Taiwanese Parents’ Experience of Making a “Do Not Resuscitate” Decision for Their Child in Pediatric Intensive Care Unit

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Introduction

A common belief in Chinese culture is that a young child’s pending death challenges the natural life cycle and that death at a young age violates the child’s filial obligation toward the parent (Tang, 2012). When a child has a life-threatening condition and is hospitalized in the pediatric intensive care unit (PICU), most parents cling to the hope that their child will recover, not wanting to or able to face the possibility of their child’s impending death (de Vos et al., 2011). Unfortunately for some parents, hope for recovery is not realized and they must endure the difficult process of having their child die in spite of all efforts by themselves and others. The introduction of increasingly invasive medical interventions and technologies has made an impact on this process, so that children with life threatening conditions who previously would have experienced a more immediate, natural death, are spending increasing lengths of time in a prolonged state of postponed death.

When a child in the Taiwanese PICU is facing death with an irreversible health condition, the prevailing practice is for the healthcare team to continuously treat the illness, including providing cardiopulmonary resuscitation (CPR), and thus prolonging the process of dying (Jaing et al., 2007). Tibballs (2007) suggests that when making treatment decisions for a critically ill child, four aspects of care should be considered. This includes the chance that the treatment might be successful, the risks inherent in the chosen treatments, the psychological impacts on the child and family, plus the child’s expected quality of life. Thus, in addition to considerations regarding maintaining physical life, ways to care for the child and family at the end of life (EOL) in PICUs need to be considered. Little is
known about how Taiwanese parents perceive these discussions and decisions regarding “do not resuscitate” (DNR) when their child is critically ill and dying in the PICU. How do parents experience the signing of a DNR form for their child under these conditions? This study offers insights regarding how the parents of children who are terminally ill experience the signing of the DNR form for their child. Based upon these findings, we suggest methods to improve staff knowledge and skills in how to help parents cope with the difficult decisions they face when their child is terminally ill.

In recent years improving the quality of EOL in the PICU has been emphasized in many Western countries (Moore, Kerridge, Gillis, Jacobe, & Isaacs, 2008; Robinson, Thiel, Backus, & Meyer, 2006), and instituting the concept of palliative care has been proposed for ICUs (Docherty, Miles, & Brandon, 2007). Pediatric palliative care is focused on improving the quality of life for critically ill children and their families through relief from pain and stress, and inclusion in medical decision-making processes (Liben, Papadatou, & Wolfe, 2008). Once a child is critically ill, the healthcare team communicates with parents, collaborates with the family to choose the best treatment, and helps the child and their family to adjust to their present circumstances which may include impending death. Whether or not to forgo CPR is one of many EOL decisions parents of children in the PICU commonly need to make (Perin, 2006). The healthcare team needs to help parents prepare for making a decision regarding whether or not and to what extent to provide resuscitation. This help comes in the form of not only providing information, but also through provision of psychological and spiritual support. These supports also may be regarded as help for preparing to face death (Fallat & Deshpande, 2004). One issue being addressed through this research is whether or not health professionals in Taiwan PICUs are adequately trained in palliative care and communicating with parents about EOL care issues including forgoing CPR (Tang, 2012).

When a child is admitted to a PICU, besides feeling worried and uncertain about the child’s condition, parents commonly experience limited communication with health professionals. Parents find themselves powerless in an unfamiliar environment where visitation rules dictate limited time to be with their child to comfort and protect him/her (Lee & Hung, 2008). Under these and other pressures, it may be even more difficult for parents to make a DNR decision. Even though in paternalistic cultures like Taiwan parents tend to abdicate to the physician’s authority (Lin, Yeh, & Chen, 2009), studies indicate that a miss-match exists between the opinion of the parents and the physicians: that parents tend to have a more positive view of their child’s prognosis than physicians do (de Vos et al., 2011). Thus, conflicts between the family and health professionals may arise. This research adds to the present body of knowledge about the perspective of parents who have experienced the trauma of having to experience the death of their child. Lessons learned can be used to improve staff knowledge and skills in helping families cope when their hospitalized child is terminally ill.

Method

Study design

A descriptive qualitative design was used for the study. This design is “the method of choice when straight descriptions of phenomena are desired” (Sandelowski, 2000, p. 339). In-depth interviews focused on the parents’ experience of the process of making a DNR decision for their child in PICU.

