BMJ Open

Parental readiness for pediatric resuscitation: A qualitative study

Journal:	*BMJ Open*
Manuscript ID	bmjopen-2021-055599
Article Type:	Original research
Date Submitted by the Author:	23-Jul-2021
Complete List of Authors:	Ghavi, Arezoo; Tabriz University of Medical Sciences, Department of Pediatric Nursing Hassankhani, Hadi; Tabriz University of Medical Sciences, Powers, Kelly; University of North Carolina at Charlotte, School of Nursing Bostanabad , Mohammad ; Tabriz University of Medical Sciences Namdar Areshtanab, Hossein ; Tabriz University of Medical Sciences, Department of Psychology Nursing Heidarzadeh, Mohammad; Tabriz University of Medical Sciences
Keywords:	Health informatics < BIOTECHNOLOGY & BIOINFORMATICS, Paediatric intensive & critical care < INTENSIVE & CRITICAL CARE, Paediatric intensive & critical care < PAEDIATRICS

Parental readiness for pediatric resuscitation: A qualitative study

Arezoo Ghavi [1], Hadi Hassankhani [2,] *, Kelly Powers [3], Mohammad Arshadi Bostanabad [4], Hossein Namdar Areshtanab [5], Mohammad Heidarzadeh [6]

[1] PhD Student, Department of Pediatric Nursing, School of Nursing and Midwifery, Tabriz University of Medical Sciences, Tabriz, Iran

[2] Professor, Department of Medical-Surgical Nursing, School of Nursing and Midwifery, Tabriz University of Medical Sciences, Tabriz, Iran

[3] Assistant professor, School of Nursing, University of North Carolina at Charlotte, Charlotte, NC, United States

[4] Associate professor, Department of Pediatric Nursing, School of Nursing and Midwifery, Tabriz University of Medical Sciences, Tabriz, Iran

[5] Associate professor, Department of Psychology Nursing, School of Nursing and Midwifery, Tabriz University of Medical Sciences, Tabriz, Iran

[6] 1. Director of newborn health in MOH, Tehran, Iran 2. Associate professor of neonatology, Tabriz University of Medical Sciences, Tabriz, Iran

Corresponding Author:

Hadi Hassankhani, Department of Medical-Surgical Nursing, School of Nursing and Midwifery, Tabriz University of Medical Sciences, Tabriz, Iran, Email: hassankhanihadi@gmail.com

Cell Phone number: +989183181267, Telephone number of work: +984134796770 (134), Telephone number of home: +984134796969

Abstract

Objective: The aim of this study was to examine parents' and healthcare professionals' experiences and perceptions of parental readiness for resuscitation of their child in a pediatric hospital.

Design: This exploratory descriptive qualitative study utilized content analysis. Participants shared their experiences and perceptions about parental readiness for resuscitation through semi-structured and in-depth interviews. MAXQDA 2020 software was also used for data analysis.

Setting: The setting was two large teaching pediatric hospitals in Iran (Ash and Mashhad).

Participants: Participants were 10 parents and 13 pediatric healthcare professionals (8 nurses and 5 physicians). Selection criteria were: a) Parents who experienced their child's resuscitation crisis at least 3 months prior and b) Nurses and physicians who were working in emergency rooms or intensive care wards with at least 2 years of experience on the resuscitation team.

Results: Participants shared their experiences about parental readiness for resuscitation of their child in four categories: Awareness (acceptance of resuscitation and its consequences; providing information about the child's current condition and prognosis), Chaos in providing information (defect of responsibility in informing; provide selective protection of information; hardness in obtaining information), Providing situational information (honest information on the border of hope and hopeless; providing information with apathy; providing information as Individual; dualism in blaming; assurance to parents; presence of parents to better understand the child's situation), and Psychological and spiritual requirements (reliance on supernatural power; need for access to a psychologist; sharing emotions; collecting mementos).

Conclusion: The results of this study provide insight on the needs of parents and strategies to use to prepare them for their child's resuscitation crisis, which can be used to enhance family-centered care practices in pediatric acute care settings.

Key word: Readiness, Parents, Resuscitation, Pediatrics

Article summary

Strengths and limitations of this study

- The findings from this study provide insight about parents' and healthcare professionals' experiences and perceptions of parental readiness for resuscitation.

- The study examined the pre-resuscitation readiness of parents, which is important for identifying strategies to help them prepare.

- Cultural considerations emerged when examining the experiences and perceptions of healthcare professionals who work in large hospitals in two major cities in Iran.

- Most of the participants were female because most pediatric healthcare providers are women and the main caregiver of children are mothers.

- In this study, the children of the parents were all 5 years of age or younger because older children and adolescents are usually hospitalized in adult hospitals.

Introduction

Child resuscitation is a critical time for parents (1). In the United States, approximately five percent of children who go to the emergency department for critical care need resuscitation (2). However, this statistic varies between four and six percent of hospitalized children in intensive care units (3). In a study in Iran, approximately five percent of patients referred to the emergency department for critical care were under 18 years old (4). Among resuscitated children, less than 20% survive and are discharged from the hospital (5,6).

In pediatric hospitals, especially in wards such as the emergency room where critical care for children is provided, parents are mostly present (7). When parents are faced with their child being acutely hospitalized, they can suffer from psychological stress, which will also have a negative effect on the treatment results (8). Anxiety, stress, depression and post-traumatic stress are some of the psychological problems that parents can face when their child requires resuscitation (9). In the study of Lisanti et al. (2017), mothers in the pediatric intensive care unit had the highest score of stress and anxiety at the time of resuscitation of their child (10). Parental well-being is essential for the well-being of children with life-threatening illnesses (11). Therefore, healthcare professionals have a vital role in parental preparedness for resuscitation (9). In addition to providing specialized clinical care, healthcare providers should also consider parental support needs at this time (12), as parental support is one tenet of family-centered care structures that leads to increased quality of care (13).

Many studies have focused on the presence of parents during resuscitation of their child, but few studies have examined the pre-resuscitation readiness of parents, which is important for identifying measures to help them prepare. Further, cultural differences may affect the support of parents in these critical situations; therefore, there is a need for examination of parental readiness among various cultures and countries. This study was conducted in Iran to explore the readiness of parents for resuscitation of their child.

Methods

This study used an exploratory descriptive qualitative approach to examine parents' and healthcare professionals' experiences and perceptions of parental readiness for resuscitation of their child.

Setting and Participants

The setting was two large teaching pediatric hospitals in Iran (Ash and Mashhad). Using purposive sampling, there were 10 parents of 7 children and 13 pediatric healthcare professionals (8 nurses and 5 physicians) who participated in the study. Selection criteria were: a) Parents who experienced their child's resuscitation crisis at least 3 months prior because after a stressful family event, the symptoms of depression, anxiety and post-traumatic stress disorder are decreased after 3 months (14) and b) Nurses and physicians who were working in emergency rooms or intensive care wards with at least 2 years of experience on the resuscitation team.

Data collection and analysis

Participants were invited to participate in the study by telephone, and face-to-face individual interviews were conducted from February to November 2020. The first author conducted the tape-recorded, semi-structured, and in-depth individual interviews at the hospitals (for the healthcare professional participants) and at the parents' homes (for the parent participants). Each of the interviews lasted between 45 to 75 minutes.

An interview guide was designed to elicit participants' experiences and perceptions of parental readiness for resuscitation. Parent and healthcare professional participants were encouraged to share their experiences about parental preparation needs, how these needs were met, and perceptions of strategies that healthcare professionals can utilize to effectively provide help to parents. Examples of the interview guide questions are available in Table 1. For in-depth understanding of participants' experiences and perceptions, clarification and probing questions were asked after each of the questions in the guide. Interviews were continued to data saturation (15), which was confirmed when no new information or codes were uncovered in the last 4 interviews.

Table 1: Interview guide questions asked of parents and healthcare professionals.

Parents	Healthcare professionals
- In your experience, what readiness did you need before your child's resuscitation? - How were you treated before your child's resuscitation? - What actions helped you become ready for and endure your child's resuscitation? - In your experience, what barriers were there to your readiness for your child's resuscitation? - What factors do you think would have improved your readiness for your child's resuscitation?	- In your experience, what preparation do parents need before their child's resuscitation? - How do you treat parents to help promote their readiness before their child's resuscitation? - What actions do you take to help parents prepare for and endure the resuscitation of their child? - In your experience, what barriers there are to readying parents for their child's resuscitation? - What do you think are the factors that helped improve parents' readiness for their child's resuscitation? - In your experience, how can parental readiness for their child's resuscitation lead to better parenting experiences?

Recorded interviews were transcribed verbatim and then analyzed using content analysis according to Bengtsson's proposed steps (16). First, the text of each interview was read several times. The text was then broken down into meaningful units and coded. MAXQDA 2020 software was also used to encode the data. A list of codes related to all transcribed texts was prepared and each code was identified to which domains it belongs. The codes were also categorized according to their similarities and differences. To increase trustworthiness, this process of data analysis was conducted by two researchers who extracted and then categorized the codes. The extracted categories and subcategories were then confirmed and agreed upon by the other authors. Participant quotes were selected to enrich understanding of the categories. Participant words were spoken in Persian and then translated to English; some quotes have been edited to increase clarity.

To promote rigor (17–19), the experiences of different persons involved, both healthcare professionals (physicians and nurses in different categories) and parents (having children with chronic or acute illness, different literacy levels, urban and rural residences, etc.). These characteristics of participants were collected via a paper-and-pencil survey that was administered prior to the start of each interview. After the research team performed the analysis, the first author returned the extracted codes of each text to participants for review and approval; thus, rigor was further enhanced via member check.

Ethical considerations

This study was approved by the ethics committee of Tabriz University of Medical Sciences with the ID IR.TBZMED.REC.1398.1080. The objectives and procedures of the study were explained to all participants, including measures to protect confidentiality. Participants' personal information was kept confidential, and their experiences were used in the study without names and details. Informed consent was obtained from participants.

Patient and public involvement

We did not involve patients in the development of the research questions. We obtained collaboration agreements with two large teaching pediatric hospitals. We approached the hospitals for that purpose. All gave us positive feedback on the study aims, acknowledging that more research is needed on patients' experiences related to support of parents surrounding resuscitation of their child. Thus, the hospitals supported recruitment of study participants by sending messages for study participation. No individual patient was involved in recruitment and conduct of the study. we plan to send the published results to the teaching hospitals to disseminate our findings.

Results

In this study, 13 pediatric healthcare professionals participated; five pediatrician physicians and eight nurses in different categories of practice (from bedside nurse to head nurse) and education (bachelor to master's degree). There were 10 parents of 7 resuscitated children (children aged one to five years; 3 boys and 4 girls) who participated. At the time of the interview with the parents, between 3 and 12 months had passed since the resuscitation. Parents were aged 31 to 48 years, and seven were mothers and three were fathers. Three of the parents had only one child (one child was born after many years of infertility). Two children of two of the parents had no previous history of illness or hospitalization, while the other 5 children had a history of chronic illness. Demographic details of the participants are provided in Table 2.

Table 2. Participants' demographic characteristics.

Parents	**n**	**%**	**Healthcare Professionals**	**n**	**%**
- Relation to child			- Field of education		
Father	3	30	Nurse	8	61.5
Mother	7	70	Pediatric physician	5	38.5
- Education level			- Gender		
Academic	5	50	Female	9	69.2
Non-academic	5	50	Male	4	30.8
- Location			- Years of experience		
Town	8	80	< 10	3	23.1
Village	2	20	≥ 10	10	76.9
- Number of times experienced their child's resuscitation			- Marital status		
			Married	9	69.2
Once	5	50	Single	4	30.8
Twice or more	5	50	- Parent status		
			Having own child(ren)	9	69.2
			No children	4	30.8

Participants in this study shared their experiences and perceptions about parents' readiness for resuscitation of their child in four categories: Awareness (acceptance of resuscitation and its consequences; providing information about the child's current condition and prognosis), Chaos in providing information (defect of responsibility in informing; provide selective protection of information; hardness in obtaining information), Providing situational information (honest information on the border of hope and hopeless; providing information with apathy; providing information as Individual; dualism in blaming; assurance to parents; presence of parents to better understand the child's situation), and Psychological and spiritual requirements (reliance on supernatural power; need for access to a psychologist; sharing emotions; collecting mementos).

1. Awareness

Based on the experiences and views of the parents and healthcare professionals, awareness about a child's condition and health problems was considered to be a parents' right. There were two sub-categories that emerged in this category of awareness:

1.1: Acceptance of resuscitation and its consequences

Some parents were informed about their child's condition before resuscitation, and this helped the parents better understanded their child's condition and its severity. This action of healthcare professionals was considered a proper and necessary behavior. By informing parents of their child’s condition, parents felt satisfied with the care of the healthcare team, even after the death of the child. One father stated (table 3-1.1-F7).

Both parents and healthcare professionals expressed how having awareness of the child's poor condition before resuscitation helped parents to prepare for the crisis. Having awareness was also felt to help with acceptance of the death of the child and preventing shock caused by the crisis. Informing parents of their child’s condition, also provided the opportunity for healthcare professionals to prepare parents to be present in the resuscitation room. As a result of having awareness, the parents prepared themselves, psychologically and mentally, that their child was in critical condition, even in acute cases. A doctor explained (table 3-1.1-D8). Two fathers also stated (table 3-1.1-F1, F7).

1.2: Providing information about the child's current condition and prognosis

Healthcare professionals' experiences indicated that in hospitalized children, if parents were informed about their child's condition during hospitalization, they were better prepared for a resuscitation crisis than if the crisis were an unexpected emergency. Even then, explanation about the child's prognosis could help parents accept this crisis. In this regard, a nurse stated (table 3-1.2-N2).

Parents, based on their experiences, also explained that they needed to be constantly informed about their child's condition and the actions that were being taken for him/her during the hospitalization. This was especially important during the time when their child's condition was worsening, and even could occur over the phone. In this regard, a father said (table 3-1.2-F7). While a mother who had no awareness of her child's condition, stated (table 3-1.2-M4).

To express the possibility of resuscitation and death in hospitalized cases, both parents and healthcare professionals believed that parents should be told about the care interventions that could be used in attempt to save the child's life. One nurse described how this was done (table 3-1.2-N4).

A mother's statement highlighted why receiving this information is so important (table 3-1.2-M9)

In emergency cases, where the resuscitation was not expected, opinions were different about informing the parents of the possibility of resuscitation and of the child's death. One doctor stated (table 3-1.2-D9).

When expressing the possibility of resuscitation, in addition to making parents aware of resuscitation actions and equipment, it was also deemed important to talk to parents about their desire for and location of presence during resuscitation, although it is common for parents to be directed to leave the resuscitation room. A nurse stated (table 3-1.2-N10).

The experiences of the parents and the healthcare professionals showed that in cases when the possibility of losing the child was told to the parents, the field of parents' bereavement needs were not considered. Parents expressed a need for a private space to be with their deceased child and release their emotions. A father said (table 3-1.2-F1). A mother also expressed her need for a private space after the death of her child (table3-1.2-M9).

Table 3. Awareness

1.1: Acceptance of resuscitation and its consequences	"Thanks to all of them [healthcare professionals]. They did everything that they could. Well, I knew my child's problem, nothing could be done for her." F7 "A child was brought to the emergency room with severe dehydration. The child's parents brought the child to the hospital too late from fear of Corona, so that the child was in a state of shock. I fully explained to the parents about the bad condition of the child, that the child was breathing with the device and his heart was working with the injected drugs. I fully informed them about the bad condition of the child. The child died in the ICU that night, but when the parents were informed, I felt the shock did not happen in these parents the same as for other parents. It seemed to me that they accepted it more easily ... " D8 "... Because we had already been told that our child might die, his mother and me decided to donate his corpse to the University of Medical Sciences if he died." F1 "Since I was told the truth, I realized that if my child survives, it might not be good for her either. Because I was told the truth and I understood the truth, I was satisfied that if my child were to die, she would not suffer." F7
1.2: Providing information about the child's current condition and prognosis	"A child was hospitalized and intubated for a long time. The parents witnessed our actions. The parents were informed of the child's condition and prognosis during this time. They thanked us after their child died, even while they were in a bad mood." N2 "Because I was already told that her condition was not good and she [his child] was very ill, I had background about resuscitation of my child." F7 "My daughter was hospitalized about 6 months, but I was not told that my child was getting worse. I thought everything was well and I was not at all ready that my child was getting worse, and I did not expect her death at all." M4 "When there was a possibility of resuscitation, I would give the parents full information about their child's condition. I was telling them that your child might need us to squeeze her chest or, like this child, insert a breathing tube so that the device could help your child breathe." N4 "I did not know what they were doing and why. I was dying and living every moment." M9 "We say that the child is in critical condition, but we have never said that he/she may need resuscitation or the child may die because the child is brought to the emergency room at once, and we do not know exactly what the problem is and the situation is not predictable ..." D9 "If parents were not agitated and could control their emotions and did not disrupt the resuscitation process, I was telling them that they could be in the room. Otherwise, they would be directed out of the room or they could watch the resuscitation from the window of the room." N10

	"In any hospital, it's much better if there is a private place at this moment [after the failed resuscitation of the child] so parents can release themselves. If there is such the place, no one told me anything before." F1 "Immediately after the resuscitation, they took my child to the mortuary and did not let me say goodbye to my daughter and see her for the last time. I was also told not to make noise and cry because other mothers were in the ward and they might scare. I was running to the mortuary looking for my child's corpse. Unfortunately, there were no facilities for us. At least others should lose their children in a calm situation." M9

2. Chaos in providing information

The experiences of parents and healthcare professionals indicated that there was no specific process for providing information, as demonstrated in three sub-categories:

2.1: Defect of responsibility in informing

The parents in this study wanted doctors and nurses to be available to provide information. But they most preferred to get the information from a doctor who was responsible for and aware of their child's condition. Yet, in this study, participants' words demonstrated there was defect of responsibility to provide information to parents. Physicians considered it their duty to provide information to parents, and one physician stated (table 4-2.1-D9).

But the nurses discussed doctors' irresponsibility in informing the parents about their child's condition. Although nurses considered providing diagnostic information to be duty of the physicians, they felt discussing care information is their duty. At the same time, they were confused about providing information and responding to the parents, feeling uneasy because they were more in touch with parents. One of the nurses stated (table 4-2.1-N2).

2.2: Provide selective protection of information

In the culture of the participants in the study, there was withholding of information and information was transferred from healthcare professionals to parents selectively and protectively. Parents in this study tended to realize the condition of their child without actually having been provided such information from the healthcare team, and some of the healthcare professionals withheld information to help protect the parents. In some cases, healthcare professionals preferred to give information about the child's poor condition to relatives or close friends rather than the parents, and these individuals then transferred the information to the parents. In this regard, a nurse stated (table 4-2.2-N4).

In providing information to parents, healthcare professionals also preferred to provide unpleasant information about the child to the father rather than the mother. A doctor stated (table 4-2.2-D8).

But the healthcare professionals did not ensure the transfer of this information to the mother. The desire of the father to protect the mother was also evident. This withholding of information had caused the mother, in some cases, not to have awareness and readiness for their child's crisis. A father said (table 4-2.2-F7).

2.3: Hardness in obtaining information

The experiences of most of the parents showed that information about their child's condition was obtained with difficulty, consuming their time, and that doctors especially spent little time providing parents with information. Participating parents in the study wanted to receive information from physicians at their child's bedside. A mother stated (table 4-2.3-M9).

Table 4. Chaos in providing information

2.1: Defect of responsibility in informing	"If the doctor gives information, it is better because the parents trust the doctors more. Now, if there is no doctor [available], the nurses will be next. It is better for a male doctor to talk to the father because the father accepts more easily than if a woman doctor, especially when she is young. But it also depends on how the doctor is expressing. Even if she is a woman or young, it depends on how she speaks so that she can convince the father." D9 "The doctor and head nurse of ward were telling us not to talk to the parents about their child. I personally do not know what to say when parents ask. Because the doctor is only there for one hour in the ward every day. When we do not respond to parents, they think we know nothing and lose confidence in us and our care of their child." N2
2.2: Provide selective protection of information	"In one case, a child was brought to the hospital and the child did not have a specific illness before. The parents were agitated and very anxious. I talked to the child's uncle about the child's poor condition and what had happened." N4

	"I prefer to give bad news to the father so that he tells the mother. Fathers usually act more logically." D8 "I knew my child's problem at that time. I realized she was dying and it was good. Therefore, I could say goodbye to my baby at the last moment. But I wish I told her mother, so she was ready too." F7
2.3: Hardness in obtaining information	"If we wanted to be told about our child's illness, we had to run to the doctor in the hospital corridors, but we could not see him. Everyone was around. We had to go to the office of the doctor. Well, I was foreign in this city, I had to request a taxi to take me to the doctor's office. After difficulty finding it, I had to pay a visit to the doctor to have my baby's condition explained for a few minutes, otherwise they [doctors] would not answer us." M9

3. Providing situational information

The experiences and perceptions of parents and healthcare professionals revealed that providing information to parents should be done according to the situation of the child and in consideration of parental condition. Six sub-categories were approved in this category:

3.1: Honest information on the border of hope and hopeless

Healthcare professionals and parents emphasized the importance of honest and truthful information. The healthcare professionals had experienced situations where there was lack of correct information and it caused mistrust in parents. Also, parents' experiences showed that if they received untrue information, they were not prepared for the crisis ahead. A mother stated in this regard (table 5-3.1-M5)

The healthcare professionals explained how when they provided honest information for parents, they worked to provide information that was on the border of hope and hopeless. A nurse explained (table 5-3.1-N1).

