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Parents' Experience During a Child's Resuscitation: Getting Through It

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ABSTRACT

Purpose: The purpose of this study was to elucidate the experiences of parents during their child's resuscitation in the hospital setting.
Design and methods: This qualitative descriptive study took place in a 280 bed children's hospital with parents whose children experienced resuscitation while they were present in the room or nearby. Semi-structured interviews were conducted between one and twelve months following a child's resuscitation. A rigorous thematic analysis was performed.
Results: This study elucidates parent experience during a child's resuscitation using four overarching themes; "Overwhelming chaos", "Getting through it", "Cognitive presence" and "Joy mixed with heartache". Parents described their experience to be stressful, yet identified things that helped them get through it and make sense of the experience.
Conclusions: During a child's resuscitation parents perceived a sense of overwhelming chaos, yet still had an innate need to be present and know what was going on. While emotional support was appreciated, most important was to receive real time clinical information from healthcare staff and to see and feel that the team was personally invested in their child.
Practice implications: During a child's resuscitation, parents should be allowed to choose their level of presence to meet their individual needs. A clinical staff member should answer questions and share clinical information with parents. In addition, clinicians should allow themselves to connect with parents on a personal level. This research provides a foundation for further study, including parents' experience after experiencing a child's resuscitation.

Introduction

One of the most stressful healthcare experiences for a parent is a cardiorespiratory arrest and attempted resuscitation of their child. Each year, almost 16,000 American children experience cardiorespiratory arrest and resuscitation in hospitals (Topjian, Berg, & Nadkami, 2008). Parents fear their child will die. Parent presence during a child's attempted resuscitation during a cardiorespiratory arrest is recognized as standard care by many national organizations and hospitals have implemented policies to allow parent presence (American Association of Critical Care Nurses (AACN), 2016; American Academy of Pediatrics (AAP), 2016; American Heart Association (AHA), 2000; Cummins & Hazinski, 2000; Emergency Nurses Association (ENA), 2012; Parkman Henderson & Knapp, 2006). However, despite strong evidence that parents want and need to be present, some providers do not allow parent presence during resuscitation. Some providers believe witnessing the event will be too traumatic for parents (Bauchner, Waring, & Vinci, 1991; Fulbrook, Latour, & Albarran, 2007; Jarvis, 1998; Vavarouta, Xanthos, Papadimitriou, Kouskouni, & Iacovidou, 2011). Ten studies have explored parent experience during their child's resuscitation (Curley et al., 2012; Dudley et al., 2009; Ebrahim, Singh, & Parshuram, 2013; Harvey & Pattison, 2012; Mangurten et al., 2006; Maxton, 2008; McGahey-Oakland, Lieder, Young, & Jefferson, 2007; O'Connell et al., 2017; Sawyer et al., 2015; Tinsley et al., 2008). Only six studies go beyond survey methodology (Harvey & Pattison, 2012; Maxton, 2008; McGahey-Oakland et al., 2007; O'Connell et al., 2017; Sawyer et al., 2015). Six studies were completed in the United States (U.S.) in Pediatric Intensive Care Units (PICU) and Emergency Departments (ED) (Curley et al., 2012; Dudley et al., 2009; Mangurten et al., 2006; McGahey-Oakland et al., 2007; O'Connell et al., 2017; Tinsley et al., 2008). Others were completed in a Canadian PICU (Ebrahim et al., 2013), United Kingdom Labor & Delivery (L&D) (Harvey & Pattison, 2012; Sawyer et al., 2015) and an Australian PICU (Maxton, 2008).

Parent experience during resuscitation of their child is described in an integrative review (Stewart, 2019). Parents experience conflict between the intense need to be present and feelings of fear and distress. Parents express a need to know what is happening and state that being physically present during resuscitation is comforting and feels better than being separated from their child. Finally, parents acknowledge a

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variety of emotional reactions to the experience, but would recommend being present to other parents. This body of available research on parents' experience during a child's resuscitation primarily describes experiences in the ED and PICU. Little is known about the experience in other areas of the hospital. In fact, there has been no research in the U.S. on parents' experience during newborn resuscitation in L&D or acute care inpatient units. It is possible that these parents have a different perspective and experience than those whose children are resuscitated in the ED and PICU. These limitations with regards to setting identify a gap in what we know about parent experience during a child's resuscitation. This informed the current study setting and participants, leading to inclusion of study participants with a wide range in hospital units in order to describe a broader experience. The purpose of this study was to elucidate the experiences of parents during and after their child's resuscitation in the hospital setting.

Methods

This qualitative descriptive study was conducted in a 280 bed Midwestern children's hospital ED, PICU, Neonatal Intensive Care Unit (NICU), L&D and inpatient pediatric units. Participants included 21 legal guardians age 18 or older whose 17 children experienced resuscitation within the hospital. Participants were present in the room or within close proximity during at least part of the event. For the purpose of this study, resuscitation was defined as an emergency intervention providing respiratory or cardiovascular support, including positive pressure airway support, ventilation, cardiac compressions and/or emergency medication administration and parent is defined as a legal guardian of the child. Legal guardians in this study were fathers, mothers and grandparents.

Semi-structured interviews were used to gain a deeper understanding of the experience of parents during their child's resuscitation. Interviews were conducted by the principal investigator (PI) in person or by telephone between one and twelve months after the resuscitation. To build trustworthiness in the data, the PI asked clarifying questions throughout the interview and reported a summary of the participant's responses back to the participant at the conclusion of the each interview to validate accurate representation of their experience. Recorded interviews were transcribed verbatim followed by verification of accuracy.

Thematic analysis, a method of qualitative analysis, was used to analyze the interviews because of the rich, descriptive nature of the data. Thematic analysis is well suited for gaining insight and exploring complex phenomena and affords consideration of the data context (Vaismoradi, Turunen, & Bondas, 2013). First, the transcripts were read three times by the PI to get a sense of the interview as a whole. Important phrases were highlighted and margin memos were made to identify possible codes, themes, and insights (Miles, Hubermann, & Saldana, 2014). The researcher then reviewed the interviews at least three more times looking for larger themes and comparisons between participant experiences before compiling an initial list of themes and sub-themes. Following this initial work, two PhD prepared mentors and three research and clinical peers reviewed transcripts and independently analyzed the data for themes. Subsequent discussions with the PI occurred, ultimately coming to consensus. This process supported credibility of the data analysis.

Rigor was established by assuring dependability, credibility, transferability and trustworthiness. An integrative review of research informed the design of the study and parent advisors assisted in the development of the interview guide and recruitment strategies which enhanced credibility of the study. To further assure credibility, study participants included all parent figures, including mothers, fathers and a grandmother in order to represent a broad range of perspectives. In addition, the context of the resuscitation included children of all ages in several hospital locations. Trustworthiness of the data was supported during data collection as the interviewer asked clarifying questions and discussed the summary of the participants' experience after the interview. A thorough description of the participants and context was provided to ensure transferability. All study procedures were clearly explained and results compared to existing research.

