry of intensive care report

ABSTRACT

Background: The needs of intensive care patient's family members are often neglected. The present study aimed to perform factorial validation and establish psychometric properties of Malay translated Critical Care Family Need Inventory (CCFNI-M) and also the needs of families of intensive care unit patients in Malaysia as perceived by family members.

Methods: This cross-sectional survey was conducted among family members of Intensive Care Unit of Hospital Universiti Sains Malaysia, Malaysia. Validation study consisted of four protocols: Forward-Backward translation, validity, internal reliability and inter domain correlations phases. This Malay validated Critical Care Family Needs Inventory then was used to identify the family needs among the respondents. Descriptive statistics as well as mean comparison analyses were employed to achieve the aim of the present study.

Results: Preliminary analyses reported the suitability of data for factorial validation. With reference to the original CCFNI, five factors were extracted which explained 49.4% of the total variance. After removal of several items for different reasons, the final items in CCFNI-M were 42. The internal consistency values for five dimensions ranged from 0.72 to 0.87 with inter domain correlation values (r) among the dimensions ranged between 0.36 and 0.61. The findings showed that family members ranked Assurance items as the most important needs. In terms of subscales scores, Assurance and Information evidenced higher mean scores compared to other dimensions. All the family need dimensions had positive and significant associations with one another. The highest correlation was noted among Comfort – Support pair, $r(58) = 0.73$, $p < 0.001$. No significant differences in the mean values found across gender, history of admission and types of relationships. In contrast, significant mean difference was observed across level of education.

Conclusion: The high measures of factorial validity, internal consistency and inter domain correlations values of the CCFNI-M make it as a suitable measure for assessing the family

needs of critical care patients. Identifying the needs of family members in the intensive care unit is imperative as it raises awareness and contributes knowledge in terms of family needs to healthcare providers, policy makers, medical social workers and general public.

ABSTRAK

Latarbelakang: Keperluan penjagaan ahli keluarga pesakit yang dirawat di unit rawatan rapi selalunya dipandang remeh. Kajian ini bertujuan untuk menjalankan ujian psikometrik validasi faktorial yang diterjemah kedalam Bahasa Melayu, iaitu Inventori Keperluan Keluarga Penjagaan Kritikal (CCFNI-M) dan juga menilai keperluan keluarga pesakit penjagaan unit kritikal di Malaysia yang ditanggapi oleh ahli keluarga.

Kaedah: Tinjauan kajian keratan rentas dalam kalangan ahli keluarga pesakit dalam unit rawatan rapi Hospital Universiti Sains Malaysia, Malaysia. Kajian validasi terdiri daripada empat protocol: Terjemahan kehadapan – kebelakang, pengesahan, "reliability" dalaman dan fasa-fasa korelasi antara domain. Inventori Keperluan Keluarga Penjagaan unit rawatan rapi ini kemudiannya digunakan untuk mengenalpasti keperluan keluarga dalam kalangan responden. Statistik deskriptif dan juga analisis perbandingan purata digunakan untuk mencapai objektif kajian ini.

Keputusan: Analisis awal mencatatkan kesesuaian data untuk validasi factorial. Dengan berpandukan kepada CCFNI original, lima factor dikenalpasti dan menjelaskan total varians 49.4%. Selepas mengeluarkan beberapa item kerana beberapa sebab, item terakhir dalam CCFNI-M adalah 42. Nilai konsisten dalaman untuk lima dimensi daripada kadar 0.72 kepada 0.87 dengan nilai antara domain dalam kalangan dimensi di antara 0.36 dan 0.61. Kajian ini menunjukkan ahli keluarga menilai item Jaminan sebagai keperluan paling penting. Dari segi skor skala rendah, Jaminan dan Maklumat menunjukkan bukti skor purata berbanding dengan dimensi-dimensi lain. Kesemua dimensi keperluan keluarga mempunyai perkaitan positif dan bermakna di antara satu sama lain. Korelasi tertinggi dicatatkan di antara pasangan Keselesaan-Sokongan, $r(58)=0.73$, $p<0.001$. Tiada perbezaan signifikan dalam nilai purata yang ditemui merentasi jantina, sejarah kemasukan dan jenis-jenis perhubungan. Secara kontra, perbezaan signifikan purata dilihat merentasi tahap pendidikan.

