

## CHAPTER 4

### Findings and Discussion

The purpose of this study is to explore the intensive care experience among intensive care unit (ICU) survivors in three government hospitals in Malaysia (Hospital Tengku Ampuan Afzan, Hospital Raja Permaisuri Bainun, and Hospital Taiping). The findings are presented in two parts: (1) demographic characteristics of the samples, and (2) the level of four domains of intensive care experience. Discussion was conducted based on research objective and results of the study.

#### Findings

##### Part I: Demographic Characteristics of the Samples

Sample for this study consisted of 142 ICU survivors and the demographic characteristics of the samples are presented in the Table 2.

Table 2

*Frequency and Percentage of Demographic Characteristics of the Samples (n = 142)*

Characteristic	Frequency	Percentage (%)
Gender		
Male	81	57.0
Female	61	43.0
Age (years)		
(mean: 39.93, SD: 12.189, range: 18 - 64)		
Young adult (18-35)	56	39.0
Middle age adult (36-55)	69	49.0
Older adult (56-64)	17	12.0

Table 2 (continued)

Characteristic	Frequency	Percentage (%)
Types of admission		
Planned	47	33.1
Unplanned	95	66.9
Conscious level		
Conscious	36	25.4
Not conscious	106	74.6
Ethnicity		
Malay	100	70.4
Indian	17	12.0
Chinese	14	9.9
Others	11	7.7
Length of stay (days) (mean: 12.07, SD: 15.367, range: 2 - 90)		
Religion		
Islam/Muslim	109	76.8
Hindu	13	9.2
Buddhism	8	5.6
Christian	7	4.9
No religion	5	3.5
Education level		
High school	97	68.3
Diploma/ Certificate	21	14.8
University level	24	16.9
Severity of the condition in ICU		
Not severe	16	11.3
Moderate	79	55.6
Very severe	47	33.1
Ventilator support		
Yes	134	94.4
No	8	5.6

Table 2 (continued)

Characteristic	Frequency	Percentage (%)
Sedation		
Yes	117	82.4
No	6	4.2
Not sure	19	13.4
Medical diagnosis		
Heart problem	19	13.4
Kidney problem	15	10.6
Dengue fever	13	9.2
Respiratory problem	11	7.7
Motor vehicle accident	10	7.0
Diabetes	3	2.1
Neurology problem	2	1.4
Others	69	48.6

From table 2, a total of 142 ICU survivors were included in this study. Out of 142 samples, 81 (57%) were male and majority of the samples were Muslim (n = 109, 76.8%). More than half of the samples completed their education in high school (n = 97, 68.3%) and length of stay ranged from two to 90 days (mean: 12.07). From 142 samples, 95 (66.9%) were categorized as unplanned admission, and 106 (74.6%) samples claimed not fully conscious during stay in ICU. More than half (n = 79, 55.6%) reported having moderate severity of the condition in ICU, and almost all of the samples had been intubated (n = 134, 94.4%). Around 117 (82.4%) samples received the sedation during their stay in ICU. Approximately 13% of samples had heart problem as their main medical diagnosis, and 7.7% had respiratory problem.

## Part II: The Levels of Four Domains of Intensive Care Experience

The levels of each domain from intensive care experience were classified into two levels by using class interval, high and low. Under the level of each domain, the summary of response from open-ended question was presented (Appendix I).

Table 3

*The Level of Domain Awareness of Surrounding (n = 142)*

Domain/Score	High [n (%)]	Low [n (%)]
Awareness of surrounding (9 questions) (Mean: 25.61, SD: 8.916, range 9 - 44)	71 (50.0%)	71 (50.0%)

*Note.* Range of possible score: Low = 9-26, High = 27-45

Table 3 showed 71 (50.0%) samples that claimed highly aware with their surroundings and another half samples were unaware about what has happened. Results below were the responses from the open-ended question and further information can be seen in Appendix I.

Further question was obtained in this domain regarding presence of whom that makes samples felt safe during their stay in ICU. The samples claimed they felt safe with the presence of family members, and the reason was only family members know them well so the sense of familiarity made them feel safer (n = 72, 50.7%). About 31 (21.8%) samples answered presence of both staff and family members make them felt safe as long as there was someone nearby. Fourteen (9.9%) samples reported presence of staff whose was always by their side whenever they need help and always encouraged samples for the recovery made them felt safe in ICU.

