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Family presence during resuscitation in paediatric and neonatal cardiac arrest: A systematic review

Katie N. Dainty
North York General Hospital

Dianne L. Atkins
North York General Hospital

Jan Breckwoldt
North York General Hospital

Ian Maconochie
North York General Hospital

Steve M. Schexnayder
North York General Hospital

See next page for additional authors

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Authors

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Review

Family presence during resuscitation in paediatric cardiac arrest: A systematic review

Katie N. Dainty*, Dianne L. Atkins, Jan Breckwoldt, Ian Maconochie, Steve M. Schexnayder, Markus B. Skrifvars, Janice Tijssen, Jonathan Wyllie, Marie Furuta, for the International Liaison Committee on Resuscitation's (ILCOR) Pediatric and Neonatal Life Support Task Forces^a

North York General Hospital, Li Ka Shing Knowledge Institute, 4001 Leslie Street, Toronto, Ontario M3K 3E1, Canada

Abstract

Context: Parent/family presence at pediatric resuscitations has been slow to become consistent practice in hospital settings and has not been universally implemented. A systematic review of the literature on family presence during pediatric and neonatal resuscitation has not been previously conducted.

Objective: To conduct a systematic review of the published evidence related to family presence during pediatric and neonatal resuscitation.

Data sources: Six major bibliographic databases was undertaken with defined search terms and including literature up to June 14, 2020.

Study selection: 3200 titles were retrieved in the initial search; 36 ultimately included for review.

Data extraction: Data was double extracted independently by two reviewers and confirmed with the review team. All eligible studies were either survey or interview-based and as such we turned to narrative systematic review methodology.

Results: The authors identified two key sets of findings: first, parents/family members want to be offered the option to be present for their child's resuscitation. Secondly, health care provider attitudes varied widely (ranging from 15% to >85%), however, support for family presence increased with previous experience and level of seniority.

Limitations: English language only; lack of randomized control trials; quality of the publications.

Conclusions: Parents wish to be offered the opportunity to be present but opinions and perspectives on the family presence vary greatly among health care providers. This topic urgently needs high quality, comparative research to measure the actual impact of family presence on patient, family and staff outcomes.

PROSPERO registration number: CRD42020140363.

Keywords: Family presence, Pediatric resuscitation, Neonatology, Cardiac arrest, Systematic review

Introduction

Sudden cardiac arrest (SCA) in children is a dramatic and traumatic event for patients, parents and healthcare providers.¹ Survival rates range from 5 to 17% for out of hospital cardiac arrest (OHCA) to

approximately 40% for in-hospital cardiac arrest in post-newborn age groups, with variation related mainly to location and cause of the arrest.^{2,3} In most cases, the child's parents or family members will be present, and an important question is whether parents should be allowed to be present during for the cardiopulmonary resuscitation (CPR) or whether they should be asked leave the room. The

Abbreviations: SCA, sudden cardiac arrest; OHCA, out of hospital cardiac arrest; CPR, cardio-pulmonary resuscitation; FPDR, family presence during resuscitation; HCP, health care provider; CINAHL, Cumulative Index to Nursing & Allied Health.

* Corresponding author at: North York General Hospital, 4001 Leslie Street, Toronto, Ontario M3K 3E1, Canada.

E-mail address: katie.dainty@utoronto.ca (K.N. Dainty).

^a The members of the International Liaison Committee on Resuscitation (ILCOR) Pediatric and Neonatal Life Task Forces are given in Appendix A.

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complexity of this issue is intertwined with the nature of existing hospital policies as well as personal provider beliefs about whether parents should be allowed to be present during resuscitation and other types of invasive medical procedures, such as tracheal intubation.⁴

Family presence during resuscitation (FPDR) was first discussed in the literature by Doyle et al.⁵ Previous cardiac arrest guidelines have allowed parents to be present during CPR i.e. advocating a “family-centered” approach to CPR.¹ Many hospitals have implemented policies allowing for, or even recommending family presence during CPR.⁶ The situation is slightly different at birth when a mother is always initially present, sometimes with other supporting family members. In this situation, family presence has been assumed in the past but this has never been fully assessed by a systematic review.

The advocates of family presence have suggested an improved ability to deal with grief in family members who witnessed the event. For the health care professional (HCP), the question is more nuanced with the strongest arguments against family presence being that it may negatively impact on the performance of resuscitation team⁷ and fear of litigation.⁸ However, some studies suggest that family presence decreases the risk of litigation by increasing parental understanding of what was actually done.⁶ Some proponents of family presence suggest that the HCP may even act in a more professional way if the family is present.⁹

Even though resuscitation guidelines have supported the presence of family members during CPR for many years, the quality of the evidence on which support is based has not been evaluated. It is also clear that there are diverse opinions, especially among practicing hospital physicians and nurses. In this systematic review, the focus was on the effects of family presence during pediatric and neonatal cardiac arrest on multiple outcomes, including short and long-term survival, neurological outcome for patients and stress and mental health outcomes for healthcare providers and parents.

Methods

The PICO question for this review was defined as “In children with cardiac arrest, in any setting (P), does family presence during resuscitation (I) compared to no family presence during resuscitation result (C) in improved patient outcomes (short and long term), family-centred outcomes (short and long term, perception of the resuscitation), and health care provider-centred outcomes (perception of the resuscitation, psychological stress) (O)?”¹⁰ We conducted this systematic review with reference to the PRISMA Systematic Review Checklist and the protocol was registered with the PROSPERO international prospective register of systematic reviews (<http://www.crd.york.ac.uk/PROSPERO/CRD42020140363>).

Initial search strategy

An Information Specialist from St. Michael’s Hospital Toronto conducted database searches in the Ovid Medline, Embase, the Cochrane Central Register of Controlled Trials, the Cochrane Database of Systematic Reviews, Cumulative Index to Nursing & Allied Health (CINAHL), and PsycINFO databases. The search strategies, adapted for each database, used a comprehensive combination of subject headings and keywords for the concepts of resuscitation, family presence, and pediatrics or neonatal. The term neonatal was defined as birth to 4 weeks and pediatric were defined as being any individual aged between 4 weeks to 18 years of age.¹¹

Review articles, editorials and those articles not mentioning the pediatric or neonatal setting were excluded. The databases were searched from inception to June 14, 2020, without language limits. This review considered all full-text language articles published in peer-review journals. Abstracts or reports of conference presentations were excluded.

