

Being a Parent of the Sickest Child: Malaysian Perspectives

W Solihatul Hafidzah Wan Mohd Annuar¹, Lee Siew Pien^{2,*} Aniawanis Makhtar³

^{1,3} Kulliyyah of Nursing, International Islamic University, Malaysia

² Department of Special Care Nursing, International Islamic University, Malaysia

*Corresponding author. Email: siewpien@iium.edu.my

ABSTRACT

Mechanically ventilated children make up a small but growing segment of society's vulnerable population. The aim of the study was to understand the caring experiences of parents toward their mechanically ventilated children. This interpretive descriptive study was performed in the PICU of one tertiary hospital in Malaysia. The participants were purposively sampled. Semi-structured interviews were conducted with 21 parent caregivers of 18 children. Data were analysed by using Atlas.ti version 9. Thematic analysis was done and yielded the main theme, "The unpleasant experience in PICU" which emerged from two sub-themes: "The feeling of uncertainty" and "Recognizing the new child". The study concluded that parents had fluctuating emotion throughout the stay. Positive parent-nurses interaction maintain the psychosocial health in embracing their journey.

Keywords: "Experience", "Parents", "Critically Ill Children", "Paediatric Intensive Care", "Mechanical Ventilation".

1. INTRODUCTION

In the setting of complex chronic disorders, patients hospitalised to the paediatric intensive care unit (PICU) may develop acute illness or acute exacerbations. The most common diagnoses are respiratory diseases. Children admitted to the PICU range in age from less than one year to 1.9 years. Respiratory disease, heart disease, and neurologic diseases are the most prevalent reasons for admission to the PICU. PICU hospitalizations can account for up to 38% of all children with developmental delays. More than 35 percent -40 percent of hospitalised patients have a LOS of more than 7 days, and more than 40% of PICU admissions require mechanical breathing. In PICUs, severe sepsis and septic shock are also common. [1]

The child needs parents to be around them. Being in the PICU, the environment for instance the alarms, monitors made them new to the ambience. They also need to deal with various paediatric subspecialist for example pulmonologists, cardiologists, anesthesiologists and

surgeon. Different terminology maybe came to their hearing when discussing on the child's management [2] Therefore, to describe what the parents went through in this period the research was carried out to summarizes our results on the experiences of parents for their mechanically ventilated child in PICU from Malaysian view.

2. MATERIAL AND METHODS

2.1. Design

A qualitative exploratory study was used to investigate the experiences of the participants. Parents were interviewed alone while their child was in the hospital. Semi structured interview questions were used.

2.2. Settings and participants

This study was conducted at paediatric intensive care unit in a tertiary hospital on of the states in Malaysia. Ethical approval for the study was gained from the relevant University and Hospital ethics committees. The inclusion criteria were parents who

able to speak Malay or English who had child stayed at least for three days. All parents who fit the inclusion criteria were identified and approached by the researcher. The interview was scheduled after giving the parents of extra information. The researcher offered additional information to those that expressed an interest in participating, and an interview was scheduled. The verbal and written consent were obtained before the interview.

The researcher conducted the semi-structured interviews in the patients' room or an adjacent consultation room, either individually parents to prevent any distraction. Following the receipt of oral and written information, the chance to ask questions was provided, and an informed consent was signed. Table 1 shows some examples of questions. Interviews were audio-recorded and verbatim transcribed.

2.3. Data Analysis

The interviews were analyzed with thematic analysis [3]. The data were repeatedly and critically to find the data's meanings and patterns. Open coding was done and the interesting ideas on the data were listed out and work systematically to find patterns of across the data set. The researcher collated relevant coded extraction of data in the themes identified. Thematic map was generated to further understand the data. Lastly, themes were defined and reviewed and reported analytically to audience.

3. RESULT AND DISCUSSION

The main theme that emerged was "The unpleasant experience in PICU" which emerged with two sub-themes: "The feeling of uncertainty" and "Recognizing the new child".

