ICU SURVIVORS' AND CAREGIVERS' EXPERIENCES OF IN-PATIENT CARE: EXPLORATORY QUALITATIVE STUDY

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FACULTY OF MEDICINE
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ICU SURVIVORS' AND CAREGIVERS' EXPERIENCES OF IN-PATIENT CARE: EXPLORATORY QUALITATIVE STUDY

ABSTRACT

INTRODUCTION: A greater number of patients are surviving to ICU discharge with the advancement in intensive care and medical field these days. However, the nature of these admissions with strict isolations with no visitation policies and protracted course of illness is unprecedented and contributes to great anxiety for both patients and families. The voices and experiences of ICU survivors are missing from the policy development. Hence, we conducted this study to explore patients' and caregivers' experiences from ICU admission until discharge from the hospital. Apart from that, we aimed to explore the interactions between patients and caregivers with various hospital staff including specialists, medical officers, nurses, and allied health professionals as well to propose interventions including patients and family educational materials, ICU staff training and ICU workflow as well to improve the quality of ICU care.

METHOD: This qualitative study involved ICU patients and their caregivers which was conducted in-depth interviews based on a semi-structured interview guide. All interviews were audio-recorded and transcribed verbatim. The NVivo qualitative software package was used to manage the data. The themes and subthemes were generated and confirmed by literature and expert opinion.

RESULT:

Data was collected from 24 interviewees which comprised of 12 patients and 12 caregivers whose age ranging from 28 to 82 years old. Two main themes emerged from the analysis: (I) Recognition of potential sources of discomfort, (II) Intensive care services. From the potential source of discomfort, two subthemes which include physical and psychological source of discomfort were mentioned. Pain, sleep disturbances, immobility and noise were among the most concerning discomforts being highlighted. While for psychological discomfort often associated with worry, ineffective communication, experience of loss of memory and fear were mentioned. By recognition of the potential source of discomfort, patients' and caregivers' perspectives on intensive care services were gathered as well. Three subthemes were developed for intensive care services: (I) Medical requisite, (II) Social requisite, (III)Psychological requisite. Medical aspect of care such as effective communication, good nursing care, excellent pain management and conducive ICU environment were highly appreciated. Social aspect of care such as multicultural sensitivity, favourable waiting area and longer visiting hours were mentioned. Healthcare workers play a vital role in psychological needs such as providing emotional support as part of routine care. ICU support or counselling group could be beneficial for some cases.

CONCLUSION:

This study uncovered patients' and caregivers' experiences on the potential source of discomforts and the intensive care services. Potential discomforts were classified into physical, psychological and social discomforts which include pain, immobility as well as ineffective communication and worry. Further exploration on the intensive care received in ICU were further classified into medical, social and psychological requisites. These include effective communication, good nursing care, excellent pain management, conducive ICU environment, ICU emotional support and counselling group, multicultural sensitivity, longer visiting hours as well as more seats at waiting room were mentioned. With the recognition of potential source of discomforts as highlighted in this study, as well as through patients' and caregivers' first hand experiences as recorded, together with the current literatures regarding ICU experiences, these will be useful references on establishing patients-centred and family centred intensive care services.

PENGALAMAN PESAKIT DI ICU DAN PENJAGANYA SEMASA DI UNIT RAWATAN RAPI : KAJIAN KUALITATIF PENEROKAAN

ABSTRAK

PENGENALAN: Sebilangan besar pesakit masih hidup untuk keluar dari ICU dengan kemajuan dalam rawatan rapi dan bidang perubatan hari ini. Walau bagaimanapun, sifat kemasukan ini dengan pengasingan yang ketat tanpa polisi lawatan dan perjalanan penyakit yang berlarutan tidak pernah berlaku sebelum ini dan menyumbang kepada kebimbangan yang besar untuk kedua-dua pesakit dan keluarga. Suara dan pengalaman mangsa ICU hilang daripada pembangunan dasar. Oleh itu, kami menjalankan kajian ini untuk meneroka pengalaman pesakit dan penjaga dari kemasukan ICU sehingga keluar dari hospital. Selain itu, kami berhasrat untuk meneroka interaksi antara pesakit dan penjaga dengan pelbagai kakitangan hospital termasuk pakar, pegawai perubatan, jururawat, dan profesional kesihatan bersekutu serta untuk mencadangkan intervensi termasuk bahan pendidikan pesakit dan keluarga, latihan kakitangan ICU dan aliran kerja ICU juga untuk meningkatkan kualiti penjagaan ICU.

KAEDAH: Kajian kualitatif ini melibatkan pesakit ICU dan penjaga mereka yang telah menjalankan temu bual mendalam berdasarkan panduan temu bual separa berstruktur. Semua temu bual dirakam audio dan ditranskripsikan secara verbatim. Pakej perisian kualitatif NVivo digunakan untuk mengurus data. Tema dan subtema dijana dan disahkan oleh kesusasteraan dan pendapat pakar.

KEPUTUSAN:

Data dikumpul daripada 24 orang yang ditemu bual yang terdiri daripada 12 pesakit dan 12 penjaga yang berumur antara 28 hingga 82 tahun. Dua tema utama muncul daripada analisis: (I) Pengenalan potensi sumber ketidakselesaan, (II) Perkhidmatan penjagaan rapi. Daripada potensi sumber ketidakselesaan, dua subtema yang merangkumi ketidakselesaan fizikal dan psikologi telah disebutkan. Kesakitan, gangguan tidur, ketidakbolehgerakan dan bunyi bising adalah antara ketidakselesaan yang paling membimbangkan yang diketengahkan. Manakala untuk ketidakselesaan psikologi sering dikaitkan dengan kebimbangan, komunikasi yang tidak berkesan, pengalaman kehilangan ingatan dan ketakutan disebut. Dengan mengiktiraf potensi sumber ketidakselesaan, persepsi pesakit dan penjaga terhadap perkhidmatan rawatan rapi telah dikumpulkan juga. Tiga subtema telah dibangunkan untuk perkhidmatan rawatan rapi: (I) Keperluan perubatan, (II) Keperluan sosial, (III) Keperluan psikologi. Aspek penjagaan perubatan seperti komunikasi yang berkesan, penjagaan kejururawatan yang baik, pengurusan kesakitan yang sangat baik dan persekitaran ICU yang kondusif amat dihargai. Aspek penjagaan sosial seperti sensitiviti pelbagai budaya, ruang menunggu yang menggalakkan dan waktu melawat yang lebih panjang telah dinyatakan. Pekerja penjagaan kesihatan memainkan peranan penting dalam keperluan psikologi seperti membuktikan sokongan emosi sebagai sebahagian daripada penjagaan rutin. Sokongan ICU atau kumpulan kaunseling boleh memberi manfaat untuk sesetengah kes.

KESIMPULAN:

Kajian ini mendedahkan pengalaman pesakit dan penjaganya tentang potensi sumber ketidakselesaan dan perkhidmatan rawatan rapi. Ketidakselesaan yang berpotensi dikelaskan kepada ketidakselesaan fizikal, psikologi dan sosial yang merangkumi kesakitan, ketidakbolehbergerak serta komunikasi yang tidak berkesan dan kebimbangan. Penerokaan lanjut mengenai rawatan rapi yang diterima di ICU diklasifikasikan lagi kepada keperluan perubatan, sosial dan psikologi. Ini termasuk komunikasi yang berkesan, penjagaan kejururawatan yang baik, pengurusan kesakitan yang sangat baik, persekitaran ICU yang kondusif, kumpulan sokongan emosi dan kaunseling ICU, sensitiviti pelbagai budaya, waktu melawat yang lebih lama serta lebih banyak tempat duduk di ruangan menunggu disebut. Dengan pengenalan potensi sumber ketidakselesaan yang diketengahkan,juga melalui pengalaman peribadi pesakit dan penjaga yang direkodkan, bersama-sama dengan bukti kajian terkini mengenai pengalaman ICU, ini akan menjadi rujukan yang berguna untuk menubuhkan perkhidmatan rawatan rapi berpusatkan pesakit dan keluarga.

