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REVIEW

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Family perception of and experience with family presence during cardiopulmonary resuscitation: An integrative review

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Abstract

Objective: The objective was to consider family presence during resuscitation (FPDR) from the perspective of the family member.

Background: FPDR has been a topic of interest internationally since the first report of this practice more than 25 years ago. Worldwide, many studies have provided insight into the perspective of healthcare professionals (HCPs); however, there is limited research on the perspective and experiences of family members.

Design: An integrative review was conducted. An electronic database search was conducted for the years from 1994–2017.

Methods: The Cumulative Index of Nursing and Allied Health Literature (CINAHL), PyschINFO, Academic Search, SocINDEX, PubMed, ProQuest databases and Google Scholar were searched. Search terms were family perceptions, family presence and resuscitation.

Results: Twelve reviews met inclusion criteria. Findings suggest that family members view family presence as a fundamental right. Family members involved in a FPDR experience reported that their presence benefitted the patient and healthcare team. In an international sample of studies, family presence overall was viewed positively by family members and they voiced wanting to be given an option to be present during a loved one's resuscitation.

Conclusions: Findings support that family members' desire for FPDR; however, the literature reflects that HCPs do not always embrace the practice of FPDR. Stronger educational preparation of nurses and other HCPs related to FPDR is warranted. Policy initiatives include the formulation of policies that allow family presence during resuscitation of a family member.

Relevance to clinical practice: The findings are relevant for a clinical practice that promotes a more family-centred approach to allowing FPDR. Creating policy and providing FPDR education for HCPs based on evidence provide more consistency in clinical practice and help to eliminate the moral distress experienced by clinical nurses forced to make difficult decisions during a stressful event.

KEYWORDS
experience, family-centred care, systematic review

1 | INTRODUCTION

Family presence during resuscitation (FPDR) was first discussed by Doyle et al. (1987). As early as 1982, healthcare professionals (HCPs) began to question excluding family members from resuscitation attempts based on a survey where 72% of surviving relatives indicated that they would like to have been present in the resuscitation room (Doyle et al., 1987). Hanson and Strawser (1992) provided the first discussion of this option in the nursing literature, which resulted in increased nursing interest in the topic. While many studies have provided insight into the perspective of various HCPs (Al Mutair, Plummer, O'Brien, & Clerhan, 2013; Davidson, Buenavista, Hobbs, & Kracht, 2007; Robinson, MacKenzie-Ross, Campbell-Hewson, Egleston, & Prevost, 1998; Steinhauser et al., 2000), there is more limited research on the perspective of and experiences of family members who have witnessed the cardiopulmonary resuscitation (CPR) of a close relative.

1.1 | CPR: A historical perspective

CPR as we know it today began around 1960 (Hermreck, 1988). In 1958, the National Research Council of the National Academy of Sciences recommended mouth-to-mouth or mouth-to-nose ventilation as the methodology of choice to provide oxygen to persons who had stopped breathing. In a landmark article published in the Journal of the American Medical Association, Kouwenhoven, Jude, and Knickerbocker (1960) reported the successful results of closed-chest cardiac massage. Because of these developments, standard procedure in hospitals soon included attempted CPR on all patients who developed sudden cessation of heartbeat or breathing.

1.1.1 | Family involvement

As HCPs have increasingly recognised the value of including the family in patient care, fathers have moved from the waiting room to the labour and delivery suite (Phillips, 1999), and children are no longer expected to remain in the hospital while parents are limited to brief weekly visits (Sainsbury, Gray, Cleary, Davies, & Rowlandson, 1986). Overall, visiting restrictions have been relaxed, allowing longer visits and younger visitors. With shorter hospital stays, families have been included in the care of patients, in part because more of the care is delivered in the home. With this increase in family involvement, it is inevitable that some families will want to be included during resuscitation.

