SATISFACTION, ANXIETY, DEPRESSION AND STRESS AMONG FAMILY MEMBERS OF PATIENTS IN TWO REGIONAL TERTIARY INTENSIVE CARE UNIT IN MALAYSIA

BY

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ABSTRACT

Introduction: Family satisfaction has been identified as a quality indicator in critical care area. It reflects the capabilities of health care professionals to meet the expectations and needs of the family members. The impact of family satisfaction level was also found to be associated with symptoms of psychological distress such as anxiety, depression and stress among family members. We evaluated the satisfaction level and prevalence, risk factor and correlation of psychological distress symptoms with the satisfaction level among family members in two Intensive Care Unit (ICU) in Malaysia. **Methods:** This is a cross-sectional, multicentre survey conducted in ICU at Hospital Sultanah Aminah Johor Bahru and International Islamic University Medical Centre. Inclusion criteria were family members aged more than 18 years old whose relatives were admitted in ICU for more than 3 days. They were enrolled 3 days after ICU admission and need to complete a modified version of Critical Care Family Needs Inventory (CCFNI) and the Depression, Anxiety and Stress Scales (DASS) questionnaires. **Results:** A total of 176 family members were enrolled in this study. The result of the study highlighted that 116 (66%) of the family members scores ≥ 3 denoting satisfaction with the mean CCFNI score was 3.11 (SD=0.3). Prevalence of depression, anxiety and stress were of 30.1%, 41.4% and 28.9% respectively. Risk factor for psychological distress symptoms were five family members related (female sex, spousal relationship, lower education, median income less than RM 4000 and staying with patient) and one patient related (age). Negative correlation between depression, anxiety and stress with CCFNI score were found ($p < 0.05$) but with low correlation coefficient ($r=-0.178$ to -0.209). Family members without symptoms of psychological distress were more satisfied (higher CCFNI score) with ICU care compared to those with symptoms of psychological distress ($p < 0.05$). **Conclusions:** Family members of ICU patient were satisfied with the care provided in the ICU. High rates of psychological distress symptoms in this study and its correlation with the satisfaction level highlight the need to identify and implement preventive and management strategies for family members to improve the overall ICU care.

الملخص

رضاء الأسرة معرَّف بمعشر الجودة في مجال الرعاية الحرجة. إنه يعكس مدى استطاعة أخصائي الرعاية الصحية لتلبية التوقعات وحاجات أهل الأسرة. إن تأثير مستوى رضاء الأسرة أيضا يُقال أن يكون مرتبط بأعراض المعاناة النفسية مثل القلق والاكتئاب والضغط بين أعضاء الأسرة. نحن نقيم مستوى الرضاء والتفشي وعامل الخطر وارتباط بين أعراض المعاناة النفسية بمستوى رضاء الأسرة حول أعضاء الأسرة في غرفتي وحدة العناية المركزة بماليزيا. وهذا التقييم المقطعي ومتعدد المراكز أقام به في وحدة العناية المركزة في مستشفى السلطانة أمينة بجوهر بارو والمركز الطبي بالجامعة الإسلامية العالمية بماليزيا. المعيار الاشتمال هو أعضاء الأسرة عمرهم أكثر من 18 سنة، وعندهم أعضاء الأسرة الذين يلتحقون بوحدة العناية المركزة أكثر من 3 أيام. وهؤلاء المرضى يحتاجون أن يقوموا بصيغة معدلة لقائمة احتياجات الأسرة للرعاية الطارئة (CCFNI) واستبيانات مقاييس الاكتئاب والقلق والضغط (DASS). وعدد أعضاء الأسرة الذين يشتركون في هذا البحث هم 176 شخصا. والنتيجة أشارت إلى أن 166 شخصا (66%) حصلوا على ≤3 مستوى الرضاء مع متوسط الدرجات CCFNI هو 3.11 (SD=0.3). إن نسبة الاكتئاب والقلق والضغط هي 30.1% و41.4% و28.9% على التوالي. وهناك خمس عوامل الخطر لأعراض المعاناة النفسية التي ترتبط بأعضاء الأسرة (أنثى الجنسية، والعلاقة الزوجية، ومستوى التربية المنخفض، ومتوسط الدخل أقل من RM4000، والسكن مع المرضى)، وعامل واحد يرتبط بالمريض (العمر). إن العلاقة السلبية موجودة بين الاكتئاب والقلق والضغط مع CCFNI ($p<0.05$) ولكن بأقل معامل الارتباط ($r=-0.178$ to -0.209). إن أعضاء الأسرة بدون أعراض المعاناة النفسية هم أكثر رضاء (أعلى CCFNI) برعاية في وحدة العناية المركزة، مقارنة بأعضاء الذين عندهم أعراض المعاناة النفسية ($p<0.05$). إن أعضاء أسرة مرضى وحدة العناية المركزة مقتنعون بالرعاية في الوحدة. إن ارتفاع المعدلات لأعراض المعاناة النفسية في هذا البحث وارتباطها مع مستوى الرضاء أشار لنا عن الحاجة إلى التعرف عن الوقاء وتنفيذ طرق إدارتها عند أعضاء الأسرة، لتحسين جودة رعاية وحدة العناية المركزة بشكل كلي.