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ICU : intensive care unit

PTSD : post traumatic stress disorders

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CHAPTER 1: INTRODUCTION

A greater number of patients are surviving to ICU discharge with the advancement in intensive care and medical field these days. A few qualitative studies have interviewed patients and/or family members on their experience during ICU stay and the ensuing recovery period. For patients and family caregivers, home discharge represents positive progress, but also a new challenge. At the time of ICU discharge and even at the time of hospital discharge, survivors of critical illness experience real and profound impairments. Just as physical weakness is common, so too are challenges with thinking, anxiety, fear, loneliness, difficulty coping with these symptoms, and difficulty sleeping. All these sequalae can be minimised by providing an excellent care during their ICU stay.

The nature of these admissions (strict isolations with no visitation policies and protracted course of illness) is unprecedented and contributes to great anxiety for both patients and families. Patients may perceive their admission differently, some may take it as positive experience while some may consider themselves being unfortunate. There are many predisposing factors that contribute to these perceptions. Being ICU patients, apart from the fact that they are in critical phase, they are also being subjected to multiple invasive procedures which include invasive and non invasive ventilatory support, invasive line insertion and monitoring, frequent blood sampling and venepuncture which may can affect patients physically as well as psychologically. Some tolerated the procedures very well as they believed the care given by the doctors are at their best interest. On the other hands, certain procedures such as painful venepuncture and blood taking as well as the noises coming from ventilator alarm and monitors could be the source of discomfort for some patients in ICU as well.

It is important to recognise the source of discomfort and develop ways to improve the care. Hence, it is very vital for us to take into considerations from their perspectives on the care being delivered in order to provide an excellent service to meet their needs.

The interaction by healthcare workers plays role especially in providing emotional support for these patients. They may not at their best mental state, some might be depressed with the condition, hence it is important to be empathy with the patients and show compassion and support. Communication is the key in ICU management in terms of the care being delivered and decision for treatment which always involves multidisciplinary team. Having said effective communication is the pillar, this is not limited among doctors and healthcare staffs only, patients and caregivers should be included as well.

Very seldom, the carers' point of view being heard. Having their loved ones admitted to intensive care, there will be a great impact to everyone in the family, be it psychologically , emotionally or financially. Hence, this study aims to explore on how the admission affect the carers of the critically ill patients.

A high-quality interaction with healthcare workers is a great help for the carers in order to provide adequate information and explanation of the patients' condition to make them understand the whole situation in detailed as well as emotional support. Besides, knowledges on general caregiving experiences from the carers as well as their expectations were explored. This information is important to provide great satisfaction for the carers and patients as well.

The voices and experiences of ICU survivors are often missing from the policy development. Our understanding of the experiences of ICU survivors and their caregivers during ICU stay and post ICU discharge will help to inform the development of strategies towards improvement of services to patients and their caregivers during and after their ICU stay.

Some practices during ICU stay which affect patients and their caregivers unfavorably will need to change. Post discharge, support in the form of rehabilitation medical services, counselling services or educational materials may provide timely intervention to improve long term function in critical care survivors.

CHAPTER 2: OBJECTIVE

2.1 Primary objective

To explore patients' and caregivers' experiences from ICU admission until discharge from the hospital.

2.2 Secondary objectives

1) To explore the interactions between patients and caregivers with various hospital staff including specialists, medical officers, nurses, and allied health professionals.
2) To propose interventions including patients and family educational materials, ICU staffs.

CHAPTER 3 : LITERATURE REVIEW

Van de Leur et al. describes a link between patient's factual recall of ICU events and the recollection of discomfort experienced during an ICU stay with the most frequent sources of discomfort cited were presence of an endotracheal tube, hallucinations and medical interventions.[1]

The IPREA studies show that sleep deprivation, discomfort due to lines and tubes, pain, and thirst are the highest scored items on the discomfort scale.[2] Hence, it is crucial to recognise the potential discomfort to patients in ICU to ensure greater insight into their perspectives and improve the quality of care.

Latour et al. highlighted the most important intervention in order to improve family experiences in ICU by making family-centred care a quality standard.[3] Therefore, healthcare workers should be able to have optimal communication with family members and the way in which families are included in care and decision making. Apart from that, support for the psychological and spiritual health of the family is essential as part of component of patient-centered care for critically ill.[4]

An insightful qualitative study on 49 subjects, using semi-structured interviews were conducted by Auriemma et al to explore what mattered to patients and their families during and after critical illness.[5]

Two key concepts were identified:

1. The process of care within the ICU - communication, patients' comfort, and sensing that the medical team is providing exhaustive care emerged as essential aspects of the ICU experience that indicate the quality of care.
2. Patient's discharge outcomes after ICU care – patient's quality of life, the physical function, and the cognitive function are additional functional outcomes that are equal to, or more important than survival outcomes alone.

Leslie et al. in 2019 utilized a sample of 39 subjects to look at patients' priorities and implications after hospital discharge from critical illness.[6] The analysis revealed 12 core patient priorities during recovery: feeling safe, being comfortable, engaging in mobility, participating in self-care, asserting personhood, connecting with people, ensuring family well-being, going home, restoring psychological health, restoring physical health, resuming previous roles and routines, and seeking new life experiences.

Besides patients' priorities after ICU discharge, there were also concerns about the importance of addressing the caregivers' need and supports. Choi et al. conducted a qualitative study using semi-structured interview data drawn from a parent study that longitudinally examined stress responses in the family caregivers of adult ICU patients.[7] The period ranges from patients' ICU hospitalization to 4 months post-ICU discharge. The results showed that the family caregivers viewed home discharge as a positive progress but reported having insufficient time to switch roles from being family visitor to being active caregiver.

Meyer et al, in an editorial, had addressed the importance of ICU physicians following up patients after ICU discharge.[8] Following them up has the following benefits:

a. Patient: a safety netting and coordination of ongoing care, provision of information/knowledge, contextualization of events, improvement in health-related quality of life (HRQOL), and as signpost to social and welfare benefits.
b. The family: providing understanding and information, signpost to resources and support, and expression of gratitude and emotional link to the unit.

CHAPTER 4: METHODOLOGY

4.1 Study design

A qualitative study design was used for this study. A qualitative description is appropriate for this topic, as it allows open responses to questions about how people feel, detailed descriptions of their experiences, and factors that facilitate or hinder aspects of their care in the hospital. Therefore, this type of study is used to explore and understand the patients' and their families' experiences of the critically ill patients needing admission to ICU.

4.2 Setting

The study was conducted exclusively at University Malaya Medical Centre Anaesthesiology Department. This study was approved by the departmental board review and the UMMC Ethics Committee. MREC ID 2023513-12440

4.3 Duration of study

The study was conducted from June 2023 until March 2024.

4.4 Study population

This qualitative study includes patients (ICU survivors who had received intensive care in UMMC for at least 48 hours) and their caregivers. Patient recruitment was done based on the inclusion and exclusion criteria.