In this study, samples were asked regarding their awareness towards place, people and time. The given answer were samples claimed they were not aware about people, place and time during their stay and the reason was they were in massive pain caused by the illness (n = 54, 38%); samples were aware about place, people and time after received an explanation from the staff (n = 25, 17.6%); and samples claimed of full consciousness about their surrounding including time, place and people (n = 23, 16.2%).

Table 4

*The Level of Domain Frightening Experiences (n = 142)*

Domain/Score	High [n (%)]	Low [n (%)]
Frightening experience (6 questions) (Mean: 20.39, SD: 5.447, range: 6 - 30)	96 (67.6%)	46 (32.4%)

*Note.* Range of possible score: Low = 6-17, High = 18-30

Table 4 showed 96 (67.6%) samples had high level of frightening experiences, while 46 (32.4%) were not frightened. Results below were the responses from the open-ended question and further information can be seen in Appendix I.

More than half of the samples reported were afraid when they were asked regarding their feeling while staying in ICU. About 22 (15.5%) samples claimed they had no comment, and 16 (11.2%) samples answered they had unexplainable feeling about their stay.

The events or moments that made samples in this study felt helpless, scared, felt like dying, or pain were felt scared (n = 46, 32.4%) resulted from nightmares, seeing things or scary creatures like shadows or ghosts, afraid of dying, progress of illnesses, and some procedures in ICU; pain (n = 29, 20.4%) resulted from procedures, positioning, immobility, and affected side of the body; and felt helpless when they feel weak on parts of their body (n = 21, 14.8%).

Samples were asked about their frightening moments or events in ICU, and the most frightened events or moments among samples were nightmares (n = 35, 24.6%), noises that described as weird and scary (n = 16, 11.3%), and seeing other patient's death or dying (n = 15, 10.6%).

Table 5

*The Level of Domain Recall of Experiences (n = 142)*

Domain/Score	High [n (%)]	Low [n (%)]
Recall of experience (5 questions) (Mean: 12.70, SD: 2.979, range: 5-20)	25 (17.6%)	117 (82.4%)

*Note.* Range of possible score: Low = 5-14, High = 15-25

Table 5 revealed most of the samples (n = 117, 82.4%) had low level on recalling the experiences, and 25 (17.6%) samples were able to recall their experiences while staying in ICU. Results below were the responses from the open-ended question and further information can be seen in Appendix I.

This study revealed that samples remembered the most about seeing scary thing (n = 20, 14.1%), loud sound from machines (n = 14, 10%), and feeling pain (n = 12, 8.5%). However, despite of scary moments, 11 (7.7%) samples remembered that the loudness in ICU did make them felt happy including the services, staffs as well as the environment.

Samples in this study desperately wanted to forget about their admission and stay in the ICU (n = 51, 37%); pain from illness, suctioning, and discomforting experience (n = 24, 17.4%); and seeing ‘things’ and witnessing dead of other patient (n = 12, 8.7%).

Regarding sleeping patterns, around 97 (68.3%) samples claimed they had enough sleep, and sedation or pain killer were the reasons behind this event. About 41 (28.9%) claimed could not sleep well with various reasons including loud sound, discomfort, pain, afraid, and could not figure out why it happened.

Table 6

*The Level of Domain Satisfaction with Care (n = 142)*

Domain/Score	High [n (%)]	Low [n (%)]
Satisfaction with care (4 questions) (Mean: 12.06, SD: 2.257, range: 4-19)	61 (43.0%)	81 (57.0%)

*Note.* Range of possible score: Low = 4-11, High = 12-20

Table 6 reported 81 (57.0%) samples had low level on domain satisfaction with care and 61 (43.0%) claimed satisfied with the care service in ICU. Results below were the responses from the open-ended question and further information can be seen in Appendix I.

However, in the open-ended question, more than half from total samples (n = 89, 62.7%) claimed that they received good services from the staff in the ICU and claimed that the staffs were kind, diligently doing their works, and delivered the best services to the patients. Twenty six (18.3%) samples satisfied with the care and 14 (9.9%) claimed that the services were not so good in terms of attitudes of staff when handling patients.

About 38 (27%) samples reported nothing disturbed them from receiving the treatment in ICU, while 32 (22.5%) claimed noises from various sources and pain (n = 22, 15.5%) do disturbed them.