Yet, the experiences of parents in this regard showed that most fathers did not have or want false hope, and most mothers didn’t all hope removed when being provided information about their child's condition. This is demonstrated in the following exemplar quotes from a father and a mother (table 5-3.1-F7, M2).

3.2: Providing information with apathy

Parents emphasized the importance of receiving information from the treatment team in a kind, compassionate, and respectful manner. Some parents appreciated the kind words of healthcare professionals. But most parents indicated that healthcare professionals could not comprehend their mental state when providing information to them and they provided information about their child's situation with apathy and without empathy. One father expressed his dissatisfaction with the way the doctor provided information to his wife (table 5-3.2-F7).

Also, a mother whose baby was in critical condition immediately after delivery explained receiving unempathetic care from nurses (table 5-3.2-M5).

3.3: Providing information as Individual

The experiences of both parents and healthcare professionals indicated that it is not possible to have a same method of providing information to all parents. It depended on the parents’ level of understanding, education, age, language, whether the parents have only the one child, if the child has been hospitalized before, and whether the child’s illness is acute or chronic. Their experiences showed that for low-education parents, it is important to provide information in simpler, brief and tangible ways. But for higher-education parents, this information could be provided more scientifically and completely. In this regard, two fathers with different levels of education expressed (table 5-3.3-F7, F3). A doctor also shared his experience (table 5-3.3-D13).

The experiences of parents and healthcare professionals also showed that the speed of transmitting information to parents was important, especially when providing information to mothers. It was also necessary to be more sensitive when providing information to parents with a single child or golden baby (born after years of infertility issues and treatment) as this child might be the foundation of the family. A mother who got pregnant after eight years, said of her missing child (table 5-3.3-M4).

Healthcare professionals’ experiences indicated that older parents are more receptive and have a better understanding of information than younger parents. A nurse explained (table 5-3.3-N2)

Linguistic differences in multilingual countries make it difficult for healthcare professionals to provide information to parents. In this regard, a doctor offered a solution (table 5-3.3-D9).

The healthcare professionals’ experiences showed that it is easier to provide information to parents with a child who has a chronic illness or has been hospitalized for at least a few days rather than in an acute emergency situation because unexpected crises can cause parents to be agitated and the high stress prevents them from understanding the information. A nurse and a doctor described their experiences as follows (table 5-3.3-N5, D8).

3.4: Dualism in blaming

Doctors' experiences showed that if parents were blamed, this prevents the doctors themselves from being blamed and prevents future complaints. Yet, when parents were blamed for the situation of their child, it caused great remorse and grief in them. A mother who lost her child to influenza said (table 5-3.4-M6).

Some healthcare professionals acted differently. They believed that even if parents may be to blame for the situation of their child, healthcare professionals should not blame them. The healthcare professionals felt that if they were unable to release their pain, they at least needed to make sure they did not add any additional pain. A nurse spoke about her experience with a mother who brought her baby to the emergency room with hypoxia due to falling asleep while feeding with her breast on her baby's face (table 5-3.4-N1).

3.5: Assurance to parents

The experiences of healthcare professionals and parents showed that in order to prepare parents for the crisis ahead, the transfer of information must be accompanied by efforts to facilitate trust. This was felt to be important so that both in practice and in speech, parents could be assured that everything necessary for the child would be done. To best ensure trust, it was felt that healthcare professionals should coordinate the providing of information and there should be no inconsistencies in the information. Also, healthcare professionals should avoid accusing their colleagues when providing information to parents because this can cause insecurity in the parents. As one mother said (table 5-3.5-M10). Also, in sharing of information, a physician said (table 5-3.5-D12).

3.6: Presence of parents to better understand the child's situation

Providing information through verbal speech was felt to not always be enough. Instead, it can be necessary to improve understanding of the child's situation by having parents be present to witness their condition and care. The experiences of parents and healthcare professionals showed that parents who were with their child during the child's hospitalization, especially in the last moments of the child's illness, better understood their child's illness and how severe it was. They felt that parents who were present were better prepared to face the crisis than parents who were not present. A nurse stated (table 5-3.6-N2).

In one case of acute infant death, in which the child did not previously have a chronic illness and had been hospitalized for approximately five days prior to death due to influenza, the mother seemed to be better prepared for the crisis because she was with her child throughout the deterioration (table 5-3.6-M6).

Table 5. Providing situational information

3.1: Honest information on the border of hope and hopeless	"In the first days, everyone [healthcare providers] told us that my child was fine, then suddenly he died and they said that his heart was stopped. I said that you said it was good, but now what happened..." M5 "We have to talk between the border of hope and hopeless. We have to say the positives and the negatives of the points. We should not be too hopeful and not too disappointed …" N1 "Do not provide false information and tell the truth. For example, my child had a seizure. They [healthcare professionals] should not say do not worry, it was nothing. I knew my child had a problem." F7 "I knew my child was not well, but I did not like to be constantly disappointed. I was afraid to call the ward because I was afraid that they [nurses] would say that my child was very ill, or I would enter the ward in fear." M2
3.2: Providing information with apathy	"One of them [a doctor] said very badly to his mother [the participant's wife] that this child of yours is like this, you have to get used to her [child]. If you can't hold her, take her to Welfare." F7 "I had so much pain, but I did not think about myself. I was anxiously requesting information about my baby's condition, and I was constantly asking what happened to my child? Do not let him get cold. They [nurses] said that we know our work, please do not interfere." M5
3.3: Providing information as Individual	"... I have not studied medicine to know. If they had given me this information in simple language so that I could understand it, it would have been very good. I did not understand what they [healthcare professionals] told me." F7 "We really needed someone to explain my child's situation to me. Well, I was somewhat familiar with English terms. If someone explained it to me, I would understand because I am also a language teacher and translator." F3 "When I was at the beginning of my career, I was talking with a father using scientific terms about his child's condition. I had not finished my explanation yet; I saw he was angry and said 'Do you make fun of me?' …" D13 "... Slowly with the introduction, perhaps our audience [the mother herself] might not be strong enough to endure. When one of the nurses was providing bad information about my child, in the middle of her conversation, I did not understand what happened to me, as the world was ruined on me ... When I opened my eyes, I saw the doctor and the nurses and my husband around me…" M4 "Young parents have no responsibility at all and do not seem to understand or care about it at all. These parents are not the decision-makers themselves, and the grandparents are the decision-makers." N2 "Linguistic differences may make it difficult to explain. For example, the language of parents may be Kurdish and they do not know Persian. In these cases, we look for personnel who are at least fluent in the parent language and try to provide information to parents through them." D9 "Families who come to the emergency room frequently ask questions. I can't completely answer their questions and need to repeat the information because they are so anxious, and they can't understand." N5 "A person should speak to them [parents] calmly, respectfully and in their own language. But often it does not work. When parents are very agitated, I go forward to talk to them, but I see that it gets worse, and they are aggressive and told me 'What are you doing? You go and do your work.'" D8
3.4: Dualism in blaming	"I asked the doctors: 'Could the flu kill a healthy child in a week because my daughter didn't have a problem before?' They said it was probably because your daughter didn't feed on your breast milk and you fed her with dry milk and you gave birth to her by cesarean section .... [The mother did not continue, she sighed and then cried]" M6 "I tried to make sure she [the mother] didn't feel guilty. I said to her that she wasn't the only person who experienced the accident and it could happen to anybody" N1
3.5: Assurance to parents	"The opinion of the doctor who spoke to us was that they [other doctors] should not operate at all: 'They took your child to the operating room to look for where the problem was. What do you expect from a one-and-a-half-kilogram child?'" M10 "Before, in the emergency room, everyone was talking to the parents [nurse, intern, resident, etc.]. Everyone was asking the parents what happened and why did you bring the child to the emergency room? Also, parents' questions were answered in different ways, and it caused the parents to become agitated. But since we managed this situation, the pediatrician or senior resident is in the emergency room, and this has reassured the parents that there is someone who can manage the team." D12

3.6: Presence of parents to better understand the child's situation	"A child was hospitalized. His parents were not present at the bedside of the child. When I saw that the child was getting worse, I called his parents to come to see their child. I think this caused the parents to have readiness for the resuscitation crisis of their child" N2 "I was always in the hospital with my child. Before she died, the nurse called me and said, 'Your child is in critical condition and her blood pressure is constantly dropping. She is not well at all.' It was good to be able to be with her at the last moment and say goodbye to her." M6

4. Psychological and spiritual requirements

The experiences of parents and healthcare professionals revealed that parents also need mental and spiritual preparation for facing the terrible crisis of their child's resuscitation. Four sub-categories emerged:

4.1: Reliance on supernatural power

Parent and healthcare professional participants' words showed that most parents needed to rely on supernatural powers, other than medical science, when they were faced with critical situations. In this time, reminding parents of the will and trust in God and providing access to holy text, chaplains, and even a place to pray can be soothing to them. One mother stated (table 6-4.1-M6). A father also stated (table 6-4.1-F3).

4.2: Need for access to a psychologist

The experiences of parents and healthcare professionals indicated that parents needed to have access to a psychologist (or other mental health specialist) to help prepare them for these critical situations, especially when a child is likely to not survive. Parents needed a psychologist to be present by their side in these critical situations so that they could consult with them. In this regard, a mother expressed her need for a psychologist as follows (table 6-4.2-M6).

Most parents also felt that all staff working in a children's hospital should have completed psychology courses that prepare them to treat parents in critical situations appropriately, with a specific need to know how to give bad information to parents. A father said (table 6-4.2-F3).

4.3: Sharing emotions

According to both parents and healthcare professionals, there is a need for parents to be able to share their feelings and emotions with others when they are in a critical psychological state. Parents needed to be understood during their critical situation and supported by those around them. It was important to parents that staff understand their situation. A mother stated (table 6-4.3-M2).

Parents also needed to be accompanied by family or relatives, especially their spouse. All of the mothers who were with their husbands during their child's resuscitation said that their husband's presence had helped them to cope and provided calm for them. But a mother who was alone during her child's illness in the intensive care unit said (table 6-4.3-M9).

The experiences of the healthcare professional participants showed that the presence of other family members or other companions, especially in emergencies where both parents are in shock, can be a supportive force and better prepare parents in the face of the crisis. A nurse described her individual performance in these situations as follows (table 6-4.3-N2).

4.4: Collecting mementos

Parents expressed the need to communicate internally with their child after they died during resuscitation. Having mementos of the child can be an effective way to maintain this relationship. Healthcare professionals can assist parents to collect mementos of their child before the resuscitation. A mother who was provided mementos said (table 6-4.4-M6). But another mother who was not given any mementos of her child said (table 6-4.4-M9).

Table 6. Psychological and spiritual requirements

4.1: Reliance on supernatural power	"My daughter had no problems before, and she was admitted to the ICU because she had the flu. Her condition was getting worse every day. I was very impatient. One of the staff told me: 'God created us and all of us will die one day. The fate of everyone has been decided by God in some way. Trust in God.' And she relieved me in this way." M6 "While we were waiting in the back of the operating room, one person told me to repeat the holy phrase. I wondered why I should repeat it only ten times. At that time, I needed to consult with an informed person. I needed to be alone with my God in a quiet place and pray and read the Quran." F3
4.2: Need for access to a psychologist	"I think it would be better if a psychologist was with the mothers in the ICU and talked to them calmly. She/He could provide consolation support for them. It is true that all the staff treated me well. But if there was a staff that was with the mothers and talked to them for a few hours, I think it is better. A psychologist can better prepare mothers for the fact that they are losing their baby so that they can pass this period more easily." M6 "What's wrong that a doctor or a nurse knows about psychology or a businessman knows about management? Being multi-disciplined makes us complete in one discipline but all of us are educated only in one special field. For example, according to the body of a person, we let him be a guard, and we do not care at all how literate this person is, does he know how to treat others or not?" F3
4.3: Sharing emotions	"A nurse came and told me and said, 'I am mother too and understand you. Many of these things have happened here [in the ICU], and it has happened to many families that their child was in a critical situation. I know it is very difficult, but you have to endure.' It was good that she was telling me." M2 "... I just had stress, no one was there, my husband couldn't come. I wish someone was with me." M9 "When a child is ill and there is a possibility of resuscitation for him/her, I call the parents to come and I emphasize that the mother should not be alone and come with her husband or a companion. If I know a supporter, relatives or friends of the parents, I will call them to come and be with the parents." N2
4.4: Collecting mementos	"I still miss her. I still see her photos and hear her voice." M6 "... They [staff] didn't give me the things that I had put on her bedside. I had put a comb for her and brushed her hair with it. They [staff] didn't give me it to keep a few of her hair for myself. Her bottle of milk or the things I put there, they give me any of them. My baby was touching them. I wanted to keep them to myself." M9

Discussion

In this study, parents and healthcare professionals shared their experiences and perceptions of pre-resuscitation parental preparation. Parents' preparation before the resuscitation of their child was divided into four categories: Awareness, Chaos in providing information, Providing situational information, and Psychological and spiritual requirements.

The results revealed that facilitating parents' understanding of the child's condition and readying them for the resuscitation of their child helps to prevent the shock caused by the crisis. All parents, without exception, emphasized the importance of knowing what is happening to their child, and helping them to understand was an essential support need (11,20). Having information about the child's condition provides the parents with the ability to better adapt and accept the child's death (20,21). Also, participants in this study shared how transmitting truthful information promotes trust and gives emotional support to parents, enhancing their readiness for resuscitation (22). Because having information about the child's condition helps parents maintain a sense of control, they can better manage the situation (23). Giving information about the child's condition and even telling of the possibility for resuscitation and death should be done continuously during the child's hospitalization, especially during the child's deterioration. Another study found that parents of children with chronic illness who were informed of the possible death of their child several months prior but then did not receive information updates and normalization, were not be prepared for the stage of health deterioration and death (24).

In this study, the physicians considered it their duty to provide information to parents; however, this did not always occur. While diagnostic information was provided by physicians and care information was provided by nurses, nurses in this study expressed frustration over the parents not being told of their child’s condition. In one study, some parents did not recall having received clinical information before their child’s resuscitation and reported waiting hours to talk to a healthcare provider (1). A worrisome finding is that when several of the parents did receive information from physicians and nurses, it was not delivered in a kind or empathetic manner. Some parents believed that the presence of a psychologist (or other mental health specialist) when they received bad information about their child could be helpful in preparing them for their child's critical situation.

In some cultures, such as the culture of the participants in this study, a selective protection of information is observed in order to protect the parents from stress and anxiety. In this instance, information is given to the relatives of the parents who can then transmit the information. Many other cultures, such as in China and South Africa, also believe in withholding information about the disease from the patient as a means of protecting them (25–27). In this study, some of the healthcare professionals preferred to give bad information about the child to the person accompanying the parents (such as another relative). In the absence of accompanying persons, they provided this information to the father, and a refusal to provide bad information to the mother was expressed. It is possible that information is then not transmitted from father to mother, causing the mother to not be ready to face the crisis. In one study, this withholding of information led to the loss of the opportunity for a last farewell to loved ones (27). On the other hand, providing information to persons other than parents also creates a challenge related to information confidentiality. This may in turn jeopardize the respect, honesty and human value that is the principle of autonomy (28,29). We found that the issue of confidentiality of information was important for the parents under study, especially those from rural villages because all persons are known to one another in their small communities.

Providing bad news to parents to prepare them for a resuscitation crisis is handled in a unique manner, meaning that it depends on the condition of the child and parents and the events surrounding the resuscitation. Truth telling is as a right and medical requirement (28); however, when designing his model, Nierengarten said that while a doctor's honesty is a necessity, like all areas of medicine and life, nothing is certain (30). Preferences and values about access to and receipt of information also influence how healthcare professionals give information to parents. It has been shown that some people do not want to hear some information, especially information that has a negative element in it (26,31), parents need to be neither completely hopeful nor completely hopeless when receiving information (1), and preparation for receiving medical information should be considered because sometimes expressing this information may harm the mental health of the person (26,32). These findings are consistent with those of this study. In light of this, healthcare professionals should use appropriate language when providing information (33,34). Providing information to parents at a high speed (27,31) and not providing understandable information to parents (26,34) causes lack of proper information processing, especially in unexpected emergency situations. This was again consistent with the experiences and perceptions of parents and healthcare professionals in this study. Therefore, when providing information to parents, healthcare professionals should ensure the quantity and quality of information is appropriate for individual parents and the situation at hand.

Facilitating parents' trust in the received information is important and can be accomplished by coordinating the provision of information from different treatment team members (35), ensuring parents that we have done all we can (31), and relaying bad news in an empathetic and compassionate way (35–37) that does not place blame on the parents (38,39). According to participants in this study, these are considered professional and helpful behaviors of healthcare providers. Also, healthcare professionals can support parents by providing information to parents at their child's bedside in order to magnify their understanding (24), especially when the child is very ill and near the last moments of her/his life (36). In the present study, it was felt that parents being present during their child's hospitalization promoted better understanding and acceptance of the resuscitation crisis, even with acute problems and no previous history of illness, compared to similar cases who died in the emergency room.

The psychological and spiritual needs of parents are important for healthcare professionals to consider when preparing parents for the upcoming crisis. The results of this study indicate the need for parents to have access to a psychologist and a chaplain, as well as the presence of their spouse and other relatives or friends. This helps ensure parents have support for the crisis ahead. In one study, nurses considered the provision of consolation, empathy, emotional support, and religious support to parents as their role in end-of-life care, and they informed parents about the availability of religious services and clergy visits. Also, they allowed family visits, for example grandparents, which was outside of the policy but was something they considered to be part of their role (40). Of course, the beliefs and desires of parents must consider when attempting to meet their spiritual needs. In this study, the expression of God's will by a healthcare professional was not acceptable to one of the parents, while most parents considered it to provide consolation and relief.

This study, like other qualitative studies, has a selection bias. We examined the experiences and perceptions of healthcare professionals working in large hospitals in two major cities in Iran, and also selected parents who were referred to these centers. The participants may have different experiences and views than those working in or referred to small medical centers. However, this limitation is minimized because small towns and rural communities frequently refer to the public hospitals in these cities and 50% of the parent participants were from surrounding towns or villages. We also examined the experiences and perceptions of one male nurse and 3 fathers because in our pediatric hospitals, most nurses are female. Based on our context, mothers are the main caregivers of their children and hospital regulations do not allow fathers to stay at the hospital for their child’s care and they can only meet their child and wife for a short time (except in emergency situation) because most of healthcare staff in the pediatric hospitals are women. Another limitation is that the children of the parents in this study were all 5 years of age or younger, and it is possible that parental needs differ if the children are older. In our country, older children and adolescents are usually hospitalized in an adult hospital. Despite the limitations of this study, the findings are important to stimulate additional research and the creation of guidelines or protocols for preparing parents for their child’s resuscitation as the healthcare professional participants stated no such tool exists in their workplace and having this guidance would help them better support parents.

Conclusion

This study provides insight on parental needs prior to pediatric resuscitation, as well as strategies to promote readiness for their child's resuscitation crisis. Findings can be used to promote family-centered care in pediatric critical care and emergency settings. The results of this study reveal that to prepare parents for resuscitation, it is important to continuously provide information about the child's condition, with a need to consider the parents' culture, ensure confidentiality of information, and by spending enough time with the parents. This information should be provided to parents empathetically and without blame, honestly yet in a way that helps balances hope and hopelessness, and in a unique and individual way that considers the child’s situation and parents’ needs. It can be helpful to provide this information while parents are present at the child's bedside, especially when the child is very ill. Psychological and spiritual needs should also be considered to help prepare parents for their child’s resuscitation and potential death. As the results of this study showed that parents need attention to promote their readiness to face this stressful event, and each of the healthcare professional participants acted according to their experiences/preferences without access to instructions and protocols in this regard, there is a need for more research to be able to develop effective protocols. Further, future research should examine parental readiness among various cultures, as parent needs may differ.

Contributors

AG developed and designed the research proposal. HH, MAB, HNA, and MH supervised the design of the study. AG obtained the required approvals, recruited participants, and conducted the interviews. AG and HH conducted the data analysis, which was then confirmed and agreed upon by the other authors. AG, HH, and KP were the major contributors in writing the manuscript. All authors contributed to data analyses and interpretation and read and approved the final manuscript.

Funding

This research received no specific grant from any funding agency in the public, commercial or not-for-profit sectors.

Competing interests

None.

Patient consent

Obtained.

