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Measuring parent satisfaction in the PICU across the world: does one size fits all?

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Pediatric Intensive Care Units (PICU) are complex environments where specialist trained health care professionals are working hard to optimize health outcomes for critically ill children. The successes of the advanced PICU treatments are improved mortality rates. However, the reverse is that children might be prone to new morbidities, such as reported in a multi-center study where the incidence of new morbidity was 4.8%, twice the mortality rate (1). Another challenge for PICU staff is the expansion of family-centered care in clinical practice. In brief, family-centered care refers to respecting and being responsive to the needs and values of family members (2).

Although family-centered care is standard practice in the many PICUs, the reality remains that in many countries across the world parents are not fully incorporated as partners in care. Even in PICUs where it is claimed that parents are fully involved in care, such as their presence during medical rounds, resuscitation and in decision-making processes, there is limited evidence of effective family-centered care interventions (3). This was recently highlighted in the new guidelines for family-centered care in the ICU which provided weak recommendations for clinical practice (4). More importantly, evidence of reliable parent reported outcome measures to evaluate the impact of family-centered care interventions has been sparse.

Few parent satisfaction instruments in PICU have been developed and tested in recent years. The pediatric Family Satisfaction in the Intensive Care Unit 24 (pFS-ICU 24) is an adapted version of the Family Satisfaction in the Intensive Care Unit survey (5). The pFS-ICU 24 survey has 24 Likert-scale questions divided in two domains; satisfaction with care (14 questions) and satisfaction with medical decision-making (10 questions). The survey was tested among 50 parents or

caregivers and revealed adequate psychometric properties (5). The authors acknowledge the limitations of the small sample size. But more interestingly, the main limitation might be that the survey has not been translated and tested in different languages. In addition, the pFS-ICU 24 survey was derived from the adult ICU version which does not specifically originate from a family-centered care perspective but from frameworks of patient satisfaction, decision making, and quality of end-of-life care (6).

Family-centered care is widely implemented in pediatric health care and in PICUs around the world. Thus, instruments measuring parent satisfaction in the PICU should ideally be based on these principles. The Family-Centered Care Scale (FCCS) is one of the few instruments related to the core principles of family-centered care (7). The FCCS was developed and tested in three phases. In the last phase the shortened version with 7 questions was validated among 454 parents in a children's hospital in the USA.(7) Although not specifically designed for measuring parent satisfaction in the PICU, the FCCS could be an appropriate instrument for parents in the PICU given the short and easy design. However, a major limitation of the FCCS is that it measures the perceptions of parents regarding nursing care only.

Two other parent satisfaction instruments have been developed in the Netherlands; the EMpowerment of PArEnts in The Intensive Care (EMPATHIC) questionnaire and the shortened version EMPATHIC-30 (8, 9). The 57-item EMPATHIC was developed by consultation rounds with parents and PICU staff in eight children's hospitals (10, 11). The items in both instruments are divided in five domains related to family-centered care principles; information, care and treatment, organization, parental participation, and professional attitude. Statistical redundancy of the EMPATHIC instrument to the shortened version was achieved by 3,354

parents who completed the questionnaire (8). The explained variances of the 30 items on domain level ranged between 85 to 93% and on total items level 97%. Both versions seem to be valid for a heterogeneous group of parents as no significant difference were found between ethnicity of the parents and the five domains. However, the instruments were developed and validated in Dutch making it difficult to transfer to other countries. In considering transferability, PICU colleagues will need to do two things; 1) translate and validate parent satisfaction instruments into their own language and 2) ensure cultural adaptation (12).

In this issue of *Pediatric Critical Care Medicine*, Wen Sng et al (13) report the results of the impact of ethnic and cultural differences on parental satisfaction in a PICU in Singapore. They translated the EMPATHIC-30 instrument into English and tested some psychometric properties. Their PICU serves Singaporeans and non-citizens of various ethnicities. The majority of the study participants were ethnic Chinese, followed by Malay, Indian and 'others'. Significant differences were observed between the four groups in four of the five EMPATHIC-30 domains. Compared to the Chinese parents, statistically significant differences were found in the satisfaction scores in Malay, Indian and 'others'. Parents from the Malaysian ethnic group rated the items in the domain parental participation the lowest on the 6-point rating scale (mean 5.27, SD 0.72). These results are still higher than reported by the EMPATHIC study performed in three Italian PICUs (14). The Italian parents (n=150) also rated the items in the domain parental participation as the lowest compared to the other four domains. In fact, the Italian parents rated parental participation lower than the Malay parents in the study of Wen Sng et al (mean 4.65, SD 1.45). Another study from Switzerland and France showed the same outcomes. Grandjean et al (15) reported a similar trend where Swiss and French parents scored

the items in the parental participation domain the lowest among all other items of the 57-item EMPATHIC questionnaire (mean 5.22, SD 0.79). Seemingly the parent satisfaction outcomes of the reported studies have one common message. Regardless of the country or ethnicity of parents within a country, the outcomes related to parent participation in care is still an area of concern. It might well be that PICU staff are not yet ready to fully integrate and accept parental involvement into daily practice. Cultural differences of parents should not be an excuse for PICU health care professionals to ignore their values and needs. Maybe we should shift the focus and work towards a culturally effective health care as described by the American Academy of Pediatrics (16), because the PICU population will look different in the near future in many countries in the world. For example in the USA it is expected that by 2020, 44.5% of American children will belong to a racial or ethnic minority group (16). Excellent and simple strategies for supporting parents with different cultural and ethnic background already exist such as a parent buddy program, hospital cultural interpreters program or community collaboration (17). We now have several validated parent satisfaction instruments to evaluate family-centered care interventions in the PICU and also in Neonatal Intensive Care (18, 19). The next step is called science; implementing and testing family-centered care interventions among all parents regardless of their ethnic or cultural background.

If the aim of measuring parent satisfaction in PICU is to improve clinical practice, we might need to step away from figures and focus more on the narratives of parents when asking for their feedback, particular in units with an ethnic diverse population. Adding open-ended questions in a satisfaction survey (as exists in the EMPATHIC instruments) can provide insight and valuable information addressing the experiences of parents related to their specific unit. However, if we aim to

benchmark parent satisfaction outcomes the quantitative data is more simple to report and provide evidence to learn from other PICUs. An example is the Dutch Pediatric Intensive Care Evaluation report providing parent satisfaction outcome data that shows significant differences between the eight Dutch PICU services (20). In small countries like the Netherlands and Singapore, with vast ethnic minorities, the EMPATHIC-30 questionnaire seems to grasp well the satisfaction levels of all parents. The ideal parent satisfaction measure will include both quantitative and qualitative approaches. One size might fit all, but the bottom line is that we need to proceed in using a uniform and standardized parent report outcome measure for clinical practice, research and education.

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