Participant demographics and context of the resuscitation

Fig. 1 outlines recruitment procedures. While parents were the participants in this study, contextual elements of the resuscitation event are important. These are included with the parent demographics in Table 1. The child's age ranged from newborn to 17 years. The majority (n = 17; 81%) of children survived the resuscitation, there were four (19%) deaths. Of the surviving children, ten (48%) had no significant sequelae after the resuscitation and six (29%) children had at least one new functional disability. Eight (38%) parents had experienced a child's resuscitation prior to this study. Illnesses and injuries leading to resuscitation experiences in this study included new or pre-existing seizure disorders, complications of prematurity, all-terrain vehicle (ATV) injury, motor vehicle accident trauma, cardiomyopathy leading to heart failure, and complex genetic disorder.

Results

The thematic analysis resulted in four overarching themes for parents' experience: “Overwhelming chaos”, “Getting through it”, “Cognitive presence” and “Joy mixed with heartache”. Each overarching theme was supported by two to five subthemes which are listed and defined in Table 2.

Overwhelming chaos

Most (n = 19; 90%) parents recalled a sense of chaos during their child's resuscitation. The sudden rush of people descending upon the room left them feeling overwhelmed and out of control. Some parents reported that they tried to share information with the staff, but felt they were not heard. Four parents (19%) who were not able to be present during the entire resuscitation reported they were highly anxious when separated from their child. They could not see what was happening and had no information. All participants in this study reported they would have liked more information during their child's resuscitation. Two parents had experiences in two different facilities and described differences in their communication style. At one facility, they were given clinical information in a calm manner, while in the other facility they received no direct communication and observed staff that appeared uncomfortable caring for the child, shouting to other team members “we need to get this kid out of here!” Six parents (29%) did not recall receiving clinical information until after the resuscitation and reported waiting hours to speak with a provider. Despite a perceived lack of information, some parents (n = 6; 29%) were faced with making life and death decisions for their child.

So much coming at you

Of the 21 participants, 18 (86%) felt a sense of panic during the resuscitation. Parents were often unfamiliar with resuscitation events, had difficulty making sense of the sudden rush of activity, and yet knew their child's life was in danger. Some participants likened the experience to something they had seen on television, even stating “It's just like Grey's Anatomy”. A mother of a teen who developed breathing complications in the ICU summarized her overwhelming feelings. She stated;

> All these people — just so many people were coming. I ended up out of the room. He could not breathe. They could not get air in … Everyone was in there. I knew that all the crash carts and all the stuff they were bringing — you could tell it was bad.

Some participants felt in shock and had an out of body experience. One mother whose infant was being resuscitated in the ED stated;

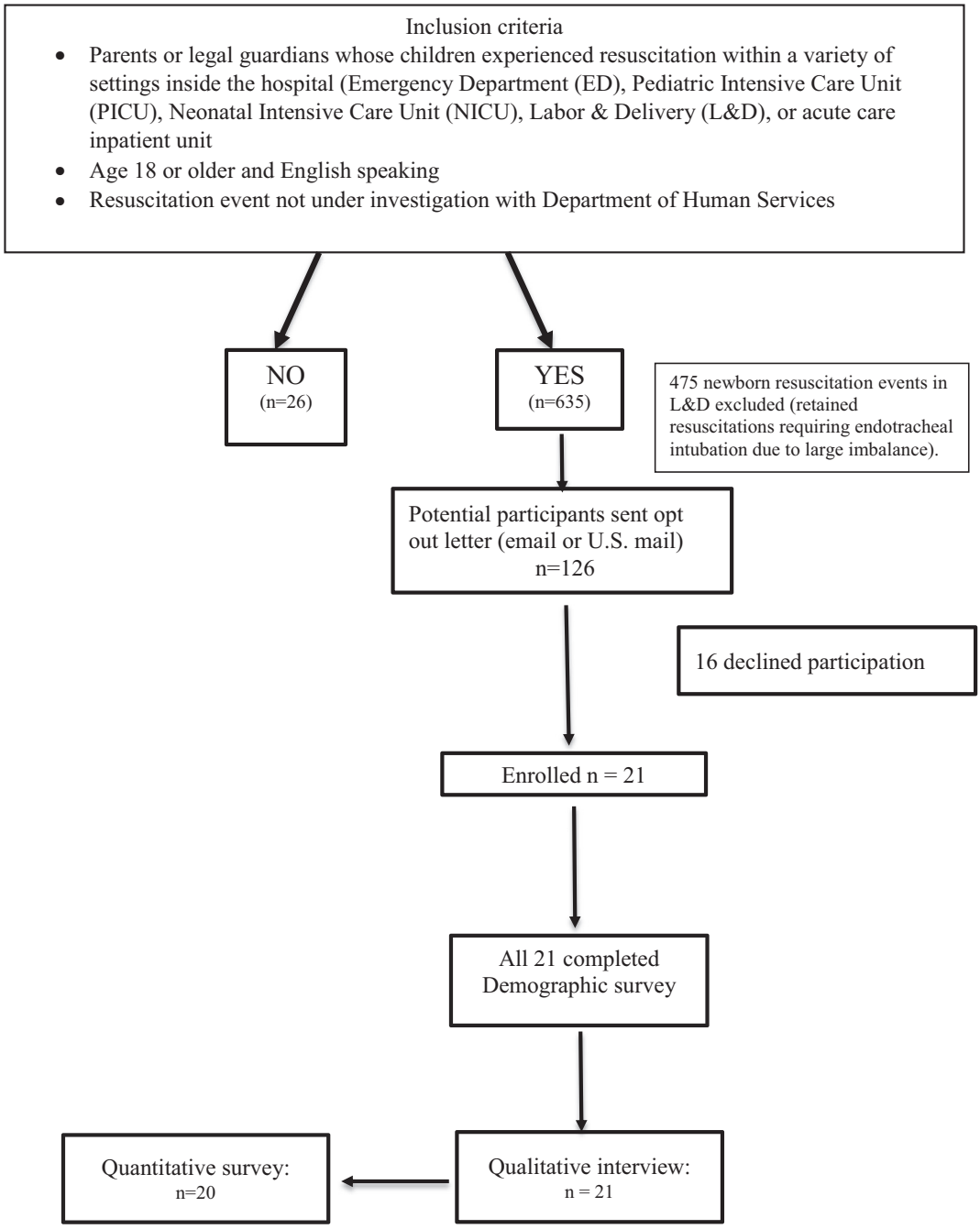

Fig. 1. Recruitment diagram.