Literature describing the concept of family-centred care is often found in the specialty of paediatrics. One such example is *Family-Centred Theory*, which provides foundational support for FPDR practice in both paediatric and adult populations (Bamm & Rosenbaum, 2008; Sak-Dankosky, Andruszkiewcz, Sherwood, & Kvist, 2017). A major premise of this theory is that family members can support the patient and HCPs (by providing information) during critical times of a patient's illness (Bamm & Rosenbaum, 2008). For almost 20 years, there has been considerable interest in the practice of FPDR (Boyd & White, 2000; Davidson et al., 2007; Sak-Dankosky et al. (2017).

What does this paper contribute to the wider global clinical community?

- Family members expressed that it is their right to be present if they so choose.
- Family members described benefits to the patient and to themselves.
- Establishment of policies with adequate training and resources should promote the success of family presence during resuscitation.

1.2 | The beginning of FPDR

Doyle et al.'s seminal (1987) article reported on how the emergency room staff of Foote Hospital in Jackson, Michigan had been faced with an ethical dilemma. On two separate occasions, family members had demanded to be present during the resuscitative efforts. Evaluation of those two incidents and a subsequent survey of family members of patients who had recently died caused the Emergency Department staff in 1982 to create a FPDR program. Hanson and Strawser (1992) provided follow-up to the Foote Hospital FPDR program and described that although there has been concern that family members may be disruptive during resuscitation, "In our 9 years of experience, not one instance of actual interference with resuscitation activities has occurred" (p. 106). By 1994, the Emergency Nurses Association in the United States had begun to consider the issue of FPDR. (Emergency Nurses Association, 2010).

1.3 | The position of professional organisations

Several professional organisations have published position papers or guidelines on the issue of FPDR. In the United States, the Emergency Nurses Association's (ENA) *Presenting the Option for Family Presence* (1995), now in the third edition, was one of the earliest educational efforts that provided information on how a hospital could develop a program for FPDR and suggestions for staff education related to this. The ENA also published a position statement in 1994, *Family Presence at the Bedside During Invasive Procedures and/or Resuscitation* (Emergency Nurses Association, 2010), which has been frequently revised, most recently in 2010. Their *Clinical Practice Guideline: Family Presence During Invasive Procedures and Resuscitation*, revised in 2012, is designed to provide nurses with evidence to support their evolving practice (Emergency Nurses Association, 2012).

The American College of Emergency Physicians, in their *Family Presence Fact Sheet* (2012), is also supportive of FPDR. It states "The option of family member presence should be encouraged for all aspects of emergency care" (p. 1). The International Emergency Car-

diovascular Care (ECC) and Cardiopulmonary Resuscitation (CPR) Guidelines (Cummins & Hazinski, 2000) resulted from a thorough review of the international literature by an international panel of experts. In addition to changes in the way resuscitation is conducted and in training for management of cardiopulmonary arrest, the guidelines included a section on support for family presence at resuscitation attempts (Cummins & Hazinski, 2000). The guidelines indicate "whenever possible, family members should be given the option, but they will require support and specific attention during the resuscitation" (Cummins & Hazinski, 2000, p. I-374). The guidelines further note that initiatives to include families require advance planning, indicating the need for hospitals to develop protocols which include a plan for a support person to be with the family during this traumatic event. In spite of professional guidelines that support FPDR, research has shown mixed support by HCPs (Al Mutair et al., 2013; Davidson et al., 2007; Robinson et al., 1998; Steinhauser et al., 2000). Issues raised by HCPs included resuscitation may be too traumatic for family to observe, team members might experience performance anxiety and limited space is available in the room. Support for FPDR included that the family member may be able to advocate for continuation or cessation of CPR and it may facilitate the grieving process.

1.3.1 | Aim

There have been much published on HCPs' perceptions about FPDR. However, there is a dearth of literature about family members' perceptions of FPDR. The first aim of this integrative review was to consider FPDR from the perspective of the family member. The second aim was to consider family members' experiences with FPDR.