Data sharing statement

No additional data are available

Acknowledgments

We thank the patient advisers in pediatric hospitals of Ash and Mashhad.

References

1. Stewart SA. Parents' experience during a child's resuscitation: Getting through it. *J Pediatr Nurs*. 2019 Jul 1;47:58–67.

2. Chavez H, Garcia CT, Sakers C. Epidemiology of the Critically Ill Child in the Resuscitation Bay. *Pediatr Emerg Care*. 2018;34(1):6–9.

3. Wolfe HA, Sutton RM, Topjian A, Nishisaki A, Niles DE, Meaney PA, et al. Reporting in Pediatric Resuscitation : Get with the Guidelines-Resuscitation Registry. *Pediatr Congenit Card Care*. 2015;2:145–51.

4. Majidi A, Mahmoodi S, Adineh VH. An Epidemiologic Study of Emergency Department Visits before and after Executing Health Sector Evolution Plan; a Brief Report. *Iran Emerg Med J*. 2017;4(3):130–4.

5. Loaec M, Himebauch AS, Kilbaugh TJ, Berg RA, Graham K, Hanna R, et al. Pediatric cardiopulmonary resuscitation quality during intra-hospital transport. *Resuscitation*. 2020;152:123–30.

6. Shimoda-Sakano TM, Schvartsman C, Reis AG. Epidemiology of pediatric cardiopulmonary resuscitation. *J Pediatr (Rio J)*. 2020;96(4):409–21.

7. Toomey SL, Elliott MN, Zaslavsky AM, Klein DJ, Ndon S, Hardy S, et al. Variation in Family Experience of Pediatric Inpatient Care As Measured by Child HCAHPS. *Pediatrics*. 2017;139(4):e20163372.

8. Doupnik SK, Hill D, Palakshappa D, Worsley D, Bae H, Shaik A, et al. Parent Coping Support Interventions During Acute Pediatric Hospitalizations: A Meta-Analysis.

Pediatrics. 2017;140(3):e20164171.

9. Davidson JE, Aslakson RA, Long AC, Puntillo KA, Kross EK, Hart J, et al. Guidelines for Family-Centered Care in the Neonatal, Pediatric, and Adult ICU. *Crit Care Med*. 2017;45(1):103–28.

10. Lisanti AJ, Allen LR, Kelly L, Medoff-Cooper B. Maternal Stress and Anxiety in the Pediatric Cardiac Intensive Care Unit. *Am J Crit Care*. 2017;26(2):118–25.

11. Koch K, Jones B. Supporting Parent Caregivers of Children with Life-Limiting Illness. Vol. 5, *Children*. 2018. p. 85.

12. Foster M, Whitehead L, Maybee P. The Parents', Hospitalized Child's, and Health Care Providers' Perceptions and Experiences of Family-Centered Care Within a Pediatric Critical Care Setting: A Synthesis of Quantitative Research. *J Fam Nurs*. 2016;22(1):6–73.

13. Rostami F, Hassan ST, Yaghmai F, Ismaeil SB, Suandi TB. Effects of family-centered care on the satisfaction of parents of children hospitalized in pediatric wards in a pediatric ward in Chaloos in 2012. *Electron Physician*. 2015;7(2):1078–84.

14. Curtis JR, Treece PD, Nielsen EL, Gold J, Ciechanowski PS, Shannon SE, et al. Randomized trial of communication facilitators to reduce family distress and intensity of end-of-life care. *Am J Respir Crit Care Med.* 2016;193(2):154–62.

15. Saunders B, Sim J, Kingstone T, Baker S, Waterfiel J, Bartlam B, et al. Saturation in qualitative research : exploring its conceptualization and operationalization. *Qual Quant*. 2018;52(4):1893–907.

16. Bengtsson M. How to plan and perform a qualitative study using content analysis. *NursingPlus Open*. 2016;2:8–14.

17. Hays DG, Wood C, Dahl H, Kirk-Jenkins A. Methodological Rigor in Journal of Counseling & Development Qualitative Research Articles: A 15-Year Review. *J Couns Dev*. 2016;94(2):172–83.

18. Cypress BS. Rigor or Reliability and Validity in Qualitative Research : Perspectives , Strategies , Reconceptualization , and Recommendations. *Dimens Crit Care Nurs*. 2017;36(4):253–63.

19. Nowell B, Albrecht K. A Reviewer's Guide to Qualitative Rigor. *J Public Adm Res Theory*. 2019;29(2):348–63.

20. Doumit M, Rahi AC, Saab R, Majdalani M. Spirituality among parents of children with cancer in a Middle Eastern country. *Eur J Oncol Nurs*. 2019;39:21–7.

21. Currie ER, Christian BJ, Hinds PS, Perna SJ, Robinson C, Day S, et al. Parent Perspectives of Neonatal Intensive Care at the End-of-Life. *J Pediatr Nurs*. 2016;31(5):478–89.

22. Chen C-H, Cheng Y-H, Fen-JuChen, Huang E-Y, Liu P-M, Kung C-T, et al. Association Between the Communication Skills of Physicians and the Signing of Do-Not-Resuscitate Consent for Terminally Ill Patients in Emergency Rooms (Cross-Sectional Study). *Risk Manag Healthc Policy*. 2019;12:307–14.

23. Hummelinck A, Pollock K. Parents' information needs about the treatment of their chronically ill child: A qualitative study. *Patient Educ Couns*. 2006;62(2):228–34.

24. Bogetz JF, Revette A, Rosenberg AR, DeCourcey D. "I Could Never Prepare for Something Like the Death of My Own Child": Parental Perspectives on Preparedness at End of Life for Children With Complex Chronic Conditions. *J Pain Symptom Manage*. 2020;60(6):1154–62.

25. Fan Z, Chen L, Meng L, Jiang H, Zhao Q, Zhang L, et al. Preference of cancer patients and family members regarding delivery of bad news and differences in clinical practice among medical staff. Vol. 27, *Supportive Care in Cancer*. 2019. p. 583–9.

26. Athanas R, Gasto F, Renatha SJ. Factors influencing truth-telling by healthcare providers to terminally ill cancer patients at ocean road cancer institute in dar-es-salaam, tanzania. Vol. 13, *South African Journal of Bioethics and Law*. 2020. p. 108–13.

27. Ibañez-Masero O, Carmona-Rega IM, Ruiz-Fernández MD, Ortiz-Amo R, Cabrera-Troya J, Ortega-Galán ÁM. Communicating health information at the end of life: The caregivers' perspectives. *Int J Environ Res Public Health.* 2019;16(14):2469–80.

28. Twinomujuni J. Truth telling beyond borders: an African perspective for the degree of Doctor of Philosophy. *Duquesne University*; 2017.

29. Hanssen I. From human ability to ethical principle: an intercultural perspective on autonomy. Vol. 7, *Medicine, health care, and philosophy*. 2005. p. 269–79.

30. Nierengarten MB. Pediatric truth-telling Omission vs deception. *Contemp Pediatr*. 2019;36(4):24–33.

31. Lantos JD. Tell parents the truth, but tell it slant. Vol. 142, *Pediatrics*. 2018. p. S199–204.

32. Ewuoso C. Models for truth-telling in physician-patient encounters: what can we learn

from Yoruba concept of Ooto? *Dev World Bioeth*. 2019;19(1):3–8.

33. EC K, Snaman J, Johnson L, Levine D, Powell B, Love A, et al. Communication with children with cancer and their families throughout the illness journey and at the end of life. *InPalliative Care Pediatr Oncol.* 2018;55–93.

34. Suurmond J, Lieveld A, van de Wetering M, Schouten-van Meeteren AYN. Towards culturally competent paediatric oncology care. A qualitative study from the perspective of care providers. Vol. 26, *European Journal of Cancer Care*. 2017.

35. Blazin LJ, Cecchini C, Habashy C, Kaye EC, Baker JN. Communicating effectively in pediatric cancer care: translating evidence into practice. *Children*. 2018;5(3):40–56.

36. Bekkering H, Woodgate R. The Parental Experience of Unexpectedly Losing a Child In the Pediatric Emergency Departmen. *OMEGA-Journal of Death and Dying*. 2019;23:0030222819876477.

37. Muskat B, Greenblatt A, Anthony S, Beaune L, Hubley P, Newman C, et al. The experiences of physicians, nurses, and social workers providing end-of-life care in a pediatric acute-care hospital. *Death Stud*. 2019.

38. Meert KL, Templin TN, Michelson KN, Morrison WE, Hackbarth R, Custer JR, et al. The Bereaved Parent Needs Assessment: A new instrument to assess the needs of parents whose children died in the pediatric intensive care unit. *Crit Care Med*. 2012;40(11):1–18.

39. Jones CHD, Ward A, Hodkinson PW, Reid SJ, Wallis A, Harrison S, et al. Caregivers ' Experiences of Pathways to Care for Seriously Ill Children in Cape Town , South Africa : A Qualitative Investigation. *PLoS One*. 2016;11(3):1–15.

40. Kim S, Savage TA, Song M-K, Vincent C, Park CG, Ferrans CE, et al. Nurses' roles and challenges in providing end-of-life care in neonatal intensive care units in South Korea. *Appl Nurs Res*. 2019;1(50):151204.

Section & Topic	No	Item	Reported on page #
TITLE OR ABSTRACT			
	1	Identification as a study of diagnostic accuracy using at least one measure of accuracy (such as sensitivity, specificity, predictive values, or AUC)	2
ABSTRACT			
	2	Structured summary of study design, methods, results, and conclusions (for specific guidance, see STARD for Abstracts)	2-3
INTRODUCTION			
	3	Scientific and clinical background, including the intended use and clinical role of the index test	4
	4	Study objectives and hypotheses	5
METHODS			
Study design	**5**	Whether data collection was planned before the index test and reference standard were performed (prospective study) or after (retrospective study)	5
Participants	**6**	Eligibility criteria	5
	7	On what basis potentially eligible participants were identified (such as symptoms, results from previous tests, inclusion in registry)	6
	8	Where and when potentially eligible participants were identified (setting, location and dates)	5
	9	Whether participants formed a consecutive, random or convenience series	5
Test methods	**10a**	Index test, in sufficient detail to allow replication	6
	10b	Reference standard, in sufficient detail to allow replication	6
	11	Rationale for choosing the reference standard (if alternatives exist)	6
	12a	Definition of and rationale for test positivity cut-offs or result categories of the index test, distinguishing pre-specified from exploratory	6
	12b	Definition of and rationale for test positivity cut-offs or result categories of the reference standard, distinguishing pre-specified from exploratory	6
	13a	Whether clinical information and reference standard results were available to the performers/readers of the index test	6
	13b	Whether clinical information and index test results were available to the assessors of the reference standard	5-6
Analysis	**14**	Methods for estimating or comparing measures of diagnostic accuracy	6-7
	15	How indeterminate index test or reference standard results were handled	6
	16	How missing data on the index test and reference standard were handled	-
	17	Any analyses of variability in diagnostic accuracy, distinguishing pre-specified from exploratory	6-7
	18	Intended sample size and how it was determined	6
RESULTS			
Participants	**19**	Flow of participants, using a diagram	8
	20	Baseline demographic and clinical characteristics of participants	8
	21a	Distribution of severity of disease in those with the target condition	8
	21b	Distribution of alternative diagnoses in those without the target condition	-
	22	Time interval and any clinical interventions between index test and reference standard	-
Test results	**23**	Cross tabulation of the index test results (or their distribution) by the results of the reference standard	8
	24	Estimates of diagnostic accuracy and their precision (such as 95% confidence intervals)	-
	25	Any adverse events from performing the index test or the reference standard	-
DISCUSSION			
	26	Study limitations, including sources of potential bias, statistical uncertainty, and generalisability	25
	27	Implications for practice, including the intended use and clinical role of the index test	25-26
OTHER INFORMATION			
	28	Registration number and name of registry	7
	29	Where the full study protocol can be accessed	-
	30	Sources of funding and other support; role of funders	27

STARD 2015

AIM

STARD stands for “Standards for Reporting Diagnostic accuracy studies”. This list of items was developed to contribute to the completeness and transparency of reporting of diagnostic accuracy studies. Authors can use the list to write informative study reports. Editors and peer-reviewers can use it to evaluate whether the information has been included in manuscripts submitted for publication.

EXPLANATION

A **diagnostic accuracy study** evaluates the ability of one or more medical tests to correctly classify study participants as having a **target condition.** This can be a disease, a disease stage, response or benefit from therapy, or an event or condition in the future. A medical test can be an imaging procedure, a laboratory test, elements from history and physical examination, a combination of these, or any other method for collecting information about the current health status of a patient.

The test whose accuracy is evaluated is called **index test.** A study can evaluate the accuracy of one or more index tests. Evaluating the ability of a medical test to correctly classify patients is typically done by comparing the distribution of the index test results with those of the **reference standard**. The reference standard is the best available method for establishing the presence or absence of the target condition. An accuracy study can rely on one or more reference standards.

If test results are categorized as either positive or negative, the cross tabulation of the index test results against those of the reference standard can be used to estimate the **sensitivity** of the index test (the proportion of participants *with* the target condition who have a positive index test), and its **specificity** (the proportion *without* the target condition who have a negative index test). From this cross tabulation (sometimes referred to as the contingency or “2x2” table), several other accuracy statistics can be estimated, such as the positive and negative **predictive values** of the test. Confidence intervals around estimates of accuracy can then be calculated to quantify the statistical **precision** of the measurements.

If the index test results can take more than two values, categorization of test results as positive or negative requires a **test positivity cut-off**. When multiple such cut-offs can be defined, authors can report a receiver operating characteristic (ROC) curve which graphically represents the combination of sensitivity and specificity for each possible test positivity cut-off. The **area under the ROC curve** informs in a single numerical value about the overall diagnostic accuracy of the index test.

The **intended use** of a medical test can be diagnosis, screening, staging, monitoring, surveillance, prediction or prognosis. The **clinical role** of a test explains its position relative to existing tests in the clinical pathway. A replacement test, for example, replaces an existing test. A triage test is used before an existing test; an add-on test is used after an existing test.

Besides diagnostic accuracy, several other outcomes and statistics may be relevant in the evaluation of medical tests. Medical tests can also be used to classify patients for purposes other than diagnosis, such as staging or prognosis. The STARD list was not explicitly developed for these other outcomes, statistics, and study types, although most STARD items would still apply.

DEVELOPMENT

This STARD list was released in 2015. The 30 items were identified by an international expert group of methodologists, researchers, and editors. The guiding principle in the development of STARD was to select items that, when reported, would help readers to judge the potential for bias in the study, to appraise the applicability of the study findings and the validity of conclusions and recommendations. The list represents an update of the first version, which was published in 2003.

More information can be found on http://www.equator-network.org/reporting-guidelines/stard.

BMJ Open

Parent and healthcare professional experiences and perceptions of parental readiness for resuscitation in Iranian pediatric hospitals: A qualitative study

Journal:	*BMJ Open*
Manuscript ID	bmjopen-2021-055599.R1
Article Type:	Original research
Date Submitted by the Author:	09-Feb-2022
Complete List of Authors:	Ghavi, Arezoo; Tabriz University of Medical Sciences, Department of Pediatric Nursing Hassankhani, Hadi; Tabriz University of Medical Sciences, Powers, Kelly; University of North Carolina at Charlotte, School of Nursing Arshadi-Bostanabad , Mohammad; Tabriz University of Medical Sciences Namdar Areshtanab, Hossein ; Tabriz University of Medical Sciences, Department of Psychology Nursing Heidarzadeh, Mohammad; Tabriz University of Medical Sciences
Primary Subject Heading:	Paediatrics
Secondary Subject Heading:	Intensive care, Nursing, Paediatrics, General practice / Family practice, Emergency medicine
Keywords:	Health informatics < BIOTECHNOLOGY & BIOINFORMATICS, Paediatric intensive & critical care < INTENSIVE & CRITICAL CARE, Paediatric intensive & critical care < PAEDIATRICS

Parent and healthcare professional experiences and perceptions of parental readiness for resuscitation in Iranian pediatric hospitals: A qualitative study

Arezoo Ghavi [1] iD, Hadi Hassankhani [2,*] iD, Kelly Powers [3] iD, Mohammad Arshadi-Bostanabad [4] iD, Hossein Namdar-Areshtanab [5] iD, Mohammad Heidarzadeh [6] iD

[1] PhD Student, Department of Pediatric Nursing, School of Nursing and Midwifery, Tabriz University of Medical Sciences, Tabriz, Iran

[2] Professor, Department of Medical-Surgical Nursing, School of Nursing and Midwifery, Tabriz University of Medical Sciences, Tabriz, Iran

[3] Assistant professor, School of Nursing, University of North Carolina at Charlotte, Charlotte, NC, United States

[4] Associate professor, Department of Pediatric Nursing, School of Nursing and Midwifery, Tabriz University of Medical Sciences, Tabriz, Iran

[5] Associate professor, Department of Psychology Nursing, School of Nursing and Midwifery, Tabriz University of Medical Sciences, Tabriz, Iran

[6] Associate professor of neonatology, Tabriz University of Medical Sciences, Tabriz, Iran

Corresponding Author:

Hadi Hassankhani, Department of Medical-Surgical Nursing, School of Nursing and Midwifery, Tabriz University of Medical Sciences, Tabriz, Iran, Email: hassankhanihadi@gmail.com

Cell Phone number: +989183181267, Telephone number of work: +984134796770 (134), Telephone number of home: +984134796969

Abstract

Objective: The aim of this study was to examine parents' and healthcare professionals' experiences and perceptions of parental readiness for resuscitation of their child in a pediatric hospital.

Design: This exploratory descriptive qualitative study utilized content analysis. Participants shared their experiences and perceptions about parental readiness for cardiopulmonary resuscitation through semi-structured and in-depth interviews. MAXQDA 2020 software was also used for data analysis.

Setting: The setting was two large teaching pediatric hospitals in Iran (Este Azerbaijan and Mashhad).

Participants: Participants were 10 parents and 13 pediatric healthcare professionals (8 nurses and 5 physicians). Selection criteria were: a) Parents who experienced their child's resuscitation crisis at least 3 months prior and b) Nurses and physicians who were working in emergency rooms or intensive care wards with at least 2 years of experience on the resuscitation team.

Results: Participants shared their experiences about parental readiness for resuscitation of their child in four categories: Awareness (acceptance of resuscitation and its consequences; providing information about the child's current condition and prognosis), Chaos in providing information (defect of responsibility in informing; provide selective protection of information; hardness in obtaining information), Providing situational information (honest information on the border of hope and hopeless; providing information with apathy; providing information as Individual; dualism in blaming; assurance to parents; presence of parents to better understand the child's situation), and Psychological and spiritual requirements (reliance on supernatural power; need for access to a psychologist; sharing emotions; collecting mementos).

Conclusion: The results of this study provide insight on the needs of parents and strategies to use to prepare them for their child's resuscitation crisis, which can be used to enhance family-centered care practices in pediatric acute care settings.

Key word: Readiness, Parents, Resuscitation, Pediatrics

Strengths and limitations of this study

- Examining the experiences and perceptions of both parents and healthcare professionals is a major strength of the present study, helping to provide a comprehensive perspective on parental readiness for pediatric resuscitation.
- The study investigated the pre-resuscitation readiness of parents, which is important for identifying strategies to help them prepare for their child's resuscitation.
- The children of the parent participants were all 5 years of age or younger because older children and adolescents are typically hospitalized in adult hospitals in Iran.
- Most participants were female because male healthcare professionals and fathers have limited presence in Iranian pediatric hospitals.

Introduction

Child resuscitation is a critical time for parents.[1] Pediatric cardiac arrest in children and adolescents occurs at a rate of 2.28 to 8.04 (100,000 cases/year). Cardiopulmonary resuscitation rates per age group range from 65.5-72 (infants), 3.7 (children), and 6.3 (adolescents) for the 100,000 cases/year.[2] Pediatric cardiac arrests occurred in 1.5% of the total number of patients under 17 years in Asian countries.[3] In a study in Iran, approximately five percent of patients referred to the emergency department for critical care were under 18 years old.[4] Among resuscitated children, less than 20% survive and are discharged from the hospital.[2 5]

Most Iranian doctors and nurses do not agree with parents being present during their child's cardiopulmonary resuscitation.[6] While, parents' participation in taking care of hospitalized children is considered as an indispensable principle.[7] Especially in wards such as the emergency room where critical care for children is provided, parents are mostly present.[8] When parents are faced with their child being acutely hospitalized, they can suffer from psychological stress, which will also have a negative effect on the treatment results.[9] Anxiety, stress, depression and post-traumatic stress are some of the psychological problems that parents can face when their child requires resuscitation.[10] In the study of Lisanti et al. (2017), mothers in the pediatric intensive care unit had the highest score of stress and anxiety at the time of resuscitation of their child.[11] Parental well-being is essential for the well-being of children with life-threatening illnesses.[12] Therefore, healthcare professionals have a vital role in parental preparedness for resuscitation.[10] In addition to providing specialized clinical care, healthcare providers should also consider parental support needs at this time,[13] as parental support is one tenet of family-centered care structures that leads to increased quality of care.[14]

Many studies have focused on the presence of parents during resuscitation of their child, but few studies have examined the pre-resuscitation readiness of parents, which is important for identifying measures to help them prepare. In a study, cultural differences affected the attitudes and perceptions of child caregivers.[15] Also, parents need their beliefs, values, customs, and traditions, generally, their cultural and religious practices to be respected;[16] therefore, there is a need for examination of parental readiness among various cultures and countries. This study was conducted in Iran to explore the readiness of parents for cardiopulmonary resuscitation of their child by examining the experiences and perceptions of both parents and health professionals.