Setting and sample

Purposive sampling was used. In this study a child was defined as 18 years old or younger, consistent with that of the Protection of Children and Youths Welfare and Rights Act (The Executive Yuan of Republic of China, 2012). Recruitment criteria were that parents had signed the DNR form for their child and the child was presently or had been a patient in the PICU of a medical center in a metropolitan area in Taiwan. Parents of children who were admitted for presumed or confirmed abuse, neglect, or accidental trauma were excluded.

A total of 16 parents participated including seven fathers and nine mothers. Five couples were interviewed where both parents were interviewed together (n = 10). For four couples, one parent was interviewed (n = 4). Two single mothers also were interviewed (n = 2). Parents of two children who were approached refused to participate because of severe personal distress. Once an interview began, no parents withdrew from the interview.

Ethical consideration

The study was approved by the ethical committee boards of the hospital and the university. Parents who met the criteria were referred by the PICU staff. Parents were approached by the study investigator and were given written information explaining the study. A signed consent form was obtained from each parent before the interview. During the interview, if the parents felt uncomfortable, they knew they could decline to answer any question or end the interview. The parents who agreed to participate were scheduled for an interview, at a time and place according to each parent’s preferences. In the transcript and report of each interview, children and parents were de-identified and only referred to by code.

Data collection and analysis

Interviews were held at the parent’s selected place. Parents were asked how they perceived the issue of DNR and how they felt during the process of signing the DNR form for their child. Probes were used where necessary to elicit deeper expressions. Each interview lasted about 60–90 minutes and was audio-taped and transcribed verbatim immediately after the interview. New interview data were continuously and repeatedly analyzed and only referred to by code. Two language consultants had different opinions about the translation issue. After validation of the Chinese-English translation, one of the researchers translated the transcribed data into English by herself as the first draft. Two language consultants, experts in both Chinese and English, then validated the accuracy of the language translation. In cases where the two language consultants had different opinions about the Chinese-English translation, a third language consultant, also an expert in both Chinese and English, was asked to resolve the translation issue. After validation of the Chinese-English translation, a native English speaker (American) read the translated transcript to make sure that it was understandable to native English-speaking readers. The translation was considered finished when the English language consultant agreed with the translation. If the English language consultant had any comments about the
translation, the researcher and the Chinese language consultants discussed and revised the transcript.

Trustworthiness

Trustworthiness of the data was established by addressing criteria including credibility, transferability, dependability, and confirmability (Lincoln & Guba, 1985). All interviews were conducted by the first author who was a former PICU staff member. The interviewer visited and contacted participants multiple times to establish positive relationships and rapport. Parents with children of different ages were included in order to obtain thick description of the studied phenomenon. The interviewer’s field notes included a record of each participant’s nonverbal behaviors and a summary of each interview. Each interview transcript was checked against its corresponding audiotape. The author carefully read each transcript to obtain the context, coded the meaningful texts separately, compared the codes, and formed the categories based on the relationships among the texts. The authors then reached consensus and generated themes of the parents’ experiences. During the coding process, experts in qualitative methods and nursing specialists in pediatric critical and palliative care were invited for consultation. Based on concerns about cultural relevance and consistency of the language translation, the documents were translated as described in the previous section.

Results

The ages of the nine mothers ranged from 24 to 52 years and the seven fathers’ ranged from 26 to 52 years. Participants were the parents of four boys and seven girls for whom a DNR request had been signed by one parent. All of the participants were approached about signing a DNR form by a physician who was involved in their child’s care. Three of the children were less than 1 year old, four were of early school age and four were adolescents. Four children had cancer, three had cardiovascular diseases, three had rare diseases, and one had a complicated enterovirus infection. At the time of the interview, six children were living and five were deceased. Nine of the 11 DNR forms were signed by fathers. In each of these cases the father was the one who led the discussion of the DNR issue with the mother, and the couple made the decision together. Two DNR forms were signed by divorced single mothers. Two mothers’ occupations were health professionals (one nurse, one physician).

Three major themes, (a) “convincing points to sign”, (b) “feelings immediately after signing”, and (c) “postsigning relief or regret” were identified (Table 1).

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<th>Themes</th>
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<td>Can’t bear any more</td>
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<td>Feelings immediately</td>
<td>Frustration</td>
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<td>Guilt</td>
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<td>Conflicting hope</td>
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<td>Postsigning relief or regret</td>
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<td>Our child’s life is beyond our control</td>
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Table 1 Three Major Themes and Their Subthemes

Theme one: convincing points to sign

Most of the children had been hospitalized for a period of time and the child’s health had deteriorated prior to their parents being approached about signing a DNR form. The health professionals discussed the child’s conditions and the possible DNR decision with the parents. Parents described the factors that influenced their decision to sign the DNR form. The factors clustered into three areas: “can’t bear any more”, “poor future”, and “health professional’s explanation and attitude”.