Data screening

Title and abstract screening and review of full text articles was performed independently in duplicate by two authors (KND and MF) and results were discussed with the larger review team. Disagreements during screening were settled through discussion between the two reviewers. A kappa statistic of agreement between reviewers was not calculated because the complex nature of the data required significant discussion during the screening process.

Data extraction

Data about study characteristics were extracted into a data collection tool that captured the following: study date and location; study design, population and key characteristics; main outcome measures or qualitative findings.

Data analysis

The definition and approach to “family presence” during resuscitation was very inconsistent leading to great variability in the types of published studies available on this topic. The majority of the articles were observational in nature, most of which collected data via surveys. Such articles represented low or very low-quality evidence and did not provide data which can be comparatively meta-analyzed (i.e. family presence vs. no family presence). However, the team felt that there was important knowledge to be synthesized from the research, and for this reason, a narrative review was performed.

Results

A total of 3200 citations were retrieved, reducing to 2242 citations following the removal of duplicates. The original search strategy was conducted on August 3, 2019 and updated on June 14, 2020. The articles identified from each of the 6 major databases are outlined in Fig. 1 (PRISMA diagram). The selection of articles for inclusion in this review is outlined in Table 1 (Table of included studies).

After title and abstract screening, 141 articles were selected for full-text review. No additional articles were identified from bibliography and related-article searches. In total, we chose to include 36 articles in the systematic narrative synthesis.^{12–46} The three top reasons for excluding articles were (1) inclusion of mixed populations (where pediatric or neonatal data was not separated); (2) no definition of resuscitation as the clinical situation and (3) opinion/editorial pieces or systematic reviews (see Fig. 1 for further details).

Included papers employed several different research methods including observational studies [n = 1], qualitative interviews [n = 12] and surveys [n = 26] (Table 1; two studies used both interviews and surveys). They also include combinations of participants who had experience of family presence during resuscitation [n = 17] as well as those who did not, and those who could only comment hypothetically (n = 18) (Table 1). The quality of the methods as well as the reporting of

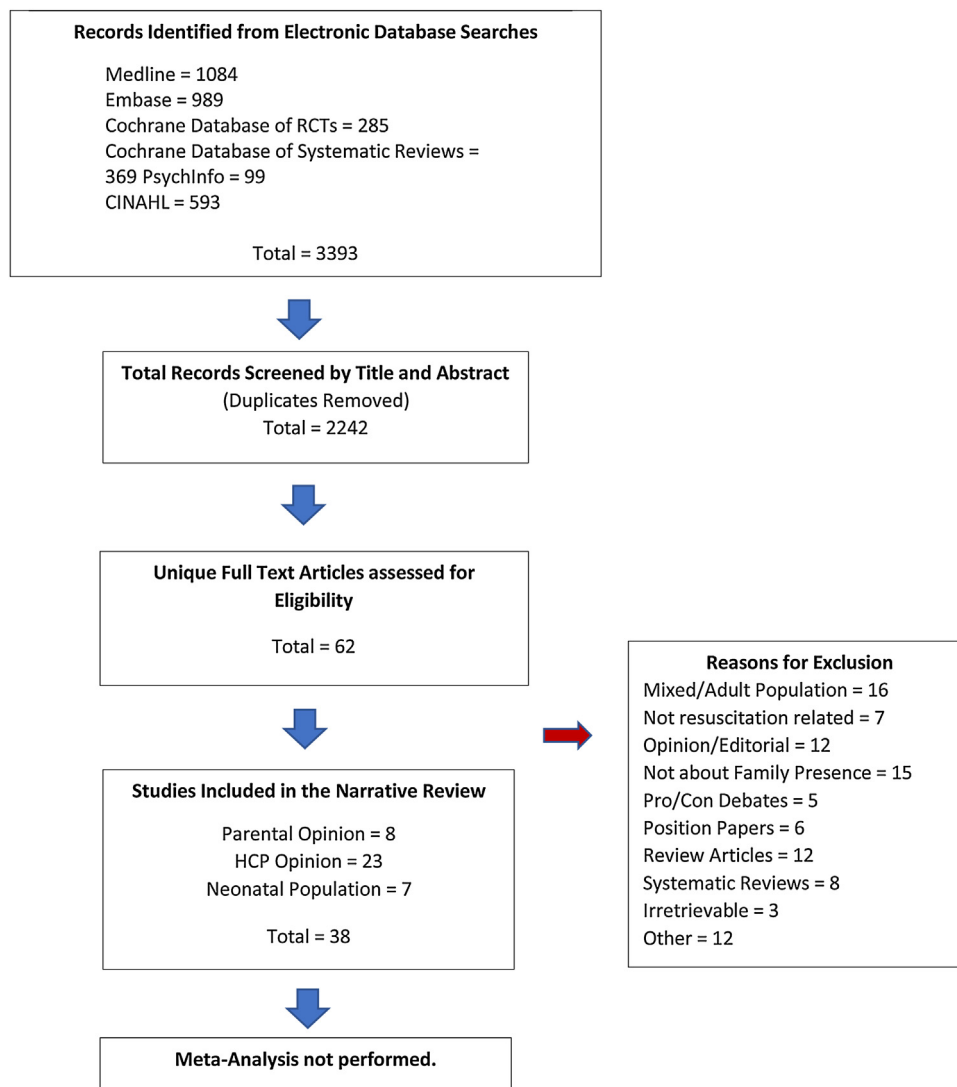


Fig. 1 – PRISMA flow chart.

Q1

126 the methodology used was highly variable and, because of this, the
 127 risks of selection bias, information or detection bias, and response
 128 bias for surveys were thought to be increased in the majority of articles.
 129 The overwhelming majority of the studies employed survey method-
 130 ology that used mostly investigator-developed tools [n = 29] or some
 131 form of pre-developed scales^{17,22,33} [n = 3]. None of the papers
 132 provided any proof of validation of the tools they used.

133 The included papers were published over 20-years (1999–2019)
 134 and were conducted in 11 different countries (Argentina, Canada,
 135 Europe (combined study), France, Greece, Hong Kong, USA, United
 136 Kingdom, Spain, Sweden and Turkey).

137 Risk of bias

138 We did not conduct a formal assessment of risk of bias owing to the
 139 high risk of perceived bias in all of the included studies. The bias came
 140 from several sources; firstly, in the majority of the papers which report
 141 health care provider opinion, experience with family presences during
 142 pediatric or neonatal resuscitation was not required of the participants.