Methods

This study used an exploratory descriptive qualitative approach to examine parents' and healthcare professionals' experiences and perceptions of parental readiness for resuscitation of their child.

Setting and Participants

The setting was two large teaching pediatric hospitals in Iran (Este Azerbaijan and Mashhad). Using purposive sampling, there were 10 parents of 7 children and 13 pediatric healthcare professionals (8 nurses and 5 physicians) who participated in the study. Selection criteria were: a) Parents who experienced their child's resuscitation crisis at least 3 months prior because after a stressful family event, the symptoms of depression, anxiety and post-traumatic stress disorder are decreased after 3 months[17] and b) Nurses and physicians who were working in emergency rooms or intensive care wards with at least 2 years of experience on the resuscitation team.

Data collection and analysis

Participants were invited to participate in the study by telephone, and face-to-face individual interviews were conducted from February to November 2020. The parent participants in this study were identified by searching records of hospitalized children for documentation of having received resuscitative care (i.e. cardiopulmonary resuscitation). The first author conducted the tape-recorded, semi-structured, and in-depth individual interviews at the hospitals (for the healthcare professional participants) and at the parents' homes (for the parent participants). Each of the interviews lasted between 45 to 75 minutes. Since these interviews were conducted during the COVID-19 pandemic, precautions were taken (i.e. masking, distancing, etc).

An interview guide was designed to elicit participants' experiences and perceptions of parental readiness for resuscitation. Parent and healthcare professional participants were encouraged to share their experiences about parental preparation needs, how these needs were met, and perceptions of strategies that healthcare professionals can utilize to effectively provide help to parents. Examples of the interview guide questions are available in supplemental appendix 1. For in-depth understanding of participants' experiences and perceptions, clarification and probing questions were asked after each of the questions in the guide. During the interviews, the term "cardiopulmonary resuscitation" was used with healthcare professional participants (included technical terms such as intubation or chest compressions), but in interviews with parent participants, we used simplified language when explaining terms (for example, “when a tube was inserted in your child's mouth” or “when your child's chest was pushed”) to ensure understanding. Interviews were continued to data saturation,[18] which was confirmed when no new information or codes were uncovered in the last 4 interviews.

Recorded interviews were transcribed verbatim and then analyzed using content analysis according to Bengtsson's proposed steps.[19] First, the text of each interview was read several times. The text was then broken down into meaningful units and coded. MAXQDA 2020 software was also used to encode the data. A list of codes related to all transcribed texts was prepared and each code was identified to which domains it belongs. The codes were also categorized according to their similarities and differences. To increase trustworthiness, this process of data analysis was conducted by two researchers who extracted and then categorized the codes, with each researcher independently coding each interview. The extracted categories and subcategories were then confirmed and agreed upon by the other authors. The peer-checking method was engaged to improve the dependability of the findings, assuring the confirmability of the findings. Participant quotations were selected to enrich understanding of the categories. Participant words were spoken in Persian and then translated to English; therefore, some quotations have been edited to increase clarity and to transmit the meaning of what the participants said when translated to English.

For rigor of the research,[20-22] the experiences and perceptions of different persons involved, both healthcare professionals (physicians and nurses in different categories) and parents (having children with chronic or acute illness, different literacy levels, urban and rural residences, etc.) were examined. These characteristics of participants were collected via a paper-and-pencil survey that was administered prior to the start of each interview. After the research team performed the analysis, the first author returned the extracted codes of each text to participants for review and approval. Thus, the rigor and credibility of the study was enhanced by checking findings with participants (i.e. member checking).

Ethical considerations

This study was approved by the ethics committee of Tabriz University of Medical Sciences with the ID IR.TBZMED.REC.1398.1080. The objectives and procedures of the study were explained to all participants, including measures to protect confidentiality. Participants' personal information was kept confidential, and their experiences were used in the study without names and details. Informed consent was obtained from participants.

Patient and public involvement

We did not involve parents in the development of the research questions. We did obtain collaboration agreements with two large teaching pediatric hospitals, and approached the hospitals for that purpose.

Hospital managers provided positive feedback on the study aims, acknowledging that more research is needed on experiences and perceptions related to the support of parents surrounding resuscitation of their child. They introduced healthcare professionals as potential rich-in-formed participant which could provide important experiences and information for this study. They also provided access to parents for participation in this study. Thus, the hospitals supported recruitment of study participants by sending messages for study participation.

Results

In this study, 13 pediatric healthcare professionals participated; five pediatrician physicians and eight nurses in different categories of practice (from bedside nurse to head nurse) and education (bachelor to master's degree). There were 10 parents of 7 resuscitated children (children aged one to five years; 3 boys and 4 girls) who participated. At the time of the interview with the parents, between 3 and 12 months had passed since the resuscitation. Parents were aged 31 to 48 years, and seven were mothers and three were fathers. Three of the parents had only one child (one child was born after many years of infertility). Two children of two of the parents had no previous history of illness or hospitalization, while the other 5 children had a history of chronic illness. Demographic details of the participants are provided in Table 1.

Table 1. Participants' demographic characteristics.

Parents	**n**	**Healthcare Professionals**	**n**
- Relation to child		- Field of education	
Father	3	Nurse	8
Mother	7	Pediatric physician	5
- Education level		- Gender	
Academic	5	Female	9
Non-academic	5	Male	4
- Location		- Years of experience	
Town	8	< 10	3
Village	2	≥ 10	10
- Number of times experienced their child's resuscitation		- Marital status	
		Married	9
Once	5	Single	4
Twice or more	5	- Parent status	
		Having own child(ren)	9
		No children	4

Participants in this study shared their experiences and perceptions about parents' readiness for resuscitation of their child in four categories: Awareness (acceptance of resuscitation and its consequences; providing information about the child's current condition and prognosis), Chaos in providing information (defect of responsibility in informing; provide selective protection of information; hardness in obtaining information), Providing situational information (honest information on the border of hope and hopeless; providing information with apathy; providing information as Individual; dualism in blaming; assurance to parents; presence of parents to better understand the child's situation), and Psychological and spiritual requirements (reliance on supernatural power; need for access to a psychologist; sharing emotions; collecting mementos).

1. Awareness

Based on the experiences and views of the parents and healthcare professionals, having awareness about their child's condition and health problems was considered to be a parent’s right and a necessary component of supporting the parents. There were two sub-categories that emerged in this category of awareness. Supportive quotations are found in Table 2.

1.1: Acceptance of resuscitation and its consequences

Four parents were informed about their child's condition before resuscitation, and this helped the parents better understanded their child's condition and its severity. This action of healthcare professionals was considered a proper and necessary behavior. By informing parents of their child’s condition, parents felt satisfied with the care of the healthcare team, even after the death of their child.

Both parents and healthcare professionals expressed how having awareness of the child's poor condition before resuscitation helped parents to prepare for the crisis. Having awareness was also felt to help with facilitating acceptance of the death of the child and preventing or lessening the shock that can result from the crisis. Informing parents of their child’s condition also provided the opportunity for healthcare professionals to prepare parents to be present in the resuscitation room. As a result of having awareness, the parents prepared themselves, psychologically and mentally, that their child was in critical condition, even in acute cases.

1.2: Providing information about the child's current condition and prognosis

Healthcare professionals’ experiences indicated that in hospitalized children, if parents were informed about their child's condition during hospitalization, they were better prepared for a resuscitation crisis than if the crisis were an unexpected emergency. Even then, explanation about the child's prognosis could help parents accept this crisis.

Parents, based on their experiences, also explained that they needed to be constantly informed about their child's condition and the actions that were being taken for him/her during the hospitalization. This was especially important during the time when their child's condition was worsening, and even could occur over the phone. Yet, the words of two mothers revealed they had not been informed of their child’s worsening condition and therefore felt unprepared and experienced emotional distress. Withholding information from parents was confirmed by a doctor who explained that in emergency cases, the situation was often unpredictable and thus parents were not informed of the possibility of resuscitation and of the child's death.

To express the possibility of resuscitation and death in hospitalized cases, both parents and healthcare professionals believed that parents should be told about the care interventions that could be used in attempt to save the child's life. One nurse described how this was explained to parents using words they would understand. Without an understanding of the care being provided, parental stress increased. When expressing the possibility of resuscitation, in addition to making parents aware of resuscitation actions and equipment, it was also deemed important to talk to parents about their desire for and location of presence during resuscitation. However, their behavior often determined whether they had this option and it is common for parents to be directed to leave the resuscitation room.

The experiences of the parents and the healthcare professionals showed that in cases when the possibility of losing the child was told to the parents, the field of parents' bereavement needs were not considered. Parents expressed a need for a private space to be with their deceased child and release their emotions. Yet, a father and a mother recalled not having a private space or time to mourn after the death of their children.

Table 2. Awareness

1.1: Acceptance of resuscitation and its consequences	"Thanks to all of them [healthcare professionals]. They did everything that they could. Well, I knew my child's problem, nothing could be done for her." F7 "A child was brought to the emergency room with severe dehydration. The child's parents brought the child to the hospital too late from fear of Corona, so that the child was in a state of shock. I fully explained to the parents about the bad condition of the child, that the child was breathing with the device and his heart was working with the injected drugs. I fully informed them about the bad condition of the child. The child died in the ICU that night, but when the parents were informed, I felt the shock did not happen in these parents the same as for other parents. It seemed to me that they accepted it more easily ... " D8 "... Because we had already been told that our child might die, his mother and me decided to donate his corpse to the University of Medical Sciences if he died." F1 "Since I was told the truth, I realized that if my child survives, it might not be good for her either. Because I was told the truth and I understood the truth, I was satisfied that if my child were to die, she would not suffer." F7
1.2: Providing information about the child's current condition and prognosis	"A child was hospitalized and intubated for a long time. The parents witnessed our actions. The parents were informed of the child's condition and prognosis during this time. They thanked us after their child died, even while they were in a bad mood." N2 "Because I was already told that her condition was not good and she [his child] was very ill, I had background about resuscitation of my child." F7 "My daughter was hospitalized about 6 months, but I was not told that my child was getting worse. I thought everything was well and I was not at all ready that my child was getting worse, and I did not expect her death at all." M4 "When there was a possibility of resuscitation, I would give the parents full information about their child's condition. I was telling them that your child might need us to squeeze

	"her chest or, like this child, insert a breathing tube so that the device could help your child breathe." N4 "I did not know what they were doing and why. I was dying and living every moment." M9 "We say that the child is in critical condition, but we have never said that he/she may need resuscitation or the child may die because the child is brought to the emergency room at once, and we do not know exactly what the problem is and the situation is not predictable ..." D9 "If parents were not agitated and could control their emotions and did not disrupt the resuscitation process, I was telling them that they could be in the room. Otherwise, they would be directed out of the room or they could watch the resuscitation from the window of the room." N10 "In any hospital, it's much better if there is a private place at this moment [after the failed resuscitation of the child] so parents can release themselves. If there is such the place, no one told me anything before." F1 "Immediately after the resuscitation, they took my child to the mortuary and did not let me say goodbye to my daughter and see her for the last time. I was also told not to make noise and cry because other mothers were in the ward and they might scare. I was running to the mortuary looking for my child's corpse. Unfortunately, there were no facilities for us. At least others should lose their children in a calm situation." M9

D=doctor, N=nurse, F=father, M=mother

2. Chaos in providing information

The experiences of parents and healthcare professionals indicated that there was no specific process for providing information, as demonstrated in three sub-categories. Supportive quotations are found in Table 3.

2.1: Defect of responsibility in informing

The parents in this study wanted doctors and nurses to be available to provide information. But they most preferred to get the information from a doctor who was responsible for and aware of their child's condition. Yet, in this study, participants' words demonstrated there was defect of responsibility to provide information to parents. Doctors considered it their duty to provide information to parents, but nurses discussed doctors' irresponsibility in informing the parents about their child's condition. Although nurses considered providing diagnostic information to be duty of doctors, they felt discussing care information is their duty. At the same time, they were confused about providing information and responding to the parents, feeling uneasy because they were more in touch with parents and were asked to provide them with information.

2.2: Provide selective protection of information

In the culture of the participants in the study, there was withholding of information and information was transferred from healthcare professionals to parents selectively and protectively. Parents in this study tended to realize the condition of their child without actually having been provided such information from the healthcare team, and there were instances where the healthcare professionals withheld information to help protect the parents. Three of healthcare professionals preferred to give information about the child's poor condition to relatives or close friends rather than the parents, and then these individuals then transferred the information to the parents. This was described as an effort to protect the parents who were already having to deal with their emotions.

When healthcare professionals did provide information to parents, they expressed a desire to provide unpleasant information about the child to the father rather than the mother. One doctor explained that this was due to fathers typically behaving more calmly. However, the healthcare professionals did not ensure the transfer of this information from father to the mother, and the desire of fathers to protect the mother was also evident. This withholding of information resulted in two of the mothers not having awareness and readiness for their child’s crisis. This led one father to express regret over holding information about his child’s situation from his spouse.

2.3: Hardness in obtaining information

The experiences of most of the parents showed that information about their child's condition was obtained with difficulty, consuming their time, and that doctors especially spent little time providing parents with information. Participating parents in the study wanted to receive information from doctors at their child's bedside, yet their stories indicted this did not occur.

Table 3. Chaos in providing information

2.1: Defect of responsibility in informing	"If the doctor gives information, it is better because the parents trust the doctors more. Now, if there is no doctor [available], the nurses will be next. It is better for a male doctor to talk to the father because the father accepts more easily than if a woman doctor, especially when she is young. But it also depends on how the doctor is expressing. Even if she is a woman or young, it depends on how she speaks so that she can convince the father." D9 "The doctor and head nurse of ward were telling us not to talk to the parents about their child. I personally do not know what to say when parents ask. Because the doctor is only there for one hour in the ward every day. When we do not respond to parents, they think we know nothing and lose confidence in us and our care of their child." N2
2.2: Provide selective protection of information	"In one case, a child was brought to the hospital and the child did not have a specific illness before. The parents were agitated and very anxious. I talked to the child's uncle about the child's poor condition and what had happened." N4 "I prefer to give bad news to the father so that he tells the mother. Fathers usually act more logically." D8 "I knew my child's problem at that time. I realized she was dying and it was good. Therefore, I could say goodbye to my baby at the last moment. But I wish I told her mother, so she was ready too." F7
2.3: Hardness in obtaining information	"If we wanted to be told about our child's illness, we had to run to the doctor in the hospital corridors, but we could not see him. Everyone was around. We had to go to the office of the doctor. Well, I was foreign in this city, I had to request a taxi to take me to the doctor's office. After difficulty finding it, I had to pay a visit to the doctor to have my baby's condition explained for a few minutes, otherwise they [doctors] would not answer us." M9

D=doctor, N=nurse, F=father, M=mother

3. Providing situational information

The experiences and perceptions of parents and healthcare professionals revealed that providing information to parents should be done according to the situation of the child and in consideration of parental condition. Six sub-categories were approved in this category. Supportive quotations are found in Table 4.

3.1: Honest information on the border of hope and hopeless

Healthcare professionals and parents emphasized the importance of honest and truthful information. The healthcare professionals had experienced situations where there was lack of correct information and this resulted in mistrust among parents. Also, parents' experiences showed that if they received untrue information, they were not prepared for the crisis ahead.

Next, the healthcare professionals explained how when they provided honest information for parents, they worked to provide information that was on the border of hope and hopeless. The experiences of parents in this regard showed that most fathers did not have or want false hope, while most mothers didn’t want all hope removed when being provided information about their child's condition.

3.2: Providing information with apathy

Parents emphasized the importance of receiving information from the treatment team in a kind, compassionate, and respectful manner. Two parents appreciated the kind words used by healthcare professionals. But most parents indicated that healthcare professionals could not comprehend their mental state when providing information to them and they provided information about their child's situation with apathy and without empathy. The lack of empathy of both doctors and nurses was recalled. One father expressed his dissatisfaction with the way the doctor coldly provided information to his wife, while a mother whose baby was in critical condition immediately after delivery explained receiving unempathetic care from nurses.

3.3: Providing information as Individual

The experiences of both parents and healthcare professionals indicated that it is not possible to use the same method of providing information to all parents. It depended on the parents’ level of understanding, education, age, language, whether the parents have only the one child, if the child has been hospitalized before, and whether the child’s illness is acute or chronic. Their experiences showed that for low-education parents, it is important to provide information in simpler, brief and tangible ways. But for higher-education parents, this information could be provided more scientifically and completely. Statements from two fathers with different levels of education confirmed different needs in regard to explanations.

The experiences of parents and healthcare professionals also showed that the speed of transmitting information to parents was important, especially when providing information to mothers. It was also necessary to be more sensitive when providing information to parents with a single child or golden baby (born after years of infertility issues and treatment) as this child might be the foundation of the family.

Healthcare professionals' experiences also indicated that older parents are more receptive and have a better understanding of information than younger parents, and that sometimes the grandparents were the decision-makers in such families. Linguistic differences in multilingual countries also were felt to make it difficult for healthcare professionals to provide information to parents. In this regard, a doctor described seeking translation services to help provide information to parents.

The healthcare professionals' experiences showed that it is easier to provide information to parents with a child who has a chronic illness or has been hospitalized for at least a few days rather than in an acute emergency situation because unexpected crises can result in parents being agitated and the high stress prevents them from understanding the information. In these instances, nurses and doctors tried to speak calmly and repeat information to help ensure understanding.

3.4: Dualism in blaming

Four of the five doctors' experiences showed that if parents were blamed, this prevents the doctors themselves from being blamed and prevents future complaints. Yet, when parents were blamed for the situation of their child, it resulted in great remorse and grief. Other healthcare professionals acted differently and believed that even if parents may be to blame for the situation of their child, healthcare professionals should not blame them. These healthcare professionals felt that if they were unable to release their pain, they at least needed to make sure they did not add any additional pain to parents.

3.5: Assurance to parents

The experiences of healthcare professionals and parents showed that in order to prepare parents for the crisis ahead, the transfer of information must be accompanied by efforts to facilitate trust. This was felt to be important so that both in practice and in speech, parents could be assured that everything necessary for the child would be done. To best ensure trust, it was felt that healthcare professionals should coordinate the providing of information and there should be no inconsistencies in the information. Also, healthcare professionals should avoid accusing their colleagues when providing information to parents because this can result in insecurity in the parents.

3.6: Presence of parents to better understand the child's situation

Providing information through verbal speech was felt to not always be enough. Instead, it can be necessary to improve understanding of the child's situation by having parents be present to witness their condition and care. The experiences of parents and healthcare professionals showed that parents who were with their child during the child's hospitalization, especially in the last moments of the child's illness, better understood their child's illness and how severe it was. It was felt that parents who were present were better prepared to face the crisis than parents who were not present. In addition to helping them prepare, a mother described how being present provided comfort through being able to say goodbye to her child.

