

Shared Decision-Making in Pediatric Intensive Care Units: A Qualitative Study with Physicians, Nurses and Parents

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Abstract

Objectives To understand how decisions are made in Intensive Care Unit (ICU) settings where critically-ill children require life-support decisions and what are the perceptions of health professionals and parents.

Methods In this qualitative study, in-depth, semi-structured, face to face interviews with 8 doctors, 9 nurses and 6 parents of critically ill children were conducted. Interviews were digitally recorded and transcribed. The transcriptions were further analyzed following open coding and formation of themes.

Results The themes were discussed in two major titles: perceived roles and emotions during the decision-making process. All nurses and patients agreed that the decision maker should be the physician. Nurses understood patients' emotions better and had a closer relation with the parents. Both doctors and nurses thought that parents could not have all responsibilities about treatment choices, because they do not have the required knowledge. Similarly parents were afraid to make a wrong decision, thus they wanted to leave this to the doctors.

Conclusions The present study revealed that shared-decision making is not well understood by health care professionals in Turkey. Doctor is the major decision-making authority and this is also accepted and preferred by the patients and nurses.

Keywords Nurse · Parents · Pediatric care units · Physicians · Shared decision-making · Turkey

Introduction

Intensive Care Units (ICUs) are settings where there is great uncertainty around decisions. Shared decision-making is an ideal way to incorporate patient choices into medical uncertainty; it is well known that decision-making is highly affected by personal preferences, experiences, *etc.* [1].

There is limited discussion around shared decision-making in most developing health-care systems. Participation of parents in decision-making of critically ill children have been studied in several countries [2, 3], but most studies did not explore the processes under the heading of “shared-decision-making”. Hospitalization in an ICU causes different family responses [2, 3] Decision-making dynamics in such situations would be expected to differ from other settings.

The aim of the present study was to examine the perceived place of shared decision-making in management of critically ill children and to examine the experiences of parents, physicians and nurses.

Material and Methods

The present study was a qualitative study, as it is most appropriate to understand the meanings of human actions and emotions, at two Pediatric ICUs (PICU) in Ankara, Turkey.

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The research protocol was approved by the ethical committee of the hospital.

The sample consisted of physicians and nurses who had worked in PICUs at least for 3 mo in the last one year. Parents, whose children had been hospitalized at least for a week in last 3 mo, with critical illness requiring life support, were included. The parents of children who were hospitalized in recent 2 wk were excluded, in order to avoid immediate emotional effects of the child's outcome.

Of 11 doctors and 13 nurses who were invited, 8 doctors and 9 nurses accepted to participate. One physician and one nurse could not be contacted. Parents of 18 children, who met the inclusion criteria, were invited. Two fathers and four mothers accepted the invitation whereas only for one child both parents accepted. Eight of the invited parents did not respond while the rest refused to participate.

A semi-structured questionnaire with open-ended questions, which was priorly pilot tested to sort out any problems in understanding was conducted. Both, professionals and parents were blinded to the purpose of the study. All interviews were audio-taped with permission from the participants, and were transcribed.

Interviews for three groups were open-coded separately, at first by two researchers and transcripts were reviewed for consistency. The themes identified during the analysis process were drawn from participants' experiences and feelings.

All inconsistencies were discussed and consensus on the final concepts were reached. Then three researchers reviewed transcripts of the groups and categorized the responses based on similarity. Later, reviewers discussed their findings and had a consensus on two domains to discuss ICU decision-making process.

The final findings were later reviewed by a PICU physician and a nurse who did not participate in the study; for credibility based on their own experiences.

Results

Parents of 5 children (4 mothers and 2 fathers) were interviewed. Mother of a newborn was divorced after the event and could not be contacted, but the father was willing to participate. The characteristics of the children and their parents are given in Table 1; nurses and physicians in Tables 2 and 3. The interviews with parents, physicians and nurses lasted 38, 10 and 16 min on average, respectively.

Findings were reported under two domains to reflect experiences and views of the participants: perceived roles in decision-making process and emotional burden.