In those studies where the sample included both participants with
 experience and without, the results were rarely reported separately.
 This introduces a high risk of reporting bias, particularly given the
 potential influence of previous experience on perception in any
 situation. The qualitative interview studies were conducted with
 participants with lived experience; however, interview studies are
 known to inherently suffer from volunteer bias towards more positive
 experiences.⁴⁸ Volunteers may differ from non-responders in terms of
 the comparison condition in terms of gender, level of self-confidence,
 willingness to take risks, or previous experience.⁴⁹ There are
 recognized methods for ensuring validity and avoiding bias in
 qualitative research but these were not heeded in the studies
 reviewed.⁵⁰ In addition, the response rates of most of the survey
 studies were extremely low, done locally within one unit or randomly
 via conference attendees. Recognized methods for improving survey
 response rates such as the Dillman method⁵¹ were not referenced.

The second major source of bias was the overwhelming use of
 investigator-derived, one-time-use surveys. None of the survey
 methods papers reported validation of the survey tools and very

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Table 1 – Table of included study characteristics.

Authors	Year	Country	Main method	N	Study description	Summary of main findings
Parent/family opinion Boie et al.	1999	USA	Survey	400	Parents recruited from the ED waiting room; pediatric scenarios	Decreasing trend regarding desire to be present for more invasive procedures except if there was a risk of the patient dying. Reasons for not wanting to be present were not reported but the parents thought that it should be their decision (93.5%).
Dwyer	2015	Australia	Survey	1208	General population survey; computer-assisted phone interviews with random adults from a national omnibus group (market research style).	875/1208 Surveyed adults in Queensland wanted to be present in the hypothetical situation of their child having CPR. If experience of “family presence” this number increased to 80%. Family presence more supported for children than if the respondent themselves were receiving CPR. More common with females and those younger.
Ebrahim et al.	2013	Canada	Survey	103	Survey to describe satisfaction, involvement, presence, and preferences of parents following their child's admission to an intensive care unit (ICU).	Only 2 (of 64) patients in the study received CPR related interventions and results showed no difference between parents present and not present during resuscitation in terms of satisfaction with health care providers ($p = 0.16$), involvement in decision-making for treatment options ($p = 0.62$) or changes in preferences for care ($p = 0.97$). Interestingly there was a difference between “primary-parent” and “secondary-parent” in their ratings of involvement in decision-making for treatment options ($p = 0.04$).
Isoardi et al.	2005	Australia	Survey	573	A prospective study using a written survey was carried out in the ED of a secondary level regional hospital in south-east Queensland. Survey consisted of seven paediatric scenarios with an increasing level of procedural invasiveness:	470/573 (85%) wished to be present if there was a risk that the child could die during the procedure. Most common reason for not wanting to be present was fear of getting in the way (33%). Mentions “Parental desire to be present decreased as procedural invasiveness increased. The exception to this trend was a notable increase in desire to be present during sedation and resuscitation” but actual data not presented.
Maxton	2008	Australia	Interviews	14	A qualitative interview study with parents based upon van Manen's interpretative phenomenological approach.	Being their for their child as an inherent need; making sense of a living nightmare (paradox of distress and uncertainty but desire to understand the procedures); maintaining hope in the face of reality (remaining positive but fully aware of the futility); living in a relationship with staff (physical and emotional support, yet aware of the impact of their presence on staff)
McGahey-Oakland	2007	USA	Interviews	21/20	Descriptive, retrospective study involved a 1-h audio-taped interview of 10 family members using the Parkland Family Presence During Resuscitation/ Invasive Procedures Unabridged Family Survey (FS) and investigator developed questions.	Five thematic categories were identified: (1) It's My Right to Be There; (2) Connection and Comfort Make a Difference; (3) Seeing is Believing; (4) Getting In; and (5) Information Giving. Family members voiced that it was their right to be present, indicating they had a special connection to the child. Seeing or not seeing the events of the resuscitation affected family members' ability to believe the outcome. Measures of mental and health functioning were similar to population norms.
Stewart	2019	USA	Interviews	21	Qualitative descriptive interview study of parent experience	Overwhelming chaos (not always heard; anxious when separated; need for more information); so much coming at you (86% felt a sense of panic; unfamiliar with resuscitation yet knew child's life was in danger; half experienced negative impressions; chaplaincy appearing very distressing); making life and death decisions (burden of having to know what to do); not

Q2

Q3

Table 1 (continued)

Authors	Year	Country	Main method	N	Study description	Summary of main findings
Tinsley et al.	2008	USA	Survey	10	Qualitative descriptive interview study of families' experience during CPR in a PICU	feeling heard (25% felt staff ignored them); getting through it (being present helped, personal connections helped them feel secure; importance of a family-centred approach; develops confidence and trust). All parents in the study wanted to be with their child, only 76% were given the option. Parents want to determine the level of closeness; keenly aware of not getting in the way; Seeking information (71% longed for more information); allow us hope; cognitive presence (protection through alternate realities or facing reality head on; talking themselves out of the reality of the situation); different depending if it is sudden or after prolonged illness Compared those present and not present; for NPG, majority believed that their presence would have comforted their child; half felt being present would have made acceptance of the death easier; half would recommend to another family to be present. In the PG most were happy with where they were located, some would have liked physical contact; majority felt their presence comforted their child; majority felt it helped acceptance of the death; majority said they would recommend that other parents be present.
HCP opinion Beckman et al.	2002	USA	Survey	105/	All staff working in ED that month (MD, RN, residents); Six clinical scenarios	95–105/298–295 (32–36%) of doctors and 135–178/326–328 (41–54%) of nurses would allow family presence in case of CPR. More likely if the likely outcome was death. 44% of doctors thought that they should decide compared to only 10% of nurses. 20–25% thought that the parent should decide.
Bradford et al.	2005	USA	Survey	76	Residents years 1–4 completed survey; 4 Likert scale questions; 5th question with reasons why they might have reservations about FP	Higher acceptance for less invasive procedures (overall 78%), lower acceptance for CPR (57%); residents with more advanced training status tend to display higher acceptance (n.s.). Major reservation to FMP: anxiety of failing during the procedure.
Carroll	2004	USA	Scales	525	HCPs from 9 ICUs including pediatric ICU (peds and neonatal); 207/592 responded; 35 from pediatric ICUs — pediatric results data separated out; Family Presence Self-Confidence Scale for Resuscitation; Family Presence Risk-Benefit Scale for Resuscitation; Family Presence Self-Confidence and Risk Benefit Scale for Invasive Procedures	Higher self-confidence and ratings of risk-benefit ratings by pediatric ICU nurses (FMP in 36–41%)
Corniero et al.	2011	Spain	Survey	222	Survey of physician and nurse opinion 13 multiple choice questions, scenario based one of which was CPR.	Rather low FMP in practice (1%, resus., to 36%, taking blood), more FMP in less invasive procedures. Reasons for no FMP: invasiveness (76%), parents' anxiety (88%), worsened performance of teams (66%) Comparing HPS: 'older physicians are more likely to support FMP than nurses'
Crowley et al.	2015	UK	Interviews	9	Qualitative Interviews with ICU Nurses with lived experience of FP	"Chaos reigns, no two cases alike"; "internal struggles of benefits and harms for each situation"; "concern whether they did everything they could"; "dichotomy between professional and personal distress about FP" ED RNs with at