Table 4. Providing situational information

3.1: Honest information on the border of hope and hopeless	"In the first days, everyone [healthcare providers] told us that my child was fine, then suddenly he died and they said that his heart was stopped. I said that you said it was good, but now what happened..." M5 "We have to talk between the border of hope and hopeless. We have to say the positives and the negatives of the points. We should not be too hopeful and not too disappointed …" N1 "Do not provide false information and tell the truth. For example, my child had a seizure. They [healthcare professionals] should not say do not worry, it was nothing. I knew my child had a problem." F7 "I knew my child was not well, but I did not like to be constantly disappointed. I was afraid to call the ward because I was afraid that they [nurses] would say that my child was very ill, or I would enter the ward in fear." M2
3.2: Providing information with apathy	"One of them [a doctor] said very badly to his mother [the participant's wife] that this child of yours is like this, you have to get used to her [child]. If you can't hold her, take her to Welfare." F7 "I had so much pain, but I did not think about myself. I was anxiously requesting information about my baby's condition, and I was constantly asking what happened to my child? Do not let him get cold. They [nurses] said that we know our work, please do not interfere." M5
3.3: Providing information as Individual	"... I have not studied medicine to know. If they had given me this information in simple language so that I could understand it, it would have been very good. I did not understand what they [healthcare professionals] told me." F7 "We really needed someone to explain my child's situation to me. Well, I was somewhat familiar with English terms. If someone explained it to me, I would understand because I am also a language teacher and translator." F3 "When I was at the beginning of my career, I was talking with a father using scientific terms about his child's condition. I had not finished my explanation yet; I saw he was angry and said 'Do you make fun of me?' …" D13 "... Slowly with the introduction, perhaps our audience [the mother herself] might not be strong enough to endure. When one of the nurses was providing bad information about my child, in the middle of her conversation, I did not understand what happened to me, as the world was ruined on me ... When I opened my eyes, I saw the doctor and the nurses and my husband around me…" M4 "Young parents have no responsibility at all and do not seem to understand or care about it at all. These parents are not the decision-makers themselves, and the grandparents are the decision-makers." N2 "Linguistic differences may make it difficult to explain. For example, the language of parents may be Kurdish and they do not know Persian. In these cases, we look for personnel who are at least fluent in the parent language and try to provide information to parents through them." D9 "Families who come to the emergency room frequently ask questions. I can't completely answer their questions and need to repeat the information because they are so anxious, and they can't understand." N5 "A person should speak to them [parents] calmly, respectfully and in their own language. But often it does not work. When parents are very agitated, I go forward to talk to them, but I see that it gets worse, and they are aggressive and told me 'What are you doing? You go and do your work.'" D8
3.4: Dualism in blaming	"I asked the doctors: 'Could the flu kill a healthy child in a week because my daughter didn't have a problem before?' They said it was probably because your daughter didn't feed on your breast milk and you fed her with dry milk and you gave birth to her by cesarean section .... [The mother did not continue, she sighed and then cried]" M6 "I tried to make sure she [the mother] didn't feel guilty. I said to her that she wasn't the only person who experienced the accident and it could happen to anybody" N1
3.5: Assurance to parents	"The opinion of the doctor who spoke to us was that they [other doctors] should not operate at all: 'They took your child to the operating room to look for where the problem was. What do you expect from a one-and-a-half-kilogram child?'" M10 "Before, in the emergency room, everyone was talking to the parents [nurse, intern, resident, etc.]. Everyone was asking the parents what happened and why did you bring the child to the emergency room? Also, parents' questions were answered in different ways, and it caused the parents to become agitated. But since we managed this situation, the pediatrician or senior resident is in the emergency room, and this has reassured the parents that there is someone who can manage the team." D12

3.6: Presence of parents to better understand the child's situation	"A child was hospitalized. His parents were not present at the bedside of the child. When I saw that the child was getting worse, I called his parents to come to see their child. I think this caused the parents to have readiness for the resuscitation crisis of their child" N2 "I was always in the hospital with my child. Before she died, the nurse called me and said, 'Your child is in critical condition and her blood pressure is constantly dropping. She is not well at all.' It was good to be able to be with her at the last moment and say goodbye to her." M6

D=doctor, N=nurse, F=father, M=mother

4. Psychological and spiritual requirements

The experiences of parents and healthcare professionals revealed that parents also need mental and spiritual preparation for facing the terrible crisis of their child's resuscitation. Four sub-categories emerged. Supportive quotations are found in Table 5.

4.1: Reliance on supernatural power

Parent and healthcare professional participants' words showed that most parents needed to rely on supernatural powers, other than medical science, when they were faced with critical situations. In this time, reminding parents of the will and trust in God and providing access to holy text, chaplains, and even a place to pray can be soothing to them. The helpfulness of being reminded of the importance of religion and faith was brought up by both mothers and fathers.

4.2: Need for access to a psychologist

The experiences of parents and healthcare professionals indicated that parents needed to have access to a psychologist (or other mental health specialist) to help prepare them for these critical situations, especially when a child is likely to not survive. Parents needed a psychologist to be present by their side in these critical situations so that they could consult with them. One mother described how all of the staff was helpful, but she felt that it would be more helpful to also have a psychologist to talk to. Most parents also felt that all staff working in a children's hospital should have completed psychology courses that prepare them to treat parents in critical situations appropriately, with a specific need to know how to give bad information to parents.

4.3: Sharing emotions

According to both parents and healthcare professionals, there is a need for parents to be able to share their feelings and emotions with others when they are in a critical psychological state. Parents needed to be understood during their critical situation and supported by those around them. It was important to parents that staff understand their situation.

Parents also needed to be accompanied by family or relatives, especially their spouse. All of the mothers who were with their husbands during their child's resuscitation said that their husband's presence had helped them to cope and provided calm for them. But a mother who was alone during her child's illness in the intensive care unit described her experience as stressful and wished she had someone there with her. The experiences of the healthcare professional participants also showed that the presence of other family members or other companions, especially in emergencies where both parents are in shock, can be a supportive force and better prepare parents in the face of the crisis. A nurse described speaking to family members over the phone, emphasizing the need to come provide companionship at the hospital.

4.4: Collecting mementos

Parents expressed the need to communicate internally with their child after they died during resuscitation. Having mementos of the child can be an effective way to maintain this relationship. Healthcare professionals can assist parents to collect mementos of their child before the resuscitation. In this regard, a mother who was not given any mementos of her child explained how she longed for them and wished the staff had given them to her.

Table 5. Psychological and spiritual requirements

4.1: Reliance on supernatural power	"My daughter had no problems before, and she was admitted to the ICU because she had the flu. Her condition was getting worse every day. I was very impatient. One of the staff told me: 'God created us and all of us will die one day. The fate of everyone has been decided by God in some way. Trust in God.' And she relieved me in this way." M6 "While we were waiting in the back of the operating room, one person told me to repeat the holy phrase. I wondered why I should repeat it only ten times. At that time, I needed to consult with an informed person. I needed to be alone with my God in a quiet place and pray and read the Quran." F3
4.2: Need for access to a psychologist	"I think it would be better if a psychologist was with the mothers in the ICU and talked to them calmly. She/He could provide consolation support for them. It is true that all the staff treated me well. But if there was a staff that was with the mothers and talked to them for a few hours, I think it is better. A psychologist can better prepare mothers for the fact that they are losing their baby so that they can pass this period more easily." M6 "What's wrong that a doctor or a nurse knows about psychology or a businessman knows about management? Being multi-disciplined makes us complete in one discipline but all of us are educated only in one special field. For example, according to the body of a person, we let him be a guard, and we do not care at all how literate this person is, does he know how to treat others or not?" F3
4.3: Sharing emotions	"A nurse came and told me and said, 'I am mother too and understand you. Many of these things have happened here [in the ICU], and it has happened to many families that their child was in a critical situation. I know it is very difficult, but you have to endure.' It was good that she was telling me." M2 "... I just had stress, no one was there, my husband couldn't come. I wish someone was with me." M9 "When a child is ill and there is a possibility of resuscitation for him/her, I call the parents to come and I emphasize that the mother should not be alone and come with her husband or a companion. If I know a supporter, relatives or friends of the parents, I will call them to come and be with the parents." N2
4.4: Collecting mementos	"I still miss her. I still see her photos and hear her voice." M6 "... They [staff] didn't give me the things that I had put on her bedside. I had put a comb for her and brushed her hair with it. They [staff] didn't give me it to keep a few of her hair for myself. Her bottle of milk or the things I put there, they give me any of them. My baby was touching them. I wanted to keep them to myself." M9

D=doctor, N=nurse, F=father, M=mother

Discussion

In this study, parents and healthcare professionals shared their experiences and perceptions of pre-resuscitation parental preparation. Parents' preparation before the resuscitation of their child was divided into four categories: Awareness, Chaos in providing information, Providing situational information, and Psychological and spiritual requirements.

The results revealed that facilitating parents' understanding of the child's condition and readying them for the resuscitation of their child may help to prevent or lessen the shock of the crisis. All parents, without exception, emphasized the importance of knowing what is happening to their child, and helping them to understand was an essential support need.[12 23] In another study, having information about the child's condition provided the parents with the ability to better adapt and accept the child's death.[23 24] Also, findings from Chen et al. (2019) confirmed results of this study showing that transmitting truthful information promotes trust and gives emotional support to parents, enhancing their readiness for resuscitation.[25] Another study also confirmed the finding that having information about the child's condition can help parents maintain a sense of control, so they can better manage the situation.[26] Giving information about the child's condition and even telling of the possibility for resuscitation and death is better done continuously during the child's hospitalization, especially during the child's deterioration. Another study found that parents of children with chronic illness who were informed of the possible death of their child several months prior but then did not receive information updates and normalization, were not be prepared for the stage of health deterioration and death.[27]

In this study, the doctors considered it their duty to provide information to parents; however, this did not always occur. While diagnostic information was provided by doctors and care information was provided by nurses, nurses in this study expressed frustration over the parents not being told of their child's condition. In one study, parents who did not recall receiving clinical information before their child's resuscitation and reported waiting hours to talk to a healthcare provider.[1] A worrisome finding is that when several of the parents did receive information from doctors and nurses, it was not delivered in a kind or empathetic manner. Most parents believed that the presence of a psychologist (or other mental health specialist) when they received bad information about their child could be helpful in preparing them for their child's critical situation.

In some cultures, such as the culture of the participants in this study, a selective protection of information is observed in order to protect the parents from stress and anxiety. In this instance, information is given to the relatives of the parents who can then transmit the information. Many other cultures, such as in China and South Africa, also believe in withholding information about the disease from the patient as a means of protecting them.[28-30] In this study, three of the healthcare professionals preferred to give bad information about the child to the person accompanying the parents (such as another relative). In the absence of accompanying persons, they provided this information to the father, and a refusal to provide bad information to the mother was expressed. It is possible that information is then not transmitted from father to mother, causing the mother to not be ready to face the crisis. In one study, this withholding of information led to the loss of the opportunity for a last farewell to loved ones.[30] On the other hand, providing information to persons other than parents also creates a challenge related to information confidentiality. This may in turn jeopardize the respect, honesty and human value that is the principle of autonomy.[31 32] We found that the issue of confidentiality of information was important for the parents under study, especially those from rural villages because all persons are known to one another in their small communities.

Providing bad news to parents to prepare them for a resuscitation crisis may be better handled in a unique manner, meaning that it depends on the condition of the child and parents and the events surrounding the resuscitation. Truth telling is as a right and medical requirement;[31] however, when designing his model, Nierengarten said that while a doctor's honesty is a necessity, like all areas of medicine and life, nothing is certain.[33] Preferences and values about access to and receipt of information also influence how healthcare professionals give information to parents. It has been shown that some people do not want to hear some information, especially information that has a negative element in it,[29 34] parents need to be neither completely hopeful nor completely hopeless when receiving information,[1] and preparation for receiving medical information should be considered because sometimes expressing this information may harm the mental health of the person.[29 35] These findings are consistent with those of this study. In light of this, healthcare professionals should use appropriate language when providing information.[36 37] Providing information to parents at a high speed[30 34] and not providing understandable information to parents[29 37] could result in lack of proper information processing, especially in unexpected emergency situations. This was again consistent with the experiences and perceptions of parents and healthcare professionals in this study. Therefore, when providing information to parents, healthcare professionals can consider if the quantity and quality of information is appropriate for individual parents and the situation at hand.

Facilitating parents' trust in the received information is important. In this regard, findings in this study were consistent with other studies that show trust can be accomplished by coordinating the provision of information from different treatment team members,[38] ensuring parents that we have done all we can,[34] and relaying bad news in an empathetic and compassionate way[38-40] that does not place blame on the parents.[15 41] According to participants in this study, these are considered professional and helpful behaviors of healthcare providers. Also, findings from Bogetz et al. (2020) and Bekkering et al (2019) confirmed results of this study that suggest healthcare professionals can support parents by providing them information at their child's bedside in order to magnify their understanding, especially when the child is very ill and near the last moments of her/his life.[27 39] In the present study, it was felt that parents being present during their child's hospitalization promoted better understanding and acceptance of the resuscitation crisis, even with acute problems and no previous history of illness.

The psychological and spiritual needs of parents are important for healthcare professionals to consider when preparing parents for the upcoming crisis. The results of this study indicate the need for parents to have access to a psychologist and a chaplain, as well as the presence of their spouse and other relatives or friends. This can help ensure parents have support for the crisis ahead. These findings are consistent with those of Kim et al. (2019) who found that nurses considered the provision of consolation, empathy, emotional support, and religious support to parents as their role in end-of-life care, and they informed parents about the availability of religious services and clergy visits. Also, they allowed family visits, for example grandparents, which was outside of the policy but was something they considered to be part of their role.[42] Of course, the beliefs and desires of parents must be considered when attempting to meet their spiritual needs. In this study, the expression of God's will by a healthcare professional was not acceptable to one of the parents, while most parents considered it to provide consolation and relief.

Strengths and limitations

Participants of this study included both parents and healthcare professionals in order to gain a more comprehensive perspective on parental readiness parents for resuscitation of their child. The study provides insight about parents' and healthcare professionals' experiences and perceptions of pre-resuscitation readiness of parents, which is important for identifying strategies to help them prepare. Cultural considerations emerged when examining the experiences and perceptions of healthcare professionals who work in large hospitals in two major cities in Iran.

This study, like other qualitative studies, has limitations affecting generalizability. One limitation is selection bias, and those who had strong views about parental readiness may have opted to participate. Next, this study enrolled participants from one geographic area and should be repeated in other locations with different cultures and religions. We examined the experiences and perceptions of healthcare professionals working in large hospitals in two major cities in Iran, and also selected parents who were referred to these centers. The participants may have different experiences and views than those working in or referred to small medical centers. However, this limitation is minimized because small towns and rural communities frequently refer to the public hospitals in these cities and 50% of the parent participants were from surrounding towns or villages. We also examined the experiences and perceptions of one male nurse and 3 fathers because in Iranian pediatric hospitals, most nurses are female. Based on Iranian context, mothers are the main caregivers of their children and hospital regulations do not allow fathers to stay at the hospital for their child's care and they can only meet their child and wife for a short time (except in emergency situations) because most of healthcare staff in the pediatric hospitals are women. Another limitation is that the children of the parents in this study were all 5 years of age or younger, and it is possible that parental needs differ if the children are older. In Iran, older children and adolescents are usually hospitalized in an adult hospital. Despite the limitations of this study, the findings are important to stimulate additional research and the creation of guidelines or protocols for preparing parents for their child's resuscitation as the healthcare professional participants stated no such tool exists in their workplace and having this guidance would help them better support parents.

Conclusion

This study provides insight on parental needs prior to pediatric cardiopulmonary resuscitation, as well as strategies to promote readiness for their child's resuscitation crisis. Findings can be used to promote family-centered care in pediatric critical care and emergency settings. The results of this study suggest that to prepare parents for resuscitation, it is important to continuously provide information about the child's condition, with a need to consider the parents' culture, ensure confidentiality of information, and spend enough time with the parents. This information should be provided to parents empathetically and without blame, honestly yet in a way that helps balances hope and hopelessness, and in a unique and individual way that considers the child's situation and parents' needs. It can be helpful to provide this information while parents are present at the child's bedside, especially when the child is very ill. Psychological and spiritual needs should also be considered to help prepare parents for their child's resuscitation and potential death. The results of this study indicate that parents need attention to promote their readiness to face this stressful event, and that each of the healthcare professional participants acted according to their experiences/preferences without access to instructions and protocols in this regard. There is a need for more research on parental readiness for resuscitation so effective protocols can be developed. Further, future research should examine parental readiness among various cultures, as parent needs may differ.

Contributors

AG and HH conceptualized the study, in consultation with MAB and HNA. AG collected the data, conducted the first level of analysis and prepared the first draft of the manuscript. HH, MAB, HNA and MH contributed to the study design and data analysis the manuscript. HH and KP led and revised the manuscript writing. All authors reviewed and revised the manuscript. HH acts as guarantor for the manuscript.

Funding

This research received no specific grant from any funding agency in the public, commercial or not-for-profit sectors.

Competing interests

None.

Patient consent

Obtained.

Data sharing statement

Not applicable

Acknowledgments

We thank the patient advisers in pediatric hospitals of Este Azerbaijan and Mashhad.

References

1. Stewart SA. Parents' experience during a child's resuscitation: Getting through it. *J Pediatr Nurs* 2019;47:58–67.
2. Shimoda-Sakano TM, Schvartsman C, Reis AG. Epidemiology of pediatric cardiopulmonary resuscitation. *Jornal de pediatria* 2020;96:409–21.
3. Tham LP, Wah W, Phillips R, et al. Epidemiology and outcome of paediatric out-of-hospital cardiac arrests: A paediatric sub-study of the Pan-Asian resuscitation outcomes study (PAROS). *Resuscitation* 2018;125:111–7.
4. Majidi A, Mahmoodi S, Adineh VH. An Epidemiologic Study of Emergency Department Visits before and after Executing Health Sector Evolution Plan; a Brief Report. *Iran Emerg Med J* 2017;4:130–4.

5. Loaec M, Himebauch AS, Kilbaugh TJ, et al. Pediatric cardiopulmonary resuscitation quality during intra-hospital transport. *Resuscitation* 2020;152:123–30.

6. Kianmehr N, Mofidi M, Rahmani H, et al. The attitudes of team members towards family presence during hospital-based CPR: A study based in the Muslim setting of four Iranian teaching hospitals. *J R Coll Physicians Edinb* 2010;40:4–8.

7. Vasli P, Salsali M. Parents' participation in taking care of hospitalized children: A concept analysis with hybrid model. *Iran J Nurs Midwifery Res* 2014;19:139–44.

8. Toomey SL, Elliott MN, Zaslavsky AM, et al. Variation in Family Experience of Pediatric Inpatient Care As Measured by Child HCAHPS. *Pediatrics* 2017;139:e20163372.

9. Doupnik SK, Hill D, Palakshappa D, et al. Parent Coping Support Interventions During Acute Pediatric Hospitalizations: A Meta-Analysis. *Pediatrics* 2017;140:e20164171.

10. Davidson JE, Aslakson RA, Long AC, et al. Guidelines for Family-Centered Care in the Neonatal, Pediatric, and Adult ICU. *Crit Care Med* 2017;45:103–28.

11. Lisanti AJ, Allen LR, Kelly L, et al. Maternal Stress and Anxiety in the Pediatric Cardiac Intensive Care Unit. *Am J Crit Care* 2017;26:118–25.

12. Koch K, Jones B. Supporting Parent Caregivers of Children with Life-Limiting Illness. *Children* 2018;5:85.

13. Foster M, Whitehead L, Maybee P. The Parents', Hospitalized Child's, and Health Care Providers' Perceptions and Experiences of Family-Centered Care Within a Pediatric Critical Care Setting: A Synthesis of Quantitative Research. *J Fam Nurs* 2016;22:6–73.

14. Rostami F, Hassan ST, Yaghmai F, et al. Effects of family-centered care on the

satisfaction of parents of children hospitalized in pediatric wards in a pediatric ward in Chaloos in 2012. *Electron Physician* 2015;7:1078–84.

15. Jones CHD, Ward A, Hodkinson PW, et al. Caregivers ' Experiences of Pathways to Care for Seriously Ill Children in Cape Town , South Africa : A Qualitative Investigation. *PLoS One* 2016;11:1–15.

16. Meert KL, Briller SH, Schim SM, et al. Examining the needs of bereaved parents in the pediatric intensive care unit: A qualitative study. *Death studies* 2009;33(8):712-40.

17. Curtis JR, Treece PD, Nielsen EL, et al. Randomized trial of communication facilitators to reduce family distress and intensity of end-of-life care. *Am J Respir Crit Care Med* 2016;193:154–62.

18. Saunders B, Sim J, Kingstone T, et al. Saturation in qualitative research : exploring its conceptualization and operationalization. *Qual Quant* 2018;52:1893–907.

19. Bengtsson M. How to plan and perform a qualitative study using content analysis. *NursingPlus Open* 2016;2:8–14.

20. Hays DG, Wood C, Dahl H, et al. Methodological Rigor in Journal of Counseling & Development Qualitative Research Articles: A 15-Year Review. *J Couns Dev* 2016;94:172–83.

21. Cypress BS. Rigor or Reliability and Validity in Qualitative Research : Perspectives , Strategies , Reconceptualization , and Recommendations. *Dimens Crit Care Nurs* 2017;36:253–63.

22. Nowell B, Albrecht K. A Reviewer's Guide to Qualitative Rigor. *J Public Adm Res*

Theory 2019;29:348–63.

23. Doumit M, Rahi AC, Saab R, et al. Spirituality among parents of children with cancer in a Middle Eastern country. *Eur J Oncol Nurs* 2019;39:21–7.

24. Currie ER, Christian BJ, Hinds PS, et al. Parent Perspectives of Neonatal Intensive Care at the End-of-Life. *J Pediatr Nurs* 2016;31:478–89.

25. Chen C-H, Cheng Y-H, Fen-JuChen, et al. Association Between the Communication Skills of Physicians and the Signing of Do-Not-Resuscitate Consent for Terminally Ill Patients in Emergency Rooms (Cross-Sectional Study). *Risk Manag Healthc Policy* 2019;12:307–14.

26. Hummelinck A, Pollock K. Parents' information needs about the treatment of their chronically ill child: A qualitative study. *Patient Educ Couns* 2006;62:228–34.