Perceived Roles in Decision-Making Process

All participants agreed that physician should be the major decision-maker. Most of them acknowledged that the parents should be informed about the process.

Physicians' Perspective

Most of interviewed physicians mentioned that the parent did not have the knowledge to make a decision and some said it would not even be a matter of question. They agreed that parents have right to be informed about what has been decided.

"It is definitely me who would decide. I am the one who would be responsible for the consequences..." (physician 1)

"Well, the parents should be informed. but they don't have a role in decision-making...they can't!" (physician 3)

Doctors also thought that the parents have emotional burden so they did not support their role in the decision-making.

"Parents are psychologically overwhelmed, they cannot think clearly, they would not have much input." (physician 2)

"The parents might regret what they have decided, they might judge themselves..." (physician 1)

Physicians were also not leaving much space for nurses. They said that nurses are not trained well enough to be involved in such decisions and mostly have a role to support physicians. Physicians also noticed that nurses have a much closer relation with the family, as physicians themselves usually do not have time.

Nurses' Perspective

Nurses had similar opinions. They said it should be physician's responsibility to make the decisions in medically critical situations.

"Physicians should make the decisions. They know much better. They have the priority..." (nurse 6)

"Parents have no space in decision-making. They don't have the knowledge to understand what is going on. But I think they should be informed about the decisions. They have the right." (nurse 5)

Two nurses emphasized that it is not just the physician who has a role in ICU, but it is a team work. But they did not consider their role in the team as actual decision-makers. They

Table 1 Characteristics of the children and parents

Patient no.	Age of the child	Sex	ICU	Diagnosis	Duration of hospitalization	Outcome	Prenatal history	Birth	Parents	Number of siblings	Mother Age/Education	Father Age/Education	Interviewee
1	NB	F	Ped	Sepsis	28 d	Death	Healthy	C/S, Term	Married	1	30 y/University	33 y/University	Both parents
2	NB	M	Ped	MAS	7 d	Death	Healthy	NSVD, Term	Divorced after death of the child	0	32 y/Primary	44 y/Primary	Father
3	5 y	M	NS	AVM	70 d	Discharged with sequel	Healthy	C/S, Term	Married	0	34 y/Primary	33 y/Secondary	Mother
4	2 mo	M	Ped	HC	43 d	Discharged with sequel	Healthy	C/S, 30 wks' pregnancy	Married	0	31 y/Secondary	30 y/High school	Mother
5	4 mo	F	NS	Shunt + MMC	35 d	Discharged with sequel	Healthy	NSVD, Term	Divorced after birth of the child	2	22 y/Primary	33 y/Primary	Mother

NB Newborn; *M* Male; *F* Female; *Ped* Pediatrics; *NS* Neurosurgery; *MAS* Meconium aspiration syndrome; *AVM* Arteriovenous malformation; *HC* Hydrocephaly; *MMC* Meningomyelocephaly; *C/S* Cesarean section; *NSVD* Normal spontaneous vaginal delivery

also mentioned that the parents could be involved but were not able to comment on how this could be done.

Parents' Perspective

Parents also believed that the decision-making role is of the physicians, except one mother who expressed wish to have been involved in the process as a decision-maker. Most of the parents were clear that the major role is of the physician. They expected to be informed about every action taken.

“The physician should make the decision. He knows treatment options and he knows which would be the best.” (parent 2)

Parents felt that they are not capable to make a medical decision and wanted to trust their physicians. Most of them appreciated what physicians and nurses have done for their children, except one mother:

“It is my child and I could best sense his condition. I could have made the decisions, but they did not even ask me. The parents should be the final decision makers, it is our blood we are talking about...” (parent 4)

All parents emphasized that they were not informed enough and the most difficult part about this process is, as one of the parents put it, “the uncertainty behind the walls”.

“...knowing nothing about what is going on and just waiting there is so hard. They don't even spend a little time to do that.” (parent 5)

Most of the participants agreed that being informed was the right of the patient. But on the other hand, parents complained that they were not informed enough.