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Table 1 (continued)

Authors	Year	Country	Main method	N	Study description	Summary of main findings
Curley et al.	2012	USA	Pre-Post survey	124/21	Clinician and parental survey in ICU at Boston Children's Hospital; Clinician Perception Survey – based on most invasive procedures the clinician had performed in the last 3 months.	least 1 year experience: torn between care of child and supporting parents; you do need them — for information and the child's point of view; make the decision to have parents present in the moment often guided by senior colleagues, protect parents while respect their rights, choosing words carefully when telling them what's happening; note risk of distracting the team; RNs who are parents would want to be present but desire to protect parents from witnessing the graphic features of a resuscitation Intervention: parent facilitator role created with training (any professional), guidelines created. Post: more clinicians offered parents to stay, according to clinicians — more parents demonstrated active behaviours, calmer, less distraught, 9% of clinicians would not allow parents to stay next time. Pre and Post: presence affected technical performance in 4%, decision-making in 5%, and ability to teach 9%. Parents: most offered option to stay, most chose to stay, did not change pre-post intervention, believed presence helped child, prefer to stay if asked again; clinician: parents more upset than other high invasive procedures, affected their ability to teach, 12% affected technical performance, therapeutic decision-making, helpful to patient in 12% and parent in 57. 65% would offer again, 25% unsure, and 10% would not. Parent: 78% stayed, 76% want the option, and 57% would stay in future
Egemen et al.	2006	Turkey	Survey	109	Questionnaire of physicians and nurses of the Dept. of Pediatrics at a University; 6 categories of invasive procedures described of increasing invasiveness; Also asked who should decide about the mother's presence; reasons for allowing FP and advantages and disadvantages to FP during invasive procedures	Higher acceptance for less invasive procedures (overall approval 28–73%), lower acceptance for more invasive procedures (67–100%). Comparing HPS: 'no relevant/inconsistent differences between physicians and nurses': Major resuscitation data separated; zero of the HCPs agreed with FP in these categories.
Enriquez	2017	Argentina	Survey	3134	Cross-sectional, multicenter, descriptive, national, and international study using a voluntary survey distributed through a medical website in Spanish.	Results not separated by experience or by pediatrics; Argentine Responders: 15.8% only children, 68.2% only adults; 16% all ages; 23% Argentinian and 20% other favour family presence. More common in those treating paediatric and neonatal. Most common fear was of family reaction or interference with lesser concerns for miscommunication and litigation.
Fein et al.	2004	USA	Survey	146	Written cross-sectional survey of all emergency department (ED) faculty, ED nursing staff, and pediatric residents of The Children's Hospital of Philadelphia; during procedures or resuscitations	High acceptance for less invasive procedures (overall 70–100%), lower acceptance for more invasive procedures (30–40%). Comparing HPS: 'attending physicians and nurses were more likely than residents to approve FMP'
Fulbrook et al.	2007	Europe	Survey	98	Survey of Nurses attending the ESPNIC symposium; 70.1% had experienced a situation in which parents were present during resuscitation; of CPR	70% had prior experience with FP during CPR. 74% of those with FP experience noted positive experiences; 41% noted at least one negative experience. 63% believe parents should always be offered the option of FP.
Jarvis	1998	UK	Survey	56/60	Surveys completed by doctors and nurses; all providers included regardless of experience with parental presence; 10 closed-ended dichotomous questions	Most (89%) felt parents should have the option for FP, and 79% had experience with FP. 61% of those with previous FP experience would give parents the option of FP in the future.

Table 1 (continued)

Authors	Year	Country	Main method	N	Study description	Summary of main findings
Jones et al.	2005	USA	Survey	300	Ethnic differences in parent preferences re presence for painful procedures; Interviews with convenience sample of parents from 4 ethnic backgrounds; chosen randomly from the ED. Participants shown a picture and read a description of 5 hypothetical situations	Parental wish to be with child: Venipuncture 94% (91–96); Suturing 88% (84–92); LP 81% (76–85); #reduction 81% (76–85); Resuscitation 81% (76–85); Hispanic (relatively less educated group) less likely to want to be present for resuscitation $p=0.01$ 1. Few differences across 4 ethnic groups 2. Only one group relatively less educated 3. Some parents 9–22% wanted physicians to decide whether they should remain 4. Reasons for staying: “Will help child” “Want to know what doctor is doing” “Child wants me” 5. Reasons for not staying: “I would be too nervous” “Child more distressed” “Trust Doctor” “Make Doctor nervous”
Jones et al.	2011	USA	Survey and interviews	137/12	Healthcare Provider survey about their views and their perception of those with opposing views	95 in favour; 42 against 1. Legal concerns for both pro and con. Each felt the other group was too influenced by this concern. 2. Risks involved concerned both groups 3. Concern for other health providers in both group. There is nothing concrete in the views of professionals to prevent parents being present. In fact a majority feel it is appropriate; concerns amongst health professionals about the risks of parental presence. Parents have a right to be present for: Resuscitation 75%; Rounds 77%; Invasive procedures 57% Most had witnessed a positive event because of family presence: 86% in rounds; 60% in procedures; 74% during resuscitation Negative effect: 47% in rounds; 54% in procedures; 45% during resuscitation; Most respondents (64%) came from units where family presence was allowed. Concerns: 1. Stress to operator during procedures 2. Distraction and stress to team during resuscitation 3. Most do not feel that presence would increase litigation 4. More non-physicians than physicians believe that parents should have the right to be present. 5. Non-physicians see more positives and less negatives than physicians
Kuzin et al.	2007	USA	Survey	211	International survey distributed to attendees of the 2004 PCICS; 20 item survey	10.1% agreed or strongly agreed to FP; 55.1% disagreed or strongly disagreed to; concerned because: 1. It might be difficult to stop resuscitation if the relatives disagreed 2. Relatives might think that the resuscitation was chaotic 3. Relatives' presence might increase the risk of litigation 4. The practice would be a breach of confidentiality if there was no prior consent from the patient 5. The emotional disturbance of the resuscitation team would be too great.
Lam et al.	2007	Hong Kong	Survey	169	Survey administered to all doctors and nurses in Paediatric dept. at hospital in Hong Kong; 28% had experience with FPDR	85% were not in favor if family witnessed resuscitation if patient a child; 28 nurses: 83% not in favor; All: no international differences, concern for psychological trauma 79%, medico-legal 24%, performance anxiety (27%), 9% other (including distraction)
McClenathan et al.	2002	USA	Survey	554	Surveyed HCPs attending the International Meeting of the American College of Chest Physicians in 2000; only analyzed those with FP experience; 6 questions on CPR experience, their opinions on FPDR	Compared to health professionals (HP) who had never invited family members to be present during paediatric resuscitation, those who had experience of inviting family to be present perceived fewer risks and more benefits in facilitating family presence as measured with FPR-BS (mean scores = 3.31 [sd = 0.33] and
McLean	2016	Australia	Survey	99	Survey of members of 1500 critical care nurses who were members of the American Association of Critical Care Nurses and 1500 emergency nurses who were members of the ENA; 30 item questionnaire including 1 open text section	