27. Bogetz JF, Revette A, Rosenberg AR, et al. "I Could Never Prepare for Something Like the Death of My Own Child": Parental Perspectives on Preparedness at End of Life for Children With Complex Chronic Conditions. *J Pain Symptom Manage* 2020;60:1154–62.

28. Fan Z, Chen L, Meng L, et al. Preference of cancer patients and family members regarding delivery of bad news and differences in clinical practice among medical staff. *Supportive Care in Cancer* 2019;27:583-9.

29. Athanas R, Gasto F, Renatha SJ. Factors influencing truth-telling by healthcare providers to terminally ill cancer patients at ocean road cancer institute in dar-es-salaam, tanzania. *South African Journal of Bioethics and Law* 2020;13:108-13.

30. Ibañez-Masero O, Carmona-Rega IM, Ruiz-Fernández MD, et al. Communicating health

information at the end of life: The caregivers' perspectives. *Int J Environ Res Public Health* 2019;16:2469–80.

31. Twinomujuni J. *Truth telling beyond borders: an African perspective for the degree of Doctor of Philosophy*. Duquesne University, 2017.

32. Hanssen I. From human ability to ethical principle: an intercultural perspective on autonomy. Medicine, *Health Care and Philosophy* 2005;7:269-79.

33. Nierengarten MB. Pediatric truth-telling Omission vs deception. *Contemp Pediatr* 2019;36:24–33.

34. Lantos JD. Tell parents the truth, but tell it slant. *Pediatrics* 2018;142:S199-204.

35. Ewuoso C. Models for truth-telling in physician-patient encounters: what can we learn from Yoruba concept of Ooto? *Dev World Bioeth* 2019;19:3–8.

36. Kaye EC, Snaman J, Johnson L, et al. Communication with children with cancer and their families throughout the illness journey and at the end of life. *InPalliative Care Pediatr Oncol* 2018;55–93.

37. Suurmond J, Lieveld A, Van de Wetering M, Schouten-van Meeteren AYN. Towards culturally competent paediatric oncology care. A qualitative study from the perspective of care providers. *Eur J Cancer Care* 2017;26:e12680.

38. Blazin LJ, Cecchini C, Habashy C, et al. Communicating effectively in pediatric cancer care: translating evidence into practice. *Children* 2018;5:40–56.

39. Bekkering H, Woodgate R. The Parental Experience of Unexpectedly Losing a Child In the Pediatric Emergency Departmen. *OMEGA-Journal of Death and Dying* 2021;84:28-

50.

40. Muskat B, Greenblatt A, Anthony S, et al. The experiences of physicians, nurses, and social workers providing end-of-life care in a pediatric acute-care hospital. *Death Stud* 2019;105-116.

41. Meert KL, Templin TN, Michelson KN, et al. The Bereaved Parent Needs Assessment: A new instrument to assess the needs of parents whose children died in the pediatric intensive care unit. *Crit Care Med* 2012;40:1–18.

42. Kim S, Savage TA, Song M-K, et al. Nurses’ roles and challenges in providing end-of-life care in neonatal intensive care units in South Korea. *Appl Nurs Res* 2019;1:151204.

Supplemental appendix 1: Interview guide questions asked of parents and healthcare professionals.

Parents	**Healthcare professionals**
- In your experience, what readiness did you need before your child’s resuscitation? - How were you treated before your child’s resuscitation? - What actions helped you become ready for and endure your child's resuscitation? - In your experience, what barriers were there to your readiness for your child's resuscitation? - What factors do you think would have improved your readiness for your child's resuscitation? - Which health professionals could better help you to become ready for this critical situation? And how could they help? - In your experience, how can the health professionals ready, or prepare, other parents for resuscitation? - What suggestions do you have to improve parents’ readiness for their child's resuscitation?	- In your experience, what preparation do parents need before their child's resuscitation? - How do you treat parents to help promote their readiness before their child's resuscitation? - What actions do you take to help parents prepare for and endure the resuscitation of their child? - In your experience, what barriers there are to readying parents for their child's resuscitation? - What do you think are the factors that helped improve parents' readiness for their child's resuscitation? - In your experience, how can parental readiness for their child's resuscitation lead to better parenting experiences? - Which health professionals could better help parents to ready for this critical situation? And how could they help?

Standards for Reporting Qualitative Research (SRQR)*

http://www.equator-network.org/reporting-guidelines/srqr/

Title and abstract

	Page/line no(s).
Title - Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended	1/1-2
Abstract - Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions	1/1-21, 2/1-5

Introduction

Problem formulation - Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement	3/19-22, 4/1-23
Purpose or research question - Purpose of the study and specific objectives or questions	5/1-2

Methods

Qualitative approach and research paradigm - Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/ interpretivist) is also recommended; rationale**	5/5-6
Researcher characteristics and reflexivity - Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability	6/1-2
Context - Setting/site and salient contextual factors; rationale**	5/8
Sampling strategy - How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale**	5/8-14
Ethical issues pertaining to human subjects - Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	7/15-19
Data collection methods - Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale**	5/16-21, 6/1-2

Data collection instruments and technologies - Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study	6/3-15
Units of study - Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	8/8-17
Data processing - Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/de-identification of excerpts	6/16-23
Data analysis - Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale**	6/16-23, 7/1-2
Techniques to enhance trustworthiness - Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale**	6/21-23, 7/1-13

Results/findings

Synthesis and interpretation - Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	9/1-21, 10/1-22, 11/1-12, 12/3-14, 13/1-21, 14/6-15, 15/1-21, 16/1-22, 17/1-21, 18/1-12, 19/3-19, 20/1-22
Links to empirical data - Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	11,12/table2, 14/tabele3, 18,19/tabele4, 21/tabele5

Discussion

Integration with prior work, implications, transferability, and contribution(s) to the field - Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field	21/5-11, 22/1-23, 23/1-23, 24/1-23, 25/1-9
Limitations - Trustworthiness and limitations of findings	25/11-23, 26/1-14

Other

Conflicts of interest - Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	27/21
Funding - Sources of funding and other support; role of funders in data collection, interpretation, and reporting	27/18-19

*The authors created the SRQR by searching the literature to identify guidelines, reporting standards, and critical appraisal criteria for qualitative research; reviewing the reference lists of retrieved sources; and contacting experts to gain feedback. The SRQR aims to improve the transparency of all aspects of qualitative research by providing clear standards for reporting qualitative research.

**The rationale should briefly discuss the justification for choosing that theory, approach, method, or technique rather than other options available, the assumptions and limitations implicit in those choices, and how those choices influence study conclusions and transferability. As appropriate, the rationale for several items might be discussed together.

Reference:

O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. **Standards for reporting qualitative research: a synthesis of recommendations.** *Academic Medicine*, Vol. 89, No. 9 / Sept 2014 DOI: 10.1097/ACM.0000000000000388

BMJ Open

Parent and healthcare professional experiences and perceptions of parental readiness for resuscitation in Iranian pediatric hospitals: A qualitative study

Journal:	*BMJ Open*
Manuscript ID	bmjopen-2021-055599.R2
Article Type:	Original research
Date Submitted by the Author:	19-Apr-2022
Complete List of Authors:	Ghavi, Arezoo; Tabriz University of Medical Sciences, Department of Pediatric Nursing Hassankhani, Hadi; Tabriz University of Medical Sciences, Powers, Kelly; University of North Carolina at Charlotte, School of Nursing Arshadi-Bostanabad , Mohammad; Tabriz University of Medical Sciences Namdar Areshtanab, Hossein ; Tabriz University of Medical Sciences, Department of Psychology Nursing Heidarzadeh, Mohammad; Tabriz University of Medical Sciences
Primary Subject Heading:	Paediatrics
Secondary Subject Heading:	Intensive care, Nursing, Paediatrics, General practice / Family practice, Emergency medicine
Keywords:	Health informatics < BIOTECHNOLOGY & BIOINFORMATICS, Paediatric intensive & critical care < INTENSIVE & CRITICAL CARE, Paediatric intensive & critical care < PAEDIATRICS

Parent and healthcare professional experiences and perceptions of parental readiness for resuscitation in Iranian pediatric hospitals: A qualitative study

Arezoo Ghavi [1] iD, Hadi Hassankhani [2,*] iD, Kelly Powers [3] iD, Mohammad Arshadi-Bostanabad [4] iD, Hossein Namdar-Areshtanab [5] iD, Mohammad Heidarzadeh [6] iD

[1] Ph.D. Student, Department of Pediatric Nursing, School of Nursing and Midwifery, Tabriz University of Medical Sciences, Tabriz, Iran

[2] Professor, Department of Medical-Surgical Nursing, School of Nursing and Midwifery, Tabriz University of Medical Sciences, Tabriz, Iran

[3] Assistant professor, School of Nursing, University of North Carolina at Charlotte, Charlotte, NC, United States

[4] Associate professor, Department of Pediatric Nursing, School of Nursing and Midwifery, Tabriz University of Medical Sciences, Tabriz, Iran

[5] Associate professor, Department of Psychology Nursing, School of Nursing and Midwifery, Tabriz University of Medical Sciences, Tabriz, Iran

[6] Associate professor of neonatology, Tabriz University of Medical Sciences, Tabriz, Iran

Corresponding Author:

Hadi Hassankhani, Department of Medical-Surgical Nursing, School of Nursing and Midwifery, Tabriz University of Medical Sciences, Tabriz, Iran, Email: hassankhanihadi@gmail.com

Cell Phone number: +989183181267, Telephone number of work: +984134796770 (134), Telephone number of home: +984134796969

ABSTRACT

Objective: The aim of this study was to examine parents' and healthcare professionals' experiences and perceptions of parental readiness for resuscitation of their child in a pediatric hospital.

Design: This exploratory descriptive qualitative study utilized content analysis. Participants shared their experiences and perceptions about parental readiness for cardiopulmonary resuscitation through semi-structured and in-depth interviews. MAXQDA 2020 software was also used for data analysis.

Setting: The setting was two large teaching pediatric hospitals in Iran (Este Azerbaijan and Mashhad).

Participants: Participants were 10 parents and 13 pediatric healthcare professionals (8 nurses and 5 physicians). Selection criteria were: a) Parents who experienced their child's resuscitation crisis at least 3 months prior and b) Nurses and physicians who were working in emergency rooms or intensive care wards with at least 2 years of experience on the resuscitation team.

Results: Participants shared their experiences about parental readiness for resuscitation of their child in four categories: Awareness (acceptance of resuscitation and its consequences; providing information about the child's current condition and prognosis), Chaos in providing information (defect of responsibility in informing; provide selective protection of information; hardness in obtaining information), Providing situational information (honest information on the border of hope and hopeless; providing information with apathy; providing information as Individual; dualism in blaming; assurance to parents; presence of parents to better understand the child's situation), and Psychological and spiritual requirements (reliance on supernatural power; need for access to a psychologist; sharing emotions; collecting mementos).

Conclusion: The results of this study provide insight on the needs of parents and strategies to use to prepare them for their child's resuscitation crisis, which can be used to enhance family-centered care practices in pediatric acute care settings.

Keywords: Readiness, Parents, Resuscitation, Pediatrics

Strengths and limitations of this study

- Participants of this study included both parents and healthcare professionals in order to enhance the rigor of the study.
- The healthcare professional participants were nurses and physicians working on resuscitation teams in large pediatric hospitals.
- Sampling of parents from large pediatric hospitals was conducted to achieve a sample of parent participants from large cities as well as surrounding towns or villages with different cultures.
- The children of the parent participants were all 5 years of age or younger as older children do not receive care in pediatric hospitals in Iran.
- Most participants were female due to the limited presence of male healthcare professionals and fathers in Iranian pediatric hospitals.

INTRODUCTION

Child resuscitation is a critical time for parents.[1] Pediatric cardiac arrest in children and adolescents occurs at a rate of 2.28 to 8.04 arrests per 100,000 cases/year.[2-4] Annual cardiopulmonary resuscitation rates per age group in most of the countries of the world were: 65.5-72 cases per 100,000 for infants, 3.7 cases per 100,000 for children, and 6.3 cases per 100,000 for adolescents.[2] Pediatric cardiac arrests occurred in 1.5% of the total number of patients under 17 years in Asian countries.[5] In a study in Iran, approximately five percent of patients referred to the emergency department for critical care were under 18 years old.[6] Among resuscitated children, less than 20% survive and are discharged from the hospital.[2 7]

Most Iranian doctors and nurses do not agree with parents being present during their child's cardiopulmonary resuscitation.[8] While, parents' participation in taking care of hospitalized children is considered as an indispensable principle.[9] Especially in wards such as the emergency room where critical care for children is provided, parents are mostly present.[10] When parents are faced with their child being acutely hospitalized, they can suffer from psychological stress, which will also have a negative effect on the treatment results.[11] Anxiety, stress, depression, and post-traumatic stress are some of the psychological problems that parents can face when their child requires resuscitation.[12] In the study of Lisanti et al,[13] mothers in the pediatric intensive care unit had the highest score of stress and anxiety at the time of resuscitation of their child. Parental well-being is essential for the well-being of children with life-threatening illnesses.[14] Therefore, healthcare professionals have a vital role in parental preparedness for resuscitation.[12] In addition to providing specialized clinical care, healthcare professionals should also consider parental support needs at this time,[15] as parental support is one tenet of family-centered care structures that leads to increased quality of care.[16]

Many studies have focused on the presence of parents during resuscitation of their child, but few studies have examined the pre-resuscitation readiness of parents, which is important for identifying measures to help them prepare. In a study, cultural differences affected the attitudes and perceptions of child caregivers.[17] Also, parents need their beliefs, values, customs, and traditions, generally, their cultural and religious practices to be respected;[18] therefore, there is a need for examination of parental readiness among various cultures and countries. This study was conducted in Iran to explore the readiness of parents for cardiopulmonary resuscitation of their child by examining the experiences and perceptions of both parents and health professionals.

METHODS

This study used an exploratory descriptive qualitative approach to examine parents' and healthcare professionals' experiences and perceptions of parental readiness for resuscitation of their child.

Setting and Participants

The setting was two large teaching pediatric hospitals in Iran (Este Azerbaijan and Mashhad). Using purposive sampling, there were 10 parents of 7 children and 13 pediatric healthcare professionals (8 nurses and 5 physicians) who participated in the study. Selection criteria were: a) Parents who experienced their child's resuscitation crisis at least 3 months prior because, after a stressful family event, the symptoms of depression, anxiety, and post-traumatic stress disorder are decreased after 3 months[19] and b) Nurses and physicians who were working in emergency rooms or intensive care wards with at least 2 years of experience on the resuscitation team.

Data collection and analysis

Participants were invited to participate in the study by telephone, and face-to-face individual interviews were conducted from February to November 2020. The parent participants in this study were identified by searching records of hospitalized children for documentation of having received resuscitative care (i.e. cardiopulmonary resuscitation). The first author conducted the tape-recorded, semi-structured, and in-depth individual interviews at the hospitals (for the healthcare professional participants) and at the parents' homes (for the parent participants). Each of the interviews lasted between 45 to 75 minutes. Since these interviews were conducted during the COVID-19 pandemic, precautions were taken (i.e. masking, distancing, etc).

An interview guide was designed to elicit participants' experiences and perceptions of parental readiness for resuscitation. Parent and healthcare professional participants were encouraged to share their experiences about parental preparation needs, how these needs were met, and perceptions of strategies that healthcare professionals can utilize to effectively provide help to parents. Examples of the interview guide questions are available in supplemental Appendix 1. For in-depth understanding of participants' experiences and perceptions, clarification and probing questions were asked after each of the questions in the guide. During the interviews, the term "cardiopulmonary resuscitation" was used with healthcare professional participants (including technical terms such as intubation or chest compressions), but in interviews with parent participants, we used simplified language when explaining terms (for example, “when a tube was inserted in your child's mouth” or “when your child's chest was pushed”) to ensure understanding. Interviews were continued to data saturation,[20] which was confirmed when no new information or codes were uncovered in the last 4 interviews.

Recorded interviews were transcribed verbatim and then analyzed using content analysis according to Bengtsson's proposed steps.[21] First, the text of each interview was read several times. The text was then broken down into meaningful units and coded. MAXQDA 2020 software was also used to encode the data. A list of codes related to all transcribed texts was prepared and each code was identified to which domains it belongs. The codes were also categorized according to their similarities and differences. To increase trustworthiness, this process of data analysis was conducted by two researchers who extracted and then categorized the codes, with each researcher independently coding each interview. The extracted categories and subcategories were then confirmed and agreed upon by the other authors. The peer-checking method was engaged to improve the dependability of the findings, assuring the confirmability of the findings. Participant quotations were selected to enrich understanding of the categories. Participant words were spoken in Persian and then translated to English; therefore, some quotations have been edited to increase clarity and to transmit the meaning of what the participants said when translated to English.

For rigor of the research,[22-24] the experiences and perceptions of different persons involved, both healthcare professionals (physicians and nurses in different categories) and parents (having children with chronic or acute illness, different literacy levels, urban and rural residences, etc.) were examined. These characteristics of participants were collected via a paper-and-pencil survey that was administered before the start of each interview. After the research team performed the analysis, the first author returned the extracted codes of each text to participants for review and approval. Thus, the rigor and credibility of the study were enhanced by checking findings with participants (i.e. member checking).

Ethical considerations

This study was approved by the ethics committee of Tabriz University of Medical Sciences with the ID IR.TBZMED.REC.1398.1080. The objectives and procedures of the study were explained to all participants, including measures to protect confidentiality. Participants' personal information was kept confidential, and their experiences were used in the study without names and details. Informed consent was obtained from participants.

Patient and public involvement

We did not involve parents in the development of the research questions. We did obtain collaboration agreements with two large teaching pediatric hospitals, and approached the hospitals for that purpose. Hospital managers provided positive feedback on the study aims, acknowledging that more research is needed on experiences and perceptions related to the support of parents surrounding resuscitation of their child. They introduced healthcare professionals as potential rich-in-formed participants which could provide important experiences and information for this study. They also provided access to parents for participation in this study. Thus, the hospitals supported recruitment of study participants by sending messages for study participation.

RESULTS

In this study, 13 pediatric healthcare professionals participated; five pediatrician physicians and eight nurses in different categories of practice (from bedside nurse to head nurse) and education (bachelor to master's degree). There were 10 parents of 7 resuscitated children (children aged one to five years; 3 boys and 4 girls) who participated. At the time of the interview with the parents, between 3 and 12 months had passed since the resuscitation. Parents were aged 31 to 48 years, and seven were mothers and three were fathers. Three of the parents had only one child (one child was born after many years of infertility). Two children of two of the parents had no previous history of illness or hospitalization, while the other 5 children had a history of chronic illness. Demographic details of the participants are provided in Table 1.

Table 1. Participants' demographic characteristics.

Parents	n	Healthcare Professionals	n

- Relation to child		- Field of education	
Father	3	Nurse	8
Mother	7	Pediatric physician	5
- Education level		- Gender	
Academic	5	Female	9
Non-academic	5	Male	4
- Location		- Years of experience	
Town	8	< 10	3
Village	2	≥ 10	10
- Number of times experienced their child's resuscitation		- Marital status	
		Married	9
Once	5	Single	4
Twice or more	5	- Parent status	
		Having own child(ren)	9
		No children	4

Participants in this study shared their experiences and perceptions about parents' readiness for resuscitation of their child in four categories: Awareness (acceptance of resuscitation and its consequences; providing information about the child's current condition and prognosis), Chaos in providing information (defect of responsibility in informing; provide selective protection of information; hardness in obtaining information), Providing situational information (honest information on the border of hope and hopeless; providing information with apathy; providing information as Individual; dualism in blaming; assurance to parents; presence of parents to better understand the child's situation), and Psychological and spiritual requirements (reliance on supernatural power; need for access to a psychologist; sharing emotions; collecting mementos).

1. Awareness

Based on the experiences and views of the parents and healthcare professionals, having awareness about their child's condition and health problems was considered to be a parent's right and a necessary component of supporting the parents. There were two sub-categories that emerged in this category of awareness. Supportive quotations are found in Table 2.

1.1: Acceptance of resuscitation and its consequences

Four parents were informed about their child's condition before resuscitation, and this helped the parents better understanded their child's condition and its severity. This action of healthcare professionals was considered a proper and necessary behavior. By informing parents of their child’s condition, parents may feel satisfied with the care of the healthcare team, even after the death of their child.

Both parents and healthcare professionals expressed how having awareness of the child's poor condition before resuscitation helped parents to prepare for the crisis. By having awareness, parents can prepare themselves, psychologically and mentally, that their child is in critical condition, even in acute cases. Having awareness was also felt to help facilitate acceptance of the death of the child and prevent or lessen the shock that can result from the crisis. In this study, informing parents of their child’s condition also provided the opportunity for healthcare professionals to prepare parents to be present in the resuscitation room.

1.2: Providing information about the child's current condition and prognosis

Healthcare professionals’ experiences indicated that in hospitalized children, if parents were informed about their child's condition during hospitalization, they were better prepared for a resuscitation crisis than if the crisis were an unexpected emergency. Even then, it was felt that explanation about the child's prognosis could help parents accept this crisis.