Emotional Perceptions During the Decision-Making Process

During all the interviews emotional burden has been seen as a major component that affects decision-making process.

Anxiety

Doctors were somehow protected from emotional burden; still they had concerns about doing the right medical actions.

“... Sometimes there are uncertainties around options. Then you feel so anxious... asking several times to yourself, have I done the right thing?” (physician 2)

The parents were overwhelmed with anxiety and fear of losing the child. They also mentioned the feeling of being unable to do anything for their child.

Table 2 Characteristics of nurses

Nurse no.	Department	Number of years since working	Number of years in intensive care	Age	Marital status	Number of children	Deceased child in the family	Seriously ill patient in the family
1.	Pediatrics	18	3	34	Married	2	No	No
2.	Pediatrics	10	3	30	Married	1	No	No
3.	Pediatrics	22	1	45	Married	2	No	Yes
4.	Neurosurgery	3	3	24	Single	–	No	No
5.	Neurosurgery	4	4	28	Married	–	No	No
6.	Neurosurgery	18	1	36	Married	2	Yes	No
7.	Neurosurgery	4	4	26	Single	–	No	No
8.	Pediatrics	3	2	26	Married	1	Yes	No
9.	Pediatrics	7	1	28	Married	1	No	No

Doubt and Blame

One of the parents had the feeling that the right things were not done.

“I believe they did something wrong, that is why he died. Perhaps there were much better doctors in other hospitals... (parent 1)

“I was scared of everything..suspecting everyone as if they were gonna hurt him... Perhaps I did something wrong, perhaps he was suffering because of me...” (parent 1)

Empathy

Nurses seemed to have more understanding of the parents' feelings, compared to the doctors. They had closer communication during the hospitalization.

“...you think yourself as a mother of such a critically ill child. You feel what that mother feels, but you have to do your work... a big conflict...” (nurse 1)

Moral and Legal Responsibility

Participants were concerned about moral responsibility, and physicians also emphasized legal responsibility.

“if one child needs an intervention and parent decides not to do...how he is gonna cope with it if the decision turns out to be wrong” (physician 1)

“... you will never know which is right and you will think that perhaps it could have been different with a different decision... I can never get rid of this idea” (nurse 6)

Hope and Hopelessness

The patients were nervous and afraid. When they heard good progress from the doctors, they had more belief in survival of the child.

“I always thought there is gonna be a miracle and we will just go back home with him completely healthy” (parent 3)

Table 3 Characteristics of physicians

Physician no.	Department	Sex	Age (in years)	Number of years of experience	Duration of working years in ICU	Marital status	Number of children	Deceased child in the family	Seriously ill patient in the family
1	Pediatrics	M	40	15 y	8 mo	Married	3	No	No
2	Pediatrics	F	38	15 y	6 mo	Married	2	No	No
3	Pediatrics	F	26	2 y	6 mo	Single	0	No	No
4	Pediatrics	F	26	2 y	6 mo	Single	0	No	No
5	Pediatrics	M	27	2 y	3 mo	Single	0	Yes	No
6	Pediatrics	F	31	4 y	3 mo	Married	1	Yes	No
7	Pediatrics	F	29	5 y	2 y	Single	0	No	Yes
8	Pediatrics	M	40	15 y	5 mo	Married	1	No	Yes

M Male; F Female; ICU Intensive care unit

“I was focusing on how I can find rehabilitation opportunities for my child after discharge... I never thought about death.” (parent 2)

There was the conflict of having hope and being hopeless at the same time.

“There is a very strong belief inside me that he will be all right. But on the other hand I know things don't go right...” (parent 3)

Sense of Lack of Control

The parents felt that the condition was out of their control. They emphasized that the difficulty was not knowing—not being able to identify the situation.

Fear of Regret

Parents were regarded as important participants in treatment decisions, but they should not bear responsibility for the decisions. At the end of the decision, the child might be affected negatively and the parents would regret their decision for the rest of their lives.