4.4.1 Inclusion criteria

1. Patients who are less than 3 months post discharge from ICU
2. Aged more than 18 years old
3. Reside in Klang Valley area
4. They are fluent in either English or Malay languages

4.4.2 Exclusion criteria

1. Patient or family refusal
2. Not fluent English or Malay
3. MMSE score of 23 or less

4.5 Sampling Method and Size

This study used purposive sampling method to ensure maximum variations in term of age, ethnicity, gender, duration of ICU and hospital stay, relationship with the caregivers, types of illness, and the wards they are admitted to following ICU discharge. This sampling method aimed to capture a wide range of perspectives considering that culture and values can influence ones' perception and experience. This strategy allowed for the exploration of similarities across and differences between groups of people.

It has been previously recommended that qualitative studies require minimum sample size of at least 12 to reach data saturation (Clarke & Braun, 2013). Therefore, the researchers agreed a sample of 12 + 5 is deemed sufficient for the qualitative analysis and scale of this study.

4.6 Recruitment Procedure

Patients' details and contact details of patient's caregivers were available in the system for all patients admitted to the intensive care unit. Date of discharge from ICU, for patients who survived hospital stay, were also be available from the system. These patients were contacted and informed regarding the study by member of research team. Once an agreement was obtained, patients who were already discharged from the ward were scheduled under post intensive care clinic follow-up or for inpatients who were still in general ward, interviews were performed in general ward itself. Patient information sheets were provided to the patients and family members if they were still in the general ward or later during the outpatient clinic follow up. Consent to participate in the study was obtained at the start of the face-to-face interview.

4.7 Data Collection and Data Management

In the study, ICU survivors and their caregivers were interviewed face-to-face using a semi structured questionnaire. The interview topic guide was developed based on two theories: the theory of critical illness survivorship and theory of family care during critical illness.[11,12] In addition, both theories were used to guide the development of the theoretical framework for the current study. Both theories provide a comprehensive understanding of the research topic. Discussion with the experts (researchers and clinicians) in the critical care further shapes the theoretical framework and topic guide to suit the local context.

A separate interview guide was developed for patients and their caregivers. The patient's interview guide focuses on their experiences of being admitted in ICU and the subsequent wards they are admitted prior to discharge; we sought to explore their perceptions on care they received, the interactions they had with healthcare workers and their expectations. As for the family members, the questions were focused on their general caregiving experience in the hospital, its impact on the caregiver's life and their interactions with the healthcare workers.

The interviews took place at Post intensive care outpatient clinic in UMMC and in general ward for inpatients. All interviews were audio- recorded to facilitate analysis.

At the end of each interview day, all audiotaped recordings of the interview was transferred in its original voice form to a computer and kept in password protected folders. Accessibility of the data was only be available to the researchers. At the end of the study, all recordings were deleted from its original audiotape recorder. A separate folder was created to store related hardcopy materials such as patients' informed consent forms. The folder was kept in a safe place. All other data related to transcriptions and analysis were stored in digital format on a password-protected computer. Upon completion of the study, data was copied to a CD and the data on the computer was erased. This data will be kept for 7 years with limited access by specific members of research team which include our principal investigator , Professor Dr. Rafidah binti Atan with the other 3 co-investigators, Assoc. Professor Dr. Julia Anak Patrick Engkasan, Dr Soo Suet Ker and Dr Nur Nabila Qaisha Aswandi.

4.8 Data Analysis

12 patients and 12 caregivers were participated in the study. Not all participants were patient-family paired. The interviews were transcribed verbatim and analysed using thematic analysis according to Braun and Clark methods (Braun)[14]. To maintain the content of the interview to its closet meaning, the language used during the interview was kept in its original form during transcription. No personal identifiers were used in the transcripts; all participants were only be identified with a special identification number.

There are six steps in this method:

Step 1: Become familiar with the data

Step 2: Generate initial codes,

Step 2: Generate initial codes,

Step 3: Search for themes,

Step 4: Review themes,

Step 5: Define themes,

Step 6: Write-up.

In brief, the transcripts were read repeatedly to familiarize with the data. Subsequently individual phrases or paragraphs was labelled with descriptive codes that reflect the meaning of the data generated the initial codes. The codes that were conceptually similar were grouped into categories and were constantly compared within and across transcripts. The coding framework was revised iteratively until the team agree on the final framework, which then was used to code the rest of the transcripts. The final process involves defining and naming the themes.

The NVivo qualitative software package was used to manage the data.

CHAPTER 5: RESULTS

Data was collected from 24 interviewers which comprised of 12 patients and 12 caregivers. There were 18 Malay and 6 Chinese. 15 of them were female. The participants' age ranging from 28 to 82 years old. (Table 1)

Table 5.1 Characteristics of participants (n=24)

	Age	Gender	Relationship with patient	Subspecialty
Patient 01	70	Female	N/A	Medical
Patient 02	71	Female	N/A	Medical
Patient 03	48	Female	N/A	Medical
Patient 04	71	Male	N/A	ENT
Patient 05	82	Male	N/A	General surgery
Patient 06	63	Female	N/A	Medical
Patient 07	63	Male	N/A	Medical
Patient 08	66	Male	N/A	Vascular surgery
Patient 09	36	Female	N/A	Medical
Patient 10	46	Male	N/A	Orthopaedics
Patient 11	60	Male	N/A	Cardiology
Patient 12	37	Female	N/A	Cardiology
Caregiver 01	36	Female	Wife	Neurosurgery
Caregiver 02	48	Female	Daughter	Medical
Caregiver 03	61	Male	Husband	Medical
Caregiver 04	38	Female	Daughter	Medical
Caregiver 05	44	Female	Daughter	General surgery
Caregiver 06	68	Male	Husband	Medical
Caregiver 07	56	Female	Mother	Neurosurgery
Caregiver 08	50	Female	Wife	Medical
Caregiver 09	68	Female	Wife	ENT
Caregiver 10	66	Male	Husband	Medical
Caregiver 11	28	Female	Sister	Medical
Caregiver 12	55	Female	Wife	Cardiology

Figure 5.1 Main themes - (I) Recognition of potential sources of discomfort, (II) Intensive care services.

From this study, two themes emerged, namely

(I) Recognition of potential sources of discomfort

(II) Intensive care services

Several subthemes were identified under each of the themes as follows (Table 5.2)

Theme 1: Recognition of potential sources of discomfort

Patients and their caregivers may view their experiences differently, in both ways either negatively or positively. This is mainly attributed by their personal encounter throughout their days in ICU. Hence, early recognition of potential source of discomfort is crucial in order to provide favourable environment for both parties. The source of discomfort identified from this study is further classified into physical discomfort and psychological discomfort.

Physical discomfort

Pain has been mentioned as one of the most unpleasant experiences by critically ill patients. It is often associated with multiple invasive procedures in ICU such as venepuncture, invasive line insertion and presence of endotracheal tube or due to underlying illness as well as tissue injury following surgery.

…Pain but it is needed. It was painful..

(Patient 10)

… Was it painful? The cannula in the hand? (Interviewer)

It was painful. It was painful. Because my veins were not so obvious. So the doctor needed to use specialised machine..

Ultrasound? (Interviewer)

Possible. Because he poked many times, however no blood came out. So many times, it does hurt…

(Patient 09)

There were tubes, there was tube for urine, tube in the mouth. Then the blood taking part..I really cannot stand the blood taking pain at three o'clock in the morning. It was painful.