2 | METHODS

2.1 | Design

An integrative review was conducted following the methodological steps recommended by Whittemore and Knafl (2005). This involved identifying the problem, conducting a structured literature search, appraising the quality of the data, extracting and analysing the data, and synthesising and presenting the findings.

2.2 | Problem

Two research questions were posed. They are as follows: (a) What are family members' perceptions of FPDR?, and (b) How do family members describe their experiences when they witnessed resuscitation of a family member?

2.3 | Structured literature search

A comprehensive electronic database literature search was conducted between March 13, 2017–April 15, 2017. Search terms and Boolean operator used included "family perceptions," "family presence" and "resuscitation." The CINAHL, PyschINFO, Academic Search, SocINDEX, PubMed, ProQuest databases and Google Scholar were searched to identify studies published between January 1994–April 2017. We selected 1994 because it was when the first professional organisation in nursing published their statement on family presence, entitled *Family Presence at the Bedside During Invasive Procedures and/or Resuscitation* (Emergency Nurses Association, 2010). Search limiters applied were as follows: published in English, abstract available and peer reviewed. Studies to be included in the review met the following criteria: (a) qualitative, quantitative and mixed methods research (including dissertations) and (b) family members' perceptions and/or experiences of family presence with paediatric or adult patients during CPR. Exclusion criteria were (a) studies that focused only on healthcare providers' perceptions of FPDR; (b) findings that only focused on invasive procedures and (c) resuscitation efforts that occurred outside of the hospital setting. Ancestry searches of retrieved articles were done to identify work that was relevant to the specific purpose of this review and was not found in the electronic databases searches. The original searches yielded 100 studies after duplicates were removed. Of these 100 studies, 67 were removed after abstract review. The remaining 33 full-text studies were independently reviewed by the two investigators based on the inclusion criteria previously described. After discussion between the two investigators, 21 studies were excluded; 20 did not meet inclusion criteria and one contained duplicate findings. The planned use of a third party for further review was not required. The detailed process of selection is presented in the PRISMA (Moher, Liberati, Tetzlaff, & Altman, 2009) diagram in Figure 1.

2.4 | Appraising the quality of the data

Hawker, Payne, Kerr, Hardy, and Powell (2002) tool guided the methodological rigour appraisal of the included research studies. The investigators critically appraised each study independently and then compared and discussed their ratings until a consensus in the final scores was achieved. All articles were assigned ratings on a scale of 1 (poor) to 4 (very good). The nine evaluated items are as follows: title and abstract, introduction and aims, methods and data, sampling, data analysis, ethics and bias, findings/results, transferability/reliability, implications, and usefulness. The range of potential scores is 9–36. Studies scoring 9–12 would be considered poor, while studies ranging from 13–24 were fair and those above 24 were considered good. The studies presented in this review ranged from 27–36. No studies were excluded based on quality appraisal. See Tables 1 and 2 for quality appraisal scores of individual studies.

2.5 | Data abstraction, analysis and synthesis

To facilitate analysis and synthesis of included research studies, two matrices were created, one for each research question. See Table 1 and 2. Analysis and synthesis of studies was guided by the following steps: (a) for each study, the following was extracted: aim/purpose, sample/setting, method/design, results/findings and quality appraisal