Kesimpulan: Ukuran tertinggi kesahan factorial, ketekalan dalaman dan nilai korelasi antara domain CCFNI-M menjadikannya ukuran sesuai untuk menilai keperluan keluarga pesakit kritikal. Mengenalpasti keperluan ahli keluarga unit penjagaan rapi adalah penting kerana ianya meningkatkan kesedaran menyumbang pengetahuan dari segi keperluan keluarga kepada penyedia penjaga kesihatan, pembuat polisi, pekerja sosial perubatan dan masyarakat umum.

CHAPTER 1: INTRODUCTION

The first Intensive Care Unit (ICU) in Malaysia was established in 1968 (MRICR,2013) Since then, intensive care has gained it's importance among medical practitioners and ICUs are now available in all tertiary care hospitals and selected secondary care hospitals under the Ministry of Health. According to MRCIR (2013), the total numbers of ICU beds in the 49 government hospitals were 600 with a median bed occupancy rate of 90.2%. The same source revealed that there was an increase of 10.5% (in the year 2013) of cases that seek ICU care compared to the previous year and the total number of cases referred and admitted in ICU for the period of 1968 - 2013 was 37, 436 (MRCIR, 2013).

Intensive Care Units (ICU) or sometime referred as Critical Care Units (CCU) or Intensive Therapy Departments are perceived as the most extreme areas compared to other hospital settings as critically ill patients are being admitted and the most worrying part is the higher mortality rate of these ICU-treated patients. The ICU admissions are usually sudden, with little time for the family members to adjust against the crisis. The patient who seeks ICU treatment needs constant medical attention which includes utmost level of care, closer observation and intensive monitoring by trained and certified medical professionals. The setting and associated environment of ICU are seen to be different from the normal or general wards. Generally, ICU wards are considered very expensively equipped with special beds, high technology instruments with wide array of equipment and facilities.

An ICU can be a very stressful and daunting environment not only for the patients but also to their respective family members and caregivers. Admission of family members or close relations into ICU ward can create a great deal of tension and overwhelming anxiety among

patient's family members or caregivers. ICU settings is also considered scary for family members compared to other general wards due to the beeping alarm sounds and multiple tubes and wires over the patients. Many authors claimed that ICU as the source of anxiety and other psychological distress to the patient's family members (Halm,1992; McClowry, 1992; Jamerson et al., 1996).

Family members of ICU-treated patients tend to experience high levels of emotional stressors such as fear of death, uncertain outcome, financial concerns and disrupted daily routine. Besides triggering devastating psychological distress, the ICU environment also tend to greatly affect the family members ability to interact or provide the best care for the ICU-treated patient. Additionally, ICU admission is often traumatic for the family members which may lead to difficulties in decision making for the patient wellbeing.

According to Paparrigopoulos et al. (2006), hospitalization period is known as a traumatic period of time as it may trigger mental stressors which potentially harm the psychological well-being of both patients and their caregivers. This ripple effect may largely be due to the strong family ties among Malaysian families (Hussain, Abdullah and Rahman, 2014). Taking care of their sick family members or relatives has been a part of their responsibilities and as consequences, many of the caregivers faced a wide ranges of problems including psychological distress.

According to Molter(1979), the needs of patient's family members are often neglected by the ICU staff. The needs of the family members are often un-noticed until the family members demonstrate weird and inappropriate coping behaviours at the bed side or until a family member directly seeks assistance in coping. Many studies(Azoulay, 2001; Leske, 2002; Rose,

1995) have highlighted the importance of healthcare providers in providing adequate emotional and physical support to family members by identifying their needs during the crisis. The identification of the needs of family members are considered essential in order to ensure the psychological and physical well-being of the family members as their roles as the primary caregivers are much needed for the quality of the life of the patients.