Can’t bear any more

Once parents realized that their child was less likely to recover and more medical treatment could only hurt their child and cause pain, they signed the DNR form. For example, child L’s oxygen saturation had been low since birth but the etiology was unknown. Her condition was not stable after being treated for a month. L’s father described having an aching feeling when seeing the CPR process done on her in the past. Thus, he decided to sign the DNR form. He said the following:

I saw her rescued every half an hour. My wife and I cried when we saw the medicine injected. Her little tummy was shivering intermittently. Her whole body’s color changed. I felt she was “living death”. We were torturing her. I thought signing the DNR form would be better for her. She suffered greatly ever since she was born. I hoped she would have a good journey from now on.

J’s mother described a close conversation with her adolescent son:

I remember one day he asked me to hold him. He brought up the topic and told me “Mom, I was born with a good life but I was too sick. I do not want to hold on anymore.” He expressed his point very clearly. He wanted me to give up any aggressive treatment. I signed on the day he died.

Poor future

Parents described that as couples, they made the DNR decision together. However, mothers more often insisted on attempts to save the child and most fathers were more likely to think about the consequences after resuscitation and how the child’s future would be affected. For example, B’s father said the following:

Ever since she was born, she stayed in the hospital. Every time you saved her, she just lay there. She had to depend on the ventilator for life and her lungs were infected repeatedly, so this time we decided not to give her more medication and not to have a tracheostomy done.

Several parents learned from doctors that after the resuscitation, children that survived would have multiple organ failure, neurological damage or need to use a ventilator or be on dialysis lifelong. L’s father said, “It is not fair for her to live her life this way and she would blame us.”

Health professional’s explanation and attitude

Almost all of the parents expressed that they felt the health professionals had more knowledge to judge their child’s condition than they did; thus they relied on the professional’s explanations and attitudes to decide whether or not to sign the form for their child. If the doctor showed empathy toward the parents’ or child’s situation when explaining the DNR form, the parents were more likely to agree with the doctor’s judgment. However, some doctors showed less empathy for the child’s family and presented information like a routine explanation. Some parents reported that the
necessity of signing the DNR form was presented repeatedly to them. Even though they signed, these parents said they felt pushed. C’s mother, a nurse, signed the DNR form because she knew it was a routine procedure. She recalled the following:

I knew they wanted me to hurry up and sign because his condition was not good, but I felt badly for my child’s critical condition. Although the doctor explained his prognosis, I could not listen. I wanted to hear how he could save my child... If you over-emphasize the bright side of the DNR order, the parents might sign the form but fail to see the possibility that their child might survive. It is not ethical to push parents because a child’s developmental potential is unpredictable. You should just let me know what to expect and let the parents have time to think.

There is no right or wrong decision made by parents and they need more support from health professionals.

Few parents were told by the doctors and nurses that signing the DNR form was a routine procedure, or that the signed consent form would always become invalid if the parents changed their minds later. Some parents expressed that thinking this way could have been comforting and helped them sign the form.

Theme two: feelings immediately after signing

Once the parents signed the DNR form, feelings related to signing it were mixed including “frustration”, “guilt”, and “conflicting hope”.

Frustration

Parents felt they had worked hard in the care of their child since the child was first diagnosed, but that they did not get the expected “rewards”, that is, saving the child for all the efforts they made. For example, child D had an inherited metabolic disorder, for which liver transplantation was a treatment option. D’s mother saw the improved quality of life among other children who had had liver transplants. She donated a part of her liver to her child, but her child’s condition became worse. She said, “I thought everything would go well after the transplantation. I did not expect her lung would get infected... I had already donated my liver, how come she would have a prognosis like this? I felt frustrated to sign the form.” Another child, J, was diagnosed with osteosarcoma. His single mother fought against hardships with her child for years. When signing the DNR form she felt that she and her son were “sentenced to death”. She said, “The doctors said it was meaningless to treat him aggressively... We were shocked... We could not believe we had followed [the medical protocol] step by step... to this unexpected dead end.”