(Patient 01)

Yes, I felt uncomfortable, I wanted to eat, I wanted to drink water. It hurts too. At that time I can't drink water yet. I kept asking for water, I was thirsty.

(Patient 12)

Immobility and physical restraints are second most common source of discomfort in ICU. Most of the responses regarding physical restraints were perceived as negative experiences by the patients.

…Very, very! They tied! They tied my body, my legs. So, I felt uncomfortable. Painful! … I didn't like it because at that time people didn't let me get out of bed. I am workaholic. So suddenly I had to sit on the bed, I can't get down. So I felt suffocated… (Patient 09)

…There were times when I felt not comfortable. For example when my hands and feet were tied. So hard to move. Sometimes, my leg just kicked the bed... It wasn't my will... I don't know how that happened..

(Patient 08)

A good quality of sleep is very important for patients' general well being in ICU. Many of the patients complained they had difficulty to sleep in ICU. One of the causes is due to noise coming from ventilators and monitors as well as interruption by staffs at night and interventions in ICU. Some says it is due to their worry of the current situation that makes them has trouble to sleep at night.

… Because of a lot of wires attached, it was really uncomfortable. I always woke up due to the alarm whenever I changed position.

(Patient 01)

… In ICU , it was hard to sleep because the surrounding was disturbing. You can hear people walking etc… how you want to sleep. Suddenly someone came to check on you. It was disturbing…

(Patient 02)

…Sleep. As I said, no. My sleep was disturbed by ventilator…

(Patient 04)

…. I rarely sleep. That's what I said. That's one of my weaknesses. Because I can't sleep in the hospital.

I do not know. Other people can sleep, I can't sleep.

It's not uncomfortable, I don't know why I don't know. I don't even know…

(Patient 11)

While us being focused on treating the immediate pathology, we often forget some discomforts either directly or indirectly caused by the intervention or procedure . For example, the use of non-invasive ventilator has been described as one of the most uncomfortable devices associated with breathing support due to its strong wind and difficulty to synchronize with the machine.

… Even though I was uncomfortable using it but I understand I had to deal with it…

(Patient 04)

…Okay, in terms of the discomfort, the wind was too strong, that's all. But I think overall was okay…

(Patient 07)

…I was worried because I have never used that thing. It was my first time. Hence I was worried about it. When I wanted to breathe, I had to synchronize with the machine, I was not good at it at first, however after some time, I got used to it..

(Patient 11)

…The wind was strong and made throat dry. Some more, I can't drink a lot of water that time. I was on fluid restriction for my heart failure…

(Patient 12)

Other source of discomforts mainly associated with invasive and non-invasive ventilatory support such as feeling thirsty, hunger and inability to talk with presence of endotracheal tube.

…Does the ETT in the throat hurt?(Interviewer)

Indeed, the big tube, right? Of course it does hurt.. I was in pain and I was hungry..

(Patient 01)

…Yes, I felt uncomfortable, I was hungry, thirsty. It was painful as well. That time, I cannot drink yet. And I kept asking for water.

(Patient 12)

…I cannot talk. If I had something to say, I can only nod my head…

(Patient 01)

…I did not like that tube. Because cannot talk.

(Patient 10)

…What we see is that he can't eat. Also, if you wanted to talk anything, it was hard as well. But we accept that thing, because it is one of treatment, right..

(Caregiver 02)

Most of ICU patients tend to be admitted for longer duration and due to this nature of admission, it carries higher risk to develop pressure injury as they are usually bedridden and immobilised. Hence, proper regular turning by good nursing care is an excellent way for preventing the pressure sores. There was negative feedback by a patient and the caregiver that suffered from pressure injury following her prolonged ICU stay.

.. The only thing was the bedsore. I think the situation is the same for everyone who stays for quite some time in the hospital, you can get sore, right? After I discharged from the hospital, I did daily dressing at the clinic. So now, thank goodness it is improving. I used to have a big hole at the back...

(Patient 02)

…I'm not happy in the same reason that my mum had that sore, and we don't think it was actually a bad sore, it was because the delay in changing the diapers. So, if I had any complaints, that would only be it. (Caregiver 04)

Psychological discomfort

ICU admission has caused great impact to both patients and caregivers psychologically. Most caregivers expressed their mixed feelings when having their loved ones in such critical state. From making decision associated with the treatment for patients' well-being to hoping for miracles to happen is never easy for them.

Most of them are worried and unsure with the decision they made. Some see it as it is the best for doctors to decide on the treatment and they have their whole trust to hospital for patients' best interest.

…When I made the decision, I was confused and unsure whether that was the right decision. That makes me worried regarding this decision making. Because if we did not do, it will affect him, if we felt like he doesn't need it, he might need it. We feel like it might affect him in the future…

(Caregiver 01)

…Of course, age and all that, so we worried the survival because he has to go on the anaesthetic, right? So that was all concerned.

(Caregiver 05)

Some worries are related to the critically ill condition with its dynamic state in nature and the prognosis is often unclear, hence it is never easy for both patients and their caregivers.

…That time how I feel?! It's very difficult to express it … I was very, very worried because she doesn't know… The way it looks like she doesn't know herself. Because she started removing herself, she cannot walk. So we have to call the ambulance to carry her…

(Caregiver 06)

…So, it's like worrying that we do not know what will happen to her whether she will be alive or not…

(Caregiver 11)

…Oh I felt so worried and there were so many things in my mind. I have never faced this. The doctor told me that he has a lot of complication, because he is a diabetic patient…

(Caregiver 12)

…Worried, because we have never experienced this kind of situation. This was the first time for me. Because I never had any treatments, nor hospital admission whatsoever. So, I was so scared at that time…

(Patient 11)

Ineffective communication has been emphasised as one of most concerns for both patients and caregivers. This includes conveying of incomprehensible patients' information with medical jargon use, inadequate information, not having regular update regarding patients' progress to caregivers and improper delivery of nursing care.

… So, every time we want to get updates, you know, so we had to call early morning you know. So, my daughter would call the ICU counter there. So, like from 7 to 9. you know we noticed that nobody would pick up that call. I think the doctors or nurse were very busy but after 9, then usually someone will pick up the call and we will get update you know.

(Caregiver 09)

…Because we are not... Because I don't fully understand what they try to do. Okay. So, they are trying to tell me in a way of... In a doctor's term that she needs this… in the manner of a normal person unable to understand the terms or the words…

(Caregiver 06)

…Some of the nurses were very good. But, there was one time, the machine beside me kept alarming. I think it was midnight and the sound was very noisy. Then I pressed the button to call them but they took so long to come. So, I called again, so after that, one nurse came and scolded me. She said, 'Do you think you are the only one patient I have to attend?' I replied to her, 'No, you just off the machine and then you can attend to your patient after that.' That was the worst experience so far…

(Patient 06)

Table 5.2 Themes, subthemes and sub-subthemes of ICU Survivors' and Caregivers' Experiences of Inpatient Care

THEMES	SUBTHEMES	SUB-SUBTHEMES
POTENTIAL SOURCE OF DISCOMFORT	Physical	▪ Pain ▪ Sleep disturbances ▪ Immobility ▪ Noise ▪ Discomfort with NIV ▪ Hunger ▪ Thirst ▪ Inability to talk ▪ Pressure injury
	Psychological	▪ Worry ▪ Ineffective communication ▪ Experience of loss of memory ▪ Fear ▪ Hallucination ▪ Orientation impairment ▪ Depressed ▪ Despair
INTENSIVE CARE SERVICES	Medical requisite	▪ Effective communication and high quality of information ▪ Excellent pain management ▪ Good nursing care ▪ Conducive ICU environment
	Psychological requisite	▪ Emotional support ▪ ICU support and counselling group
	Social requisite	▪ Multicultural sensitivity ▪ Favorable waiting area ▪ Longer visiting hours

Many of ICU patients especially intubated patients were unable to recall their experiences in ICU as well. Some had orientation impairment during their stay, possibly due to ICU environment condition without proper window and clock which might be helpful to reorientate these patients.