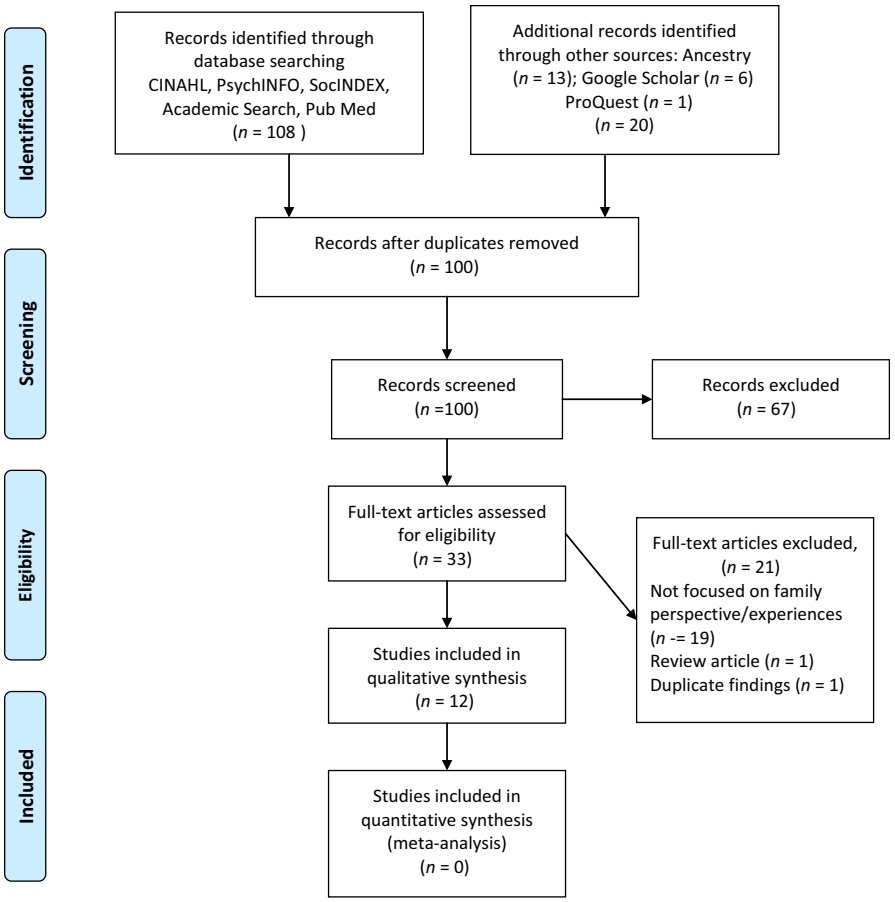

FIGURE 1 PRISMA flow diagram. From Moher, Liberati, Tetzlaff, Altman and The PRISMA Group (2009)

score/limitations. (b) For each research question, categorised data from appropriate studies were analysed for similarities and differences (patterns). (c) These patterns were synthesised into unifying themes. (d) Agreement between authors was reached on study patterns and key themes. Question one resulted in the following two themes: fundamental right and psychological impact. Question two resulted in two themes: being there for the patient, which was further divided into sharing information and providing physical and emotional comfort to the patient. The second theme for question two was seeing is believing.

3 | RESULTS

3.1 | Study characteristics

Twelve articles (*N* = 12) met inclusion criteria for this review (Champ-Gibson, Severtsen, Vandermause, & Corbett, 2016; Duran, Oman, Abel, Koziel, & Szymanski, 2007; Leske, McAndrew, & Brasel, 2013; Leung & Chow, 2012; Maxton, 2008; McGahey-Oakland, Lieder, Young, & Jefferson, 2007; Meyers, Eichhorn, & Guzzetta, 1998; Meyers et al., 2000; Mortelmans et al., 2010; Tinsley et al., 2008; Wagner, 2004; Weslien, Nilstun, Lundqvist, & Fridlund, 2006). The studies reviewed were primarily from the United States (Champ-Gibson et al., 2016; Duran et al., 2007; Leske et al., 2013; McGahey-Oakland et al., 2007; Meyers et al., 1998, 2000; Tinsley et al., 2008; Wagner, 2004). The remaining four were one each from Hong Kong, Australia, Belgium and Sweden (Leung & Chow, 2012; Maxton, 2008; Mortelmans et al., 2010; Weslien et al., 2006). The comprehensive search included the years 1994–2017. However, all of the studies were published between 1998–2016. Of the 12 studies, three focused exclusively on family members of paediatric patients (Maxton, 2008; McGahey-Oakland et al., 2007; Tinsley et al., 2008); five were family members of adult patients (Leske et al., 2013; Leung & Chow, 2012; Mortelmans et al., 2010; Wagner, 2004; Weslien et al., 2006). Four studies considered both adult and paediatric patients (Champ-Gibson et al., 2016; Duran et al., 2007; Meyers et al., 1998, 2000). Regarding methodology, an equal number of studies employed mixed methods (Duran et al., 2007; McGahey-Oakland et al., 2007 Meyers et al., 1998, 2000; Tinsley et al., 2008) and qualitative methods (Champ-Gibson et al., 2016; Leske et al., 2013; Maxton, 2008; Wagner, 2004; Weslien et al., 2006). Two articles used quantitative methods (Leung & Chow, 2012; Mortelmans et al., 2010). Resuscitated patients were in various areas of the hospital. These included the Emergency Department (Leske et al., 2013; McGahey-Oakland et al., 2007; Meyers et al., 1998, 2000; Mortelmans et al., 2010; Weslien et al., 2006) and intensive care units (Leung & Chow, 2012; Maxton, 2008; Tinsley et al., 2008; Wagner, 2004). The remaining studies included various areas of the hospital (Champ-Gibson et al., 2016; Duran et al., 2007). Sample size in the studies ranged from six–150 participants.