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Table 1 (continued)

Authors	Year	Country	Main method	N	Study description	Summary of main findings
O'Brien et al.	2002	USA	Survey	245	A 10-question survey was distributed to attendees of the American Academy of Pediatrics annual Uniformed Services Pediatric Seminar meeting, as well as pediatric staff and residents at both Tripler Army Medical Center and Kapiolani Women's and Children's Medical Center, Honolulu, Hawaii; 43% had experience with FP during a pediatric code;	2.96 [sd = 0.34] for HP with family presence and those without FP, respectively; $p < 0.001$. Similarly, self-confidence in facilitating family presence during paediatric resuscitation was higher in health professionals who had experience in inviting families to be present during paediatric resuscitation than those who had never experienced family presence as measured with FPS-CS (mean scores = 3.11 [sd = 0.5] and 2.51 [sd = 0.55] for HP with family presence and those without FP, respectively; $p < 0.001$). Only 1 or 2 data points reported separately for those with experience; 65% indicated they would not allow FP. Of the 43% that had experienced FP during CPR, 63% said they would be willing to repeat the practice. Physicians who routinely care for inpatients were more likely to support FP than other types of HCPs
Perry	2009	UK	Survey	32	Postal survey of a convenience sample of children's nurses; Structured questionnaire with some open ended responses; 15 statements with 5 point Likert scale of agreement on positive and negative aspects of FP	Overall, 69% of the nurses had a positive attitude to family-witnessed resuscitation based on a Likert scale questionnaire specifically developed for the study by the author. However, outcome data (i.e. attitudes to the concept of family-witnessed resuscitation) obtained from those who had experience with paediatric resuscitation were neither presented separately from those of inexperienced, nor compared between those who had family presence and no family presence during the resuscitation. The authors also stated that 'these with more experience of paediatric resuscitation . . . were more likely to favour FWR', but this statement was not supported by qual nor quant data.
Sacchetti et al.	2000	UK	Survey	85	HCP from three different emergency departments completed a written survey.	60% of those who had experienced FP during CPR supported the concept vs. ~20% of those who had not experienced it. Identified lack of previous experience as a barrier to more widespread adoption. Interesting editorial observation: the institution with the least experience and support was an academic pediatric ED, likely influenced by era of survey.
Tripon et al.	2014	France	Survey	343	Survey of HCP who had taken Paediatric Emergency Procedure university course	Of 343 total health professionals working in emergency teams, only 17% ($n = 59$) favoured parental presence during child CPR, 73% ($n = 251$) were not in favour of it, and 10% ($n = 33$) were indifferent. The rate of favourable opinions was higher for those who had experience with parental presence during CPR (24% $n = 39$) compared to those without experience of parental presence during CPR (13%, $n = 20$); the difference was statistically significant, while adjusting for potential confounding factors (gender, occupation, professional experience, parenthood, religion considered important) (OR = 1.96, 95% CI = 1.06–3.65, $p = 0.033$). "The reasons against parental presence were psychological trauma for the parents, risk of interference with medical management and care team stress" (p. 310).

Table 1 (continued)

Authors	Year	Country	Main method	N	Study description	Summary of main findings
Vavarouta et al.	2011	Greece	Survey	111	Physicians and nurses working in neonatal-pediatric departments and intensive care units; data reported separately based on experience with FP.	The majority of the participants (73.6%) were not familiar with FPDRAIP, were neither educated (72.7%) nor did they agree with the issue (71.9%) Overall, the majority of respondents had negative attitude towards family presence (FP) during paediatric resuscitation and invasive procedures (e.g. 71.9% disagreed or strongly disagreed with a statement that 'parents should be offered the choice to be with the patient during resuscitation or invasive procedures'. Results show that those who were familiar with existing guidelines on FP, or those who had relevant personal experience, had more positive attitudes towards FP compared to those who were unfamiliar with the guideline or without experience (difference was statistically significant at $p < 0.05$). However, the comparison was not made between those with experience of FP during resuscitation and those without. The reasons given for negative attitudes were the following: FP would be too traumatic for the family (86%, $n = 104$), and may interfere with the procedure (84.3%, $n = 102$), FP could be stressful to the person performing the procedure (81%, $n = 99$), healthcare personnel would find it difficult to concentrate and would make them nervous (79.3%, $n = 96$), and would lead to increased rates of legal action against the team (74.4%, $n = 90$).
Zavotsky et al.	2014	USA	Survey	660	Single academic medical center survey of 3000 health care workers including physicians, nurse, all types of ancillary staff, chaplains, security guards; 22% response rate.	Some of the pediatric data reported separately but not by experience with FPDR; Pediatric health care providers (65%) were more likely to support FP than adult HCPs (50%); those involved in direct care (MDs, RNs) were also more likely to support FP than other groups. Most were unaware the institution had a policy on FP during resuscitation.
Neonatal population Harvey	2013	UK	Interviews	37/49	A large UK Teaching hospital; Qualitative descriptive retrospective, using critical incident approach. Impact of father's presence on newborn resuscitation	Participants felt the midwife was the most appropriate person to support the father. All said they did not know what to say top fathers during a prolonged resuscitation. Teamwork essential. Absence of training in how to deal with it. Incidents when the baby did not survive were not addressed.
Harvey	2012	UK	Interviews	23	A large UK Teaching hospital; A descriptive, retrospective design using tape-recorded semistructured interviews with fathers present during the resuscitation of their baby at delivery	<ol style="list-style-type: none"> Preparation: Just over half the fathers (12) knew during the antenatal period that their baby may require NNU admission and sought information about pre-eclampsia, congenital abnormalities or prematurity. In most cases, they did not realise their baby might require this level of support at delivery. Knowing what happened: Most fathers did not know what specific resuscitation their baby had received; they were unaware at the time and most had not been told subsequently. A father's lack of awareness was influenced by his position in the room, his not asking questions either at the time or afterwards. Although most fathers did not attempt to watch the resuscitation because they were focusing on their partner.