…Yeah, but frankly while you're in the hospital in such places. You cannot know whether it's daytime or nighttime…

(Patient 05)

One of the patients shared her experience being in ICU as the most pleasant feelings. She described her hallucination as if she was sitting in the clouds.

…Well, it's like I'm sleeping, it's like I'm sitting in the clouds. Yes, feeling calm, relax.

(Patient 12)

Other psychological discomforts such as fear, depressed and despair have been described by caregivers and patients. When it comes to shared decision making in relation to intubation, it may cause a tremendous fear in the caregivers of losing their loved ones especially after the Covid-19 pandemic.

… When they said they were going to intubate my mom and have to sedate her. And we all know during COVID, especially intubation, usually the people don't wake up from an intubation. So, when we heard that she was going to be intubated, we didn't think she was going to wake up. So, at that point, until she's out of the ICU, and then we had hopes again.

(Caregiver 04)

…Well the facts you told me, I would be scared because we don't know what's happening...

(Caregiver 06)

…Everyone was afraid. Fear, sad, all of these because our family have experienced the death in the family before. So, we don't want that to happen again. The first was our late sister, then our late father. So, we felt the loss, When she got admitted, we were afraid, sad. We don't want to go through the same again…

(Caregiver 11)

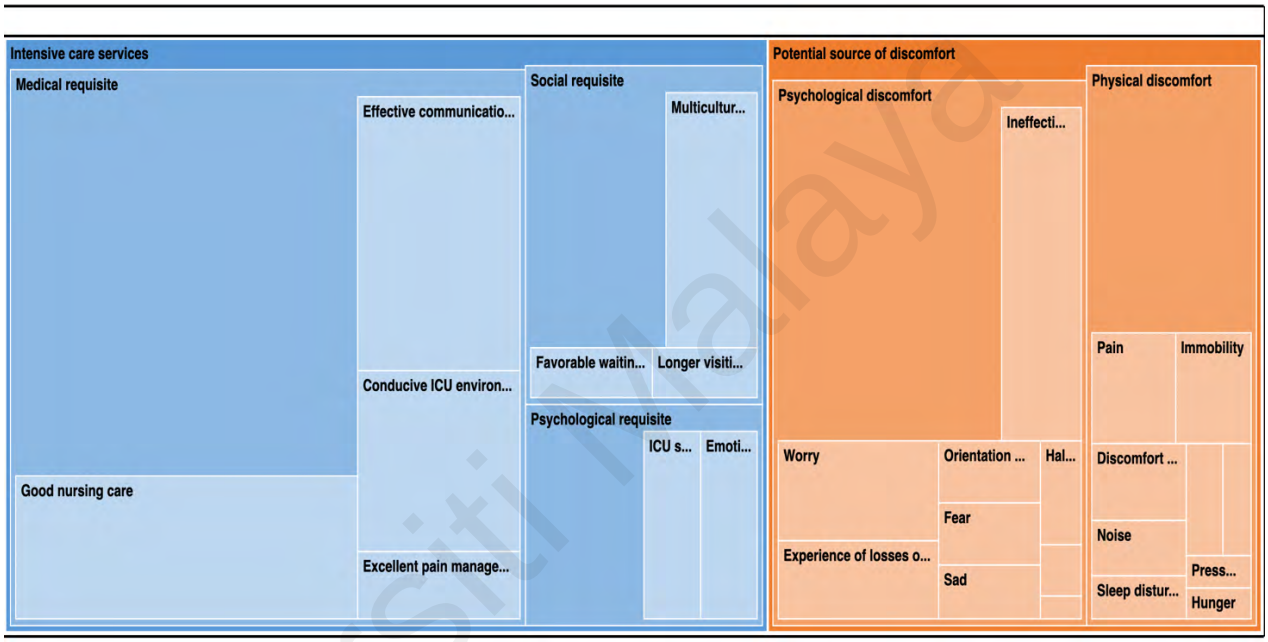

Figure 5.2 – Hierarchy chart of themes, subthemes and sub-subthemes of ICU survivors' and Caregivers' Experiences of Inpatient Care

Second theme developed is intensive care services which comprised of medical , psychological and social requisite. This theme is developed as a result of combination of patients' and caregivers' experience, their requisites and the uncovered discomfort sources during their intensive care unit stay.

Medical requisite : Effective communication

For medical requisite, effective communication and high quality of information are the major concerns for both patients and caregivers. Being a critically ill patient with a constant threat to death, an explanation for better understanding regarding the condition is valuable by these patients. The same thing applied to their caregivers, with strict ICU visitation policy, daily update on patients' progress may help alleviate the stress faced by the caregivers.

…And when talking about the good thing, I think the doctor's part, I would say they are very informative and cooperative. Whenever I ask questions, they will explain thoroughly.

(Caregiver 01)

…Doctors came up to us and said they never, you know, asked us to go away even if they were busy and they could see us being very distraught. They came up and explained very nicely, which is how you should deal with people, distraught people. So, yeah, I've got no complaints so far…

…Like I said, they explained very well, adequate. It was enough for us to make any sort of decision in the future.

(Caregiver 04)

…We were told that the UH doctors are good and I believe so. And I think they were also dedicated to provide updates to us which we appreciated…

(Caregiver 05)

…I think they were doing very good because every time when I was there, I mean there was a doctor who informed you, highlighted you every day..

(Caregiver 06)

…Yeah, I trusted the doctor and of course I don't know what is it, how they treat the patient. So my full trust is with the doctor and whatever they do, I believe is for the welfare of the patients...

…Yeah, they were very good and very professional, very helpful. Even in the ward also, they were willing to share information to me whenever I asked them and I think they were very committed…

(Caregiver 10)

…Frankly, I am really satisfied with the nurses there, including the doctor. I have no problem in ICU, I have no problem communicating with nurses or doctors. They explained to me what I needed to know, or whenever I wanted updates, I can get information quickly, without any problem..

(Caregiver 12)

…No, everything was okay even though I was not good at English but someone explained to me...

(Patient 01)

…I have no problem with communication. They were very easy. Whenever I asked, they answered. Because I am the type who likes to ask…

(Patient 02)

…Of course, I have difficulty in communication because of my speech, slurred speech and hearing. When I was in ICU, I did not have my hearing aids on. So the nurses came and sat with me and I had to search for my hearing aids and plugged in. Then only I can hear them and replied to them but they did not understand me (because of slurred speech) , so I had to ask for a piece of paper and write it down. Then communication was improved…

(Patient 04)

…I think I understood. My husband also can accept it…

(Patient 12)

Medical requisite : Good nursing care

Caring for critically ill patients is an essential aspect of medical requisite in intensive care services. From this study, although some respondents described their negative experiences, majority of them complimented the good nursing care they received while admitted in intensive care unit. Good nursing care has significant impact on the quality of care delivered as well as satisfaction of both patients and caregivers.