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## Discussions

The results of this study are discussed accordingly to the research objective.

### **Objective: To Explore the Intensive Care Experiences Among Intensive Care Unit Survivors**

The discussion is divided into four (4) parts according to the domain of intensive care experience: (1) awareness of surrounding, (2) frightening experiences, (3) recall of experiences, and (4) satisfaction with care.

**Part I: Awareness of surrounding.** This study showed that 71 (50.0%) samples had high awareness towards their surroundings, while another half samples were unaware with their surroundings (Table 3). Meanwhile, study from Ho et al. (2008) found out that 20 (44%) samples had high level of awareness towards their surroundings. Similarly, Soh et al. (2014) reported, from 104 samples, 47 (45.2%) remembered about their admission to the ICU and around 36 (35%) samples did not remember anything about their stay. However, Alasad et al. (2015) found high awareness among patients towards their surrounding especially on relatives (83%). Somehow, the reason why patients were not aware about the surrounding came from various reasons such as the disease process, pain, lack of information, unable to communicate, or the factor that they received the sedation during their stay, and for this study about 82.4% samples received sedation. Patients in ICU who experienced pain showed less awareness towards the environment (Demir, Korhan, Eser, & Khorshid, 2013).

The result of additional question (Appendix I) in this study showed that 54 (38%) samples were not aware about people, place and time and stated that feeling pain come from the illness turned them to be unaware with the surrounding. Sometimes, procedures in ICU can also contribute to pain sensation among patients. The results indicated that the patient's awareness can be affected by many factors including inability to communicate.

Rattray et al. (2004), reported more than half samples felt loss of control, but able to tell other of their needs. One of the reasons patients unable to tell others their own needs and leads to loss of control was the presence of ETT, which in this study almost



all samples were given intubation (94.4%). Presence of ETT or due to weakness made patients could not express what they really wanted (Engstrom et al., 2012). Patient felt loss of control when they cannot communicate (Rotondi et al., 2002; Wenham & Pittard, 2009) and this disability was perceived as threat among patients (Fredriksen & Ringsberg, 2007). Somehow, restraining from communicating was like the individual's social needs taken away from their life.

In this study (Appendix I), about 72 (50.7%) samples felt safe with the presence of the family members, and the reason behind it was only family member knows them better inside out. Close family member can give encouragement and motivation for their speedy recovery and fighting for life. However, around 31 (21.8%) samples thought they felt safe with the presence of both family members and staffs as long as there was someone nearby. Around 14 (9.9 %) samples really think that the presence of staffs whose always by their side to help the recovery phase make them felt safe. Being in dependence state make patient had to develop trust to the person nearby in order to fulfill their needs as human being and for the sake of speedy recovery. This was congruent with other study mentioned that presence of relatives did help in overcome fear (Granberg et al., 1998; Hofhuis et al., 2008); presence of staffs help patients by gave hope and helped in recovery, besides encouraged their will to survive (Karlsson et al., 2012); presence of technology and staff in ICU were associated with the secured feeling, and patients trusted and had confidence with the staff (Lof et al., 2008). Patients in ICU, especially the ventilated one more likely felt safe with the presence of staffs (Karlsson et al., 2012). About 76% patients felt safe most of the time and it was influenced by family members, staff, monitor and, religious belief (Alasad et al., 2015). This study concludes that the presence of family members and staff do ease the patient's mind and gave positive vibe for their recovery.

**Part II: Frightening experiences.** This study revealed 96 (67.6%) samples had high level of frightening, and 46 (32.4%) were in low level (Table 4). This finding is consistent with Ho et al. (2008) that figured 31 (69%) reported frightening experience, while 14 (31%) claimed not frightened. Result of this study indicates that frightening experiences were common among patients when staying and receiving treatment in ICUs. The frightening experiences can come from many causes, such as environment,

diseases, treatments, and consequences from the disease or treatment. The most rated frightening events or moment while staying in ICU varied depending on the individual perceptions. The frightening events or moments listed by the samples in this study were nightmares, seeing other patients dying, noises from machines or equipments, afraid of dying, ETT or ventilator not functioning, surrounded with unknown people, and were confined on bed (Appendix I).