The unpleasant experience in PICU refers to the experiences which were perceived as uneasy experience, even from the beginning. This identified the journey that they have been through with their child. On a broad overarching level, three categories of experience were identified: new and unpleasant experience, recognizing the new child and embracing new child. These was how parents described their lives following the admission of their children to PICU. It was noted from the interview that the burden of caring for a child with mechanical ventilator emerged from these three main areas. The following sections explain how parents described the new and unpleasant experience, recognizing the new child and embracing new child as the uncomfortable things in PICU.

3.1. Feeling of uncertainty

The feelings of uncertainty refer to the feelings that were being experienced by the parents during the start of admission to PICU. Almost all the parents spoke about new and unpleasant experience in the beginning of the journey. This subtheme is discussed in three categories: the anguish, being helpless and living in fear.

3.1.1. The Anguish

Parents had to deal with a wide range of feelings. Sorrowfulness frequently experienced by most parent whose children have admitted to PICU. Most parents of the study stated that their emotion was affected when their child admitted to PICU and was intubated. They expressed that they were depressed and sobbed every day during the first week of their child's admittance due of their child's unsure sentiments. For instance, Madam Izumie expressed that she felt like crazy, affecting her quality of life after not able to eat, sleep and like normal. Other than crying memorising the poor child alone in PICU. She explained thoroughly:

"Haa .. First week..emm .. that first week is really down, it's really the days of crying, I think it's not about the child .. Why is he all..haa .. Sometimes it can be crazy to think back. I cried for a long time, I didn't eat .. I didn't eat rice for two days. I ate bread, drank boiled water. It's not like those two days I didn't sleep, I cried, looked at the pictures, cried, looked at everyone, looked at the clothes, I was crying. Hmm hmm hmm ... The reason is that I think he's here alone. got intubated anyway umm .. that's why I was a little over this time cried."(Madam I)

Being caesarean, mothers were in pain of their surgery. Receiving bad news during this period made their heart shattered into pieces. The husband protects their wife's mental health by supporting the wife emotionally, afraid of the sorrow will lead to postpartum blues. Madam AA shared her view where she was not able to accept that the child is unwell:

"I was feeling sad. . I am about to cry.. (. mother cried) Yeah. At first, you couldn't accept that he was sick. (I was just) crying at home. Then the husband gave (me) (moral) support, because he afraid it will be different (bad). Because I was still in postpartum. Underwent operate (caesarean) some more." (Madam AA)

In addition, the parents expressed their sorrow as when thinking out of her mind, thinking of whether the child can make it or not. This is as described by

Madam S, the negative mind and feelings that come after being sad towards her admission:

"Feeling sad .. There are also thoughts of nonsense about him .. (I was) thinking about it .. think about what it is .. think that whether he can live or not... Hmm .. like that." (Madam S)

During the first week of hospitalisation, parents were the most affected. They felt at the bottom of their lives because of the harrowing encounter. Their days were punctuated by self-inflicted crying episodes. Even eating and sleeping were difficult for them. When the parents were thinking critically about their child, everything that reminded them of the child made them unhappy. Madam R, the other parent, cannot process what's going on since it's all happening so fast, she says:

"Sadly, the first time we went (to hospital) because, he started coughing. (We) went to the emergency he said first he gave nebulizer; the baby is getting better. Then he said the baby wasn't (looked) tired, so he was admitted to (general ward). We said ok. Then that's when he was looking for a (intravenous) line. It went blindly, it can't be found because the veins are really difficult. Then he said its ok, he told me to obtain the (iv) line upstairs (in PICU) because he did not managed to get it through. Entered (general ward), I only got a bed and had a chance to sit down, then my child was (suddenly) unconscious, like he fainted, I don't know. So continue to intubate, it's time in the treatment room while waiting for the ICU room to be ready." (Madam R)

Clearly, the severe state of their child made the parents feel much worse at the start of the admission because of two primary contributing factors: the unpleasant news and the child's physical condition.