APPROVAL PAGE

I certify that I have supervised and read this study and that in my opinion, it conforms to acceptable standards of scholarly presentation and is fully adequate, in scope and quality, as a dissertation for the degree of Master of Medicine (Anaesthesiology).

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DECLARATION

I hereby declare that this dissertation is the result of my own investigations, except where otherwise stated. I also declare that it has not been previously or concurrently submitted as a whole for any other degrees at IIUM or other institutions.

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LIST OF ABBREVIATIONS

BAI	Beck Anxiety Inventory
BDI	Beck Depression Inventory
CCFNI	Critical Care Family Need Inventory
CCFSS	Critical Care Family Satisfaction Survey
CES-D	Center for Epidemiological Studies Depression Scale
DASS	Depression Anxiety Stress Scale
FS ICU	Family Satisfaction Intensive Care Unit
GDSS	General Sleep Disturbance Scales
HSAJB	Hospital Sultanah Aminah Johor Bahru
HADS	Hospital Anxiety and Depression Scale
HRQOL	Health Related Quality of Life
ICU	Intensive Care Unit
IES	Impact of Event Scale
IIUMMC	International Islamic University Malaysia Medical Centre
LOS	Length of Stay
NMI	Needs Met Inventory
NRS-F	Numerical Rating System for Fatigue
PHQ-9	Patient Health Questionnaire – 9
PICS-F	Post Intensive Care Syndrome - Family
PTSD	Post-Traumatic Stress Disorder
SAPS II	Simplified Acute Physiology Score II
SEQ	Self-Elaboration Questionnaire

CHAPTER ONE

INTRODUCTION

1.1 BACKGROUND OF THE STUDY

The intensive care unit (ICU) is a specialized centre which accommodates the most ill and unstable patients in a hospital, who need strict control of vital parameters and continuous care. In Malaysia, over 30000 patients were admitted in ICU annually since 2012 and there was an increment of 30 % in the number of ICU admission over the past 5 years from 2011 until 2015 (Tong, Tai, Tan, Lim, & Ismail, 2016). With the expansion of the ICU services and increase in the number of patients admitted to the ICU, patients have always been given high priority causing the lack of attention to the family members. The importance of family members in the ICU care is now being more recognized and the concept of 'Family-centred care' was introduced. It is an approach which was designed to be responsive and respectful to family members needs and expectations. These leads to the publication of the first guideline on family-centred care by the Society of Critical Care Medicine (SCCM) (Davidson et al., 2007).

Health care professionals often unintentionally ignored the presence of family members as they are more concern about the treatment and progress of the patient. These will put the family members in a high level of emotional stress (Al-Mutair, Plummer, O'Brien, & Clerehan, 2013; Siddiqui, Sheikh, & Kamal, 2011). Families often feel helpless and vulnerable with no clear knowledge in regard to the severity of the disease and prognosis of their loved one. These can expose them to the symptoms of anxiety, depression and post-traumatic stress disorder (Pochard et al., 2005). The end result will lead to what has been termed as "Post-Intensive Care Syndrome-Family"

(PICS-F) (Needham et al., 2012). According to surveys conducted in the United States (Jennifer L. McAdam, Dracup, White, Fontaine, & Puntillo, 2010), more than two thirds of family members reported a high level of stress both during and 3 months after the patients' ICU admission. In another study, they reported up to half of the family members experience symptoms of anxiety and posttraumatic stress (Anderson, Arnold, Angus, & Bryce, 2008; Yilmaz et al., 2016).

Family satisfaction has now been identified as a quality indicator of ICU care (de Vos, Graafmans, Keesman, Westert, & van der Voort, 2007). It reflects the capabilities of health care professionals to meet the expectations and needs of the family members (Rothen, Stricker, & Heyland, 2010). Dutch Society of Intensive Care (NVIC) and Scottish Intensive Care Society Audit Group (SICSAG) for example has include monitoring of the quality of care including satisfaction of the relatives with respect to the care as one of its quality standards (Rensen et al., 2017; Scottish Intensive Care Society Audit Group, 2015). The College of Intensive Care Medicine of Australia and New Zealand has also included family satisfaction as outcome measures in the quality of care in the ICU. However, there is no uniform definition of family satisfaction being used. Family members may be referred to as a group of people with close familial or social relationship with the patient. They may be related by blood or marriage to the patient.