In respect of this, many studies in the West were conducted to investigate the needs of ICU-treated patient's family members or caregivers.The needs of patients' family members were first analysed by Molter(1979) by performing an exploratory descriptive study. A list of 45 "need" statements developed by Molter from literature reviews and a survey of 23 nursing students. Leske(1986) later developed and established Critical Care Family Needs Inventory (CCFNI) based on Molter's study as reference.

Subsequently, many scholars investigated the family needs among patient's family members from various countries. For examples, Lee and Lau (2003) assessed the family needs in Hong Kong while Takman and Severinsson (2006) performed the study in Norway and Sweden and Chatzaki et al. (2012) replicated the family needs research among suburban and rural Greek population. Besides that, studies pertaining to family needs were also been conducted at Middle East regions such as Saudi Arabia (Al-Mutair et al., 2013) and Jordan (Omari, 2009; Al-Hassan and Hweidi, 2014).

Leske(1991) established the internal psychometric properties and factor analysis of the CCFNI tool with 677 family members over a 9-year period (1980-1988). The factor validation of CCFNI led to generation of five dimensions: (1) Support, (2) Comfort, (3) Proximity, (4) Information, and (5) Assurance. Since then, CCFNI has gained its popularity

and been utilized globally to identify family needs of hospitalized patients. In the context of Malaysia, even though the needs of family members are largely recognized, there is no Malay validated and reliable CCFNI to assess the needs of patient's family members among Malay speaking populations. It is reminded that those psychometric inventories and instruments created in the West may not adequately address the need of local citizens due to language, cultural, geographical and religious differences and barriers.

To date, no local study has been designed to validate and establish psychometric properties of CCFNI in Malaysia. Since the majority of Malaysian populations are Malays and Malay language is the national language, it is extremely crucial to validate CCFNI into Malay language (henceforth, CCFNI-M). Consequently, valid and reliable CCFNI-M is important for two reasons: first, to establish the adequacy of this inventory specially designed to assess the needs of family members in a Malaysia cultural context and second, to further inspire future researches related to the needs of patient's family members.

As medical personnel, it is vital to understand the needs of families undergoing wide ranges of psychological distress such as depression and anxiety. This assessment will help us to be able to provide adequate support and needs to families to ensure a better psychosocial environment. Although a significant number of studies were conducted in Western settings, only few national studies were conducted. Noteworthy examples are (Faridah, 2012). It is reminded that, the results obtained in Western studies, cannot be transmitted or applied within local hospital settings due to the cultural, environmental and also language differences. Hence, inadequate local studies in this area are pivotal in the desire of conducting the present study.

CHAPTER 2: STUDY PROTOCOL

2.1 Background of study

The intensive care unit is an extreme environment which monitors the most critically ill patients in a hospital. As a result, an array of equipment, IV lines, medications, and sounds that are unfamiliar to the general public can be found. These factors, added to the fragile emotional state of families who have recently admitted a loved one, can be overwhelming. This rush of unforeseen stimuli often leads to feelings of fear and powerlessness (Farrell, Joseph, & Schwartz-Barcott, 2005).

Family members of patients admitted in the Intensive Care Units (ICUs) will experience high levels of emotional stress. The impact is often traumatic for the family members of the patient till results 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).

Over the years the issue of understanding family needs has received significant research attention in the medical field, yet some four decades after Molter (1979) initially investigated this topic, the issue of understanding family needs still remains important. Access to information about patient's medical conditions and quality relationships with healthcare staff are high priority needs for these families and meeting these needs of the family members is a primary responsibility of ICU physicians and nurses.

This lack of attention to family members is often overlooked in the health care environment as families are not given high priority. However, families are expected to make essential

decisions regarding their loved one's care, as well as provide the patient with continuous love and support. The family's ability to provide love and support for the patient, as well as make decisions about the patient's care is hindered during periods of emotional distress, especially in situations where patients cannot speak for themselves (Bailey et al., 2009).