(continued on next page)

Table 1 (continued)

Authors	Year	Country	Main method	N	Study description	Summary of main findings
Yoxall	2015	UK	Interviews	20	Qualitative interview study with semi-structured interviews after resuscitation stabilisation; 20 clinicians views of newborn care immediately adjacent to mother	<p>3. His response: Fathers' focus of concern, whether they stayed with their partner or went to the baby and the coping strategies they used. All fathers talked about the conflict they felt over their focus of concern; their partner or their baby.</p> <p>4. Impact on him: Fathers said they were worried, distressed, petrified, panic-stricken or scared. However, none regretted being present. None of the fathers felt they received emotional support from HCPs during the resuscitation and none were chaperoned. Several wanted to talk to someone about their feelings and experiences afterwards, but most had not done so.</p> <p>1. Of the 16 participants who spoke about the impact on clinicians, the majority had no reservations about being watched by parents, but 5 thought that staff with less experience might feel insecure being watched</p> <p>2. 8 clinicians reported on positive comments made by parents as a result of being close to their baby when he/she was being cared for</p> <p>3. 18 clinicians mentioned that bedside care at birth allowed parents to see and touch their baby, and to see what the clinical team were doing. They felt this was especially important for babies subsequently admitted to the neonatal unit, as the parents were able to see and be with their baby before transfer. This is in contrast to usual 'room-side care', where the mother might not have been able to see the baby until the mother visited the neonatal unit</p> <p>4. Twelve clinicians commented on the impact that watching neonatal care at birth might have on parents. Five felt that it would be beneficial, while four were unsure or thought that parents might be scared, but in reality found that they were not</p>
Sawyer	2015	UK	Interviews	30	Qualitative study with semistructured interviews. Results were analysed using thematic analysis. 30 participants from 19 deliveries with initial neonatal care next to mother.	<p>1. Reassurance, which included 'Baby is OK', 'Having baby close', 'Confidence in care', 'Knowing what's going on' and 'Dad as informant'</p> <p>2. Involvement of the family, which included 'Opportunity for contact', 'Family involvement' and 'Normality'</p> <p>3. Staff communication, which included 'Communication' and 'Experience'</p> <p>4. Reservations, which included 'Reservations about witnessing resuscitation', 'Negative emotions' and 'Worries about the impact on staff'</p> <p>5. This not relevant to us</p>
Katheria	2018	US	Survey	60	Private questionnaires post resuscitation filled in by professionals and parents; 60 resuscitations/stabilisations by the side of parents	No parents were uncomfortable with newborn interventions/resuscitation at the bedside
Lindburg	2007		Interviews	8	Narrative interviews with thematic analysis in Tertiary maternity unit	At birth: Fathers had their own needs and required care. Little relevant for this review.
Arnold	2012	UK	Interviews	39	3 tertiary care neonatal units South East UK; Qualitative study with semistructured interviews. 44–344 days after birth; 32 mothers, 7 fathers (of 123 invited). 21 couples saw their baby at birth	1. The first contact between parent and baby was characterised by turbulent emotions, whether it occurred immediately after birth or later in NICU

Table 1 (continued)

Authors	Year	Country	Main method	N	Study description	Summary of main findings
						<p>2. Several mothers and some fathers referred to the experience of childbirth being a sudden or surreal experience which they did not feel part of</p> <p>3. When anticipating seeing the baby, parents were divided between those who were eager and even desperate to see them, and those who dreaded the experience. Some wished to stay naive to health problems that might be made obvious by the sight of the baby. Their fear was not of the baby itself, but rather of witnessing the seriousness of a situation they would rather avoid. This contrasted with the excitement felt by other parents. Being separated from their newborn baby frustrated some mothers who were not only desperate to see their baby but angry and confused about why they could not see them earlier</p>

few included a copy of the actual survey for review so it was not possible to assess the content validity and appropriateness of the questions related to the reported findings.

Parental/family experience and opinion

Eight of the papers focused on the parental or family opinion of being present (or not) during their child's resuscitation.^{12–19} Five of these papers sampled parents or family members who were present during a resuscitation.^{14,16–19} The other three papers included a random sample of parents in an emergency department waiting room,¹² a general population survey¹³ and a survey of parents which did not specifically require first-hand experience.¹⁵

The papers which reported data collected from parents who had experienced being present at a resuscitation of their child were from Canada, Australia and the United States; and they were conducted between 2008–2019.^{14,16–19} One qualitative interview study compared experiences of parents who had been present and those who had not been present for various reasons.¹⁹ Overall, the findings in these studies reflected that being present during the resuscitation of their child was a very helpful experience for parents. In all studies, parents who were present discussed their belief that their presence brought their child comfort and that it helped them to adjust to the loss of their child.

Qualitative themes reported were very similar across studies which used interviews or open-ended survey questions. Parents desire to be present, to understand what was happening, the need for physical contact with their child, that witnessing helped them to know that all had been done was very prominent.^{16–18} As was stated in one study "*Being there for their child, providing comfort and support and in doing so, comforting themselves, was an inherent need for parents*".¹⁶ Many studies discussed how the process of accepting their child's death began for family members while they were present during the resuscitation; seeing the resuscitation allowed them to realize the severity of their child's condition.¹⁷ Another common theme was the sense of chaos and panic parents recalled during the resuscitation but that they placed tremendous importance on the relationship with the staff during the process.¹⁸

In the study that compared the experiences of parents who had been present and those that were not, 40% were absent because they had not been invited to be present during CPR and 10% had declined to be present when invited (the remaining 45% were not in the hospital at the time of CPR).¹⁹ Of those that were not present (regardless of reason), 55% wished they had been given the opportunity to be there. They felt their presence would have comforted their child, that in some way their child might still be alive if they had been there, and many still had unanswered questions about the resuscitation situation. These missing experiences almost directly mirrored the elements felt to be helpful by parents who were present. The majority of parents in both the present and non-present groups would recommend being present during resuscitation to other families if given the option.