3.1.2. Being Helpless

This category refers to the feelings of the parents when in PICU, which they felt to be not doing anything else rather than observing the child. It was the feeling of cannot do anything as they became blank. According to R, she felt not knowing what to do next:

"..I'm so stunned I don't know (sigh)..".paused..emm..don't know what to say .. (deep breath) .. my son is really really special." (Madam R)

In addition, Madam SS explained that a child's stay in PICU is indefinite due to his or her frail condition, she said:

"(My feelings) wants to say okay .. not very okay .. because he's like Doctor's talking .. he's down syndrome .. so he's kind of fragile right .. fragile .. he's umm .. he has kind of long story .. so I don't know how long he's going to be in the hospital .. because now it's just finished one .. heart .. but he has a ventilator on.. I don't know yet anymore."(Madam SS)

Feelings of helplessness arose because of their child's various underlying difficulties that had not resolved after admission. When asked about their feelings, the parents struggled to express whether they were okay or not so okay. They expected the admission to be a never-ending narrative because just one issue had been resolved but another, ventilation concerns, had not. Madam Sofia's remark indicated that they were still trying to figure out what would happen next in their child's journey.

Another interviewee mentioned that she had the worst experience in the first week of admission. She told in the interview

"The first week was really horrible experience. However subsequent days became better seeing my child was coughing less."(Madam I)

After a few days of warded, Madam I was mildly relieved when her child's symptoms improved. The child is now coughing indiscriminately. The parents felt better when their child was doing good.

3.1.3. Living in Fear

The strange episode in the PICU has been started from the parents they stand in front of the entrance door, realizing the words. The words "P-I-C-U" itself made the parents fearful as intensive care units sounds serious and usually relate to death. The parents were primarily terrified, especially at the beginning of the episode. Mr H characterised the initial admission as unpleasant and unsettling, especially considering all that transpired throughout the interview.

"That experience was like that..at first, (like people said) I was upset and was afraid of everything." (Mr. H)

When Madam R reflected on the initial admittance, she felt as if everything happened in the blink of an eye when the child abruptly became unconscious, despite of the fact that the child had only simple coughed. The parents did not have time to "feel" why these events occurred to their child, nor did they have time to make sense of the situation right away. Apart from that, fear was

also frequently expressed by the parents when they were informed regarding the child's diagnosis. For instance, Madam A expressed:

"The emotion, at first I knew (the news).. it was scary, yes .. sad (also present), because of looking at him.. he was small again, right .. having all the tubes, what all ..(having)the needle .. Because that day the doctor called to put the needle in his head because he said he couldn't find a vein .. Maybe it's because the (frequent poking of needles)."(Madam A)

The parents were scared after hearing the news from their husband. It also made the parents sad, especially when they saw their young child, who was surrounded by "alien" tubes and intravenous catheterization, including intravenous catheterization in the child's head.

This may be due to that the process of adapting the situation that happened to his child. Other parents, on the other hand, said that Madam L had indicated that the dread had become recurrent at times. She felt fear repeatedly, especially when the child was in a poor circumstance. Many times, for example, the child's health was jeopardised.

"Fear aa .. fear .. because he has been critical four times." Fear aa .. fear .. because he is already four times critical in the ICU Aa .. four times .. four times to five times plus blood .. because he was born very small right .. always very pale .. bad .. until aa .. said that one got bronchopulmonary who coughed for a hundred days .(Madam L)

The parents were scared after hearing the news from their husband. It also made the parents sad, especially when they saw their young child, who was surrounded by "alien" tubes and intravenous catheterization, including intravenous catheterization in the child's head.

The parents have had panic situations after learning that their child has been in critical condition several times during therapy. As a result of the frequent worrisome condition, it made the parents to become more distressed.

Their thoughts were also encircled by the worry of becoming critical once again. During the interview, Madam I clarified:

"Ummmmm .. I'm afraid he'll enter the ICU in front of you again (referring to other ICU rooms in front of the ward) .. because then I'll look there .. when I look at the baby there it's kind of worse and the same age It's as if that thing will ... what if our son goes in there? ha .. That thing is really the days I

think .. until he was extubated, then I don't think like that anymore .. the whole time he was intubated, every day I will think what if the child goes in there? Because I once asked the nurse "what's the difference between those rooms?" .. Then she said the first one was really bad (critical) .. I said okay ... so it's kind of scary that incase my child is admitted into those rooms."(Madam I)

Madam I, another parent, expressed her fear of the child's relapse into critical condition. They went through the "important" room every time they passed through. Even everytime they passed through the "critical" room. After living in fear, the parents next had to face their child which has been changed due to the disease and treatment in PICU. They now need to embrace their "new" child.