Parents, based on their experiences, also explained that they needed to be constantly informed about their child's condition and the actions that were being taken for him/her during the hospitalization. This was especially important during the time when their child's condition was worsening, and even could occur over the phone. Yet, the words of two mothers revealed they had not been informed of their child’s worsening condition and therefore felt unprepared and experienced emotional distress. Withholding information from parents was confirmed by a doctor who explained that in emergency cases, the situation was often unpredictable and thus parents were not informed of the possibility of resuscitation and the child's death.

To express the possibility of resuscitation and death in hospitalized cases, both parents and healthcare professionals believed that parents should be told about the care interventions that could be used in attempt to save the child’s life. One nurse described how this was explained to parents using words they would understand. Without an understanding of the care being provided, parental stress increased. When expressing the possibility of resuscitation, in addition to making parents aware of resuscitation actions and equipment, it was also deemed important to talk to parents about their desire for and location of presence during resuscitation. However, parents’ behavior often determined whether they had this option and participants indicated that it is common for parents to be directed to leave the resuscitation room.

The experiences of the parents and the healthcare professionals showed that in cases when the possibility of losing the child was told to the parents, the field of parents' bereavement needs was not considered. Parents expressed a need for a private space to be with their deceased child and release their emotions. Yet, a father and a mother recalled not having a private space or time to mourn after the death of their children.

Table 2. Awareness

1.1: Acceptance of resuscitation and its consequences	"Thanks to all of them [healthcare professionals]. They did everything that they could. Well, I knew my child's problem, nothing could be done for her." F7 "A child was brought to the emergency room with severe dehydration. The child's parents brought the child to the hospital too late from fear of Corona, so that the child was in a state of shock. I fully explained to the parents about the bad condition of the child, that the child was breathing with the device and his heart was working with the injected drugs. I fully informed them about the bad condition of the child. The child died in the ICU that night, but when the parents were informed, I felt the shock did not happen in these parents the same as for other parents. It seemed to me that they accepted it more easily ... " D8 "... Because we had already been told that our child might die, his mother and me decided to donate his corpse to the University of Medical Sciences if he died." F1

	"Since I was told the truth, I realized that if my child survives, it might not be good for her either. Because I was told the truth and I understood the truth, I was satisfied that if my child were to die, she would not suffer." F7
1.2: Providing information about the child's current condition and prognosis	"A child was hospitalized and intubated for a long time. The parents witnessed our actions. The parents were informed of the child's condition and prognosis during this time. They thanked us after their child died, even while they were in a bad mood." N2 "Because I was already told that her condition was not good and she [his child] was very ill, I had background about resuscitation of my child." F7 "My daughter was hospitalized about 6 months, but I was not told that my child was getting worse. I thought everything was well and I was not at all ready that my child was getting worse, and I did not expect her death at all." M4 "When there was a possibility of resuscitation, I would give the parents full information about their child's condition. I was telling them that your child might need us to squeeze her chest or, like this child, insert a breathing tube so that the device could help your child breathe." N4 "I did not know what they were doing and why. I was dying and living every moment." M9 "We say that the child is in critical condition, but we have never said that he/she may need resuscitation or the child may die because the child is brought to the emergency room at once, and we do not know exactly what the problem is and the situation is not predictable ..." D9 "If parents were not agitated and could control their emotions and did not disrupt the resuscitation process, I was telling them that they could be in the room. Otherwise, they would be directed out of the room or they could watch the resuscitation from the window of the room." N10 "In any hospital, it's much better if there is a private place at this moment [after the failed resuscitation of the child] so parents can release themselves. If there is such the place, no one told me anything before." F1 "Immediately after the resuscitation, they took my child to the mortuary and did not let me say goodbye to my daughter and see her for the last time. I was also told not to make noise and cry because other mothers were in the ward and they might scare. I was running to the mortuary looking for my child's corpse. Unfortunately, there were no facilities for us. At least others should lose their children in a calm situation." M9

D=doctor, N=nurse, F=father, M=mother

2. Chaos in providing information

The experiences of parents and healthcare professionals indicated that there was no specific process for providing information, as demonstrated in three sub-categories. Supportive quotations are found in Table 3.

2.1: Defect of responsibility in informing

The parents in this study wanted doctors and nurses to be available to provide information. But, they most preferred to receive information from a doctor who was responsible for their child and aware of their condition. Yet, in this study, participants' words demonstrated there was defect of responsibility to provide information to parents. Doctors considered it their duty to provide information to parents, but nurses discussed doctors' irresponsibility in informing the parents about their child's condition. Although nurses considered providing diagnostic information to be duty of doctors, they felt discussing care information is their duty. At the same time, nurses were confused about providing information and responding to the parents, feeling uneasy because they were more in touch with parents and were asked to provide them with information.

2.2: Provide selective protection of information

In the culture of the participants in the study, there was withholding of information and information was transferred from healthcare professionals to parents selectively and protectively. Parents in this study tended to realize the condition of their child without actually having been provided such information from the healthcare team, and there were instances where the healthcare professionals withheld information to help protect the parents. Three healthcare professionals preferred to give information about the child's poor condition to relatives or close friends rather than the parents, and then these individuals then transferred the information to the parents. This was described as an effort to protect the parents who were already having to deal with their emotions.

When healthcare professional participants did provide information to parents, they expressed a desire to provide unpleasant information about the child to the father rather than the mother. One doctor explained that this was due to fathers typically behaving more calmly. However, the healthcare professionals did not ensure the transfer of this information from father to the mother, and the desire of fathers to protect the mother was also evident. This withholding of information resulted in two of the mothers not having awareness and readiness for their child's crisis. This led one father to express regret over withholding information about his child's situation from his spouse.

2.3: Hardness in obtaining information

The experiences of most of the parents showed that information about their child's condition was obtained with difficulty, consuming their time, and that doctors especially spent little time providing parents with information. Participating parents in the study wanted to receive information from doctors at their child's bedside, yet their stories indicated this did not occur.

Table 3. Chaos in providing information

2.1: Defect of responsibility in informing	"If the doctor gives information, it is better because the parents trust the doctors more. Now, if there is no doctor [available], the nurses will be next. It is better for a male doctor to talk to the father because the father accepts more easily than if a woman doctor, especially when she is young. But it also depends on how the doctor is expressing. Even if she is a woman or young, it depends on how she speaks so that she can convince the father." D9 "The doctor and head nurse of ward were telling us not to talk to the parents about their child. I personally do not know what to say when parents ask. Because the doctor is only there for one hour in the ward every day. When we do not respond to parents, they think we know nothing and lose confidence in us and our care of their child." N2
2.2: Provide selective protection of information	"In one case, a child was brought to the hospital and the child did not have a specific illness before. The parents were agitated and very anxious. I talked to the child's uncle about the child's poor condition and what had happened." N4 "I prefer to give bad news to the father so that he tells the mother. Fathers usually act more logically." D8 "I knew my child's problem at that time. I realized she was dying and it was good. Therefore, I could say goodbye to my baby at the last moment. But I wish I told her mother, so she was ready too." F7
2.3: Hardness in obtaining information	"If we wanted to be told about our child's illness, we had to run to the doctor in the hospital corridors, but we could not see him. Everyone was around. We had to go to the office of the doctor. Well, I was foreign in this city, I had to request a taxi to take me to the doctor's office. After difficulty finding it, I had to pay a visit to the doctor to have my baby's condition explained for a few minutes, otherwise, they [doctors] would not answer us." M9

D=doctor, N=nurse, F=father, M=mother

3. Providing situational information

The experiences and perceptions of parents and healthcare professionals revealed that providing information to parents should be done according to the situation of the child and in consideration of parental condition. Six sub-categories were approved in this category. Supportive quotations are found in Table 4.

3.1: Honest information on the border of hope and hopeless

Healthcare professionals and parents emphasized the importance of honest and truthful information. The healthcare professionals in this study had experienced situations where there was incorrect information relayed to parents and felt this can result in mistrust among parents. Also, some of the participating parents' experiences indicated they had received untrue information, and this seemed to make them unprepared for the crisis ahead.

Next, the healthcare professionals explained how when they provided honest information for parents, they worked to provide information that was on the border of hope and hopeless. The experiences of parents in this regard showed that most fathers did not have nor want false hope, while most mothers didn’t want all hope removed when being provided information about their child's condition.

3.2: Providing information with apathy

Parents emphasized the importance of receiving information from the treatment team in a kind, compassionate, and respectful manner. Two parents appreciated the kind words used by healthcare professionals. But, most parents indicated that healthcare professionals could not comprehend their mental state when providing information to them and they provided information about their child's situation with apathy and without empathy. The lack of empathy of both doctors and nurses was recalled. One father expressed his dissatisfaction with the way a doctor coldly provided information to his wife, while a mother whose baby was in critical condition immediately after delivery explained receiving unempathetic care from nurses.

3.3: Providing information as Individual

The experiences of both parents and healthcare professionals indicated that it is not possible to use the same method of providing information to all parents. It depended on the parents' level of understanding, education, age, language, whether the parents have only the one child, if the child has been hospitalized before, and whether the child's illness is acute or chronic. Their experiences showed that for low-education parents, it can be helpful to provide information in simpler, brief, and tangible ways. For higher-education parents, this information could be provided more scientifically and completely. Statements from two fathers with different levels of education confirmed different needs in regard to explanations.

The experiences of parents and healthcare professionals also showed that the speed of transmitting information to parents was important, especially when providing information to mothers. It was also felt necessary to be more sensitive when providing information to parents with a single child or golden baby (born after years of infertility issues and treatment) as this child might be the foundation of the family.

Healthcare professionals' experiences also indicated that older parents can be more receptive and have a better understanding of information than younger parents, and that sometimes the grandparents were the decision-makers in such families. Linguistic differences in multilingual countries also were felt to make it difficult for healthcare professionals to provide information to parents. In this regard, a doctor described seeking translation services to help provide information to parents.

The healthcare professionals in this study felt it is easier to provide information to parents with a child who has a chronic illness or has been hospitalized for at least a few days rather than in an acute emergency situation because unexpected crises can result in parents being agitated and the high stress prevents them from understanding the information. In these instances, nurse and doctor participants tried to speak calmly and repeat information to help ensure understanding.

3.4: Dualism in blaming

Four of the five doctors' experiences showed they felt that when parents were blamed, this can prevent the doctors themselves from being blamed and prevents future complaints. Yet, when parents were blamed for the situation of their child, their experiences revealed this may result in great remorse and grief. Other healthcare professionals acted differently and believed that even if parents may be to blame for the situation of their child, healthcare professionals should not blame them. These healthcare professionals felt that if they were unable to release their pain, they at least needed to make sure they did not add any additional pain to parents.

3.5: Assurance to parents

The experiences of healthcare professionals and parents revealed that in order to prepare parents for the crisis ahead, the transfer of information must be accompanied by efforts to facilitate trust. This was felt to be important so that both in practice and in speech, parents could be assured that everything necessary for the child would be done. To best ensure trust, it was felt that healthcare professionals should coordinate the providing of information and there should be no inconsistencies in the information. Also, healthcare professionals in this study explained the need to avoid accusing their colleagues when providing information to parents because this can contribute to insecurity in the parents.

3.6: Presence of parents to better understand the child's situation

Providing information through verbal speech was felt to not always be enough. Instead, it can be necessary to improve understanding of the child's situation by having parents be present to witness their condition and care. The experiences of both parent and healthcare professional participants showed that parents who were with their child during the child's hospitalization, especially in the last moments of the child's illness, better understood their child's illness and how severe it was. It was felt that parents who were present were better prepared to face the crisis than parents who were not present. In addition to helping them prepare, a mother described how being present provided comfort through being able to say goodbye to her child.

Table 4. Providing situational information

3.1: Honest information on the border of hope and hopeless	"In the first days, everyone [healthcare providers] told us that my child was fine, then suddenly he died and they said that his heart was stopped. I said that you said it was good, but now what happened..." M5 "We have to talk between the border of hope and hopeless. We have to say the positives and the negatives of the points. We should not be too hopeful and not too disappointed …" N1 "Do not provide false information and tell the truth. For example, my child had a seizure. They [healthcare professionals] should not say do not worry, it was nothing. I knew my child had a problem." F7 "I knew my child was not well, but I did not like to be constantly disappointed. I was afraid to call the ward because I was afraid that they [nurses] would say that my child was very ill, or I would enter the ward in fear." M2
3.2: Providing information with apathy	"One of them [a doctor] said very badly to his mother [the participant's wife] that this child of yours is like this, you have to get used to her [child]. If you can't hold her, take her to Welfare." F7 "I had so much pain, but I did not think about myself. I was anxiously requesting information about my baby's condition, and I was constantly asking what happened to my child? Do not let him get cold. They [nurses] said that we know our work, please do not interfere." M5
3.3: Providing information as Individual	"... I have not studied medicine to know. If they had given me this information in simple language so that I could understand it, it would have been very good. I did not understand what they [healthcare professionals] told me." F7 "We really needed someone to explain my child's situation to me. Well, I was somewhat familiar with English terms. If someone explained it to me, I would understand because I am also a language teacher and translator." F3 "When I was at the beginning of my career, I was talking with a father using scientific terms about his child's condition. I had not finished my explanation yet; I saw he was angry and said 'Do you make fun of me?' …" D13 "... Slowly with the introduction, perhaps our audience [the mother herself] might not be strong enough to endure. When one of the nurses was providing bad information about my child, in the middle of her conversation, I did not understand what happened to me, as the world was ruined on me ... When I opened my eyes, I saw the doctor and the nurses and my husband around me…" M4 "Young parents have no responsibility at all and do not seem to understand or care about it at all. These parents are not the decision-makers themselves, and the grandparents are the decision-makers." N2 "Linguistic differences may make it difficult to explain. For example, the language of parents may be Kurdish and they do not know Persian. In these cases, we look for personnel who are at least fluent in the parent language and try to provide information to parents through them." D9 "Families who come to the emergency room frequently ask questions. I can't completely answer their questions and need to repeat the information because they are so anxious, and they can't understand." N5 "A person should speak to them [parents] calmly, respectfully, and in their own language. But often it does not work. When parents are very agitated, I go forward to talk to them, but

	I see that it gets worse, and they are aggressive and told me 'What are you doing? You go and do your work.'" D8
3.4: Dualism in blaming	"I asked the doctors: 'Could the flu kill a healthy child in a week because my daughter didn't have a problem before?' They said it was probably because your daughter didn't feed on your breast milk and you fed her with dry milk and you gave birth to her by cesarean section .... [The mother did not continue, she sighed and then cried]" M6 "I tried to make sure she [the mother] didn't feel guilty. I said to her that she wasn't the only person who experienced the accident and it could happen to anybody" N1
3.5: Assurance to parents	"The opinion of the doctor who spoke to us was that they [other doctors] should not operate at all: 'They took your child to the operating room to look for where the problem was. What do you expect from a one-and-a-half-kilogram child?'" M10 "Before, in the emergency room, everyone was talking to the parents [nurse, intern, resident, etc.]. Everyone was asking the parents what happened and why did you bring the child to the emergency room? Also, parents' questions were answered in different ways, and it caused the parents to become agitated. But since we managed this situation, the pediatrician or senior resident is in the emergency room, and this has reassured the parents that there is someone who can manage the team." D12
3.6: Presence of parents to better understand the child's situation	"A child was hospitalized. His parents were not present at the bedside of the child. When I saw that the child was getting worse, I called his parents to come to see their child. I think this caused the parents to have readiness for the resuscitation crisis of their child" N2 "I was always in the hospital with my child. Before she died, the nurse called me and said, 'Your child is in critical condition and her blood pressure is constantly dropping. She is not well at all.' It was good to be able to be with her at the last moment and say goodbye to her." M6

D=doctor, N=nurse, F=father, M=mother

4. Psychological and spiritual requirements

The experiences of parents and healthcare professionals revealed that parents also need mental and spiritual preparation for facing the terrible crisis of their child's resuscitation. Four sub-categories emerged. Supportive quotations are found in Table 5.

4.1: Reliance on supernatural power

Parent and healthcare professional participants' words indicated that most parents needed to rely on supernatural powers, other than medical science, when they were faced with critical situations. In this time, reminding parents of the will and trust in God and providing access to holy text, chaplains, and even a place to pray can be soothing to them. The helpfulness of being reminded of the importance of religion and faith was brought up by both mothers and fathers.

4.2: Need for access to a psychologist

The experiences of parents and healthcare professionals indicated that parents needed to have access to a psychologist (or other mental health specialists) to help prepare them for these critical situations, especially when a child is likely to not survive. Participating parents wanted a psychologist to be present by their side during their child's critical situation so that they could consult with them. One mother described how the staff was helpful, but she felt that it would be more helpful to also have a psychologist to talk to. Most parents also felt that all staff working in a children's hospital should have completed psychology courses that prepare them to treat parents in critical situations appropriately, with a specific need to know how to give bad information to parents.

4.3: Sharing emotions

According to both parents and healthcare professionals, it is important for parents to be able to share their feelings and emotions with others when they are in a critical psychological state. Parents expressed a need to be understood during their critical situation and supported by those around them. It was important to parents that staff understand their situation.

Parents in this study also needed to be accompanied by family or relatives, especially their spouse. All of the mothers who had their husbands at their side during their child's resuscitation said that their husband's presence had helped them to cope and provided calm for them. But a mother who was alone during her child's illness in the intensive care unit described her experience as stressful and wished she had someone there with her. The experiences of the healthcare professional participants also revealed that the presence of other family members or other companions, especially in emergencies where both parents are in shock, can be a supportive force and may better prepare parents in the face of the crisis. A nurse described speaking to family members over the phone, emphasizing the need to come to provide companionship at the hospital.

4.4: Collecting mementos

Parent participants expressed the need to communicate internally with their child after they died during resuscitation. Having mementos of the child can be an effective way to maintain this relationship. Healthcare professionals can assist parents to collect mementos of their child before the resuscitation. In this regard, a mother who was not given any mementos of her child explained how she longed for them and wished the staff had given them to her.

Table 5. Psychological and spiritual requirements

4.1: Reliance on supernatural power	"My daughter had no problems before, and she was admitted to the ICU because she had the flu. Her condition was getting worse every day. I was very impatient. One of the staff told me: 'God created us and all of us will die one day. The fate of everyone has been decided by God in some way. Trust in God.' And she relieved me in this way." M6 "While we were waiting in the back of the operating room, one person told me to repeat the holy phrase. I wondered why I should repeat it only ten times. At that time, I needed to consult with an informed person. I needed to be alone with my God in a quiet place and pray and read the Quran." F3
4.2: Need for access to a psychologist	"I think it would be better if a psychologist was with the mothers in the ICU and talked to them calmly. She/He could provide consolation support for them. It is true that all the staff treated me well. But if there was a staff that was with the mothers and talked to them for a few hours, I think it is better. A psychologist can better prepare mothers for the fact that they are losing their baby so that they can pass this period more easily." M6 "What's wrong that a doctor or a nurse knows about psychology or a businessman knows about management? Being multi-disciplined makes us complete in one discipline but all of us are educated only in one special field. For example, according to the body of a person, we let him be a guard, and we do not care at all how literate this person is, does he know how to treat others or not?" F3
4.3: Sharing emotions	"A nurse came and told me and said, 'I am mother too and understand you. Many of these things have happened here [in the ICU], and it has happened to many families that their child was in a critical situation. I know it is very difficult, but you have to endure.' It was good that she was telling me." M2 "... I just had stress, no one was there, my husband couldn't come. I wish someone was with me." M9 "When a child is ill and there is a possibility of resuscitation for him/her, I call the parents to come and I emphasize that the mother should not be alone and come with her husband or a companion. If I know a supporter, relatives, or friends of the parents, I will call them to come and be with the parents." N2
4.4: Collecting mementos	"I still miss her. I still see her photos and hear her voice." M6 "... They [staff] didn't give me the things that I had put on her bedside. I had put a comb for her and brushed her hair with it. They [staff] didn't give me it to keep a few of her hair for myself. Her bottle of milk or the things I put there, they give me any of them. My baby was touching them. I wanted to keep them to myself." M9

D=doctor, N=nurse, F=father, M=mother

Discussion

In this study, parents and healthcare professionals shared their experiences and perceptions of pre-resuscitation parental preparation. Parents' preparation before the resuscitation of their child was divided into four categories: Awareness, Chaos in providing information, Providing situational information, and Psychological and spiritual requirements.