However, there were studies that found that procedure related with ETT was reported as the most stressful procedures in ICU (Davydow et al., 2008), followed by pain and nightmares (Granja et al., 2005). The worst experiences in ICU related with the presence of ETT were unable to speak and breathlessness (Karlsson et al., 2012). In other study, been confined on bed, unable to speak due to presence of ETT, and unable to move were classified as stressful experiences among the patients (Lof et al., 2008). Confined on bed related with discomfort feeling, limited the movement, and put patients in condition that make them felt in control and became helpless (Hupcey, 2000; Wenham & Pittard, 2009). In addition, Soh et al. (2014) addressed more than half of patients reported general discomfort resulted from various reasons.

The moments in ICU sometimes make samples felt helpless, felt like dying, and put them in pain. One of the moments was felt scared (Appendix I), which occurred from various reason such as nightmares, seeing scary things, afraid of death, afraid about not getting the best treatment, and scared because of procedures in ICU. Some of the treatment was reported gave the stressful experience, painful, and made patients felt helpless. One of the treatments in ICU was ventilator, and being attached to ventilator itself caused patients felt restricted (Rotondi et al., 2002; Tembo et al., 2012). Furthermore, suctioning via ETT was the most stressful procedure and being confined on bed was claimed as stressful environment (Soh et al., 2014). The common procedures in ICU related with the ventilator and ETT were intubation, suctioning, and extubation.

The moment that put patients in pain were the procedures, positioning, immobility, and pain on the affected side of their body (n = 29, 20.4%). Pain was one of the major stressful experiences among ICU survivors (Davydow et al., 2008; Rotondi et al., 2002; Zeilani & Seymour, 2010), which at least half of the patients experienced it

during stay in ICU (Alasad et al., 2015; Demir et al., 2013; Granja et al., 2005; Soh et al., 2014). Pain among patients in ICU commonly related with the presence of ETT, and it can be reduced by giving analgesic in order to reduce the pain sensation (Rotondi et al., 2002). Furthermore, samples in this study reported felt helpless when they were unable to move their own body and felt like everybody was watching them. Similarly, previous study stated that felt helpless among patients occurred when they had body weaknesses and became dependence on ventilator to breathe (Engstrom et al., 2012). In addition, this study indicates that pain, felt helpless and felt scared were the negative experiences among critically ill patients which might put patient to the risk of late consequences such as post-traumatic stress disorder if not been handled properly.

**Part III: Recall of experiences.** Domain recall of experience showed only 25 (17.6%) samples were able to recall their memory precisely, while most of them (117 [82.4%]) had low level recalling the experiences during stay and received treatment in ICU (Table 5). This finding was inconsistent with other studies (Granja et al., 2005; Ho et al., 2008; Samuelson, 2011) those approximately more than half samples were able to recall being in ICU. Meanwhile the study by Alasad et al. (2015) found that more than half samples wished to know more what was happening while staying in ICU, and it indicated that patients received lack of information regarding the environment and own conditions. In this study, patient's ability to recall their experiences may be vary due to many contributing factors such as sleeping patterns.

When asking about the events that samples remember the most during staying in ICU, 31 (21.1%) samples claimed there was nothing to remember about, and 20 (14.1%) remember about seeing scary things like shadows and creatures (Appendix I). Other responses including loud sounds from machines, feeling pain at the affected site, procedures in ICU, ETT and ventilator, saw other patients death, been scolded by the staff, and experienced CPR. Patient mostly recalled about nightmares during their stay in ICU (Clay, 2013; Granja et al., 2005). However, for this study nightmares did not give the big percentage as one of the most remembered events, and samples might overlap it with other responses like seeing scary things. Most of the listed responses were the negative experiences which might affect patients in long time period including PTSD (Cartwright, 2012), anxiety, and depression (Jones et al., 2000; O'neil &

McAuley, 2011). However samples in this study also remembered about the positive things of ICU such as hearing loudness in ICU that made them felt happy, good encouragement from the staff, and sophisticated equipments. Hence, it is important for the staff to monitor the patients since they were admitted to the place with full of life saving monitor which they were not familiar with, and had potential to make them feel scared (Alasad et al., 2015).