Guilt

Once they signed the DNR form, parents described how they felt pressure or like an “executioner” who had given up on their own child. They blamed themselves, feeling that they were not being good guardians of their child by signing the DNR form. Some parents felt sorry for not being able to give their child a healthy body and felt guilty that they participated in “terminating their child’s life”, which they had in fact created. Some parents expressed concerns that the signing of the DNR form might be against the child’s will and that it would dampen the child’s will to live. The parents who were health professionals appeared to experience the same degree of impact from signing the DNR form as that experienced by the other parents. C’s mother was a nurse in an adult ICU. The scene of her healthy child suddenly lying on the bed in the PICU reminded her of patients she had cared for who had died. When encountering the fact that she might lose her child, she was described by her friends as being “hysterical”. She said, “I was asked to choose aggressive treatment or forego treatment for my child. It sounded simple but was actually very difficult for me.” From her professional point of view, she chose to sign the DNR form, but she still felt conflicted between her role as a medical provider and that of being a mother. She described, “I felt it was like throwing my child into water but he could not swim and was going to drown... I really could not stand this... I felt I was not a good mother.”

Facing the situation of having an ill child and being asked to sign a DNR form provided health care professional parents the unique perspective of viewing the situation from both the parent side and from the provider side. This resulted in their reflecting on and reconsidering their professional role in similar situations. J’s mother who was a doctor expressed her guilty feeling when acting in the parental role even though she was also a physician.

Because of his cancer, I realized there was a big limitation in medical practice and started to doubt what on earth a doctor was doing...When hearing of other patients with a good prognosis after an amputation, I would doubt if I managed the situation [signing the DNR form] correctly. I could not forgive myself.

Conflicting hope

In the PICU, parents expected that signing a DNR form would shorten their child’s suffering. If they saw the child still suffered, they would hope “god will let her be at rest and go fast.” However, in the parents’ hearts they still hoped for a miracle that their child might survive even after they signed the DNR form. A’s mother said, “But if the doctor mentioned there might be a new treatment, we would still try even just having faint hope.”

Theme three: postingsign relief or regret

After they had signed the DNR form, parents tried to persuade themselves “I have done my best,” and “the child’s life is beyond my control.” These thoughts alleviated their concerns about signing the DNR form. However, some parents whose child had died before the time of the interview tended to feel “regret not having enough time to be with and talk to my child.”

I have done my best

For the child’s sake, parents wanted their child to have every possible treatment. Besides medical treatment, several parents had tried alternative therapies. They had spent a lot of money buying dietary supplements for their child and had tried folk therapies. Some had heard of miracles occurring at a religious temple, and would go to worship there. Therefore, after they signed the DNR form, parents told themselves they had done everything to save their child. This thought was a way to help the parents relieve the pressure of signing the DNR form. H’s mother said, “I took him to see different famous doctors and even to have a body-mind-soul therapy. When we reviewed the whole process, we kept on telling ourselves that we did our best.”

Our child’s life is beyond our control

Parents, mostly fathers, adjusted their attitude by shifting the power of life on to an external force. These parents found that they could not determine the child’s destiny but rather it was up to divine intervention or destiny if the child survived or not. E’s father, a pastor, depended on his faith to support him. He said, “I was not worried after I signed the form because I believed in God. If she was destined to live, God would save her.” D’s father signed the DNR form for his 2-year-old daughter. He said, “I tried to follow her will
of living. If she hoped to live, she would work harder to get better. If she did not want to live, her condition would deteriorate.” A father followed the drift of his child’s condition and responded one step at a time believing it was futile to worry too much.

Many parents believed that the parent and child were bonded by “yuan-fen” (a predestined relationship). If the child died, that meant the relationship ended in this life and might continue in the next life. Thus, one mother planned to get pregnant later so she could have her child “re-born” with a healthy body to continue their mother-child relationship.

I regretted not having enough time to be with and talk to my child

Most parents chose to conceal the child’s EOL condition from the child, expressing that they did not know how to have this discussion with their child. Parents whose child had already died at the time of the interview expressed regret at not having had time to be with their child. Parents of the adolescent children also regretted not knowing what the child thought about his/her terminal condition. Even though J’s mother was a physician, she mentioned that she could not tell her son he was in his terminal stage. Three of the four adolescents in this study had learned from people other than their parents that their condition was terminal and had initiated the DNR conversation with their parents. H’s mother said the following:

In the hospital I was afraid and I hoped that day [death] would not come so soon… I chose to avoid the conversation because I did not know what to do… But after he died, I regretted not discussing the medical decisions with him.