The results revealed that facilitating parents' understanding of the child's condition and readying them for the resuscitation of their child may help to prevent or lessen the shock of the crisis. This result is consistent with other studies in which all parents, without exception, emphasized the importance of knowing what is happening to their child, and helping them to understand was felt to be an essential support need.[14 25] In another study, having information about the child's condition provided parents with the ability to better adapt and accept the child's death.[25 26] Also, findings from Chen et al[27] confirmed results of this study showing that transmitting truthful information promotes trust and gives emotional support to parents, enhancing their readiness for resuscitation. Another study also confirmed the finding that having information about the child's condition can help parents maintain a sense of control, so they can better manage the situation.[28] Based on this current study's findings, giving information about the child's condition and even telling of the possibility for resuscitation and death is better done continuously during the child's hospitalization, especially as the child is deteriorating. This is consistent with another study that found that parents of children with chronic illness who were informed of the possible death of their child several months prior but then did not receive information updates and normalization were not be prepared for the stage of health deterioration and death.[29]

In this study, the doctors considered it their duty to provide information to parents; however, this did not always occur. While diagnostic information was provided by doctors and care information was provided by nurses, nurses in this study expressed frustration over the parents not being told of their child's condition. This finding is consistent with other recent studies in which parents recalled a lack of received information from healthcare professionals and they desired to receive information about what is or likely will be happening with their child.[1 30] In one of the studies, parents did not recall receiving clinical information before their child's resuscitation, and reported waiting hours to talk to a healthcare provider.[1] These findings contradict those of Kim et al[31] who found that physicians and nurses believed that providing information is one of their roles in supporting parents. A worrisome finding in our study is that when several of the parents did receive information from doctors and nurses, it was not delivered in a kind or empathetic manner. Most parent participants believed that healthcare professionals should receive training about delivering bad news, and that when they received bad information about their child, the presence of a psychologist (or other mental health specialists) could be helpful in preparing them for their child's critical situation.

In some cultures, such as the culture of the participants in this study, a selective protection of information is observed in order to protect the parents from stress and anxiety. In this instance, information is given to the relatives of the parents who can then transmit the information. Many other cultures, such as in China and South Africa, also believe in withholding information about the disease from the patient as a means of protecting them.[32-34] In this study, three of the healthcare professionals preferred to give bad information about the child to the person accompanying the parents (such as another relative). In the absence of accompanying persons, they provided this information to the father, and a refusal to provide bad information to the mother was expressed. However, it is possible that information is then not transmitted from father to mother, and this may result in the mother not being ready to face the crisis. In one study, this withholding of information led to the loss of the opportunity for a last farewell to loved ones.[34] Further, providing information to persons other than parents also can create a challenge related to information confidentiality. This may in turn jeopardize the respect, honesty, and human value that is the principle of autonomy.[35 36] We found that the issue of confidentiality of information was important for the parents under study, especially those from rural villages because all persons are known to one another in their small communities.

Providing bad news to parents to prepare them for a resuscitation crisis may be better handled in a unique manner, meaning that it depends on the condition of the child and parents and the events surrounding the resuscitation. Truth telling is as a right and medical requirement;[35] however, when designing his model, Nierengarten said that while a doctor's honesty is a necessity, like all areas of medicine and life, nothing is certain.[37] Preferences and values about access to and receipt of information also influence how healthcare professionals give information to parents. It has been shown that some people do not want to hear some information, especially information that has a negative element in it,[33 38] parents need to be neither completely hopeful nor completely hopeless when receiving information,[1] and preparation for receiving medical information should be considered because sometimes expressing this information may harm the mental health of the person.[33 39] These findings are consistent with those of this study. In light of this, healthcare professionals should use appropriate language when providing information.[40 41] Providing information to parents at a high speed[34 38] and not providing understandable information to parents[33 41] could result in lack of proper information processing, especially in unexpected emergency situations. This was again consistent with the experiences and perceptions of parents and healthcare professionals in this study. Therefore, when providing information to parents, healthcare professionals can consider if the quantity and quality of information are appropriate for individual parents and the situation at hand.

Facilitating parents' trust in the received information is important. In this regard, findings in this study were consistent with other studies that show trust can be accomplished by coordinating the provision of information from different treatment team members,[42] ensuring parents that we have done all we can,[38] and relaying bad news in an empathetic and compassionate way.[30 42 43] Although most of the healthcare professionals in this study did not blame parents when providing information, most of the participating doctors had different opinions. Their words about placing blame on parents contradicts findings of other studies.[17 44] According to participants in this study, these are considered professional and helpful behaviors of healthcare professionals. Also, findings from Bogetz et al[29] and Bekkering et al[30] support the results of this study that suggest healthcare professionals can support parents by providing them information at their child's bedside in order to magnify their understanding, especially when the child is very ill and near the last moments of her/his life. Participants in the current study also felt that parents being present during their child's hospitalization promoted better understanding and acceptance of the resuscitation crisis, even with acute problems and no previous history of illness.

The psychological and spiritual needs of parents are important for healthcare professionals to consider when preparing parents for the upcoming crisis. The results of this study indicate parent participants preferred to have access to a psychologist and a chaplain, as well as the presence of their spouse and other relatives or friends. This can help ensure parents have support for the crisis ahead. These findings are consistent with those of Kim et al[31] who found that nurses considered the provision of consolation, empathy, emotional support, and religious support to parents as their role in end-of-life care, and they informed parents about the availability of religious services and clergy visits. Also, they allowed family visits, for example grandparents, which was outside of the policy but was something they considered to be part of their role. Of course, the beliefs and desires of parents must be considered when attempting to meet their spiritual needs. In this study, the expression of God's will by a healthcare professional was not acceptable to one of the parents, while most parents considered it to provide consolation and relief.

Strengths and limitations

Participants of this study included both parents and healthcare professionals in order to gain a more comprehensive perspective on parental readiness for resuscitation of their child. The study provides insight about parents' and healthcare professionals' experiences and perceptions of pre-resuscitation readiness of parents, which is important for identifying strategies to help them prepare. Cultural considerations emerged when examining the experiences and perceptions of healthcare professionals who work in large hospitals in two major cities in Iran.

This study, like other qualitative studies, has limitations affecting generalizability. One limitation is selection bias, and those who had strong views about parental readiness may have opted to participate. Next, this study enrolled participants from one geographic area and it should be repeated in other locations with different cultures and religions. We examined the experiences and perceptions of healthcare professionals working in large hospitals in two major cities in Iran, and also selected parents who were referred to these centers. The participants may have different experiences and views than those working in or referred to small medical centers. However, this limitation is minimized because small towns and rural communities frequently refer to the public hospitals in these cities and 50% of the parent participants were from surrounding towns or villages. We also examined the experiences and perceptions of one male nurse and 3 fathers because in Iranian pediatric hospitals, most nurses are female. Based on Iranian context, mothers are the main caregivers of their children and hospital regulations do not allow fathers to stay at the hospital for their child's care and they can only meet their child and wife for a short time (except in emergency situations) because most of healthcare staff in the pediatric hospitals are women. Another limitation is that the children of the parents in this study were all 5 years of age or younger, and it is possible that parental needs differ if the children are older. In Iran, older children and adolescents are usually hospitalized in an adult hospital. Despite the limitations of this study, the findings are important to stimulate additional research to lead to the creation of guidelines or protocols for preparing parents for their child's resuscitation as the healthcare professional participants stated no such tool exists in their workplace, and having this guidance would help them better support parents.

CONCLUSION

This study provides insight on parental needs prior to pediatric cardiopulmonary resuscitation, as well as strategies that may help ready parents for their child's resuscitation crisis. Findings can be used to promote family-centered care in pediatric critical care and emergency settings. The results of this study suggest that to prepare parents for resuscitation, it is important to continuously provide information about the child's condition, with a need to consider the parents' culture, ensure confidentiality of information, and spend enough time with the parents. This information should be provided to parents empathetically and without blame, honestly yet in a way that helps balances hope and hopelessness, and in a unique and individual manner that considers the child's situation and parents' needs. It can be helpful to provide this information while parents are present at the child's bedside, especially when the child is very ill. Psychological and spiritual needs should also be considered to help prepare parents for their child's resuscitation and potential death. The results of this study indicate that parents need attention to promote their readiness to face this stressful event, and that each of the healthcare professional participants acted according to their experiences/preferences without access to instructions and protocols in this regard. Thus, there is a need for more research on parental readiness for resuscitation so effective protocols can be developed. Further, future research should examine parental readiness among various cultures, as parent needs may differ.

Contributors

AG and HH conceptualized the study, in consultation with MAB and HNA. AG collected the data, conducted the first level of analysis, and prepared the first draft of the manuscript. HH, MAB, HNA, and MH contributed to the study design and data analysis of the manuscript. HH and KP led and revised the manuscript writing. All authors reviewed and revised the manuscript. HH acts as a guarantor for the manuscript.

Funding

This research received no specific grant from any funding agency in the public, commercial or not-for-profit sectors.

Competing interests

None.

Patient consent

Obtained.

Data sharing statement

Not applicable

Acknowledgments

We thank the patient advisers in pediatric hospitals of Este Azerbaijan and Mashhad.

REFERENCES

1. Stewart SA. Parents' experience during a child's resuscitation: Getting through it. *J Pediatr Nurs* 2019;47:58–67.
2. Shimoda-Sakano TM, Schvartsman C, Reis AG. Epidemiology of pediatric cardiopulmonary resuscitation. *Jornal de pediatria* 2020;96:409–21.
3. Atkins DL. Cardiac arrest in children and young adults: we are making progress. *Circulation* 2012;126:1325–7.
4. Meyer L, Stubbs B, Fahrenbruch C, *et al*. Incidence, causes, and survival trends from cardiovascular-related sudden cardiac arrest in children and young adults 0 to 35 years of age: a 30-year review. *Circulation* 2012;126:1363–72.
5. Tham LP, Wah W, Phillips R, *et al.* Epidemiology and outcome of paediatric out-of-hospital cardiac arrests: A paediatric sub-study of the Pan-Asian resuscitation outcomes study (PAROS). *Resuscitation* 2018;125:111–7.
6. Majidi A, Mahmoodi S, Adineh VH. An Epidemiologic Study of Emergency Department Visits before and after Executing Health Sector Evolution Plan; a Brief Report. *Iran Emerg Med J* 2017;4:130–4.
7. Loaec M, Himebauch AS, Kilbaugh TJ, *et al.* Pediatric cardiopulmonary resuscitation quality during intra-hospital transport. *Resuscitation* 2020;152:123–30.

8. Kianmehr N, Mofidi M, Rahmani H, *et al.* The attitudes of team members towards family presence during hospital-based CPR: A study based in the Muslim setting of four Iranian teaching hospitals. *J R Coll Physicians Edinb* 2010;40:4–8.

9. Vasli P, Salsali M. Parents' participation in taking care of hospitalized children: A concept analysis with hybrid model. *Iran J Nurs Midwifery Res* 2014;19:139–44.

10. Toomey SL, Elliott MN, Zaslavsky AM, *et al.* Variation in Family Experience of Pediatric Inpatient Care As Measured by Child HCAHPS. *Pediatrics* 2017;139:e20163372.

11. Doupnik SK, Hill D, Palakshappa D, *et al.* Parent Coping Support Interventions During Acute Pediatric Hospitalizations: A Meta-Analysis. *Pediatrics* 2017;140:e20164171.

12. Davidson JE, Aslakson RA, Long AC, *et al.* Guidelines for Family-Centered Care in the Neonatal, Pediatric, and Adult ICU. *Crit Care Med* 2017;45:103–28.

13. Lisanti AJ, Allen LR, Kelly L, *et al.* Maternal Stress and Anxiety in the Pediatric Cardiac Intensive Care Unit. *Am J Crit Care* 2017;26:118–25.

14. Koch K, Jones B. Supporting Parent Caregivers of Children with Life-Limiting Illness. *Children* 2018;5:85.

15. Foster M, Whitehead L, Maybee P. The Parents', Hospitalized Child's, and Health Care Providers' Perceptions and Experiences of Family-Centered Care Within a Pediatric Critical Care Setting: A Synthesis of Quantitative Research. *J Fam Nurs* 2016;22:6–73.

16. Rostami F, Hassan ST, Yaghmai F, *et al.* Effects of family-centered care on the satisfaction of parents of children hospitalized in pediatric wards in a pediatric ward in Chaloos in 2012. *Electron Physician* 2015;7:1078–84.

17. Jones CHD, Ward A, Hodkinson PW, *et al.* Caregivers ' Experiences of Pathways to Care for Seriously Ill Children in Cape Town , South Africa : A Qualitative Investigation. *PLoS One* 2016;11:1–15.

18. Meert KL, Briller SH, Schim SM, *et al.* Examining the needs of bereaved parents in the pediatric intensive care unit: A qualitative study. *Death studies* 2009;33(8):712-40.

19. Curtis JR, Treece PD, Nielsen EL, *et al.* Randomized trial of communication facilitators to reduce family distress and intensity of end-of-life care. *Am J Respir Crit Care Med* 2016;193:154–62.

20. Saunders B, Sim J, Kingstone T, *et al.* Saturation in qualitative research : exploring its conceptualization and operationalization. *Qual Quant* 2018;52:1893–907.

21. Bengtsson M. How to plan and perform a qualitative study using content analysis. *NursingPlus Open* 2016;2:8–14.

22. Hays DG, Wood C, Dahl H, *et al.* Methodological Rigor in Journal of Counseling & Development Qualitative Research Articles: A 15-Year Review. *J Couns Dev* 2016;94:172–83.

23. Cypress BS. Rigor or Reliability and Validity in Qualitative Research : Perspectives , Strategies , Reconceptualization , and Recommendations. *Dimens Crit Care Nurs* 2017;36:253–63.

24. Nowell B, Albrecht K. A Reviewer's Guide to Qualitative Rigor. *J Public Adm Res* Theory 2019;29:348–63.

25. Doumit M, Rahi AC, Saab R, *et al.* Spirituality among parents of children with cancer in a

Middle Eastern country. *Eur J Oncol Nurs* 2019;39:21–7.

26. Currie ER, Christian BJ, Hinds PS, *et al.* Parent Perspectives of Neonatal Intensive Care at the End-of-Life. *J Pediatr Nurs* 2016;31:478–89.

27. Chen C-H, Cheng Y-H, Fen-JuChen, *et al.* Association Between the Communication Skills of Physicians and the Signing of Do-Not-Resuscitate Consent for Terminally Ill Patients in Emergency Rooms (Cross-Sectional Study). *Risk Manag Healthc Policy* 2019;12:307–14.

28. Hummelinck A, Pollock K. Parents' information needs about the treatment of their chronically ill child: A qualitative study. *Patient Educ Couns* 2006;62:228–34.

29. Bogetz JF, Revette A, Rosenberg AR, *et al.* "I Could Never Prepare for Something Like the Death of My Own Child": Parental Perspectives on Preparedness at End of Life for Children With Complex Chronic Conditions. *J Pain Symptom Manage* 2020;60:1154–62.

30. Bekkering H, Woodgate R. The Parental Experience of Unexpectedly Losing a Child In the Pediatric Emergency Departmen. *OMEGA-Journal of Death and Dying* 2021;84:28-50.

31. Kim S, Savage TA, Song M-K, *et al.* Nurses' roles and challenges in providing end-of-life care in neonatal intensive care units in South Korea. *Appl Nurs Res* 2019;1:151204.

32. Fan Z, Chen L, Meng L, *et al.* Preference of cancer patients and family members regarding delivery of bad news and differences in clinical practice among medical staff. *Supportive Care in Cancer* 2019;27:583-9.

33. Athanas R, Gasto F, Renatha SJ. Factors influencing truth-telling by healthcare providers

to terminally ill cancer patients at ocean road cancer institute in dar-es-salaam, tanzania. *South African Journal of Bioethics and Law* 2020;13:108-13.

34. Ibañez-Masero O, Carmona-Rega IM, Ruiz-Fernández MD, *et al.* Communicating health information at the end of life: The caregivers' perspectives. *Int J Environ Res Public Health* 2019;16:2469–80.

35. Twinomujuni J. *Truth telling beyond borders: an African perspective for the degree of Doctor of Philosophy*. Duquesne University, 2017.

36. Hanssen I. From human ability to ethical principle: an intercultural perspective on autonomy. Medicine, *Health Care and Philosophy* 2005;7:269-79.

37. Nierengarten MB. Pediatric truth-telling Omission vs deception. *Contemp Pediatr* 2019;36:24–33.

38. Lantos JD. Tell parents the truth, but tell it slant. *Pediatrics* 2018;142:S199-204.

39. Ewuoso C. Models for truth-telling in physician-patient encounters: what can we learn from Yoruba concept of Ooto? *Dev World Bioeth* 2019;19:3–8.

40. Kaye EC, Snaman J, Johnson L, *et al.* Communication with children with cancer and their families throughout the illness journey and at the end of life. *InPalliative Care Pediatr Oncol* 2018;55–93.

41. Suurmond J, Lieveld A, Van de Wetering M, Schouten-van Meeteren AYN. Towards culturally competent paediatric oncology care. A qualitative study from the perspective of care providers. *Eur J Cancer Care* 2017;26:e12680.

42. Blazin LJ, Cecchini C, Habashy C, *et al.* Communicating effectively in pediatric cancer

care: translating evidence into practice. *Children* 2018;5:40–56.

43. Muskat B, Greenblatt A, Anthony S, *et al.* The experiences of physicians, nurses, and social workers providing end-of-life care in a pediatric acute-care hospital. *Death Stud* 2019;105-116.

44. Meert KL, Templin TN, Michelson KN, *et al.* The Bereaved Parent Needs Assessment: A new instrument to assess the needs of parents whose children died in the pediatric intensive care unit. *Crit Care Med* 2012;40:1–18.

Supplemental appendix 1: Interview guide questions asked of parents and healthcare professionals.

Parents	**Healthcare professionals**
- In your experience, what readiness did you need before your child's resuscitation? - How were you treated before your child's resuscitation? - What actions helped you become ready for and endure your child's resuscitation? - In your experience, what barriers were there to your readiness for your child's resuscitation? - What factors do you think would have improved your readiness for your child's resuscitation? - Which health professionals could better help you to become ready for this critical situation? And how could they help? - In your experience, how can the health professionals ready, or prepare, other parents for resuscitation? - What suggestions do you have to improve parents' readiness for their child's resuscitation?	- In your experience, what preparation do parents need before their child's resuscitation? - How do you treat parents to help promote their readiness before their child's resuscitation? - What actions do you take to help parents prepare for and endure the resuscitation of their child? - In your experience, what barriers there are to readying parents for their child's resuscitation? - What do you think are the factors that helped improve parents' readiness for their child's resuscitation? - In your experience, how can parental readiness for their child's resuscitation lead to better parenting experiences? - Which health professionals could better help parents to ready for this critical situation? And how could they help?

Standards for Reporting Qualitative Research (SRQR)*

http://www.equator-network.org/reporting-guidelines/srqr/

Title and abstract

	Page/line no(s).
Title - Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended	1/1-2
Abstract - Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions	2/1-21, 3/1-6

Introduction

Problem formulation - Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement	4/1-23, 5/1-5
Purpose or research question - Purpose of the study and specific objectives or questions	5/6-8

Methods

Qualitative approach and research paradigm - Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/ interpretivist) is also recommended; rationale**	5/11-12
Researcher characteristics and reflexivity - Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability	6/4-5, 7/4-6
Context - Setting/site and salient contextual factors; rationale**	5/14
Sampling strategy - How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale**	5/15-20
Ethical issues pertaining to human subjects - Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	7/20-23, 8/1-2
Data collection methods - Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale**	6/1-21

Data collection instruments and technologies - Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study	6/9-13, supplemental Appendix 1
Units of study - Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	8/13-22, 9/Table 1
Data processing - Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/de-identification of excerpts	6/22-23, 7/1-19
Data analysis - Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale**	6/22-23, 7/1-19
Techniques to enhance trustworthiness - Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale**	7/6-19

Results/findings

Synthesis and interpretation - Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	9/1-16, 10/1-22, 11/1-17, 12/3-9, 13/1-22, 14/1-15, 15/1-21, 16/1-22, 17/1-22, 18/1-6, 19/3-13, 20/1-23, 21/1-6
Links to empirical data - Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	11,12/table2, 14/tabele3, 18,19/tabele4, 21/tabele5

Discussion

Integration with prior work, implications, transferability, and contribution(s) to the field - Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field	22/1-23, 23/1-23, 24/1-23, 25/1-23, 26/1-3
Limitations - Trustworthiness and limitations of findings	26/11-23, 27/1-4

Other

Conflicts of interest - Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	28/15
Funding - Sources of funding and other support; role of funders in data collection, interpretation, and reporting	28/12-13

*The authors created the SRQR by searching the literature to identify guidelines, reporting standards, and critical appraisal criteria for qualitative research; reviewing the reference lists of retrieved sources; and contacting experts to gain feedback. The SRQR aims to improve the transparency of all aspects of qualitative research by providing clear standards for reporting qualitative research.

**The rationale should briefly discuss the justification for choosing that theory, approach, method, or technique rather than other options available, the assumptions and limitations implicit in those choices, and how those choices influence study conclusions and transferability. As appropriate, the rationale for several items might be discussed together.

Reference:

O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. **Standards for reporting qualitative research: a synthesis of recommendations.** *Academic Medicine*, Vol. 89, No. 9 / Sept 2014
DOI: 10.1097/ACM.0000000000000388