I could not believe what I was watching. I see it now as I saw it then — I was sitting there, and I was in the corner — I was in a state of shock.

During parents' experience of their child's resuscitation, almost half of the parents (n = 10; 48%) experienced frustration and negative impressions of staff. In some situations, parents (n = 4; 19%) perceived that providers lacked confidence in caring for sick children. Some staff articulated their desire to get the child out of their unit. One participant recalled her experience at a community ED during the resuscitation of her son, stating;

They just kept saying 'There's nothing we can do here but stabilize him and get him out of here'. They would say over and over 'we need to get him out of here'. It just seemed like it was so scattered and disorganized. Not a good feeling.

Another couple whose five day old daughter was being resuscitated in their local ED perceived "they just didn't know what to do".

While trying to offer emotional and spiritual support, a chaplain's appearance during the resuscitation caused distress for some (n = 6; 29%) parents. For them, the arrival of the chaplain indicated the resuscitation was going poorly and that the child was dying. A mother of a newborn with sepsis described her experience in the ED stating;

All of a sudden, there was a lady talking to me, and I'm like, 'Why is this woman so nice to me?' Until I read her name tag and saw who she was, and then I kind of put two and two together. Like, why would they send in a chaplain? And I think that's when I kind of had a minor meltdown.

Parents reported they wanted clinical information during the

Table 1
Participant demographics and resuscitation context.

Variable	N	%
Participants	21	100
Gender		
Female	15	71.4
Male	6	29.6
Parent role		
Mother	14	66.7
Father	6	28.6
Grandmother	1	4.7
Education		
Some high school	1	4.8
High school graduate	5	23.8
Some college	5	23.8
Associate or bachelor's	7	33.3
Graduate school	3	14.3
Family income rage		
<$10,000 a year	2	9.5
$10,000–$20,000 a year	1	4.8
$20,000–$40,000 a year	8	38.1
$40,000–$70,000 a year	3	14.3
$70,000–$100,000 a year	5	23.8
>$100,000 a year	2	9.5
Hospital location of event		
Neonatal intensive care unit	1	4.8
Labor & delivery	6	28.6
Emergency department	5	23.8
Pediatric intensive care unit	4	19.0
Acute care pediatric unit	4	19.0
Clinic	1	4.8
Age-range of child		
Newborn-age 1	10	47.6
Age 1–10	8	38.1
Age 14–17	3	14.3
Child's outcome after event		
Survived — no change	11	52.4
Disability	6	28.6
Death	4	19.0
Participant experience with child resuscitation		
First experience	13	61.9
Multiple experiences	8	38.1

Table 2
Code book of themes.

Theme	Sub-theme	Conceptual definition
Overwhelming chaos	So much coming at you	Experiencing a sense of too much going on at once. Lots of people rushing around and lots of activity all at once.
	Making life and death decisions	Process of learning about choices and options and/or making the decision to begin or continue resuscitation of child
	They didn't listen to me	Parents recall trying to communicate important facts to the resuscitation team without being listened to.
	Forced separation	Parents were forced to be away from their child during part or all of the resuscitation event. This included staff members not allowing presence as well as during emergency transport to a higher level of care.
	I didn't know what was going on	Parents expressing the lack of knowing or understanding what was happening during the resuscitation, whether present or not.
Getting through it	Family-centered personal connection	When staff showed a personal interest in family members involved in the emergency event.
	Level of presence needs to be my choice	Indications that parents want to choose whether they are present during a child's resuscitation and what "presence" means for them, whether it is by their child's side, inside the room but away from the bedside, in the doorway watching from a distance but able to hear, or in the hallway nearby in case they are needed.
	Seeking information	Indications that parents want to know what is going on. They want someone to tell them what is happening during the resuscitation.
	Allow us hope	Parent reporting that being allowed a sense of hope positively impacted them during the time around resuscitation.
	Keeping it all together	Having to make sure everything is "OK" for everyone in the family
Cognitive presence	Alternate reality	Reported perceptions of disbelief or denial when parents were telling themselves everything was going to be just fine — it wasn't as bad as it seemed.
	Abrupt reality	Parents' experiences of abruptly being thrust into the child's resuscitation event by having to participate in the resuscitation at home or by being drawn into it by an emergent phone call from an Emergency Medical Services provider.
Joy mixed with heartache	Present, but not really	Explanations of mothers in labor and delivery who were present for their newborn's resuscitation, but felt as though they really weren't a part of the event. This may be because they were receiving their own medical care or because they could not see or hear what was happening.
	Unmet expectations	Mothers expectations of meeting their child for the first time, including holding, nursing or touching to establish a bond were not met.

resuscitation and tried to listen to what the providers were saying but felt a duty to speak to the chaplain. One mother of a child in the clinic who was having a seizure and stopped breathing recalled;

> The clergy lady kept trying to talk to me, and I didn't want anything to do with her because I wanted to listen.

Making life and death decisions

Of the 21 participants, 8 (38%) were involved with making critical decisions to begin, continue or stop resuscitation of their child. A father of a terminally ill child summarized an intense interaction at their local ED;

> They're like 'Well do you want us to stop?' and I'm like 'No. Stabilize her. Get her to the U, and then we'll decide.

Making decisions of this magnitude is burdensome, yet parents are an integral part of this process. A mother in extremely premature labor with twins recalled the difficult moment when doctors came to her with information about her unborn twins' chances for survival;

> The only part that I did not like, but it had to happen, was right at the beginning. One of the fellows had to come give us the survival percentages …if they are going to live or not. Everyone is trying to keep me calm and then this lady has to come and give me all of this information.

One couple was presented with the choice of letting extremely premature twins die in their arms or trying resuscitation with a small chance of survival in the NICU. This mother recalled;

> The doctors told us 'We don't know if their mouths are big enough to get the tubes in, but if you want us to we can try. The risk is that we don't know how long they are going to live for. If you would like for that time to be yours, we don't need to try. You can just be with them… walk them to heaven.'

This couple wondered if they would feel regret later if they did not try to save their children.

They didn't listen to me

Five parents (24%) felt staff was not listening to them. A father was frustrated when the ED staff ignored his attempts to explain things about his child. Despite his attempts to share information about his daughter's central venous access port, the ED staff attempted peripheral venous access. He summarized his frustrations saying;

> They didn't realize that we were the experts on her. There was nothing [in their communication to us] that said, 'hey, you know, obviously you've got a significantly ill child here. What are we supposed to be doing? What are your plans?'

Parents felt they were the best resources when it came to their child. They expected to be utilized for assistance with their care, especially when the child had complex healthcare needs. When parents were not consulted, they had negative impressions and lost trust in the team.