3.2. Recognizing the new child

The subsequence experience was that the parents are now attempting to recognise their child due to physical changes. Firstly, is when their child is not covered with any hospital outfit but only dressed in a diaper and being covered by a blanket. Their one of the fingertips was attached with a pulse oximetry sensor and their chest were attached with three chest lids, connected to a huge digital monitor. At this time, the ETT tubes were anchored to the mouth with plaster and their eyes were closed. They were fasted and they were having at least two to three intravenous line infusion for intravenous drips and medicine. Seeing their child covered with various tubes and sensing various alien things with alarm and sound made them unable to see their 'normal' child. They are currently in denial of another child is lying on the bed instead of their child. Several things contributed to this, including the child's restraining and the presence of a peripheral scalp intravenous line in the head.

3.2.1. The Physical Changes

Other than that, the child was looking pale, unconscious with some bruises on the limbs where the attempted needle poking was done. With the anchored ETT, the child may shed tears due to coughing from secretion in the tube neither or after being suctioned in closed methods by the nurse in charged. Parents need time to digest on what is happening for instance when recognizing the new child. Other visible difference then and now was there were scars, or any hole or inlet due to the operation, as explained by a mother with some regrets that she brings back home a different child

"Children's episode.. we bring the perfect (normal) child.. (but) back (home)with a hole (tracheostomy)." (Madam E)

During the treatment, the child may have lost some weight which may be seen different with the child before sick. Furthermore, due to poor circulation, the child may have edema at their limbs or even have some skin reaction towards the sticky plaster that secure the iv lines, for instance if already having eczema skin. Also, the most terrifying thing is the abrasion or scar on the edge of the mouth, which is the site of anchoring the ETT resulted from the strong plaster. Poor hydration and the air conditioner in PICU made the child had chapped lips and dry skin. One obvious observation from the parent was that their child had changed, from an active to in active child which was unbelievable. The physical changes also referred to the changes from at home till the admission. One shared view from a father was that the situation became complicated because his daughter was referred to the physiotherapy now after unable to walk post PICU admission. Not knowing on how to describe the pain, his daughter will only cry when being consoled to walk. It made him more worried comparing how active she was before. He told in the interview:

It's been a long time since she's been sick, right? because she can't walk.. I don't know what the problem is, (they) check and scan .. Like Noreayh, she wanted to walk .. even though she doesn't want to move on her own, we hold her to step .. she follows .. like Noreen (the sister) when we asked her to step; she cried. He em .. that's so worrying .. because before this she was active right .. (Mr M)

Despite of many changes to their child, the parents were optimistic and try to accept the way their child are now.

3.2.2. Denial

While accepting is hard, the parents chose to deny the situation. They questioned why they were chosen to be tested. At many times, during the fragile period the parents keep on rejecting and denying the fate. The big question that around their head was "why", why their child was not healthy as other people's child and felt bad to them and their child. As Madam A told in the interview:

"Sometimes there are times where we were sort of cannot accept why (it's) our children.. why we faced many challenges, as other people's child were okay." (Madam A)

Hearing the bad news from the doctor also made

the parents not accepting the fate at that time. Especially when it comes to the possibilities of the child's death. When hearing this statement from the doctor, the parents felt unbelievable seeing the chances of their loved child to be alive after all the sick events. Another father elaborated that he cannot accept when he had the chances to lose the child. He explained that:

"Because (the) doctor said (the condition is) 50-50 haaa .. that's the time you can't accept .. at that time." (Mr H)

Apart from that, another father, Mr. N kept asking himself why this would happen to his child. But he couldn't discover the answers since he was weak and unable to deal with it mentally at this point, as he described:

"I didn't expect a boy to be 4 months old .. 10 days (admission) into this hospital .. I thought that it was only that (my child has) a lot of phlegm .. apparently he has a bacterial infection .. in the lungs .. so I feel affected .. affected with the Doctor (had) told me.. feel very affected .. why aa... I asked .. "why .. why .. can .. why .. why .. and why?" I'm looking (for the reason) .. if I can, I want to look (for the reason).. I wanted to .. but when I look at my son, I'm strong enough to look for all that .. so I'm just facing... I'm facing .. see (though) what will happen next .. from day to day there will be no recession." (Mr. N)

In the beginning, he thought that it was impossible for the young child to be infected. The infection that his child had was impactful. He kept doing on the reasoning of the situation. He had no choice, which was waiting for the next thing to happen to their child.

Other than finding the reasoning, certain parents avoided the situation of seeing the child as it was vividly remembered by Madam E that during the initial admission, she never wanted to see her child, as she told her story:

"I looked from afar, the doctor called in .. I said .. it's okay, I'm scared, it's me, I'm scared, I can't accept it (yet) anymore, right .. because we think our child .. our child .. we're here then our child were okay." (Madam E)

It meant that parents would need time to adjust and accept their fate because what had occurred was such a huge shock to them. It was significant to her, in which she was "paralyzed" by the terror and fear that went deep into her bones and her body was invaded by the feeling. It needs a courage to see the child in the beginning she admitted.

3.2.3. Hurting vs Treating

It is undeniable that the child required the most care and had a variety of procedures during the initial admission to the PICU. During the admission, some of the children must be restrained by the doctors and nurses to guarantee the best possible therapy. Most of the participants of the study revealed that the child was still partly conscious during mechanical ventilation as stated by one of the participants:

“.. (In a) week. and my daughter is strong.. her body, (due to) the movement (the nurses) has to tie his legs and hands... even though she was given sleeping pills (sedation) but she is still strong .. he had to take sleeping pills (sedation) twice, through the needle (line) from the hands and syrup (orally) .. mouth. Looking at the tube that goes into the nose and the mouth, the limbs have to be tied up .. Oh God .. look, it's really sad.. It's more sad... but the Dr gave me an explanation .. (the tubes and restrains) not for what not to make it difficult for her, not to restrict her movement but to make it easier to carry out her treatment.”(Mr. M)

Mr M agreed that everything that has been done to the child is for the best even it made him sad after been explained by the doctors. Even when it looked like they are hurting the child by placing such tubes and catheters in the mouth and the child's limbs. He however agreed to the intervention in view of treating the child. This is agreed by another parent, Madam EE, seeing the situation as for the child's best. She agreed on the purpose of restraining the child as she experienced:

“Yes .. because when he first warded in the PICU, he replied .. the struggle was very much to the point..aa ..then the nurse advised.... "if possible, we need to tie (restrain) his hands and foot"..then again the nurse asked, "mother, we want to tie the child's hands, is it okay? (they) ask for (my) permission .. (I answered) "Yes" because we understand how is our child (behaving).” (Madam EE)

The parents (both mother and father) agreed to restrain the child even it looked uncomfortable.

Apart from being restrained, other things that may seemed uncomfortable to the child was the placement of the IV cathether, where some of the child need to have intravenous line in the head as all other peripheral lines were collapsed. When seen with bare eyes, it seemed “cruel” to do this to their child as it looked painful. Nevertheless, due to emergency, the permission from the parents were not asked by the doctor. This is where parents were

not staying in PICU or failed to be reached prior to the insertion. As explained by Madam R:

“..It's like what .. like a prick in the head .. (the doctor) didn't ask (my permission).. But I'm not sure why it was (not asked for permission) at that night. Because I came at noon (to visit the child and saw the line in the head)... but the doctor apologized. He said the reason (of the line) because there was no (other) place, he apologized a lot. Then my husband said it's ok. I understand .. Yes, I do (understand). The doctor did that for my child's good.”(Madam R)

Madam R was concerned that the doctor had failed to inform her that an intravenous line would be placed in her child's skull. She, too, was distressed by the circumstance, but she saw it to offer the child the finest care possible. Also, the repeatedly apology from the in charged doctor made her accepted the mistake.