In those papers which measured the hypothetical opinion of parents/families,^{12,13,15} two used scenarios of different procedures and clinical situations which increased in invasiveness from venipuncture to resuscitation.^{12,15} A third study used computer-assisted phone interviews with random, adult members of the public from a national omnibus group.¹³ Overall, there was a decreasing trend regarding the desire to be present for more invasive procedures except if there was a risk of the patient dying. Overwhelmingly in the included studies parents believed it should be their decision whether or not to be present (>80%).

Health care provider experience and opinion

Similar to the papers reporting on family opinion, the literature focused on health care provider opinions that included studies which sampled participants' experience of family presence in their child's resuscitation (n = 7) and those that could only provide a hypothetical opinion (n = 15). These papers typically combined health care provider respondents^{21–23,25,26,28,30–32,34,36–40} and three included trainees.^{23,24,28} Four surveyed nurses only^{20,29,33,35} and one focused solely on physicians.²⁷

Of those that reported results for HCPs with experience with having family present during resuscitation, one study used qualitative interviews,²⁰ one surveyed staff before and after the introduction of a family navigator intervention,²¹ and the remaining studies used

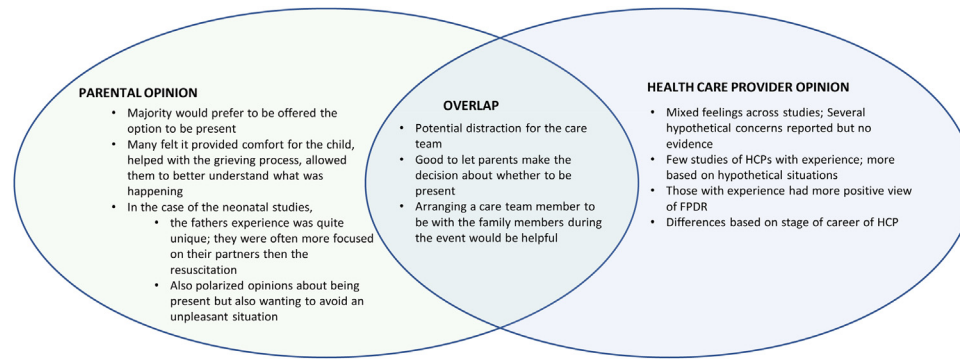


Fig. 2 – Figurative summary of findings.

different survey methods to collect data.^{21,32,33,35,37,38} The results were mixed, ranging from 85% disagreement with FP³⁸ during resuscitation to >60%^{30,35,36,39} acceptance. However, overall agreement with, and confidence in facilitating family presence during paediatric resuscitation, was higher in health professionals with experience in inviting families to be present during paediatric resuscitation. In those surveys which included open ended responses to assess why HCPs were against FP during pediatric resuscitation, the most common themes included concern for psychological trauma for the parents, the risk of interference with medical management, and the stress on the attending care team including performance-related anxieties.

An additional fifteen articles reported on the opinions of various HCPs but did not require participants to have had actual experience with family presence during resuscitation.^{22–30,34,36,39,40} Many of these studies also used clinical scenarios of varying invasiveness to assess clinician agreement, ranging from parental presence in team rounds to parental presence during cardiopulmonary resuscitation.^{23,25,26,28,36} Others used tools that were more oriented towards general attitudes and beliefs as well as potential barriers and facilitators to using FP in practice.^{22,24,27,29,31,32–34,35,37–39,40}

Overall, the acceptance of family presence during resuscitation varied from 35 to 85%. There did not seem to be any relevant differences between physicians and nurses. However, experience with family presence and clinical seniority appeared to positively influence acceptance. For example, attending physicians and senior nurses were more likely than residents to approve of family presence.^{24,26,28} Almost all studies that surveyed nurses about their attitudes toward FPDR in pediatrics found the nurses were supportive of the practice, especially in the intensive care context.

Hypothetical concerns reported were similar to those in the experience-based group and included care team stress, the potential for distraction, adverse psychological impact on parents/family members and the potential for litigation.

Neonatal studies of family presence during immediate resuscitation after birth

The literature on family presence during neonatal resuscitation includes seven papers, six of which were qualitative^{41–46} and one used survey methodology.⁴⁷ Two of the qualitative papers focused on the experience of fathers during their baby's resuscitation,^{42,43} two focused on the experience of both parents^{41,45} one looked at provider

opinion⁴⁶ and one included both parent and provider opinions.⁴⁷ These are very different types of studies; hence the evidence is not easy to synthesize but the key findings were that:

- the experience of fathers is unique, particularly around their knowledge of what happened and their focus, at the time of the event, being on their partner;
- parents felt that being present provided reassurance and opportunities for involvement and communication, but parents also reported some reservations about the emotional toll of witnessing the resuscitation;
- there is a need for staff training for support and debriefing;
- first contact between parent and baby was characterised by intense but polarized emotions ranging from desperation to see the baby immediately, to fear of witnessing a situation around their baby they would rather have avoided.

Figurative summary of findings

A bullet-point summary of the findings in each group (parents/families, health care providers, neonatal papers) as well as some areas of actual overlap are represented in Fig. 2.

Discussion

Overall, the findings of this review reveal four key findings; firstly, there is no evidence available to assess the direct or indirect impact of family presence on any patient outcomes (patients short/long-term survival and neurological outcome; stress or mental health outcomes for health care providers and parents) for pediatric or neonatal resuscitation. Secondly, parents tend to support family presence being offered to all parents, although not all parents wish to be present. Thirdly, health care providers remain divided in their approval of family presence during pediatric resuscitation, however, positive perceptions seem to be facilitated by previous experience with FPDR and level of seniority in practice. Lastly, staff and some parents felt that education and training were needed for those staff expected to support parental presence during pediatric and neonatal resuscitation.