Forced separation

The majority (n = 15; 71%) of parents were able to be present for the duration of their child's resuscitation. Those who were not (n = 6; 29%) recalled escalated fear when they were separated during the event. Parents feared they might not see the child alive again. A mother of a newborn with sepsis who was transported to a tertiary medical center recounted;

> That was a god-awful car ride. You're really worried about what you are going to find out when you get there. I was scared I'm walking in on a dead child. I wasn't ready to face at that point in time.

There were times when parents were kept apart from their child during resuscitation despite being at the same location. One mother who was called to the ED after her son was involved in a vehicle accident explained her panic;

> I was pretty scared when I got there. She told me 'You need to take a seat, and a social worker will be with you.' Well, immediately my mind started freaking out more because I'm thinking 'I don't need a social worker. I just need to see my son.'

Getting through it

While experiencing a child's resuscitation was distressing, there were things that helped parents get through it. Parents acknowledged that being present to the level that met their needs and bidirectional communication were important. Parents reported it was helpful when the staff interacted with them during the resuscitation, listened to information offered and communicated back to them. When a personal connection was made between parent and staff, parents felt secure and well cared for. One couple described that being allowed hope was important in their experience. Some parents simply felt the best way to get through their child's resuscitation was to "keep it all together" emotionally.

Family centered personal connection

A family-centered approach made the experience better for some parents. A majority (n = 17; 80%) of parents talked about the connection they felt with the staff. Parents appreciated the skill and intensity of the work during this critical time, but also received emotional support and reassurance from staff. Parents who were well-supported during resuscitation developed confidence and trust in the staff. A mother experiencing resuscitation of her extremely premature newborn twins remembers the connection she felt. She recalled;

> Everybody there was so involved in everything … it was a group of people that were willing to put all their hearts and minds into it. Everybody in that room was willing to pour out their love and to enter into that crazy time. I think that was the biggest support I had, was that I never felt that they were coming to [do a job].

Some parents felt fortunate to have previously established relationships with staff who provided comfort and security during a child's resuscitation. The father of a child with complex illness and disabilities pointed out;

> It goes to show that the relationships that you build prior to those events are what get you through things. Especially when they happen in that same place [ICU].

Parents (n = 3; 14%) felt that reciprocal trust between staff and parents made the experience better. When the staff recognized that the parents were expert on their child and questions came up, staff seemed to listen more to the parents. Having the parents participate in the care of their child allowed parents a sense of control. One father whose child with complex healthcare needs was transported to the hospital during a resuscitation attempt explained;

> They let me access her port — not many people can get it. Then we asked tons of questions. What are the vitals? What is the epinephrine doing? Her pediatrician was our communicator with the ED. I have a feeling, had she not been there we would have been carted off to a waiting room and just left.

Level of presence needs to be my choice

All parents in this study wanted to be with their child during resuscitation. However, only 16 (76%) parents in this study were given the option to be with their child. Context of the event and individual parental needs factored into what 'being present' meant for parents during resuscitation. Parents wished to determine the level of closeness.

Participants conveyed that they were keenly aware of the critical work of the staff, did not want to be in the way, and recalled staying quiet to avoid disrupting the staff. The father of twins who were extremely premature described his delivery room resuscitation experience;

> I kind of watched over their shoulders as they were working on him. It was pretty incredible. I could see most of what was going on. I didn't ask questions at that time. I was just trying to stay out of the way. I didn't want to disrupt their concentration or anything.

Parents adjusted their level of presence to assure adequate room for providers. A mother of a child in the PICU for exacerbation of a chronic illness recalled;

> I did not go in the room. I stood in the hallway. There were too many people in the room, and there was a lot of commotion.

Parents defined being "present' in a variety of ways. In two (10%) resuscitations, parents were their child's 'chief care coordinator', staying in the room close to the child. They felt a need to be vigilant to make sure their child's unique needs were met and monitored the communication between staff. During resuscitation of a teen whose new tracheostomy had become plugged on the pediatric floor, his mother remembered;

> I was there for [the resuscitation] because I wanted to hear what they were all saying to make sure they were all on the same page — things can easily get missed. I was going to stay there to make sure they got it right.

Parents (n = 2; 10%) were directly involved in the resuscitation as they initiated cardiopulmonary resuscitation (CPR) at home. Others (n = 2; 10%) stayed close to their child to be in physical contact or to talk to their child during the resuscitation. Some parents spent time

alternating inside and outside of the room during the resuscitation and five (31%) parents felt that the best thing was for them to stay out of the way. One parent remembered her NICU experience and stated;

> We never left the room. We instinctively moved back. We stepped back to let them have more access, just trying to stay out of the way. Parents sometimes made their way to the back of the room or into the hallway outside the child's room yet they felt present and close to their child.

Seeking information

Parents wanted to know what was going on during resuscitation. Fifteen (71%) parents in this study said it was frustrating not knowing and they longed for information. One mother explained the experience in L&D during her newborn's resuscitation;

> We wanted to know how he was doing and what was going on. In the midst of having the child early your mind is really blank…only thing you focus on is him. I could not see anything. I just wondered 'what's going on'?
> During a child's resuscitation, parents watched and waited for someone to tell them what was happening. Most of the staff was engaged in clinical care. Parents acknowledged that whether they were inside the child's room or outside the room in the hallway, it was common that no staff talked to with them during the resuscitation. Despite little direct communication, parents gathered information in other ways. Listening carefully to staff during the event reassured several (n = 17; 81%) parents. Only a few (n = 4; 19%) parents whose children had long term, complex health needs felt comfortable to ask questions during resuscitation. A mother of one child with a terminal illness who was admitted to PICU for exacerbation of illness stated;

> I did ask questions. 'What exactly happened? I wasn't even gone a full 15 minutes. When I left the room she looked okay.' When I came back I said 'what the hell's going on? What happened here?'
> In a small number (n = 2; 10%) of experiences, a staff member stayed next to parents throughout the resuscitation to explain what the team was doing. A father whose child had experienced several resuscitations described what it was like when someone communicated with them during the event;

> If you've got somebody there who's able to translate what's going on in roughly real time, information calms people. Even if it's bad news. Having the news is better than the anxiety of not knowing.
> Some parents (n = 4; 19%) got intermittent updates from staff who were actively involved in the resuscitation. A mother of a child who was had stopped breathing during a seizure explained;

> We got two updates from one of the doctors working on him. They gave us a nice update. They said 'he's ok, but the meds aren't working'.
> The majority (n = 19; 90%) of parents described wanting more meaningful communication than they received during their child's resuscitation. Parents described feeling frustrated when staff were visibly uncomfortable during the resuscitation and offered no information to parents. The mother of a newborn with sepsis described her frustration;

> In the ED they kept asking what happened over and over; asking me questions. They were so busy working on her. No one talked to me except to ask questions. I just sat in the corner by myself — watching and crying.

