


# BMJ Open Parents' and healthcare professionals' experiences and perceptions of parental readiness for resuscitation in Iranian paediatric hospitals: a qualitative study

Arezoo Ghavi,<sup>1</sup> Hadi Hassankhani <sup>2</sup>, Kelly Powers,<sup>3</sup> Mohammad Arshadi-Bostanabad,<sup>4</sup> Hossein Namdar Areshtanab,<sup>5</sup> Mohammad Heidarzadeh<sup>4,6</sup>

**To cite:** Ghavi A, Hassankhani H, Powers K, *et al.* Parents' and healthcare professionals' experiences and perceptions of parental readiness for resuscitation in Iranian paediatric hospitals: a qualitative study. *BMJ Open* 2022;**12**:e055599. doi:10.1136/bmjopen-2021-055599

► Prepublication history and additional supplemental material for this paper are available online. To view these files, please visit the journal online (<http://dx.doi.org/10.1136/bmjopen-2021-055599>).

Received 23 July 2021  
Accepted 26 April 2022



© Author(s) (or their employer(s)) 2022. Re-use permitted under CC BY-NC. No commercial re-use. See rights and permissions. Published by BMJ.

For numbered affiliations see end of article.

## Correspondence to

Professor Hadi Hassankhani; [hassankhanihadi@gmail.com](mailto:hassankhanihadi@gmail.com)

## 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 paediatric hospital.

**Design** This exploratory descriptive qualitative study used 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 paediatric hospitals in Iran (Este Azerbaijan and Mashhad).

**Participants** Participants were 10 parents and 13 paediatric 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 centred care practices in paediatric acute care settings.

## INTRODUCTION

Child resuscitation is a critical time for parents.<sup>1</sup> Paediatric cardiac arrest in children

## STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ Participants of this study included both parents and healthcare professionals in order to enhance the rigour of the study.
- ⇒ The healthcare professional participants were nurses and physicians working on resuscitation teams in large paediatric hospitals.
- ⇒ Sampling of parents from large paediatric 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 paediatric hospitals in Iran.
- ⇒ Most participants were female due to the limited presence of male healthcare professionals and fathers in Iranian paediatric hospitals.

and adolescents occurs at a rate of 2.28 to 8.04 arrests per 100 000 cases/year.<sup>2-4</sup> 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.<sup>2</sup> Paediatric cardiac arrests occurred in 1.5% of the total number of patients under 17 years in Asian countries.<sup>5</sup> In a study in Iran, approximately 5% of patients referred to the emergency department for critical care were under 18 years of age.<sup>6</sup> Among resuscitated children, <20% survive and are discharged from the hospital.<sup>2,7</sup>

Most Iranian doctors and nurses do not agree with parents being present during their child's cardiopulmonary resuscitation.<sup>8</sup> While parents' participation in taking care of hospitalised children is considered as an indispensable principle.<sup>9</sup> Especially in wards such as the emergency room where critical care for children is provided, parents are

mostly present.<sup>10</sup> When parents are faced with their child being acutely hospitalised, they can suffer from psychological stress, which will also have a negative effect on the treatment results.<sup>11</sup> Anxiety, stress, depression and post-traumatic stress are some of the psychological problems that parents can face when their child requires resuscitation.<sup>12</sup> In the study by Lisanti *et al*,<sup>13</sup> mothers in the paediatric 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.<sup>14</sup> Therefore, healthcare professionals have a vital role in parental preparedness for resuscitation.<sup>12</sup> In addition to providing specialised clinical care, healthcare professionals should also consider parental support needs at this time,<sup>15</sup> as parental support is one tenet of family centred care structures that leads to increased quality of care.<sup>16</sup>

Many studies have focused on the presence of parents during resuscitation of their child, but few studies have examined the preresuscitation 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.<sup>17</sup> Also, parents need their beliefs, values, customs and traditions, generally, their cultural and religious practices to be respected<sup>18</sup>; 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 paediatric hospitals in Iran (Este Azerbaijan and Mashhad). Using purposive sampling, there were 10 parents of 7 children and 13 paediatric 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<sup>19</sup> 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 hospitalised children for documentation of having received resuscitative care (ie, 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 and 75 min. Since these interviews were conducted during the COVID-19 pandemic, precautions were taken (ie, 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 use to effectively provide help to parents. Examples of the interview guide questions are available in online 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 (eg, "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,<sup>20</sup> which was confirmed when no new information or codes were uncovered in the last four interviews.

Recorded interviews were transcribed verbatim and then analysed using content analysis according to Bengtsson's proposed steps.<sup>21</sup> 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 categorised according to their similarities and differences. To increase trustworthiness, this process of data analysis was conducted by two researchers who extracted and then categorised the codes, with each researcher independently coding each interview. The extracted categories and subcategories were then confirmed and agreed on 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 rigour of the research,<sup>22–24</sup> 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 rigour and credibility of the study were enhanced by checking findings with participants (ie, member checking).