In the ICU, family satisfaction may be influenced by a variety of factors. Indeed, the main focus of ICU care is to treat the patient himself, but family members should be given a special interest too. Most of the ICU patients are incompetent. They are either too sick to speak or are prevented from expressing themselves due to attached devices. Family members will serve as a surrogate to assess the care that patient received and play an important role in decision making.

1.2 STATEMENT OF THE PROBLEM

The recognition of family members satisfaction is important in order to develop a high quality and holistic approach of care in the ICU. Meeting the needs of the family members were found to be associated with higher satisfaction level (Khalaila, 2013). The impact of family satisfaction level were also found to be affected by the symptoms of psychological distress experienced by the family members such as anxiety, depression and stress (Fumis, Ranzani, Faria, & Schettino, 2015). Despite the importance of these two topics to improve the outcome of ICU care, only few studies were conducted in south east Asian region, in particular Malaysia. Most of the previous studies were conducted in the western countries. The results might differ because of the different in socioeconomic background, cultural adaptation and religion.

Limited data regarding level of satisfaction and incidence of psychological distress among family members in Malaysian ICU have been published. There are few studies conducted looking at the needs among ICU-treated patients' family members (Dharmalingam, Kamaluddin, & Hassan, 2016b; Hashim & Hussin, 2012) but little being explored regarding the determinants of satisfaction and psychological distress among family members. Furthermore, all of the previous studies were conducted in a teaching hospital, which have a better facilities and staff to patient ratio. It may not represent the true response of family members of ICU patient as most of the critically ill patient in Malaysia were actually admitted in the ICU in government hospital. In addition to filling this gap, this study will evaluate the impact of psychological distress symptoms towards the level of satisfaction.

1.3 PURPOSE OF THE STUDY

This study was designed to evaluate the satisfaction and prevalence of anxiety, depression and stress among family members of patient in ICU. Apart from that, this study will also assess the correlation between satisfaction level and anxiety, depression and stress among family members.

1.4 RESEARCH OBJECTIVES

General:

i. To evaluate the satisfaction and prevalence of anxiety, depression and stress among family members of patients in two regional tertiary intensive care unit in Johor Bahru and Kuantan.

Specific:

i. To determine the level of satisfaction among family members.
ii. To investigate the association between level of satisfaction and demographic profile of the family members.
iii. To identify the prevalence and risk factor of anxiety, depression and stress among family members.
iv. To investigate the association between anxiety, depression and stress with the level of satisfaction.

1.5 RESEARCH QUESTIONS

This study was conducted to search for answers of the following questions:

i. What is the level of satisfaction among family members of patient admitted in the ICU?

ii. Is there any association between level of satisfaction and demographic profile of the family members?

iii. What is the prevalence of anxiety, depression and stress among family members of patient admitted in the ICU?

iv. Is there any association between anxiety, depression and stress with the level of satisfaction?