Allow us hope

One way parents got through this experience is by being allowed hope. In being offered a choice to resuscitate their child, parents hoped it might be successful. Sometimes hope had a spiritual tone, and sometimes it manifested as determination not to quit on the child. One couple spoke of their strong sense of hope and faith during their journey with a twin pregnancy and extremely premature labor. The staff they encountered allowed them hope despite the small chance for survival. This mother explained;

> The doctor told us 'we're going to do everything we can to stop the contractions and see where we go from there.' So that way, in our head, it was baby steps. It wasn't like immediately we're going to miscarry. It gave us things to think about and pray about. Our faith is so important that it was the number one thing we held onto throughout the entire thing. If she had said 'there's nothing we can do,' I think that would have caused more distress and it would have gone completely different. The way the doctor shared information just allowed room for hope, then it helps you believe a little, even if you know that's going to happen at the end.
> In this study, hope had many contexts for parents during the child's resuscitation. A majority (n = 18; 86%) of parents talked about hope. One mother who was separated from her child during transport to a larger hospital hoped she would "see her daughter alive again". Another expressed that she was confident that he would survive this resuscitation, but hoped "that this didn't mean another setback" A father hoped that he and his wife were "making the right decision to keep pushing forward with the resuscitation of their daughter".

Keeping it together

While most parents acknowledged feeling overwhelmed and scared, several (n = 13; 62%) mothers talked about getting through the experience by keeping calm. These mothers spoke of a need to 'hold it all together', to remain strong to maintain family stability or support other family members' emotions. No fathers mentioned this as a part of their experience.

Five (24%) participants described their experience in a 'matter of fact' manner or recalled the experience being a calm situation. These parents were comfortable with less control of the situation. A mother of a teenage daughter whose heart was failing spoke about relying on the doctors as 'they knew what they were doing' and she was 'in good hands'. Sometimes, parents felt they had no choice but to remain calm and pragmatic.

Cognitive presence

Parents experienced their child's resuscitation in the hospital in different ways, either protecting themselves with alternate realities or facing reality head on. Eight (38%) parents described building an alternate reality by talking themselves out of the severity of the situation. They seemed to resist the reality that their child's life was at risk. As they felt themselves begin to panic, they tried to convince themselves they were overreacting and things would be fine. The mother of a newborn with sepsis summed this up stating;

> I told myself in my head, 'maybe I'm just a mom overreacting. We'll be on our way soon. This is going to be fine…I told myself she was seizing from low blood sugar. 'Let's give her some sugar water and she will be alright.'
> Despite instincts and clues indicating something was wrong, parents tried to think positively or maybe subconsciously wanted to avoid what was coming. Parents felt disbelief and also hoped that everything would be fine. Participants who experienced this eventually accepted reality.

Some parents were thrust into the reality of the situation. Children of three (14%) participants were involved in a traumatic accident. These parents had no time to insert alternate realities. The parents received calls that their child was injured and involved in emergency

resuscitation, so they rushed to be with their children. One father was abruptly enveloped into the resuscitation event when he had to initiate compressions on his daughter at home. These parents described the event with less ambiguity and described knowing the situation was clearly critical from the onset.

Participants whose children were resuscitated in NICU after a long hospitalization or L&D didn't describe an internal cognitive discussion regarding the reality of the resuscitation. A parent of an infant in the NICU had experienced numerous resuscitations during the child's course. This 'became normal' after a while. Parents of newborns who were resuscitated in L&D may have been more prepared by the staff ahead of time.

Joy mixed with heartache

The experience of newborn resuscitation in L&D has unique context for 'being present'. A significant other is often present during the birth of a child. The complicating factor is the mother is a patient at the same time. Another noteworthy component of this experience is that the birth of a child is generally expected to be a time of joy and happiness. In this study, five (31%) participants experienced a child's resuscitation in L&D.

Present…but not really.

Parents present during newborn resuscitation had variable levels of participation. One father was an active observer; he baptized his son, cut the umbilical cord and observed the resuscitation over the shoulders of the resuscitation team. The four mothers in this study were awake and alert during their infant delivery and resuscitation. Three mothers (75%) explained that they could not see their newborn during resuscitation, nor did they remember anyone explaining what was happening. One mother described her experience, stating "I didn't see him at all. They didn't do anything in front of me". Two of the four mothers who experienced newborn resuscitation spoke of "not really being there". They could not see and did not know what was going on. One of these mothers described her feelings;

> I could not see what was happening. I didn't even try to see. I just saw they [staff] were working… I wish I had more pictures of that time of when they were resuscitating him because I wasn't there. I wish I could've seen or I could go back and see. I would like more tangible memories.

Unmet expectations

Mothers whose newborns that were resuscitated in L&D experienced unmet expectations. During pregnancy parents eagerly anticipated meeting their child. Mothers planned to hold and bond with their baby immediately after delivery. All mothers who experienced newborn resuscitation spoke about seeing their newborn for only a moment before staff took the baby to the NICU. Mothers understood the importance of getting the baby to the NICU but were disappointed. The mothers explained;

> I didn't get a chance to look at him or anything … they already took him out.

> All they were able to do was kind of wheel him to the side of me so I could look over and see him and then they had to take him out.

One of the mothers explained that she and her son missed a critical time for bonding that impacted her stress and attachment to him during his first weeks of life.

> The fact that I could not see him physically…when you have a baby you want to see him, you want to look at him, and I couldn't. I could not touch him. I could not look at him…that really took a toll on me. It would have been better seeing myself that he was ok before they took him out. That was really important to me and I didn't get the opportunity.

Discussion

Four overarching themes describe parents' experience during a child's resuscitation. "Overwhelming chaos", "Getting through it", "Cognitive presence" and "Joy mixed with heartache". These themes and associated sub-themes are depicted in Fig. 2.