TABLE 1 Studies that pertain to research question 1: Family's perceptions of family presence during resuscitation

Authors, date, country	Aim/purpose	Sample/setting	Method/design	Results/findings	Quality appraisal score/ limitations
Champ-Gibson et al. (2016) U.S.	Interpretation of family members' long-term experience and meaning of being present with a loved one during resuscitation	*N* = 9 family members; adult patients; acute care hospital	Philosophical hermeneutics qualitative research design	• All participants wanted to be present • Imperceptibility of time; surreal, dreamlike • Sacred space – sense of inclusion and exclusion • Communication provided comfort; being included in decision-making • Prayer for family and healthcare providers • Often a medical language barrier or lack of understanding • Sharing information, being with the patient, touching the patient, comforting the patient • Advocating for patient • Being there at the end provided and an opportunity to say goodbye • Witnessing that everything was done for patient • Being peaceful to sit by deceased, talk to them and help the nurse provide post mortem care	Good (36) • Small sample size • From one institution • Lack of diverse participants
Duran et al. (2007) U.S.	Describe and compare the beliefs about and attitudes toward family presence of clinicians, patients' families, and patients	*n* = 72 family members Adult and neonatal patients in ICUs and Emergency Department (ED) settings. 300-bed urban academic hospital	Mixed Methods Descriptive Survey design Instruments were adapted from the original Parkland Survey (Meyers et al., 1998)	• Felt that being present was helpful to the family member and they would do it again. • Felt they could "control" their emotions.	Good (33) • Pilot-tested survey • Qualitative data from families was minimal • Non-respondent bias • Lack of ethnic diversity
Leske et al. (2013) U.S.	Describe the family experiences of FPDR option after trauma from motor vehicle accident and gunshot wounds	*N* = 28 family members of adult patients in a Level 1 Trauma Center in the Midwest US	Descriptive qualitative using content analysis	• Valued option to be present • Role of HCPs to fix the patient • Overwhelmed with the amount of HCPs but relieved that everyone was doing all that could to help • Completion of many tasks; of all the things done by the team the most described was the ripping or cutting of the patient's clothing. Professionalism and teamwork • Valued by family members • Patient was treated with respect Role of family members to protect and support patient • Provided information to medical team and other family members (explain in lay terms) Ensure the team was doing its job • Be close proximity to provide physical and emotional comfort	Good (35) • Convenience sample • Written field notes rather than audiotape

(Continues)

TABLE 1 (Continued)