1.6 THEORETICAL FRAMEWORK

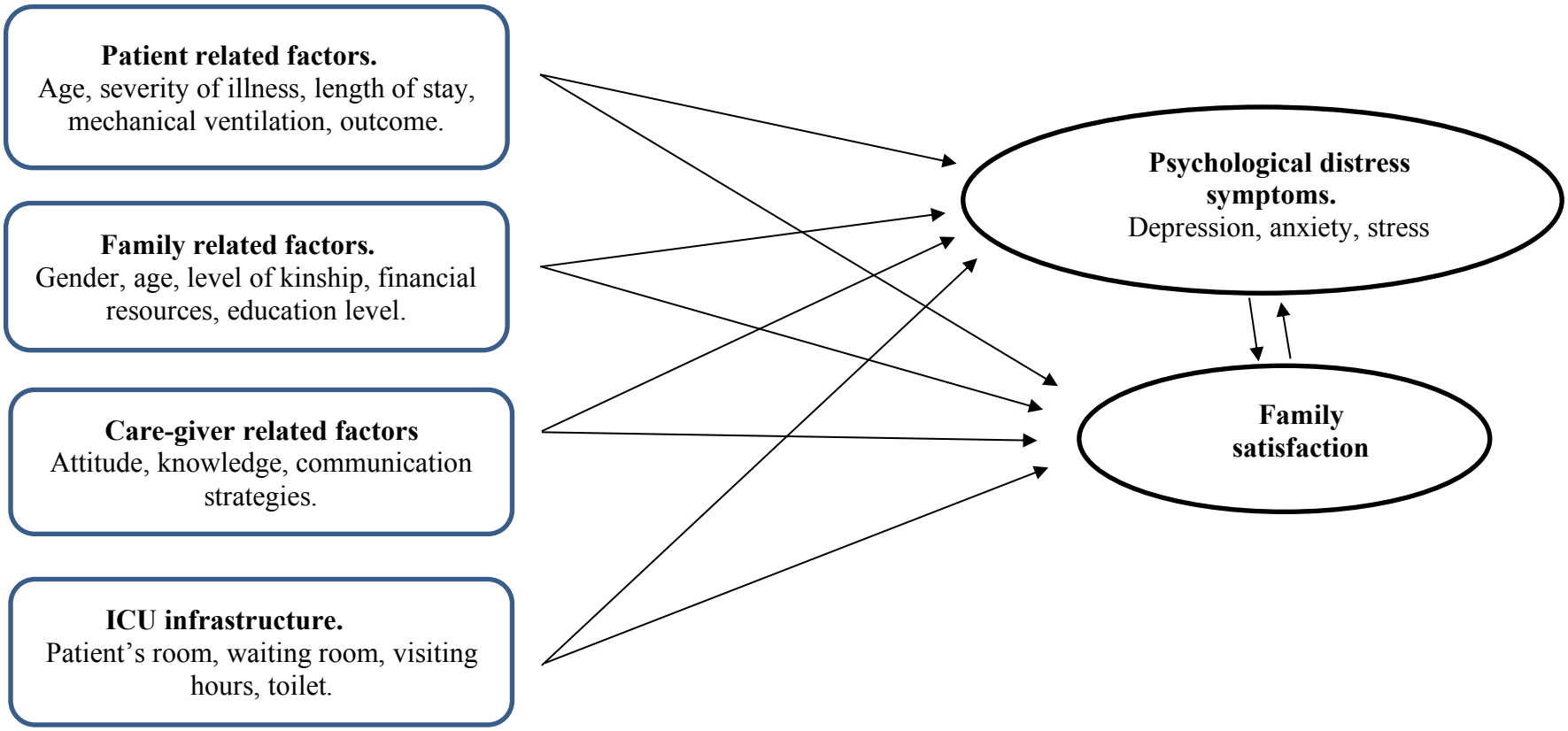

Figure 1.1 Theoretical Framework

1.7 RESEARCH HYPOTHESES

It is hypothesized that majority of the family members satisfied with the ICU care and there is negative correlation between level of satisfaction and psychological distress symptoms.

1.8 SIGNIFICANCE OF THE STUDY

This study may provide more information regarding level of satisfaction and prevalence of psychological distress symptoms among family members. By identifying the determinants of satisfaction and psychological distress symptoms, it will help to improve the quality of care while the patient and family members in the ICU and after ICU discharge.

1.9 DEFINITIONS OF TERMS

Family members

Adult over 18 years of age, related to patient by marriage or blood and visit the patient at least twice during ICU admission.

Satisfaction

Fulfilment of the needs and expectations which, if fulfilled, relieve or diminish the distress and improve sense of well-being (Leske, 1986). Measured using CCFNI questionnaire (Warren, 1993). A mean score of ≥ 3 indicates satisfaction (Freitas, Kimura, & Ferreira, 2007).

i. Assurance: Evaluate the level of satisfaction with answers given by ICU staff and the confidence that the patient is being given the best care.

ii. Information: Evaluate the level of satisfaction with the information given to family members in regard to the procedures and treatments performed.

iii. Proximity: Evaluate the level of satisfaction with the emotional and physical access to the patient.

iv. Comfort: Evaluate the level of satisfaction in terms of physical comfort and amenities in the ICU.

v. Support: Evaluate the level of satisfaction with the support given by the ICU staff.

Intensive Care Unit

Unit that admit high risk and critically ill patients which cover both surgical (operative) and medical (non-operative) patient.

Anxiety symptoms

Based on DASS -21 questionnaire (Lovibond & Lovibond, 1995). Consist of 7 items with score 0-3. A score of > 7 indicate presence of anxiety symptoms.

Depression symptoms

Based on DASS -21 questionnaire (Lovibond & Lovibond, 1995). Consist of 7 items with score 0-3. A score of > 9 indicate presence of depression symptoms.

Stress symptoms

Based on DASS -21 questionnaire (Lovibond & Lovibond, 1995). Consist of 7 items with score 0-3. A score of > 14 indicate presence of stress symptoms.