…What I saw was a nurse on the side. Two people. So, even if we can't meet. We can ask everything we wanted to ask. Regarding the progress and everything. What was the blood reading, what was the heart reading? We had two nurses on the side, so I think that was okay.

(Caregiver 02)

…I think it's amazing that I was told there are two nurses for each ICU bed, and I think that's even better than any private hospitals I've gone to…

…I usually see the nurses, at least every time I came, I saw a nurse there…

(Caregiver 04)

…We were told that for ICU patients, they have a dedicated nurse, which is good, so that they don't miss out on the things that they need to do for the patients, so that's good…

(Caregiver 05)

… No, there's nothing to be disliked. Just that I was a bit shocked when I came to ICU in the afternoon, I can't remember which day, she was not on her bed. And they told me that she went out to the garden. I was shocked. She was sick, how come can go out to garden, and so I went out looking out for her. And then I found her, she was actually at the back near some canopy...

(Caregiver 10)

…If you look at the aspect of care, it's actually good because there is one nurse for each patient, the one to one care which is good…

(Caregiver 11)

.. The care is okay. If I called, they would attend immediately. It was okay. There was no delay. Even if they had other things to sort out, they would inform me first and other staffs would do later…

(Patient 01)

…But so far, ICU services are all good, doctors all are very good. And the nurse also are very good.

(Patient 02)

…My experiences in ICU stay, I stayed many days in ICU and throughout the stay, I was very surprised at the very good care of the ICU, and the people in charge…

(Patient 04)

… I remembered they wanted to send me to the ward. Then the nurses came and dressed me and everything. I felt so very comfortable doctor...

(Patient 06)

…It's like I said earlier, the situation was very comfortable and the nurses were committed to the patients, thank goodness. We can give 5 stars to them. Sometimes they cleaned my diapers. Even if at home, it is not guaranteed we will get that. But thank God. Everything was really comfortable.

(Patient 08)

…Maybe one of the best for me. Because I have never received treatment before. But what ICU did was probably the best for me. They took a very good care of me.

(Patient 11)

…Nurses, doctors. The ones who were close to me were the nurses. They were the ones who care, gave medicine, bathed everyone…

(Patient 12)

Medical requisite : Excellent pain management

Pain management can be challenging in critically ill patients due to complex nature of diseases which is also limited by their ability to communicate the pain especially among intubated patients. Hence, structured approaches to pain with adequate prescribed pain relief will ensure optimal pain control. Most patients from this study denied of any pain associated with the presence of endotracheal tube during their ICU stay.

… But then, during, when they taking out the tube, do you remember the feeling? When they removed the tube like finally. Was it painful? (Interviewer)

No...(Patient 10)

…There is no pain with the tube. But I don't like people tied me. I really don't like it…

(Patient 09)

…Yes the surgery.. It was very good I must say because I don't feel anything..

(Patient 05)

…Do you remember the feeling at that time? Does it hurt? (Interviewer)

Nothing. No pain.

(Patient 02)

That means the sedation must be very good (family interrupts) …

Medical requisite: Conducive ICU environment

The next important requisite in medical care is providing a conducive intensive care unit to ensure patients' and caregivers' comfort while being in intensive care units as the environmental factors such as noise, lighting might interfere with normal circadian rhythms as well as affecting patients' sleep. This often results with psychological sequelae such as anxiety, worry and cognitive impairment. All participants spoke positively about ward environment and facilities.

...I like that because he was really isolated in that one glass room…

(Caregiver 02)

…Yeah, it's fine. I like the way that it's a very comfortable ICU. Like I said, I can't even see it in the private (hospital). Because they have very big room for each patient, it's not even like a tiny room. You know, no, it was very okay…

(Caregiver 04)

…Well, as far as a hospital concern, the colour is I can see there's so many colours inside. Very impressive in a way. But as you know that most of the time when we came in, we did not look at left and right, but the markers around the floor. It's a good marker to show the location of the rooms…

(Caregiver 06)

The ICU good, well equipped. You know, big rooms, all these...

(Caregiver 09)

…It's very nice. They have system and even the walkway also is easy to be detected because they have coloured lines for you to walk…

(Caregiver 10)

…When I wanted to sleep, I would tell them to turn off the light. They switched it off. It was easy, I can sleep and it was not too bright…

(Patient 02)

…No, no. If it was too bright, I would tell the staff nurses to turn off the light…

(Patient 04)

.. I think it's very nice, very good. And then the noise is normal for a hospital, isn't it?

But in ICU, they can close the door. When they closed the door, I did not hear anything…

(Patient 06)

…Comfortable. Because there is single room for each patient. They have comfortable bed. So every room has a nurse who takes care of it. So to me it's okay, everything is okay. That's good…

(Patient 09)

…Okay, now it's very clean. Very clean. Look very new. Yeah the machine is very new machine is very new. Yeah, very good..

I'm okay with the lighting. At night they would switch off the light for you…

(Patient 10)

Social requisite

One of the most important aspects in intensive care in Malaysia is multicultural sensitivity due to ethnic diversity. Most patients and caregivers claimed the religious and spiritual needs were met during ICU stay and visitation by religious figures are not required.

…Everything was well taken care. They normally would ask whether I wanted to perform ablution or recite Al-Quran…

(Patient 01)

…If you were in that situation, you did some silent prayers, this kind of thing…

(Patient 05)

…Alhamdulillah, I was also reminded by the nurses that I was in such critical situation, she told me to remember God. I think it helped a lot…

(Patient 08)

…I think it was okay. But when I passed by, I heard someone put on the Al-Quran radio ···(Caregiver 01)

…Yes, because after she was like slowly gaining consciousness, we saw them putting Quran verses and stuff, which is good because she usually recites the prayers and she never stop praying every day. So, when she listened to that, I think it was also a positive thing...(

Caregiver 04)

…Yeah, he told me that when he put on the Chanting music, then the nurses closed the door. I feel like if he wanted to put it on, should let him to put on. They did not stop him. But they closed the door…No, no, I'm not saying it was culturally insensitive. At least they didn't prevent him from doing it, then should be okay…

(Caregiver 08)

… But if talk about religion in the ICU, I feel religion shouldn't come into the picture…(Caregiver 10)

…There is a nurse, she has a friend there. So she came and palyed the verses of the Quran while she was being put to sleep. I don't think religious figure visit such as Ustaz is needed…

(Caregiver 11)

…It was in the ICU that he asked to pray , so I just told the nurse that he wanted to pray.Apparently they can assist him to perform ablution and prayer. So there is no problem with his religious need in ICU…

(Caregiver 12)

Issues that concerned patients and caregivers was the exposure of the patients as it is regarded as inappropriate and sensitive.

…Like I mentioned earlier regarding exposure. Sometimes, when they did some cleaning, if possible ,they should fasten the process. Because we have to cover the 'aurah'. That's dignity…

(Caregiver 03)

…It's like the service, they should cover the 'aurah',because we wear hijabs, but when ICU, it was exposed. It was not covered properly. Hopefully this can be improved in the future.

(Patient 03)

Other social requisite mainly expressed by the caregivers are favourable waiting area with more seats provided and consideration to extend the visiting hours. Preference for longer visiting hours was addressed due to inadequate time for relatives and friends to visit especially during pm sessions when everyone is out of work. On the other hands, most patients were comfortable with the current visiting hours as they believed being critically ill patients, they rather spare the time to rest and to limit unnecessary interaction.

… We should extend the visiting hours. It was not enough. The noon session was okay for me as no one came. But in the evening, my children were all there, and then my colleagues came back from work in the evening as well.