When arriving on the unit for the first time, family and friends are exposed to a high acuity environment as well as circumstances foreign to them, with little education by the ICU staff. For personals who work in this type of environment daily, it is easy to become desensitized. Desensitization results in a lack of sensitivity to patients and their families, causing increased anxiety due to fear of the unknown.

Without effective orientation to the unit, family and friends may assume the worst (Azoulay et al., 2002). Previous research has shown that family satisfaction and understanding of patients' treatment leads to a better experience for the family, encouraging them to be present and supportive of the patient (Ibid).

Admission to the ICU is usually unplanned and the patients will be in a critical condition. Many studies in Western societies (e.g., Rose, 1995, Azoulay, 2001; Leske, 2002) have acknowledged the importance of healthcare givers providing adequate support to family members and identifying their needs during the crisis period. This will help to ease the effects of the crisis to family member 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.

It has previously been established (*see* Davidson 2009) 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& Cardin 2003).

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).

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 Malaysia, there have been very little studies that particularly looked into the needs of the family. Faridah (2012), looked at the communication needs of family members as well as those of the 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.

2.2 Problem statement

i. During the first few days of patient's hospitalization, the patient is usually the center of attention while communication with the family by doctors and nurses takes a lower priority (Delva et al., 2002).

ii. The needs of family members are frequently neglected whereby the health care providers are primarily focused on the needs of the patient (Kotkamp-Mothes et al., 2005).

2.3 Justifications of the study

Based on the problem statement that has mentioned previously, it is vital to access the needs of the family members of the intensive care unit patients. As medical personnel, it is vital to understand the needs of families who undergoing wide ranges of psychological distress such as depression and anxiety. This assessment will help us to be able to provide adequate support and needs to families to ensure a better psychosocial environment.

Although a significant number of studies were conducted in Western settings, only few national studies were conducted. Noteworthy examples are (Faridah, 2012). It is reminded that, the results that obtained in Western studies, cannot be transmitted or applied within local hospital settings due to the cultural, environmental and also language differences. Hence, inadequate local studies in this area are pivotal in the desire of conducting the present study. Conducting local studies within Malaysian hospital would provide a better understanding on the needs of families of patients admitted to ICU which can be implemented within local settings.

There are number of psychometric instruments were created to assess the family needs. Those psychometric instruments were developed in English and other foreign languages. It should be cautioned that such instruments need to be translated into Malay language for the purpose of local use. However, to date, no Malay validated psychometric instrument to assess such needs. With that in mind, the present study aims to validate Critical care family need inventory (CCFNI) into Malay language.

2.4 Research Objectives

The general objective of this research is to investigate the needs of patients' adult family members admitted in ICU Hospital Universiti Sains Malaysia (HUSM). In order to achieve the above general objectives, seven specific objectives are formulated:

i. To validate Critical care need inventory (CCNI) questionnaire into Malay language for the purpose of local use
ii. To assess the needs of patient's adult family members admitted to ICU HUSM
iii. To ascertain the differences of needs according to socio-demographic backgrounds of the patients' family members such as gender, age, relationships and education level

2.5 Research Questions

i. Is Malay CCNI is valid and reliable for the purpose of local use?
ii. What are the needs of patient's adult family members admitted to ICU HUSM?
iii. Is there any differences of needs according to socio-demographic backgrounds of the patients' family members such as gender, age, relationships and education level?

2.6 Research Null Hypotheses (H_o)

i. The Malay CCNI is not valid and reliable for the purpose of local use.
ii. There is no differences in needs according to socio-demographic backgrounds of the patients' family members such as gender, age, relationships and education level

2.7 Benefits of the study

i. Emergence of Malay language validated critical care family need inventory. This will be useful to assess the needs of family members in Malaysian hospital settings.

ii. The needs profile would offer insight on the basic and priority needs of the family members of patients admitted to ICU. This data is very important so that steps can be taken to understand and fulfill the family members' needs.

iii. It is anticipated that implementation of such needs would provide more conducive and supportive environment for the family members. This indirectly would have potential to reduce the emotional stress among family members.