In contradict, there were inconsistency with another parent who shared her experienced that she was informed earlier on the need to set up an intravenous line in his head and the doctor justified the action:

“The emotion, at first I knew (the news).. it was scary, yes .. sad (also present), because of looking at him.. he was small again, right .. having all the tubes, what all ..(having) the needle .. Because that day the doctor called to put the needle in his head because he said he couldn't find a vein .. Maybe it's because the (frequent poking of needles).” (Madam A)

Madam A consoles herself in this scenario by supposing that the veins were collapsing because of the constant poking of needles through the admissions. The parents were assured by the justification from the doctor which made them not being angry or having any dissatisfaction due to this.

Another parent shared the same experience that the child also had IV lines all over the place towards the body.

If in case of emergency, the child has already pooped, then we should (help). Because sometimes nurses are busy. Just be careful. There's a lot of lines. Ahmad had iv lines in the head, neck. Everywhere”. (Madam N)

While embracing the treatment that the child was going through, they adapted to accept the current condition of their child. The condition will constantly be changing when parents had child that had other comorbidity.

3.2.4. Child with Multiple Diagnosis

Most of the parents had their child admitted to the PICU because of the severe lung infection. In spite the lung infection that their child had, due to multiple screening, blood investigation and radiography tests, the parents were just known that their child had many other underlying diseases as were informed by the doctors. Having child with multiple diagnoses has worsen the parents experience. They cannot control the situation. Madam W described:

“..So they did x-ray and everything, they said (my child) had heart problems, that time it was really sad .. telling that our child, it hurts .. I really can't control it at that time .. until everyone has a fever .. I have a fever, Husband has a fever until there is no voice to speak.”(Madam W)

They also face bad news subsequently, which might affect the parents differently since it was like being tested on the child's condition, one after another. They subsequently received shocking news on new findings of their child's condition throughout the stay because of the child has other underlying health problem other than respiratory.

Madam E mentioned the same condition of her daughter:

“Huh, he has this, it's from birth .. his chest has a hole but he never had an X-ray .. so bring it near here, the doctor did an X-ray .. The doctor said he did have a bacterial infection in the lungs .. The doctor was dissatisfied .. he still had holes.. then his breathing didn't seem okay.. The doctor said it should have disappeared, right .. he had a bacterial infection in the lungs .. aa he was already okay, but the doctor is not satisfied because he has (shallow breathing) chest again .. after examined by the doctor, he has a blocked airway..(another diagnosis).”(Madam E)

The child needs to be stabilized after the admission. The underlying condition such as heart problem made the journey less favourable since the doctors need to tackle multiple issue referring to the child. It went the same to the parents. They need to experience unanticipated events other than their child's ventilation issue.

In another interview, Madam N experienced the emotional stress because she was not feeling well at time, inferring that the emotional cost of having unwell child. Her child has multiple diseases. This affected her as she was hoping to have another child, yet the child that came out was abnormal

and shaken herself as she explained

“Even then, I was still not very healthy, maybe. One is because our emotions are disturbed at that time because the child is not healthy. Yes, we really hope to have a child. After all, having a child like this is not healthy, it's a shock.” (Madam N)

Despite of the uncomfortable things they went through and the uncertainty feelings to recognize their child, parents shared their perceptions in their child's care.

4. DISCUSSION

The research question was answered on what are the experiences of parents when their child admitted to PICU. There were a few factors that build and influenced the parental experience. The initial period was that the worst part where the parents were having uncertainty feelings about their child. Because of their infant's vulnerable state, parents of children in the PICU face uncertainty and increased stress. A recommendation in a study was the clinicians must communicate with parents on a regular basis and be open and honest about their concerns. [4]The anguish that parents had was consistent with other studies[2][5].However due to just having major operation such as the caesarean itself made the mothers particularly were more sensitives. A review was done by [6] and found that women with an emergency caesarean were more likely to experience emotions of emotional vulnerability following delivery, including feelings of failure, remorse, and lower self-esteem, according to studies on self-esteem.