(Caregiver 12)

… Yeah, I mean, I think it would be better if you could have three timings instead of two…

(Caregiver 04)

…Environment, I think the waiting room needs to have more seats. Need have more seats…

(Caregiver 06)

One of the participants suggests limiting the number of visitors in order to make it more private and exclusive.

… Usually, there were a lot of the family members and it was really packed which is not supposed to be that way . It should be more exclusive, private…

(Caregiver 05)

Psychological requisite : Emotional support, ICU counselling and support group

Participants have agreed that healthcare workers namely doctors and nurses play major role in providing emotional support to critically ill patients in which this effort was highly praised by both patients and caregivers.

… Doctors came up to us and said they never asked us to go away even if they were busy and they could see us being very distraught. They came up and explained very nicely, which is how you should deal with people, distraught people. So, yeah, I've got no complaint so far…

(Caregiver 04)

…Because they were nice to me. When I called, they would come. They were very nice, talked to us nicely…

(Patient 6)

Meanwhile for ICU support group and counselling, many suggest to make it as optional. It may be beneficial for those with special circumstances. For example, those who are in needs of support such as family with young children and those who lack of family support.

…But probably there are some patients who after the ICU care, maybe they need some support. Maybe they need some help, maybe they need some counselling or therapy. But for us, we're fine because we're very close to each other. So, if any one of us is down, three more to help us…

(Caregiver 04)

…I think it is necessary. Just give some supports. Like Dr (name of the doctor). I don't know his full name. But he is very good. He gave support to my husband. He would asked about his condition outside ICU and even advised my husband to get some rest. He gave a lot of support to our family…(Patient 12)

CHAPTER 6: DISCUSSION

From this study, we identify the potential source of discomfort with the aim of deepening the understanding of their needs in order to ensure a high quality intensive services is delivered. With the knowledge of potential discomfort, this will further assist us in guiding the development of better ICU policy which also takes into account both patients' and caregivers' perceptive based on their personal experiences.

As mentioned earlier, we further classify the source of discomfort into physical and psychological discomfort. Physical discomfort including pain, sleep disturbances, immobility, noise, discomfort with NIV , hunger , thirst, inability to talk as well as the occurrence of bedsore. On the other hand, there were also psychological discomfort that has been reported by both patients and caregivers such as ineffective communication caused by nurses' attitude and limited access for updates, worry , experience of loss of memory and inability to recall, fear , sad and despair. Perhaps by uncovered the potential source of discomfort, we will be able to develop a protocolised standard ICU care with focus on patient- centred and family-centred care.

Pain is one of the most discomfort being highlighted by the patients, followed by sleep disturbances and immobility. Hence , it is important to ensure excellent pain management is carried out in daily intensive care service in order to reduce physical and psychological stress of critically ill patient and to improve the quality of care. This include routine assessment of pain as 5th vital signs during daily rounds, assessment of effectiveness of prescribed analgesia as well as its side effect. Pain management in ICU can be complex as patients may experiences pain from multiple sources including disease nature or intervention. Hence, a regular pain assessment and management is vital due to the state of critically ill patients which include impaired communication and mental state. [16] Patients' self-report such as use of Numerical Rating Scale (NRS) is

the gold standard for pain evaluation in those who can communicate. Meanwhile, for those who cannot communicate their pain such as mechanically ventilated patients, other tools for pain assessment such as Behavioural Pain Scale (BPS) and Critical Care Pain Observation Tool (CPOT) have been developed and proven in clinical trials.[17] Multimodal approach should be employed which consist of combination of different analgesia with different mechanism of action and different technique such as combination of oral administration and regional technique. The various types of analgesia include opioid-based analgesia , non-opioids based analgesia such as acetaminophen, NMDA receptor antagonist, non-selective anti-inflammatory drugs, gabapentinoids as well as regional anaesthesia. The treatment should be tailored to the severity of the pain and on case-by-case basis in order to improve critically ill patients' quality of care.

From this study, the nurses have described the quality of care as a comprehensive care which includes staff capability in term of ward work and communication, ability to fulfil patients' requisite which will ensure patients' well-being and satisfaction.[18] Our participants highlighted that being managed by dedicated nurses has affected their ICU experiences positively. They also agreed these staff nurses should be acknowledged for being not just excellent providers for physical care but also for emotional support. The realisation of excellent patient-centred care would be possible if nurses have knowledge on the elements affecting patients' perception.[19]

The pillar of good nursing care made up of both verbal and non-verbal communication during daily bedside care. Verbal communication should be effective to engage with patients in order to avoid them feeling isolated in such vulnerable period and feel supported. On the other hand, non-verbal communication which includes emotional as well as physical touch by experienced, skilled and knowledgeable nurses offer a great help for critically ill patients.[20] However, there are several limiting factors to effective communication such as limited time due to workload, disparities in care giving by multidisciplinary teams, lack of awareness among the healthcare staffs.[21] Hence, for a good and quality nursing care to be delivered in ICU, regular training for nurses is necessary in order to yield a group of dedicated, skilful and informative nurses who can deliver not just proper bedside care but also able to establish good interaction with both patients and caregivers. Continuity has been mentioned as one of the important factors contributing to good nursing care.[20]

Several other discomforts being mentioned in this study including immobility and physical restraint as well as the occurrence of pressure injury. We believe these issues can be tackled with good nursing care and proper explanation is mandatory to be given to caregivers or even to patients themselves once they regain their consciousness or able to comprehend command.

Physical restraint is any methods that inhibit movement voluntarily. Movement can be restricted in many ways such as physical restraint with the use of tie or achieved with sedation.[22] However, healthcare staffs should have clear indication before applying physical restraint. Emphasis on patient's safety in this action should be highlighted to patients and caregiver, for instances, to prevent fall, prevent self extubation or removal of medical devices or tubes, or to control movement in certain patients such as in those who are combative and harmful to staffs. Risks and benefits should be carefully weighed for patients' best interest before applying physical restraint owing to its unpleasant effect on physical such as pain or direct trauma to skin as well as psychological outcomes. Patients' perspectives may differ depending on the nature of illness they have as well as their personal encounter and experiences

during ICU stay. Some patients may view this as negative experience as being recorded in this study. [23] The responsible bodies are suggested to implement a clear and proper guideline for use of restraint in ICU, in concordance with educational training to staffs to improve understanding related to ethical practices, physical restraints guidelines and patients' and caregivers' right.[24]

Pressure injury is one of the sources of discomfort being reported by participants and its occurrence reflects the level of nursing care as it is considered iatrogenic which may cause great dissatisfaction in patients and caregivers.[25] Nurses play major role in preventing pressure injury as they are the persons who spend most of time with patients at bedside and it should be guided by a protocol which is developed according to evidence-based medicine and matching patients' requirement. To ensure the effectiveness of the care, regular training and education for nurses and doctors should be incorporated as part of system to improve knowledge on bedside care.[26]

Effective communication is a collaborative effort of intensive care service among physicians, nurses, patients and caregivers. Patients and caregivers addressed the importance good communication behaviour, high quality of information, which is comprehensible by non-medical persons are necessary to improve patients' and caregivers' understanding on the situation, as well as alleviate the psychological burden such as stress and anxiety. The information conveyed should be direct and not complicated with layman terms used is important to ensure effective communication.[27] Some caregivers shared they did not understand the explanation given. For example, the meaning of intubation but still consented for patient's best interest due to their lack in medical knowledge. From recent studies, being in uncertainty state has negative correlation with quality of life either physically or mentally. With provision of adequate information, this may help to alleviate the degree of uncertainty and worries.[28,29]

Our study shows most of the time, nurses are those who interact the most with patients and caregivers while in ICU. The bedside care and their presence are noticed by patients and caregivers especially during visiting hours and they are often being referred to by caregivers to enquire regarding daily updates. Doctors and nurses play important role in improving patients' engagement in their healthcare through various communication skills and strategies. Doctors are involved in giving treatment, leading discussion and decision making, while nurses act as intermediaries between doctors and patients as well with their caregivers.[30,31] Be present and actively engaging in discussion and communication is one of the important components of communication. The idea of creating patients-centred and family-centred care, participation from both patients and caregivers are essential especially in shared decision making to ensure they are adequately informed and explained that will improve their understanding on the situation.[32] Reassurance is one of the element in effective communication dur to their dynamic state in intensive care unit. Patients were more reassured by listening to experiences of previous patients shared by nurses or doctors.[33] It has been voiced out that there is lack of designated communication channel and no specific allocation for regular updates.