Based on this comprehensive review, existing recommendations about family presence during pediatric resuscitations do not seem to be based on evidence of measurable outcomes. The evidence from

neonatal studies, where parental presence is far more common and widely accepted, was sparse. However, the themes reported in the in-depth qualitative research, especially regarding the emotional toll and the intense but polarized emotions, should inform further comparative research in both pediatric and neonatal contexts. The findings of our review agree very closely with several related systematic reviews that have been conducted in the last few years in specific populations (i.e. only parents or solely critical care nurses, etc.).^{52–54} These reviews also found that parents largely wish to be present, they expect to be offered the opportunity to be present and that it is important to them that they are there for their child. In contrast, there is tremendous variation in health care provider perception and judgment on this issue.

Despite the agreement with other reviews, there are particular findings from this systematic review that warrant discussion. Firstly, the tremendous variability in methodologic rigor for most of the included studies, particularly in how the survey tools were developed and administered was surprising and disappointing. None of the questionnaires reported appear to have been subjected to any forms of validation testing, and all surveys were highly subject to response bias. More importantly, several were based only on hypothetical case scenarios which may not equate to real-world practice. It was unfortunate that there was insufficient evidence to make any recommendation for a change in practice or policy either for or against families being present during pediatric resuscitation. However, this review does highlight two important methodologic recommendations: (a) this is an area ripe for comparative effectiveness research to truly understand what would be beneficial for patients, families and health care providers in this situation and (b) a reminder to researchers of the importance for ensuring rigor and validity in survey methods.

Nonetheless, the fact that the evidence included in this review was entirely descriptive and qualitative in nature perhaps should not be surprising. The concept of allowing families to be present during resuscitation, and in particular, the resuscitation of their child, encompasses much more than clinical outcomes. Issues such as the parent-child bond, parental responsibility, the importance of control and information in chaotic situations, ethical principles of autonomy and justice, family-centred care, shared decision-making in health care, and the hierarchical relationship between health care providers, patients and families all enter into a decision to incorporate family presence. These are significant psycho-social issues which are not easily categorized into measurable variables for statistical analysis. Large scale, validated survey work and robust qualitative research is urgently needed to understand the effect and value of family presence, to fully map the complexity of perspectives on this issue.

Health care providers who did not support family presence were most often fearful of increasing parental/family trauma and distraction/negative impact on performance of the health care team. However, evidence of these negative implications is not available in the published literature. Furthermore, those HCPs who were more senior and had actual experience with families being present during a pediatric resuscitation were more supportive, suggesting it is more a fear of the unknown impact of a new practice which leads to assumptions about negative impact from those who have little or no experience. This line of inquiry would benefit from research investigations with appropriate outcome measures. In addition, research to further elucidate other factors which may modify HCPs experience, as well as key differences in provider perceptions by care location (i.e. ED compared to ICU compared to ward, etc.) will be important to gain knowledge about how we might further target knowledge translation activities regarding family presence policies

during pediatric resuscitation. Unfortunately, a large portion of the studies in this review sampled HCPs from broad or undifferentiated populations (conferences, “pediatric departments”, etc.) so we were unable to properly conduct this level of comparison.

Finally, the evidence examined in this review spans a twenty-year timeframe and originates from 11 different countries. Owing to the nature of the studies, we were not able to analyze the effects of time and geography, although we suspect these would influence results. In addition, the opportunity for parents/families to be present during resuscitation in contagious disease situations (e.g. COVID-19 pandemic) is certainly subject to different protocols as extra precautions are necessary.⁵⁵

Strengths and limitations

The key strength of this review is that it was both systematic and comprehensive. Had we chosen to conduct a standard systematic review and meta-analysis, i.e. only included those papers which used a comparative interventional design, we would have lost the richness of literature that has led to providing these summary findings.

The majority of the evidence we reviewed is considered of very low quality by typical evaluation standards because of the lack of rigour in the observational and qualitative approaches. Randomized controlled trials may not be ethically possible, however, new methodologic approaches which allow for controlled measurement of clinical outcomes while maintaining ethical responsibility are recommended as a crucial future direction for research in this area.

Conclusions

There remains variation in opinion and practice, the evidence is of very low certainty and there is no outcome-oriented evidence to inform a recommendation for practice or policy either for or against families being present during pediatric resuscitation. This review highlights that this is an area in urgent need of high quality, comparative research for the impact of family presence to be fully understood.

Contributor's statement

Dr Dainty conceptualized and designed the study, developed the search strategy, designed the data collection instruments, extracted the data, carried out the initial analyses, drafted the initial manuscript, and reviewed and revised the manuscript.

Drs Atkins, Breckwoldt, Maconochie, Schexnayder, Schrifvars, Tijssen, Wyllie and Furuta helped design the study, develop the search strategy, participated in data extraction, refined the analyses, and reviewed and revised the manuscript.

All authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

Conflicts of interest disclosures

Ian Maconochie is the Task Force Chair Paediatric Life Support Group ILCOR; Hon Secretary for the Resuscitation Council UK; Co-Chair of the European Resuscitation Council Paediatric Scientific Advisory Group.

The remaining authors have no conflicts of interest to disclose.

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Uncited reference

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Appendix A.

Pediatric Life Support Task Forces

Richard Aickin, Chair (New Zealand), Jason Acworth (Australia), Dianne Atkins (United States), Thomaz Bittencourt Couto (Brazil), Anne-Marie Guerguerian (Canada), Monica Kleinman (United States), David Kloock (South Africa), Vinay Nadkarni (United States), Kee-Chong Ng (Singapore), Gabrielle Nuthall (New Zealand), Yong-Kwang Gene Ong (Singapore), Amelia Reis (Brazil), Antonio Rodriguez-Nunez (United Kingdom), Steve Schexnayder (United States), Barney Scholefield (United Kingdom), Janice Tijssen (Canada), Patrick Van de Voorde (Belgium).

Neonatal Life Support Task Forces

Myra Wyckoff, Chair (United States), Helen Liley, Vice-Chair (Australia), Walid El-Naggar (Canada), Jorge Fabres (Chile), Joe Fawke (United Kingdom), Elizabeth Foglia (United States), Ruth Guinsburg (Brazil), Shigeharu Hosono (Japan), Tetsuya Isayama (Japan), Mandira Kawakami (Brazil), Vishal Kapadia (United States), Han-Suk Kim (Korea), Chris McKinlay (New Zealand), Charles Roehr (United Kingdom), Georg Schmolzer (Canada), Takahiro Sugiura (Japan), Daniele Trevisanuto (Italy), Gary Weiner.

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