2.8 Limitations of the study

The present study is expected to have some limitations such as:

i. As the study only focuses on family members of patients admitted to Intensive Care Unit of Hospital Universiti Sains Malaysia, therefore, it does not cover all Malaysian hospital settings (e.g: private and government hospitals)

ii. Since the study is conducted in Hospital Universiti Sains Malaysia, Kelantan where majority of the population is Malay ethnicity, therefore, the results generated in this study most probably inclined towards Malay population.

2.9 Research Methods and Methodology

2.9.1 Research Design

This is an observational cross-sectional study and the setting is ICU in a teaching hospital, HUSM. The ICU has a bed capacity of 10. Study period is around 1 year from September 2014 till September 2015. Reference population will be all adult family members of patients admitted in ICUs of Malaysian hospitals. Source population will be family members of patients admitted in ICU, HUSM. The samples recruited for the study were adult family members who have a relative patient admitted in the ICU. The estimated duration of this study is expected to be one year long.

The research is carried out in two phases:

Phase 1: Validation Phase:

Validation of Malay language CCFNI

Phase 2: Quantitative Phase:

Observational cross-sectional study using a self-administered questionnaire

2.9.2 Sample size calculation

***Objective 1*:**

The rule of subject to variable ratio 3:1 (Costello and Osborne, 2005)

(No of item x 3) + 20% dropout = (45x 3) + 17 = 162

Objective 2:

Sample size calculation based on PS software (2 mean formulas), detect different of mean score between two demographic groups. We need 34 respondents to detect a different of 5 points score between the two groups with level of significant 0.05, power 80% and SD of the score of 4.53 (Bijjtebier et al., 2000) . This includes 20% of dropout rates. For parametric test, sample size need to be inflated to 60.

2.9.3 Inclusion Criteria Exclusion Criteria

The following lists contain information on the inclusion and exclusion criteria of the research participants:

Inclusion Criteria:

i. Adult family members ("blood" related or spouse)
ii. Age more 18 years old
iii. Malaysian citizenship.
iv. Not diagnosed with any mental illness.
v. Consented and able to read, write, and understand Bahasa Malaysia

Exclusion Criteria:

i. Adult family members other than spouse or not "blood" related
ii. Age less than 18.
iii. Mentally unfit (Diagnosed with any mental illness).
iv. Refuse to take part in the research.
v. Unable to read, write, and understand Bahasa Malaysia

2.9.4 Data collection procedures

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 &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 & Lau 2003; Lee et al., 2000; Bijttebier et al., 2000; Coutu-Wakulczyk&Chartier, 1990).

This phase consists of participation in a quantitative survey. A convenience sampling method will be used for this study. Individuals based on inclusion and exclusion criteria accompanying an admitted patient to the ICU will be approached in person, informed about the purpose of the study and invited to participate. Written consent will be obtained by those agreeing to participate and meeting the criteria. Pencils will be provided to the respondents in order to answer the questionnaires. Once respondents complete the questionnaires, the answered questionnaires will be collected for analysis.

All the family members participating will be asked to answer a set of needs assessment questionnaires adopted from (Molter&Leske, 1983) with permission for use. The questionnaires will be prepared in Malay language version. The translation into the Malay

language will be done forward- backward translation. Translated questionnaire will undergo content validation, phase validation as well as construct validation.

There were two parts to the questionnaire, part A contained 6 demographic data questions which includes - the age, gender, relationship to patient, frequency of visit and the perception of severity of illness. Part B has 45 item questions. The participant has to answer using a Likert scale of 1- 4, with 4 being very important and 1- not important.

Altogether there were 5 subscales, comfort needs, proximity needs, assurance needs and support needs. The estimated time required for a family member to answer all the questions were between 30 minutes to 45 minutes. All the questionnaires will be administered by the researcher when the relatives are waiting along the corridors leading to the ICU during visiting hour. Relatives who agree to participate will be given explanation on the information revealed and that it was used for research purposes only. Also the participation is voluntary. The participants need to answer the question with the researcher present. Any questionnaires were not allowed to be taken home. This ensures 100% return of the answered questionnaires.