Severity

Based on SAPS II (Le Gall, 1993), 12 physiological variables and 3 disease-related variables. A score of > 52 indicates 50 % mortality.

Mechanical ventilation

Artificial ventilation where a mechanical means is used to replace or assist spontaneous breathing. It can be non-invasive or invasive mechanical ventilation.

Measured as a categorical data: Yes or No

1.10 CHAPTER SUMMARY

This chapter has discussed the background of the study and introduced to the reader regarding problems that this research intended to investigate. It also presented the theoretical framework for better understanding of the issues being addressed. This chapter also outlined the study objectives, research questions and hypotheses. Finally, significance of the study was explained, followed by brief definitions of terms used.

CHAPTER TWO

LITERATURE REVIEW

2.1 INTRODUCTION

In this chapter, a review of literature related to family members satisfaction and prevalence of anxiety, depression and stress among them is presented. To begin, the concept of family-centred care and family satisfaction as a quality indicator of ICU care will be explored and factors affecting it will be reviewed. Then, published literature on prevalence of psychological distress among family members will be summarized. Knowledge gaps will be highlighted in order to situate the proposed research objectives.

2.2 IMPORTANCE OF FAMILY MEMBERS TO THE CRITICALLY ILL PATIENT

Family may be referred to as a group of people with close familial or social relationship with the patient. (Rothen et al., 2010). They may be related by blood or marriage to the patient. The importance of family members in the critical care management is now being more recognized.

There are four main reasons to include family members in the management of patient in the ICU (Gerritsen, Hartog, & Curtis, 2017). First, the critical illness of a loved one may have a significant effect towards family members with up to two-third of family members were reported to have a significant psychological symptoms including depression, anxiety and stress both during and after the critical illness (Davidson, Jones, & Bienvenu, 2012). The end result will lead to what has been termed

as “Post-Intensive Care Syndrome-Family” (Needham et al., 2012). Second, family members are often acting as a surrogate decision maker as the patient are either too sick to speak or are prevented from expressing themselves due to attached devices. Therefore, effective communication with family members are very important for a shared decision-making in the ICU. Third, most patients with critical illness reported that they would prefer to have their family to make decision for them if they were to lose decision-making capacity (Puchalski et al., 2000). Finally, incorporating family members in the care of patient may allow them to be more effective caregivers and ultimately improve patient overall outcomes (Lynn, 2015). Patient may feel more comfortable and calmer with the presence of family members around.

In 2017, the updated version of the family-centred care guideline by SCCM was published (Davidson et al., 2017). Five main recommendations in the guidelines are advocating family to be present in the ICU, family education program such as ICU diaries, strategies for a more effective communication between healthcare professionals and family members, use of specific consultations such as palliative care consultants or psychologists, and operational issues such as ICU policies to promote family-centred care.

2.3 FAMILY SATISFACTION: THE CONCEPT

In healthcare settings, patient satisfaction towards care provided is one of the most challenging yet important aspect. Health care workers are expected to provide a high quality of care while being cost effective and efficient at the same time. Satisfaction is usually measured by a survey or questionnaire that patients complete about their experience in a hospital.

Evaluating patient satisfaction in intensive care unit however a bit more complicated. Patients are often incompetent and cannot make their own decision because of their fluctuating level of consciousness and severity of illness. They are either too sick to express their thoughts or may not even remember their ICU admission experience, which makes the satisfaction surveys challenging. Therefore, family members are often the ones acting as a surrogate to determine satisfaction with the overall care offered by ICU team. Family members is considered an integral part in caring for the patient.

'Family satisfaction' is an abstract concept in which there are no uniform definition and gold standard to assess. 'Satisfaction' refers to the amount of fulfilment of one's wishes, expectations or needs. Family satisfaction reflects the capabilities of health care professionals to meet the expectations and needs of the family members (Rothen et al., 2010).

Recognizing the needs of family members of critically ill patients was the initial step to achieve the family satisfaction. Several studies have been conducted to identify these needs. The first ground-breaking study was conducted by Nancy C Molter, (1979) in which she published the Critical Care Family Needs Inventory (CCFNI) which consist of forty-five self-report questionnaires related to the needs of family members of critically ill patients (Molter & Leske, 1995). The items are subdivided into five domains (common themes): assurance, information, proximity, comfort and support.

Since the publication of Molter's five domains of family needs, various studies have been conducted using the same questionnaire to identify family needs. However, a gap exists between recognizing the needs of the family members and learning how to improve their satisfaction level. To bridge this gap, the Needs Met Inventory (NMI) was