Authors, date, country	Aim/purpose	Sample/setting	Method/design	Results/findings	Quality appraisal score/ limitations
Leung and Chow (2012) Hong Kong	Examines the attitudes of healthcare staff and patients' family members towards family presence during FPDR	*n* = 69 family members Adult patients in two ICU settings 1,360-bed urban hospital	Quantitative Cross-sectional design Author-created survey	• 80% family members strongly agree or agree FPDR practice.	Good (35) • Pilot-tested survey • Small sample size • non-random sampling
Maxton (2008) Australia	To provide in-depth understanding of the meaning for parents who were present or absent during a resuscitation attempt on their child in the PICU	*N* = 14 parents Pediatric ICU	Phenomenological van Manen approach	Four themes 1) Being only for a child • Being there for the child • Providing comfort and support for the child and themselves 2) Making sense of a living nightmare • Parents needed to see for themselves what happened during the resuscitation to understand the severity of the procedure and that all had been done to save their child 3) Maintaining hope in the face of reality • Maintaining hope and remaining positive was important when coping 4) Living in relationship with staff • Preferred support from a nurse opposed to chaplain or social service • Needed ongoing explanation	Good (35) • Small sample size • One pediatric ICU
McGahey-Oakland et al. (2007) U.S.	Describe experiences of family members who children underwent resuscitation attempts	*N* = 10 family members Pediatric patients in the ED setting Large urban Children's hospital	Mixed Methods Descriptive Retrospective design questionnaire Family Presence Attitude Scale (FPAS-FM)	• Felt it was their right to be there.	Good (35) • Small sample size • Non-respondent bias
Meyers et al. (1998) U.S.	To interview families who had experienced the death of a loved one to determine their desires, beliefs and concerns about family presence during CPR	*N* = 25 family members Adult and pediatric patients in the ED setting Large urban 1,000-bed hospital	Mixed Methods Descriptive Retrospective design Author-created survey-original Parkland survey Telephone interviews	• 80% of family members wanted to be present in the room • Significant difference was found between the relationship of the patient and the family members belief that being present would lessen the grief	Good (27) • Qualitative analysis poorly described • No reported IRB approval • Convenience sample
Meyers et al. (2000) U.S.	To examine the attitudes, benefits, and problems expressed by families and HCPs in FPDR	*n* = 39 family members Adult and pediatric patients in the ED setting Large urban 940-bed hospital	Mixed Methods Descriptive Retrospective Survey Survey -adapted from their original Parkland survey	• 98% of family members felt they had a right and obligation to be present during CPR and would do it again. • Felt it facilitated grieving	Good (29) • Possibility of recall error

(Continues)

TABLE 1 (Continued)

Authors, date, country	Aim/purpose	Sample/setting	Method/design	Results/findings	Quality appraisal score/ limitations
Mortelmans et al. (2010) Belgium	To determine the attitudes of our local patients and closest relatives towards FPDR	*n* = 150 family members 57% were the partners of the patient 31% were the children of the patient Adult patients in the ED setting Large community 436-bed hospital	Quantitative Descriptive Survey Design Five-item family member survey	• 75% expressed an interest in staying with their loved ones • 49% did not fear that this would be too traumatic • Different kinds of family relationships did not influence their opinion	Good (28) • Not clear if survey instrument was author created • Lack of clear implications or usefulness
Tinsley et al. (2008) U.S.	Determine parents' perceptions of the effects of their presence during their resuscitation efforts of their child and whether they would recommend their experience to other families	*N* = 33 families resulting in 41 interviews of parents or guardians of deceased pediatric patients in a pediatric ICU in a university children's hospital	Interview with closed and open questions	• 71% FMs believed that their presence comforted their child • Everybody worked together as a team • They did everything they could for him • I could touch him and he was not surrounded by all strangers • Cited frequent updates and staff's attitudes helped the most • 40% of FMs not present during CPR of their child expressed feeling that if they were present it would have been harder to deal with their child's death versus 35% of FMs who felt it would have been easier to deal with their child's death.	Good (34) • Inability to locate a significant number of families • Recall bias
Weslien et al. (2006) Sweden	Illuminate family members' experiences and views about being present in the resuscitation room with a relative receiving resuscitation	*N* = 17 family members Adult patient in ED setting Two academic hospitals	Qualitative Qualitative descriptive study design using content analysis Interviews (60 min long)	• Two out of 17 members were present during resuscitation. • They just walked into room and thought it was their right • Family members had different thoughts about presence. • Differences explained as depending upon relationship, knowledge of CPR, and the strength to cope with such stressful events	Good (35) • Convenience sample • Interview guide pilot tested

