



Research Article

Taiwanese Parents' Experience of Making a "Do Not Resuscitate" Decision for Their Child in Pediatric Intensive Care Unit



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SUMMARY

Purpose: The purpose of this project was to explore the parental experience of making a "do not resuscitate" (DNR) decision for their child who is or was cared for in a pediatric intensive care unit in Taiwan.

Methods: A descriptive qualitative study was conducted following parental signing of a standard hospital DNR form on behalf of their critically ill child. Sixteen Taiwanese parents of 11 children aged 1 month to 18 years were interviewed. Interviews were recorded, transcribed, analyzed and sorted into themes by the sole interviewer plus other researchers.

Results: Three major themes were identified: (a) "convincing points to sign", (b) "feelings immediately after signing", and (c) "postsigning relief or regret". Feelings following signing the DNR form were mixed and included "frustration", "guilt", and "conflicting hope". Parents adjusted their attitudes to thoughts such as "I have done my best," and "the child's life is beyond my control." Some parents whose child had died before the time of the interview expressed among other things "regret not having enough time to be with and talk to my child".

Conclusion: Open family visiting hours plus staff sensitivity and communication skills training are needed. To help parents with this difficult signing process, nurses and other professionals in the pediatric intensive care unit need education on initiating the conversation, guiding the parents in expressing their fears, and providing continuing support to parents and children throughout the child's end of life process.

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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

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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, Jacobs, & 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 (Perrin, 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 fit into the categories with no more new information added after including the last parental interview. Thematic content analysis was used to analyze data (Graneheim & Lundman, 2004).

Language translation

All interviews were conducted in the Chinese language. Because the findings of this study would be presented in English, the researchers translated each theme and quote from Chinese into English. Twinn (1997) reported that when conducting a qualitative study that involves language translation, the researcher must seriously consider the influence of translation on the validity and reliability of the qualitative data. To preserve consistency 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

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