### 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 paediatric 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 informed participants who 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 paediatric healthcare professionals participated; 5 paediatrician physicians and 8 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 1–5 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 31–48 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 history of illness or hospitalisation, while the other five children had a history of chronic illness. Demographic details of the participants are provided in [table 1](#).

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).

### 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 subcategories that emerged in this category of awareness. Supportive quotations are found in [table 2](#).

### Acceptance of resuscitation and its consequences

Four parents were informed about their child's condition before resuscitation, and this helped the parents better understand their child's condition and its severity.

Parents	N	Healthcare professionals	N
Relation to child		Field of education	
Father	3	Nurse	8
Mother	7	Paediatric 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	
Once		Married	9
Twice or more	5	Single	4
		Parent status	
		Having own child(ren)	9
		No children	4

**Table 2** Awareness

Acceptance of resuscitation and its consequences	<p>“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</p> <p>“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</p> <p>“... 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</p> <p>“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</p>
Providing information about the child’s current condition and prognosis	<p>“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</p> <p>“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</p> <p>“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</p> <p>“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</p> <p>“I did not know what they were doing and why. I was dying and living every moment” M9</p> <p>“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</p> <p>“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</p> <p>“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</p> <p>“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</p>

D, doctor; F, father; ICU, intensive care unit; M, mother; N, nurse.

This action of healthcare professionals was considered a proper and necessary behaviour. 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.

#### Providing information about the child’s current condition and prognosis

Healthcare professionals’ experiences indicated that in hospitalised children, if parents were informed about their child’s condition during hospitalisation, 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 hospitalisation. 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 hospitalised 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' behaviour 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.

### 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 subcategories. Supportive quotations are found in [table 3](#).

### 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.

### 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 realise 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.

Table 3 Chaos in providing information	
Defect of responsibility in informing	<p>'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</p> <p>'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</p>
Provide selective protection of information	<p>'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</p> <p>'I prefer to give bad news to the father so that he tells the mother. Fathers usually act more logically" D8</p> <p>'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</p>
Hardness in obtaining information	<p>'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</p>
D, doctor; F, father; M, mother; N, nurse.	

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.

#### 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.

#### 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 subcategories were approved in this category. Supportive quotations are found in [table 4](#).

#### Honest information on the border of hope and hopeless

Healthcare professionals and parents emphasised 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 did not want all hope removed when being provided information about their child's condition.

#### Providing information with apathy

Parents emphasised 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.

#### 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 hospitalised 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 hospitalised 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.

#### 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,

**Table 4** Providing situational information

Honest information on the border of hope and hopeless	<p>“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</p> <p>“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</p> <p>“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</p> <p>“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</p>
Providing information with apathy	<p>“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</p> <p>“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</p>
Providing information as individual	<p>“... 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</p> <p>“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</p> <p>“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</p> <p>“... 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</p> <p>“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</p> <p>“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</p> <p>“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</p> <p>“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</p>
Dualism in blaming	<p>“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</p> <p>“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</p>
Assurance to parents	<p>“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</p> <p>“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</p>
Presence of parents to better understand the child’s situation	<p>“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</p> <p>“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</p>
D, doctor; F, father; M, mother; N, nurse.	

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.

#### 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.

#### 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 hospitalisation, 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.

#### 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 subcategories emerged. Supportive quotations are found in [table 5](#).

##### 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.

**Table 5** Psychological and spiritual requirements

Reliance on supernatural power	<p>"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</p> <p>"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</p>
Need for access to a psychologist	<p>"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</p> <p>"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</p>
Sharing emotions	<p>"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</p> <p>"... I just had stress, no one was there, my husband couldn't come. I wish someone was with me." M9</p> <p>"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</p>
Collecting mementos	<p>"I still miss her. I still see her photos and hear her voice." M6</p> <p>"... 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</p>
D, doctor; F, father; ICU, intensive care unit; M, mother; N, nurse.	



### 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.

### 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, emphasising the need to come to provide companionship at the hospital.

### 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.

## DISCUSSION

In this study, parents and healthcare professionals shared their experiences and perceptions of preresuscitation 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, emphasised the importance of knowing what is happening to their child, and helping them to understand was felt to be an essential support need.<sup>14 25</sup> In another study, having information about the child's condition provided parents with the ability to better adapt and accept the child's death.<sup>25 26</sup> Also, findings from Chen *et al*<sup>27</sup> 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.<sup>28</sup> 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 hospitalisation, 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 normalisation were not be prepared for the stage of health deterioration and death.<sup>29</sup>