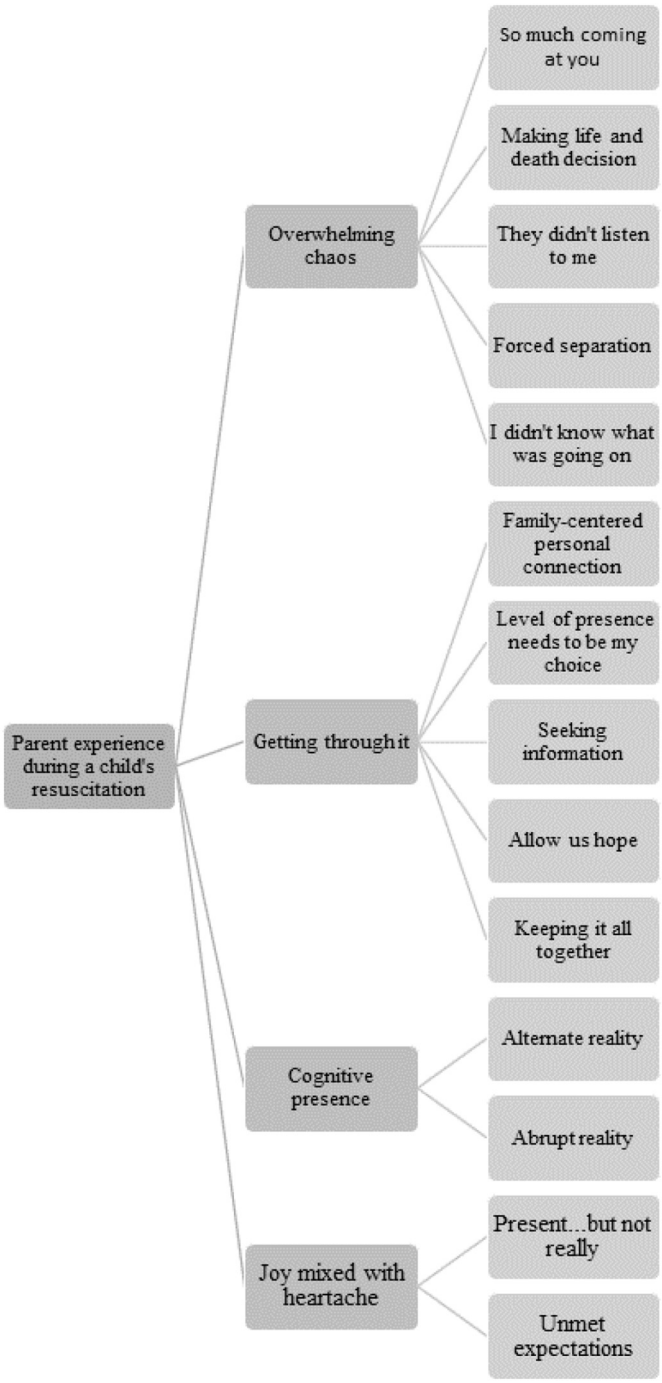

Fig. 2. Thematic diagram.

Overwhelming chaos

Parents expressed that they wanted the option to be with their children during an emergency resuscitation despite the overwhelming chaos, yet also acknowledged they need help understanding the bustle of activity and the actions to help their child. While parents gleaned information by watching and listening, more direct clinical communication was appreciated during the event. These study results are consistent with earlier findings (Harvey & Pattison, 2012; Maxton, 2008; Tinsley et al., 2008). Parents in these studies described being scared and trying to make sense of a nightmare. In Harvey & Pattison's study of fathers' experience during resuscitation of their newborn fear was doubled; fathers feared for both mom and baby's life.

The current study supports the findings of others (Harvey & Pattison, 2012; Maxton, 2008; McGahey-Oakland et al., 2007) who also described parents' intense need to be with their children and wished for someone to explain what was happening. Harvey & Pattison's study also found that parents asked questions that did not get answered and some did not feel comfortable asking questions.

What is new in these findings is the description of the difficulty parents experienced when approached to make critical decisions about their child during the stress of a child's resuscitation, sometimes knowing very little about what was happening. Another novel discovery in this study is the way parents go about making sense of the event, even when there is no one giving them direct clinical information. Parents notice non-verbal communication and listen to conversations in order to fulfill their need for any clinical information. Despite appreciating the support of a non-clinical support person such as a chaplain or social worker, some parents felt distracted by the need to make small talk with the chaplain. When the chaplain showed up unexpectedly, parents' fear and sense of overwhelm increased.

Getting through it

This study described the ways parents were able to get through the resuscitation. A family-centered personal connection was helpful during the resuscitation experience for several parents. When staff took time to interact with the family on a personal level, a connection developed even in the short duration of resuscitation. Opposite this, when parents were not acknowledged, they expressed more frustration and shared negative impressions of the resuscitation. Conversely, parents experienced a great sense of comfort when staff opened up to develop a personal connection with them. In a study done in an Australian PICU, parents also described the importance of having hope and a connection with staff (Maxton, 2008).

For participants in this study, being present was described in varying ways and was clearly an individual choice. Being “present” may mean something different to each parent. Some parents considered that they were “present” when they were inside the room and could see or touch the child. Others felt they were “present” if they could see the staff working on the child but not see their child; including outside the room in the hallway but able to look inside, or even looking through the window. Some parents felt they were “present” if they were right outside the door without the child or caregivers being in site. In contrast, mothers in L&D considered themselves ‘not really present’ because they could not see or hear what was going on during their newborn's resuscitation. These mothers wanted to be more present for their child's first minutes of life.

Mothers in this study felt a need to ‘keep it all together’, to be emotionally strong for their families. Mothers felt it was their job to maintain the integrity of the family unit and safety of other family members during a child's resuscitation. This phenomenon is explained somewhat as published resilience literature suggests that those who can focus on practical problem solving in the moment of crisis and have the ability to adapt to the situation are more likely to handle a crisis well (Siebert, 2005). Mothers demonstrated this behavior most clearly when the resuscitation event was unexpected and there were other children in the family who needed their care. This feeling was not described by fathers.

Cognitive presence

Parents reacted differently to their child's resuscitation; some needed to work through a period of alternate reality before they could accept what was happening. Parent reactions may be dependent upon the context of the illness or injury that causes the child to need resuscitation. Others found similar responses when parents could see the resuscitation but were not able to face what was happening (Harvey & Pattison, 2012; McGahey-Oakland et al., 2007).

Joy mixed with heartache

This study adds to the small body of knowledge about parents' experience during a newborn resuscitation. It was clear that parents' experience of a child's resuscitation was different in L&D than any other unit in the hospital. In the labor and delivery setting, some parents experienced extremely premature labor leading to anticipated delivery of a child that was not likely to survive. This was the beginning of their experience of their child's resuscitation. Additionally, the mother was a patient, yet still very much needed to know what was happening with her newborn. Mothers reported they wanted to see, hear and be part of the first minutes of their child's life. When there was no visibility or information shared about the child, one mother described feeling as if she wasn't there for her child at a critical moment. The frustration of not knowing what is going on and lack of information that comes with being separated from the child during other types of resuscitation applied for these mothers.

Mothers felt additional psychological distress from unmet expectations of childbirth and the missed initial connection with their newborn. In fact, unmet expectations of childbirth have been described by mothers who perceived their delivery to be traumatic and those who suffer from postpartum depression (Hollander et al. (2017); Patel, Wittkowski, Fox, and Wieck (2013).