Environment plays a crucial part in creating patient – centred and family-centered intensive care unit. An ideal intensive care unit should be designed to promote recovery and provide safety for the critically ill patients. Environmental factors such as noise from monitors and ventilators alarm as well as light may interfere with normal circadian rhythm which leads to sleep disturbances in most patients. This interference often results in psychological sequalae such as delirium , hallucination that delays the recovery process.

To maintain circadian rhythms, presence of window might be beneficial to allow natural light into the room during daytime and dimming the light at night during bedtime. On the other hands, minimising interruption by healthcare staffs, for example late night procedures, staffs' conversation, use of acoustic earplugs are strategies to reduce noise exposure in ICU.[34] Noise is one of the challenging factors that contribute to sleep disruption due to complexity and dynamic works in ICU. Knowledge on the importance of good sleep and to maintain the normal circadian rhythm of critically ill patients should be incorporated into the medical requisite of ICU care and this should be able to generate awareness among healthcare workers. Provision of conducive intensive care unit for critically ill patients and family is the ultimate goal.

ICU is a place where accidents tend to happen due to its intricacies which are attributed by the stress, complexity of care and cases.[35] One of the immense requisites by critically ill patients is feeling safe. This should be emphasized in training and daily practises to ensure the needs are met.[36]

Since this study is conducted in Malaysia, a multiracial country, an important social requisite in delivering care is respecting the values and sensitivities associated with all races in Malaysia. From this study, there was no issue arose regarding cultural sensitivity across different races and their religious and spiritual needs are well taken care in ICU. Religion and spirituality play an important role in coping with critical illness for patients and families especially when it comes to decision making and understand the prognosis.[37]

From this prospect study, 77.6% participants highlighted the important of religion and spiritual needs in their lives. Efforts to increase the satisfaction in terms of religious needs should be made such as regular assessment from patients and caregivers' perspectives on this matter daily as well as consideration on the involvement of spiritual-care providers as part of services.[38]

Cultural aspects are considered one of the protective factors against psychological adverse outcome such as depression and anxiety. From this study, it showed that family members were the ones who psychologically affected in greater extend when compared with the patients themselves especially with their loved ones passed away. The duration of sufferings among family members appeared to be longer when compared to critically ill patients which lasted for about 3 months. [39] There was positive correlation in psychological outcomes such as depression and anxiety associated with high level of spirituality. [40,41]

Apart from that, the participants expressed the need for extra seats to be provided at waiting area. Regarding visiting hours, the results shows that caregivers would like to have more visiting time, while most patients consider the current visiting hours is adequate. At the moment, flexible visiting hours has been implemented for selected cases in order to allow the caregivers to be near to their loved ones especially in severe cases requiring prolonged intensive care stay as well to directly participate in patients' care in ICU during recovery process. It has been debated over open versus closed visiting. In order to decide on the selection of types of visits, several considerations have to make such as proper planning and training for staff nurses and doctors, risk and benefits of each visit.[42] Visiting hours flexibility should be tailored to patients' condition and needs, while open visitation may increase satisfaction among caregivers.

Provision of ICU environment in parallel with patients' and caregivers' needs to increase satisfaction requires strategies to improve in many aspects such as infrastructure, by increasing the number of chairs at waiting areas, making some changes in visitation policy, increasing staffs' performance with education and training.[43]

Critical illness survivorship often associated with worsening physical state as well their psychological state. This is not limited to patients per se, their family members are equally affected at this stage. Hence, emotional support to get them through this vulnerable period is crucial by providing enough support required for them to cope with the stressful nature in ICU. There were psychological adverse outcomes such as anxiety, depression and post-traumatic disorder syndrome (PTSD) associated with critically ill patients mentioned in earlier studies. Predisposing factors to this including prolonged ICU stay and prolonged ventilation, underlying mental illnesses or orientation impairment. [44,45,46,47] Meanwhile, for caregivers, those who were devastated with poor prognosis cases as well as passing of their loved ones may suffer from psychological disturbances as well.[48,49,50] Several studies show high quality information and adequate support from healthcare staffs may help to alleviate their worries, anxieties which may lead to more serious adverse outcomes such as depression and PTSD. [51,52]

This systemic review shows the positive correlation of ICU intervention with psychological outcomes. These include having ICU diaries, rehabilitation and post-intensive care follow up, effective communication and high quality information as well as great psychological support.[53] There was less number of cases associated with PTSD with the implementation of ICU diaries in critically ill patients.[54]

It has been proven with adequate information and enhanced moral assistance have made considerable reduction in psychological adverse outcomes among caregivers in ICU. Specific intervention should be designed to adapt with patients' and caregivers' requirement. Simultaneously, other contributing factors need to be considered in order to match the intervention required. ''From this meta-analysis, significant improvement among caregivers was seen at 3 months (depression: MD = − 0.68 [95% CI, − 1.14 to − 0.22; *n* = 5], moderate certainty; posttraumatic stress: SMD = − 0.25 [95% CI, − 0.49 to − 0.01; *n* = 6], very low certainty) and 6 months (anxiety: MD = − 0.70 [95% CI, − 1.18 to − 0.22; *n* = 4], moderate certainty).''[55]

Conclusion

This study uncovers patients and caregivers' experiences on the potential source of discomforts and the intensive care services. Potential discomforts were classified into physical and psychological discomfort. The most reported physical discomfort including pain, immobility, discomfort with NIV use, sleep disturbances, noise, pressure injury, thirst and hunger. Ineffective communication, experience of loss of memory, worries, fear, sad and despair were among psychological discomfort experienced in ICU. Further exploration on the intensive care received in ICU were further classified into medical, social and psychological requisites. Medical requisites include effective communication, good nursing care, excellent pain management and conducive ICU environment were highlighted. On the other hands, ICU emotional support and counselling group were highly appreciated to meet most of psychological needs. Multicultural sensitivity, longer visiting hours as well as more seats at waiting room were mentioned as part of social requisite.

With the recognition of potential source of discomfort as highlighted in this study, as well as through patients' and caregivers' first hand experiences, together with the current literatures regarding ICU experiences, these will be useful references on establishing patients-centred and family-centred intensive care service which will be more beneficial for both patients and caregivers as well as increase their satisfaction with ICU services.

The knowledges gained from this study will be able to contribute to the development of new approach to intervention and care such as educational materials for ICU patients and caregivers as well as ICU staffs.

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