In this study, samples claimed there were two things that they desperately wanted to forget; had been in ICU (n = 55, 38.7%) and feeling pain (n = 24, 16.9%) (Appendix I). Patients recalled about been alone in unfamiliar place or ICU, while surrounded with strangers (Yousefi & Abedi, 2011). In this domain sleep pattern was part of things to be concerned about (Appendix I). When asked about ability to recall their sleeping pattern, more than half (n = 97, 68.3%) of samples claimed had enough sleep during the stay and stated that they received sedation or pain killer to help them to sleep. Sedation helped patients to get rest especially at night (Matthews, 2011; Pisani et al., 2015; Rotondi et al., 2002). However, 28.9% of the sample claimed did not have enough sleep, and the reasons behind it were loud sound from the machines, discomfort, pain, afraid not able to wake up again or afraid of scary things comes and do harm, and unsure about the reason.

Deprivation of sleep among patients in ICU comes from many sources including ICU environment, illness, psychological stress, medications, and treatments (Weinhouse & Schwab, 2006). Patient had less sleep and rest because of afraid cannot wake up if they fall asleep (Arabi & Tabvkol, 2009). Previous study addressed 42 (40.4%) samples suffered from sleep disturbance (Soh et al., 2014). Good quality of sleep help in recovery phase since the body will repair and restore by itself; enhance the mood in positive way; give time for mind and body to rest; brain trigger released of hormone that help in growth of the tissue, hence help in recovery of injury (Ratini, 2015). Enough sleep has strong relationship with good health and well-being; protect mental and physical health; promote good emotional well-being; good quality of sleep involved in healing process and repair of the heart and blood vessels (National Heart, Lung, & Blood Institute, 2012).

**Part IV: Satisfaction with care.** Domain of satisfaction with care reported 61 (43.0%) samples were highly satisfied with the care services, while more than half of samples did not satisfied with the care services (n = 81, 57.0%) (Table 6). This finding showed different result from study by Ho et al. (2008) reported huge gap between sample whose satisfied (n = 43, 96%) and whose not satisfied (n = 2, 4%) with care services in the ICU. These results differ from finding by Rattray et al. (2004) showed that out from 106 samples, 80% were satisfied with care. However in additional question (Appendix I), samples reported received good care services (n = 89, 62.7%), and claimed staff were really kind, soft spoken, diligent and concerned about patient's condition. About 26 (18.3%) samples were satisfied with the services, and they were thankful that staff helped them to overcome the illness. Only 14 (9.9%) samples claimed the service was not good, in terms of lack of professional attitudes when handling patients.

The opinion about the services might differ from one patient to another depending on various factors, such as, patient's condition, how the staff carry themselves during working, and environment. Receiving good care services help patients overcome fear and enhance the safety feeling (Hupcey, 2000; Russell, 1999; Wassenar et al., 2013). Satisfaction of care is one of the indicators to measure the successfulness of intensive care services in the hospital (Al-Abri & Al-Balushi, 2014). In this study, responses from ICEQ (n = 61, 43.0%) and from open-ended question (n = 89, 62.7%) regarding satisfaction with the care showed a gap, and answered from open-ended was high rated since it gave more chance for samples to state what they really feel without constraining only on the rigid structured answer.

Further question was asked regarding things or events that disturbed patients while receiving care services during stay in ICU (Appendix I), and around 38 (27%) of them claimed that nothing happened or nothing disturbed them from receiving care, 22 (15.5%) reported pain from operation site or illness do disturbed, and 32 (22.5%) samples claimed noises from machines and visitor's voices do disturbed them during the stay. Study by Granja et al., 2005 reported ICU was rated as a calm place (93%) by the samples. It is similar with the previous study stated that 54% of their samples think ICU was a calm place (Rattray et al., 2004). Noises from alarm, machines, voice of

staffs make patients felt discomfort (Granberg et al., 1998; Tomlin, 1977) and implicate sleep and rest patterns among patients in ICU (Pisani et al., 2015). Nurses played an important role and should avoid unnecessary activities or procedures at night (Pisani et al., 2015; Soh et al., 2014; Tomlin, 1977), and provide conducive to environment including dim light at nights and reduce the noises in order to promote sleep and rest among patients (Soh et al., 2014).

In summary, intensive care experiences among ICU survivors in this study reported same percentage between high and low level on domain awareness of surroundings, high level on frightening experiences, low level in recalling the experience, and low level about satisfaction with care. It indicates that critically ill patients especially in ICU have to face with unpleasant experience of surrounding environment besides the suffering of the critical illness. This situation must be concerned about and controlled by the health personnel, especially the critical care nurses who have important role in every critical care unit.



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