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.<sup>1 30</sup> 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.<sup>1</sup> These findings contradict those of Kim *et al*,<sup>31</sup> 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.<sup>32–34</sup> 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.<sup>34</sup> Furthermore, providing information to persons other than parents also can create a challenge related to information confidentiality. This may in turn jeopardise the respect, honesty and human value that is the principle of autonomy.<sup>35,36</sup> 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<sup>35</sup>; 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.<sup>37</sup> 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,<sup>33,38</sup> parents need to be neither completely hopeful nor completely hopeless when receiving information,<sup>1</sup> and preparation for receiving medical information should be considered because sometimes expressing this information may harm the mental health of the person.<sup>33,39</sup> These findings are consistent with those of this study. In light of this, healthcare professionals should use appropriate language when providing information.<sup>40,41</sup> Providing information to parents at a high speed<sup>34,38</sup> and not providing understandable information to parents<sup>33,41</sup> 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,<sup>42</sup> ensuring parents that we have done all we can,<sup>38</sup> and relaying bad news in an empathetic and compassionate way.<sup>30,42,43</sup> 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.<sup>17,44</sup> According to participants in this study, these are considered professional and helpful behaviours of healthcare professionals. Also, findings from Bogetz *et al*<sup>29</sup> and Bekkering and Woodgate<sup>30</sup> 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 hospitalisation promoted better understanding and acceptance of the resuscitation crisis, even with acute problems and no 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*,<sup>31</sup> 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 preresuscitation 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 generalisability. 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 centres. The participants may have different experiences and views than those working in or referred to small medical centres. However, this limitation is minimised 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 three fathers because in Iranian paediatric 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 paediatric 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 hospitalised 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 paediatric cardiopulmonary resuscitation, as well as strategies that may help ready parents for their child's resuscitation crisis. Findings can be used to promote family centred care in paediatric 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 balance 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. Furthermore, future research should examine parental readiness among various cultures, as parent needs may differ.

### Author affiliations

- <sup>1</sup>Student Research Committee, Department of Pediatric Nursing, School of Nursing and Midwifery, Tabriz, The Islamic Republic of Iran  
<sup>2</sup>Road Traffic Injury Research Center, School of Nursing and Midwifery, Tabriz University of Medical Sciences, Tabriz, The Islamic Republic of Iran  
<sup>3</sup>School of Nursing, University of North Carolina at Charlotte, Charlotte, North Carolina, USA  
<sup>4</sup>Department of Pediatric Nursing, School of Nursing and Midwifery, Tabriz University of Medical Sciences, Tabriz, East Azerbaijan, The Islamic Republic of Iran  
<sup>5</sup>Department of Psychology Nursing, School of Nursing and Midwifery, Tabriz University of Medical Sciences, Tabriz, The Islamic Republic of Iran  
<sup>6</sup>Department of Neonatology, Tabriz University of Medical Sciences, Tabriz, Iran

**Acknowledgements** We thank the patient advisors in pediatric hospitals of Este Azerbaijan and Mashhad.

**Contributors** AG and HH conceptualised the study, in consultation with MA-B and HNA. AG collected the data, conducted the first level of analysis and prepared the first draft of the manuscript. HH, MA-B, 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** The authors have not declared a specific grant for this research from any funding agency in the public, commercial or not-for-profit sectors.

**Competing interests** None declared.

**Patient and public involvement** Patients and/or the public were not involved in the design, or conduct, or reporting, or dissemination plans of this research.

**Patient consent for publication** Not applicable.

**Ethics approval** 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. Participants gave informed consent to participate in the study before taking part.

**Provenance and peer review** Not commissioned; externally peer reviewed.

**Data availability statement** All data relevant to the study are included in the article or uploaded as supplementary information.

**Supplemental material** This content has been supplied by the author(s). It has not been vetted by BMJ Publishing Group Limited (BMJ) and may not have been peer-reviewed. Any opinions or recommendations discussed are solely those of the author(s) and are not endorsed by BMJ. BMJ disclaims all liability and responsibility arising from any reliance placed on the content. Where the content includes any translated material, BMJ does not warrant the accuracy and reliability of the translations (including but not limited to local regulations, clinical guidelines, terminology, drug names and drug dosages), and is not responsible for any error and/or omissions arising from translation and adaptation or otherwise.

**Open access** This is an open access article distributed in accordance with the Creative Commons Attribution Non Commercial (CC BY-NC 4.0) license, which permits others to distribute, remix, adapt, build upon this work non-commercially, and license their derivative works on different terms, provided the original work is properly cited, appropriate credit is given, any changes made indicated, and the use is non-commercial. See: <http://creativecommons.org/licenses/by-nc/4.0/>.

### ORCID iD

Hadi Hassankhani <http://orcid.org/0000-0002-6710-5582>



## 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, Schwartsman C, Reis AG. Epidemiology of pediatric cardiopulmonary resuscitation. *J Pediatr* 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 Douplik 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 KD, Jones BL. 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 STS, 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 Chalooos 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:e0151606–15.
- 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 Stud* 2009;33:712–40.
- 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 MAA, 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, Chen F-J, 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;12:307–15.
- 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 HJ, Woodgate RL. The parental experience of unexpectedly losing a child in the pediatric emergency department. *Omega* 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;50:151204.
- 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. *Support Care 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. *S Afr J Bioeth 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. *Med Health Care Philos* 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. Communication with children with cancer and their families throughout the illness journey and at the end of life. In: *Palliative care Pediatr Oncol*, 2018: 55–93.
- 41 Suurmond J, Lieveld A, van de Wetering M, et al. 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* 2020;44:105–16.
- 44 Meert KL, Templin TN, Michelson KN. 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.