Parents expressed that they did not regret that they signed the DNR form but regretted not having enough time to say “good-bye” and other loving words to their child and blamed themselves for letting their child stay in the PICU alone during their last moments because of limited visiting hours. E’s mother had previously signed a DNR form for her father and she compared the DNR experiences for her father and her child:

If the elderly stayed in the ICU, the family would have respite because I felt I could not take care of him any more. But for a child in the ICU it is different. She was young and was isolated from her parents. Only the cold equipment surrounded her. We could not be there and hold her… We were all aching… Maybe the ICU should have a room for parents who want to be with their child after signing the DNR form.

Discussion

To our knowledge, this is the first study in Taiwan using a qualitative design to explore the parental experience regarding this sensitive topic. In this study gender role differences were reflected in the signing of the DNR form. Although each of the nine couples made the DNR decision together, the father was the one who led the discussion with the mother and it was he who finally bore the responsibility to sign. This observation supports the preferred image of men in Taiwanese society as one of autonomy and being in control. Even in the face of disaster, the husband/father must make all the decisions and protect his spouse and children (Lee, Lin, Huang, Hsu, & Bartlett, 2009).

Two additional influential factors, reducing suffering and retaining quality of life, were identified in our research. These factors had previously been identified by surrogates in other research as important factors when considering whether to sign a DNR form (Wang, 2007). However, unlike the surrogate who signs the DNR form for an elderly person in the last stage of the life cycle (Handy, Sulmasy, Merkel, & Ury, 2008), many of the parents in this study retained some hope for their child, even though they signed the DNR form. It supported our impression that most parents had difficulty facing the real possibility that their child might die young, looking for a miracle to occur. Parents need to be encouraged to express their inner conflicts to help mitigate false hope (Tang et al., 2011).

Studies prior to ours also have shown that a surrogate family member often experiences great pressure and many negative feelings during the process of signing a DNR form for a family member (Handy et al., 2008; Wiegand 2006). This extreme pressure was expressed by parents in our study, using negative descriptions such as “sentenced to death” or “executioner” to emphasize how they felt about the act of signing. The negative reactions may result from their perception of the word “DNR” because the term “DNR” in Chinese means “giving up emergency care”. People often related signing the DNR form and choosing palliative care to giving up on the patient and not giving any treatment (Tang et al., 2011). Our impression is that parents need to be reassured that after signing a DNR form, their critically ill child in the PICU will not be abandoned. Good palliative care will be provided to them to promote comfort to the greatest extent possible (Masri, Farrell, Lacroix, Rocker, & Shemie, 2000).

Communication and professional behavior are two important components of the relationship between the family and health professional (Wiegand, 2006) during the process of making a decision regarding whether or not and how to resuscitate a child. When faced with the prospect of signing the form for family members, surrogates have expressed the need for time to think and for discussion in order to make the DNR decision (Handy et al., 2008). If the doctor or the nurse presenting the form lacked empathy and good communication skills, parents often had unpleasant feelings and perhaps misunderstood the goals of the healthcare team and the DNR process (Levetown & the Committee on Bioethics, 2008), even though they signed the DNR form. A special finding in this study came from the two mothers who were also health professionals. Because of their past experiences in assisting their own patients to sign a DNR form, they knew that the procedure could be routine and hastily done in an ICU. These mothers hoped to have enough time to make the decision for their child. In spite of their healthcare background, when facing their own child’s terminal condition, these mothers could not accept the impending loss and needed a way to express their feelings and role conflict. Also, these mothers reflected on their work ethic after experiencing the DNR process with their own child.

The thought that parents had done their best, or that the child’s life was under an external locus of control, helped alleviate parents’ emotional distress about signing the DNR form. Some parents believed that the child’s survival was determined by the child’s own will, fortitude or religious belief. Previous studies found that spiritual beliefs such as “letting the lord lead” and that “the parent-child relationship endures beyond death” helped parents to sustain emotionally with the EOL decision (Robinson et al., 2006) and feel like good parents (Hinds et al., 2009). Parents with different religious beliefs expressed different perceptions about the parent-child relationship. In our study parents used the end of the predestined relationship between the parent and the child to explain the death outcome of their child. One mother hoped to have the same child with a healthy body re-born. It is possible that the mother had difficulty in detaching herself from her child because she had established such a close attachment since pregnancy (Gardner, Hauser, & Merenstein, 2006). It also might reflect the reincarnation belief (birth-death-rebirth) from Buddhism which
has a strong influence on some parents in Taiwan (Hsu, O’Connor, & Lee, 2009). These coping thoughts helped to alleviate the pressure parents felt around signing the DNR form, telling themselves that they had fulfilled their parental role in this situation.