Fathers' participation was variable. One father cut the umbilical cord and baptized the newborn, some stayed near the mother to comfort her, and another father left the mother's side to watch over the shoulder of the resuscitation team. Consistent with other resuscitations, parents did not feel comfortable asking questions during the resuscitation and didn't want to distract the team away from their child. Parents anticipate the joy of a child's birth for months. When the newborn needs emergency resuscitation, these expectations are unmet.

Findings from this study are consistent with what others have reported about parents' experiences witnessing their newborns' resuscitation. Harvey and Pattison (2012) found that fathers felt scared and were torn between staying at mom's side to support her and going to baby to find out what was happening. Some fathers could not see the baby and didn't know what was going on. In one study, resuscitation was done right next to the mother (Sawyer et al., 2015). Parents in this study reported being able to see what was happening was reassuring. Mother-side resuscitation allowed a chance for touch from mom to baby; mothers felt like they were a part of the care for their newborn child despite the need for resuscitation. Parents felt that someone explaining to them, in terms that they understood, helped them to make sense of the event and made the experience less ‘traumatic’.

Study limitations

There were limitations with this study. Data was collected by one interviewer. While providing consistency in the way questions were asked, this may have led to interview procedures with less flexibility. Participation bias may exist in this study as only parents who felt that they could talk about their experiences participated. We do not know

the experience of the 22 parents who did not answer phone calls, the 14 parents who were contacted but declined or the two parents who were "no-shows" after the interview was scheduled.

Implications for practice

In this study, parents acknowledged feeling a sense of chaos and fear during a child's resuscitation, yet identified that being present and having information about what was happening helped them get through the event. During a child's resuscitation, a clinical staff member should be assigned to answer questions and share clinical information with parents. Implementation of such a role has been successful for adult trauma and pediatric resuscitations (Leske, McAndrew, Brasel, & Feetham, 2017; Pasek & Licata, 2016). Even if parents cannot be present, this clinical communication should be provided.

Parents in this study felt it was more helpful to have clinical information, listen to clinicians and attend to the resuscitation event than to receive spiritual support, noting that the unsolicited arrival of a spiritual services provider sometimes caused increased distress. Staff should offer spiritual services as a choice, but when a spiritual services provider is a standard member of an emergency response team, it is important for staff to introduce them upon arrival and explain their role (Proserpio, Piccinelli, & Clerici, 2011).

Approaching parents about critical decisions should be done carefully, with knowledge that it may further escalate parent stress. Stress is known to deteriorate decision-making performance in many situations (Starcke & Brand, 2016). Jackson, Cheater, and Reid (2008) found that parents need information, to talk with someone and to feel in control while making decisions about their child's health care. It is important for staff to be patient, sensitive and supportive during this delicate process to support parents' decision making during a child's resuscitation.

Additionally, to help parents get through the resuscitation event, clinicians should allow themselves to connect with parents on a personal level, providing family-centered care. Connecting with parents in a compassionate manner can reduce anxiety in stressful situations (Dempsey & Wojciechowski, 2014). Parents should be allowed to choose their level of presence when possible. All parents have individual needs; some parents will need to watch from the hallway, some will need to be at their child's side. Allowing an individualized approach may help parents get through this experience.

Finally, parents whose newborns need resuscitation in L&D have a unique experience. They experience the joy of childbirth mixed with the heartache of the emergency resuscitation. Many expectations to see, touch and hold their newborn child are unmet. Staff must support parents through this loss. In addition, mothers, while physically present for their newborn's resuscitation, may feel they are not really present and feel separated from their child during a critical moment. Similar to parents of a child who experiences resuscitation, it is important to remember that mothers of newborns must be kept informed and connected with the resuscitation activities. A practice being studied in the United Kingdom, mother-side resuscitation, should be explored in the U.S. (Sawyer et al., 2015). Bringing the resuscitation to mother's side allows her to see, hear and be a part of her child's resuscitation.

Future research

This study highlighted several areas in need of further study and clarification. Further study is needed to explore parent experience and potential stress related outcomes after the event. Is there post-traumatic stress or family distress after parents experience a child's resuscitation? Further research is needed to explore potential differences in parent and family outcomes after the experience based on the amount of information they receive and level of presence during the resuscitation. Furthermore, research is needed to design and test efficient, yet effective processes for providing information and support to parents during and after a child's resuscitation.

Conclusion

During a child's resuscitation, whether in the ED, PICU, NICU, L&D or acute care unit, parents perceive a sense of overwhelming chaos, yet still have an innate need to be present and know what is going on. While emotional support is appreciated, most important is the ability to be physically present, to receive real time clinical information from healthcare staff and to see and feel that the team is personally invested in their child. All interprofessional clinical staff should work to facilitate these elements into routine practice when involved in the resuscitation of newborns in the delivery room or inpatient pediatric/neonatal units.

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References

American Academy of Pediatrics (2016). *Pediatric advanced life support provider manual.* Dallas, Texas: American Heart Association.

American Association of Critical Care Nurses (AACN) (2016). Practice alert: Family presence during resuscitation and invasive procedures. *Critical Care Nurse*, *36*(1), e11–e14 Accessed from www.ccnonline.org.

American Heart Association in collaboration with the International Liaison Committee on Resuscitation (AHA/ILCR). (2000). Guidelines 2000 for cardiopulmonary resuscitation and emergency cardiovascular care. *Circulation*, *102*, 11–374 (Suppl). Accessed online: https://eccguidelines.heart.org/index.php/circulation/cpr-ecc-guidelines-2/part-12-pediatric-advanced-life-support/?strue=1&id=4-10.

Bauchner, H., Waring, C., & Vinci, R. (1991). Parental presence during procedures in an emergency room: Results from 50 observations. *Pediatrics*, *87*(4). https://doi.org/10.1016/S0196-0644(05)81452-0.

Cummins, R. O., & Hazinski, M. F. (2000). The most important changes in the international ECC and CPR guidelines. *Resuscitation*, *46*, 431–437. https://doi.org/10.1016/S0300-9572(00)00301-4.

Curley, M., Meyer, E., Scoppettuolo, L., McGann, E., Trainor, B., Rachwal, C., & Hickey, P. (2012). Parent presence during invasive procedures and resuscitation: Evaluating a clinical practice change. *American Journal of Respiratory Critical Care Medicine*, *186* (11), 1133–1139. https://doi.org/10.1164/rccm.201205-09150C.

Dempsey, C., & Wojciechowski, S. (2014). Reducing patient suffering through compassionate connected care. *The Journal of Nursing Administration*, *44*(10), 517–524. https://doi.org/10.1097/NNA.0000000000000110.

Dudley, N., Hansen, K., Furnival, R., Donaldson, A., Van Wagenen, K., & Scaife, E. (2009). The effect of family presence on the efficiency of pediatric trauma resuscitations. *Annals of Emergency Medicine*, *53*(6), 777–784. https://doi.org/10.1016/j.annemergmed.2008.10.002.