The most difficult part of the experience were the immediate admission to PICU. The parents were being helpless and living in fear. Other than fear of their child's condition, another study by[7] suggested that instead, Instead, the absence of debate on parents' perceptions and understandings of 'the system' is likely owing to the nature of end-of-life care research, which concentrates on the end of a parent's PICU journey rather than the beginning, when parents' lack of familiarity with the system is most troubling.

Many studies has highlighted the intimidating tubes, cable and monitor as well as noise in the PICU[4] [8] some of the child went back home with oxygenation or other feeding tubes. In the study, this made a huge effect to the parents. Other physical changes, for example being active again also marked a great milestone in the parents' life who wanted to see their child gaining

back the actual health. Denial is one of the process of the parents to adapt their children's changes. having the bad news break in a correct way can reduce the parental emotional burden in the research by[9] demonstrates to healthcare practitioners how parents face challenges while discussing bad news. This is mostly about communication's practical aspects. The findings offer practical advice on how to enhance bad news communication to better meet the requirements of parents. The timing of meetings in which parents were warned that their child could not live was far too late, according to the parents. There were instances when no such discussions took place.

Being the sickest child had the child to undergo rapid and emergency procedures. In other way, it seemed like the child was hurt instead of being treated. In the study, there were physical restraints were done. Parents accepted the restraining of their child, agreeing to the conclusion which was to treat the child and became healthy again. In critical care facilities, physical restraints are employed to limit the possibility of treatment interference. Even, in children and adolescent mental health care, physical restriction is frequently employed as a reactive behaviour management method. Bodily restraint has been linked to physical harm, but the psychological effects are unknown [10]. Peripheral scalp vein is also commonly seen in ICU children. The optimal location for emergency medical personnel to perform intravenous access for the delivery of fluids or drugs is the scalp vein.[11].Although it is a convenient alternative to extremity IV access, the location, potential lack of experience because it is a less common site of catheterization, and the appearance of a patient with a scalp vein may cause distress to the patient, parent (if applicable), and healthcare team, so indications, contraindications, and decisions on choosing a scalp vein for access must be agreed upon to enhance patient safety. To maximise patient safety and the success of this operation, best practises must be shared and clinical practise guidelines must be developed.[12]

Child with complex diseases when admitted to picu has more demanding experience. This more narrow population has been defined by a history of a prolonged PICU stay, ongoing acute care needs, and reliance on technology, or persistent multiorgan dysfunction in recent years as children have survived intensive care with significant, persistent illness [13]. In the study, child with multiple diagnosis has caused the parents being surprised by one after another issues that has risen during the hospitalization. They also became

worried to each and every diagnosis that the doctors told them. It affected them mentally and physically.

After these experiences, the health care providers know what had happened to the parents. This may assist the nurses to support the parents according to their experiences. Deep understanding of the experiences may preserve the parents' mental wellbeing because the passage was not easy. There were hiccups in between and tests after tests that they went through.

5. CONCLUSION

The study has contributed the current experience of parents when their child was mechanically ventilated in paediatric intensive care unit. The limitation of the study was it may not be generalizable as the sample was collected in a single site, not representing the whole parental experience. Multiple site of investigation maybe conducted in future and in the view of pandemic to compare how the changes were since the data was collected just before the Covid 19 spread in Malaysia. The COVID-19 has altered our conventional processes, protocols, and procedures, as well as how we deal with families. Since the parents went through various mentally "testing" episodes, the situation must be slightly different during covid since being isolated and infected to contagious illness must had greater impact to the child and family. This when taken into consideration where the Ministry of Health guideline as imposed to not having visitors allowed during this pandemic [14]The reduced parental visiting in PICU may cause the psychological drain to the parents as they had no social supports by their friends and family who usually will come and had a talk with them to give moral support.