Although, according to Freyer (2004), a child older than 10 years has the capacity for EOL decision-making, parents in some cultures prevent children from knowing of their terminal condition in order to protect the child (Liben et al., 2008). In a study conducted in the Netherlands, only 36% of children participated in their EOL decisions (Vrakking et al., 2005). In Asian culture, it is commonly believed that telling patients they are at the EOL is like declaring a death sentence and patients will give up all hope of living (Liben et al.; Sherman, 2006). Family members in Taiwan often ask health professionals to conceal a patient’s health condition from the patient (Hu, Chiu, Chuang, & Chen, 2002). Talking about death is a common taboo in Chinese culture; believing that discussing the resuscitation decision is a jinx that could result in the person having bad luck (Fang, Jhing, & Lin, 2009). In our study, most parents avoided initiating the discussion of the possible death and DNR decision with their child, even if the parents knew their adolescent child had learned about their health condition from others. This may lead to a situation where the child either receives incomplete information or must try to pretend not knowing their condition in order to protect their parent (Levtown & the Committee on Bioethics, 2008).

If the child’s condition is concealed from them, parents miss the chance to learn the child’s real thoughts. Previous studies indicate that following their child’s death, parents often regret not letting the child participate in the decision and experience doubts about having made the right decision (Himelstein, 2006; Levtown & the Committee on Bioethics). In our study, none of the parents regretted the DNR decision they had made, but the parents whose child had already died at the time of the interview expressed regret at not having had time to know their child’s thoughts about the decision.

Most importantly, parent-child attachment might be interrupted by the limited visiting time for families in the PICU (Vandall-Walker & Clark, 2011). Limited visiting time interferes with opportunities for children and parents to be together and for all to prepare for the child’s impending death. This divisive external constraint often deepened the parents’ sense of regret after their child passed away.

There were several limitations to this study. As in other studies (Moore et al., 2008), most of our children who died in the PICU after the DNR decision had a chronic disease and the presence of chronic disease alone can impact parents’ decision making and ability to cope. Also, signing a DNR form and issues associated with the possible death of a child are sensitive issues. The interviewer was not a staff member in the PICU which may have allowed for greater study objectivity, but increased the difficulty in making the initial parent contacts. Trusting and sensitive relationships had to be built to overcome initial obstacles. Strategies used included introductions by trusted PICU staff members, frequent visits to the family and being a volunteer on the unit. Nevertheless, all interviewed parents expressed appreciation for the opportunity to express their emotions and thoughts during the study.

Signing the DNR form was a major decision for parents. Unfortunately, parents often felt fragile and chaotic during the process. Doctors and nurses need to sensitively explain both the pros and cons of signing a DNR form, patiently wait for parents to assimilate the information and avoid rushing to a final decision and signature.

Health professionals need to regard the signing of a DNR form not as a routine event but as a part of a process during which guidance, education, information and support are provided to the child and the family. Many Taiwanese parents did not express their emotions outwardly and avoided any talk about the child’s death with the child. Depending on the child’s age and circumstances, nurses can help parents discuss the medical condition and DNR decision with the child and guide the child and their parents toward expressing their feelings. Parents can be reassured that signing a DNR form is not giving up care and that professional caregivers will try their best to make the child comfortable postsigning. In Taiwanese culture, most parents are not used to explicitly expressing their love to their child. This tradition may have contributed to the parents expressing regret at not having a good farewell with their child at EOL. Nurses need to promote policies that include flexible visiting time and space in PICUs and to encourage parents to take advantage of this special time with their child. Creating a quiet environment would allow family members to be involved in providing loving care for their child. Through helping the child and the parents to express themselves, nurses could help to strengthen and support child–family relationships, thus paving the way for fewer parental regrets and a healthier recovery following the child’s death.

Conclusion

The concept of delivering palliative care at EOL has been proposed for ICUs in western countries as well as in Taiwan. Signing a DNR directive as part of this process can be one of the most difficult decision for a parent to endure and face with a child who is critically ill. Nurses in the PICU must be aware of and sensitive to parents’ perceptions and stressors in order to provide culturally sensitive care.

More staff training around communication skills and the concepts of palliative care at EOL is necessary and future studies should evaluate the effectiveness of this training.

Conflict of interests

The authors declared no conflicts of interest with respect to the authorship and/or publication of this article.

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