Ebrahim, S., Singh, S., & Parshuram, C. (2013). Parental satisfaction, involvement, and presence after pediatric intensive care unit admission. *Journal of Critical Care*, *28*(1), 40–45. https://doi.org/10.1016/j.jcrc.2012.05.011.

Emergency Nurses Association (2012). *Clinical practice guideline: Family presence during invasive procedures and resuscitation.* Des Plaines, IL: The Emergency Nurses Association Available at: https://www.ena.org/docs/default-source/resource-library/practice-resources/cpg/familypresencesynopsis3bdad0aaaeeb4370856e849f26e553a3.pdf?sfvrsn=21ca66b_8.

Fulbrook, P., Latour, J., & Albarran, J. (2007). Paediatric critical care nurses' attitudes and experiences of parental presence during cardiopulmonary resuscitation: A European survey. *International Journal of Nursing Studies*, *44*, 1238. https://doi.org/10.1016/j.ijnurstu.2006.05.006.

Harvey, M., & Pattison, H. (2012). Being there: A qualitative interview study with fathers present during the resuscitation of their baby at delivery. *Archives of diseases of the child fetal neonatal edition. Vol. F1.*. https://doi.org/10.1136/archdischild-2011-301482.

Hollander, M., van Hastenberg, E., van Dillen, J., van Pampus, M., de Miranda, E., & Stramrood, C. (2017). Preventing traumatic childbirth experiences: 2192 women's perceptions and views. *Archives of Women's Mental Health*, *20*, 515–523. https://doi.org/10.1007/s00737017-0729-6.

Jackson, C., Cheater, F., & Reid, I. (2008). A systematic review of decision support needs of parents making child health decisions. *Health Expectations*, *11*(3), 232–251. https://doi.org/10.1111/j.1369-1725.2008.00496.x.

Jarvis, A. (1998). Parental presence during resuscitation: Attitudes of staff on a paediatric intensive care unit. *Intensive and Critical Care Nursing*, *14*(1), 3–7.

Leske, J., McAndrew, N., Brasel, K., & Feetham, S. (2017). Family presence during resuscitation after trauma. *Journal of Trauma Nursing*, *24*(2), 85–96. https://doi.org/10.1097/JTN.0000000000000271.

Mangurten, J., Scott, S., Guzzetta, C., Clark, A., Vinson, L., Sperry, J., ... Voelmeck, W. (2006). Effects of family presence during resuscitation and invasive procedures in a pediatric emergency department. *Journal of Emergency Nursing*, *32*(3), 225–233. https://doi.org/10.1016/j.jen.2006.02.012.

Maxton, F. (2008). Parental presence during resuscitation in the PICU: The parents' experience. Sharing and surviving the resuscitation: A phenomenological study. *Journal of Clinical Nursing*, *17*, 3168–3176. https://doi.org/10.1111/j.1365-2702.2008.02525.x.

McGahey-Oakland, P., Lieder, H., Young, A., & Jefferson, L. (2007). Family experiences during resuscitation at a children's hospital emergency department. *Journal of Pediatric Healthcare*, *21*(4), 217–225. https://doi.org/10.1016/j.pedhc.2006.12.001.

Miles, M., Hubermann, A., & Saldana, J. (2014). Fundamentals of qualitative analysis. In M. Miles, A. Hubermann, & J. Saldana (Eds.), *Qualitative data analysis. A methods sourcebook* (pp. 86–101).

O'Connell, K., Fritzeen, J., Guzzetta, C., Clark, A., Lloyd, C., Scott, S., ... Kreling, B. (2017). Family presence during trauma resuscitation: Family members' attitudes, behaviors, and experiences. *American Journal of Critical Care*, *26*(3), 229–239. https://doi.org/10.4037/ajcc2017503.

Parkman Henderson, D., & Knapp, J. (2006). Report of the national consensus conference on family presence during pediatric cardiopulmonary resuscitation and procedures. *Journal of Emergency Nursing*, *32*, 23–29. https://doi.org/10.1016/j.jen.2005.11.009.

Pasek, T., & Licata, J. (2016). Parent advocacy group for events of resuscitation. *Critical Care Nurse*, *36*(3), 58–64. https://doi.org/10.4037/ccn2016759.

Patel, S., Wittkowski, A., Fox, J., & Wieck, A. (2013). An exploration of illness beliefs in mothers with postnatal depression. *Midwifery*, *29*, v682–v689. https://doi.org/10.1016/j.midw.2012.06.012.

Proserpio, T., Piccinelli, C., & Clerici, C. (2011). Pastoral care in hospitals: A literature review. *Tumori Journal*, *97*, 666–671.

Sawyer, A., Ayers, S., Bertullies, S., Thomas, M., Weeks, A., Yoxall, C., & Duley, L. (2015). Providing immediate neonatal care and resuscitation at birth beside the mother: Parents' view, a qualitative study. *British Medical Journal Open*, *5*, e008495. https://doi.org/10.1136/bmjopen-2015-008495.

Siebert, A. (2005). *The resiliency advantage: Master change, thrive under pressure and bounce Back from set-backs*. San Francisco, California: Berrett-Koehler Pubishers, Inc.

Starcke, K., & Brand, M. (2016). Effects of stress on decisions under uncertainty: A meta-analysis. *Psychology Bulletin*, *142*(9), 909–933.

Stewart, S. (2019). Parents' experience when present during a child's resuscitation: An integrative review. *Western Journal of Nursing Research*. https://doi.org/10.1177/0193945918822479.

Tinsley, C., Hill, J. B., Shah, J., Zimmerman, G., Wilson, M., Freier, K., & Abd-Allah, S. (2008). Experience of families during cardiopulmonary resuscitation in a pediatric intensive care unit. *Pediatrics*, *122*(4), e799–e804. https://doi.org/10.1542/peds.2007-3650.

Topjian, A., Berg, R., & Nadkami, V. (2008). Pediatric cardiopulmonary resuscitation: Advances in science, techniques, and outcomes. *Pediatrics*, *122*, 1086–1098. https://doi.org/10.1542/peds.2007-3313.

Vaismoradi, M., Turunen, H., & Bondas, T. (2013). Content analysis and thematic analysis: Implications for conducting a qualitative descriptive study. *Nursing and Health Sciences*, *15*, 398–405. https://doi.org/10.1111/nhs.12048.

Vavarouta, A., Xanthos, T., Papadimitriou, L., Kouskouni, E., & Iacovidou, N. (2011). Family presence during resuscitation and invasive procedures: Physicians and nurses' attitudes working in pediatric departments in Greece. *Resuscitation*, *82*, 713–716.