Emotional Bond Between Mother and Child and Anger

There was an emotional bond between mother and child. Mothers wanted to be closer to the child. They did not want their children to suffer unnecessarily.

“I remember they were asking me to calm down... I told them, ‘if there is no hope for the child and he is gonna die eventually, why are you using my child as a laboratory animal’...” (parent 1)

Some felt pity for the child and felt guilty about what was happening:

“Sometimes I said that he was small and he was suffering, but sometimes I thought that he was not aware of anything.” (parent 3)

Fear of the Child's Disability

Parents were stressed about their child's future. If the child will live, what was going to happen to him/her? They were afraid of a discharge with sequelae.

Sadness

All participants felt sad during such a situation and they said that the condition was difficult. Some nurses mentioned that it

gets easier for them as they get experienced in ICU, but they also mentioned that there is always the conflict about what is right.

All parents said that they shared feelings of other parents in similar conditions. They supported each other.

Discussion

The present study underlines the importance of management of critically ill children in PICU. The experiences of parents, physicians and nurses during the decision-making processes in PICUs were evaluated. To the best of authors' knowledge, no previous studies in Turkey have evaluated the shared decision-making process with parents, physicians and nurses all together. The importance of perceived place of shared decision-making in management of critically ill children has been emphasized.

As in previous studies, one of the highlighted issues in the present study is the responsibility for decision. In the EURONIC study, there was a general consensus that parents should be involved somehow, but there were disparities in the opinion of physicians from different countries [2].

Most parents had some concerns regarding participation in the decision-making process; they wanted to participate and learn all decision steps but they often did not understand medical terms. So, they thought physicians could make the best/appropriate decision. In the present study, which presents Turkish point of view, all participants agreed that it is the physician who should be the major decision-maker. Physicians and nurses emphasized that parents would not be ready to take responsibility to make a decision and parents supported this. A similar study published by Carnevale et al. in French parents reported that the principal theme is that physicians should be responsible for life-support decisions [3]. Another study in Italy reported that most participants believed that on-call physician is responsible for making life-sustaining decisions, and sometimes parents and nurses are involved [4].

In the present study second challenge was the fear of facing the legal consequences. Some physicians and nurses mentioned the difficulty of facing legal consequences in case parents are involved. They emphasized that legal regulations are lacking. One physician and two nurses emphasized that in case there is a difference between ideas of medical staff and parents about the decisions, this could lead to major conflicts. This also leads to legal and moral consequences to be faced. On the other hand, there are different approaches such as North American standards require that life sustaining treatment decisions should be made by the child's legal guardians [5]. Italian Society of Neonatal and Pediatric Anesthesia and Intensive Care, states that the physician has the main

responsibility for final decision and other staff and parents should participate in the process [6].

In the present study, both physicians and nurses emphasized the effective communication's influence on the quality of treatment. They believed that sparing time for parents to explain disease and possible outcomes has an important role. Meert et al. showed that parents and staff often work together to fulfil the child's needs [6].

Some participants also mentioned the certain factors like economical aspect, religious belief and lack of information affect decision process. Some physicians and nurses mentioned that the parents had low income and were concerned about how will they take care of the child in case he/she stays disabled afterwards. As this might affect parents' decisions there was a concern about involving them into decisions. This idea was not supported by the interviews with the parents. On the other hand, parents mentioned their low incomes as a challenge to seek better health care centers and better doctors. They thought they did not have the power and the confidence to search for better service.

Some parents and nurses mentioned that religious belief had an important influence on their sense of control.

Although the present sample seems to be small which could be a limitation, several similar studies in the literature have been conducted with 7 families [4], 9 patients [3] and 13 parents [7]. The strength of the present study lies in the sample groups; where different groups were interviewed for the same setting and objective. It is also the only study in Turkey exploring such views and perspectives. Another limitation is that the responses of those who refused to participate in the study or the ones who could not be reached might have been different.

Conclusions

The present study states the importance of high quality communication with doctors, nurses and parents during decision process. There is a good opportunity for improving shared

decision-making in Turkey by involvement of patients in the decision-making process in PICUs.

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