AUTHORS' CONTRIBUTIONS

WSHWMA, LSP and AM contributed conception and design of the study. WSHWMA conducted the study and wrote the original draft of the manuscript. LSP and AM involved in writing, reviewing and editing the manuscript. All authors contributed to manuscript revision, read, and approved the submitted version. The authors disclosed that they have no competing interests.

ACKNOWLEDGMENTS

The authors expressed their gratitude to everyone who took part in the research. should be in all caps and should be placed above the

references. The references should be consistent within the article and follow the same style. List all the references with full details.

REFERENCES

- [1]. Halpern N. Critical Care Statistics. Soc Crit Care Med [Internet]. 2017;1–9. Available from: <https://www.sccm.org/Communications/Critical-Care-Statistics>
- [2]. Alvarez MB. A Phenomenological Study of How the Experiences of Spanish-Speaking Parents/Family Caregivers in a Pediatric Intensive Care Unit Compare to the Principles of Patient- and Family- Centered Care [Internet]. ProQuest Dissertations and Theses. 2020. Available from: <https://www.proquest.com/dissertations-theses/phenomenological-study-how-experiences-spanish/docview/2404379253/se-2?accountid=17234%0Ahttps://libkey.io/libraries/525/openurl?genre=dissertations+%26+theses&au=Alvarez%2C+María+Beatriz&aulast=Alvarez&issn=&is>
- [3]. Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol. 2006;3(2):(2):77–101.
- [4]. Hill C, Knafl KA, Docherty S, Santacroce SJ. Parent perceptions of the impact of the Paediatric Intensive Care environment on delivery of family-centred care. Intensive Crit Care Nurs [Internet]. 2019;50:88–94. Available from: <http://www.sciencedirect.com/science/article/pii/S0964339718300375>
- [5]. Foster K, Young A, Mitchell R, Van C, Curtis K. Experiences and needs of parents of critically injured children during the acute hospital phase: A qualitative investigation. Injury [Internet]. 2017;48(1):114–20. Available from: <http://dx.doi.org/10.1016/j.injury.2016.09.034>
- [6]. Benton M, Salter A, Tape N, Wilkinson C, Turnbull D. Women's psychosocial outcomes following an emergency caesarean section: A systematic literature review. BMC Pregnancy Childbirth. 2019;19(1).
- [7]. Butler AE, Copnell B, Hall H. The impact of the social and physical environments on parent-healthcare provider relationships when a child dies in PICU: Findings from a grounded theory study. Intensive Crit Care Nurs [Internet]. 2017; Available from: <https://doi.org/10.1016/j.iccn.2017.12.008>
- [8]. Vreman J, van Loon LM, van den Biggelaar W, van der Hoeven JG, Lemson J, van den Boogaard M. Contribution of alarm noise to average sound pressure levels in the ICU: An observational cross-sectional study. Intensive Crit Care Nurs [Internet]. 2020;61:102901. Available from: <https://doi.org/10.1016/j.iccn.2020.102901>
- [9]. Brouwer MA, Maeckelbergh ELM, Van Der Heide A, Hein IM, Verhagen EAAE. Breaking bad news: What parents would like you to know. Arch Dis Child. 2021;106(3):276–81.
- [10]. Nielson S, Bray L, Carter B, Kiernan J. Physical restraint of children and adolescents in mental health inpatient services: A systematic review and narrative synthesis. J Child Heal Care. 2021;25(3):342–67.
- [11]. Wei F, Chen W, Lin X. A clinical rule for the difficulty prediction on scalp intravenous access in infants (SIAI) from emergency room. Sci Rep [Internet]. 2020;10(1):1–7. Available from: <http://dx.doi.org/10.1038/s41598-020-63771-5>
- [12]. Bergvall E, Resident C, Army T, Sawyer TL, Fellowship A, Program NF. Catheterization, Scalp Vein. 2011;1–16.
- [13]. Shapiro MC, Henderson CM, Hutton N, Boss RD. Defining Pediatric Chronic Critical Illness for Clinical Care, Research, and Policy. Hosp Pediatr. 2017;7(4):236–44.
- [14]. Ministry of Health Malaysia Updated on 27 January 2021 0. 2021;2(January):0–12.