TABLE 2 Studies that pertain to research question 2: Family's description of their experiences during family member resuscitation

Authors, date, country	Aim/purpose	Sample/setting	Method/design	Results/findings	Quality appraisal score/ limitations
Champ-Gibson et al. (2016) U.S.	Interpretation of family members' long-term experience and meaning of being present with a loved one during resuscitation	*N* = 9 family members; adult patients; acute care hospital	Philosophical hermeneutics qualitative research design	• Imperceptibility of time; surreal, dreamlike • Sacred space—sense of inclusion and exclusion • Communication provided comfort; being included in decision-making • Prayer for family and health care providers • All participants wanted to be present • Often a medical language barrier or lack of understanding • Sharing information, being with the patient, touching the patient, comforting the patient • Advocating for patient • Being there at the end provided and an opportunity to say goodbye • Witnessing that everything was done for patient • Being peaceful to sit by deceased, talk to them and help the nurse provide post mortem care	Good (36) • Small sample size • From one institution • Lack of diverse participants
Leske et al. (2013) U.S.	Describe the family experiences of FPDR option after trauma from motor vehicle accident and gunshot wounds	*N* = 28 family members of adult patients in a Level 1 Trauma Center in the Midwest US	Descriptive qualitative using content analysis	• Role of HCPs to fix the patient • Overwhelmed with the amount of HCPs but relieved that everyone was doing all that could to help • Completion of many tasks; of all the things done by the team the most described was the ripping or cutting of the patient's clothing. Professionalism and teamwork • Valued by family members • Patient was treated with respect Role of family members to protect and support patient • Provided information to medical team and other family members (explain in lay terms) Ensure the team was doing its job Be close proximity to provide physical and emotional comfort	Good (35) • Convenience sample • Written field notes rather than audiotape

(Continues)

TABLE 2 (Continued)

Authors, date, country	Aim/purpose	Sample/setting	Method/design	Results/findings	Quality appraisal score/ limitations
Maxton (2008) Australia	To provide in-depth understanding of the meaning for parents who were present or absent during a resuscitation attempt on their child in the PICU	*N* = 14 parents Pediatric ICU	Phenomenological van Manen approach	Four themes 1) Being only for a child • Providing comfort and support for the child and themselves 2) Making sense of a living nightmare • Parents needed to see for themselves what happened during the resuscitation to understand the severity of the procedure and that all had been done to save their child 3) Maintaining hope in the face of reality • Maintaining hope and remaining positive was important when coping 4) Living in relationship with staff • Preferred support from a nurse opposed to chaplain or social service • Needed ongoing explanation	Good (35) • Small sample size • One pediatric ICU
McGahey-Oakland et al. (2007) U.S.	Describe experiences of family members whose children underwent resuscitation attempts in a Children's hospital Emergency Department (ED)	*N* = 10 family members children's hospital ED	Descriptive retrospective study	Five themes: 1. It is my right to be there 2. Connection and comfort makes a difference • Tell child they love them • Gave permission to die to child • Physical connection facilitated healing for family member 3. Seeing is believing • Family members felt reassured that all possible options to help their child were exhausted 4. Getting into room—some already present, others invited 5. Information giving • Timing of information was critical	Good (35) • Small sample size • Non-respondent bias

(Continues)

TABLE 2 (Continued)

Authors, date, country	Aim/purpose	Sample/setting	Method/design	Results/findings	Quality appraisal score/ limitations
Meyers et al. (2000) U.S.	To examine the attitudes, benefits, and problems expressed by families and HCPs in family presence during invasive procedures and CPR	*N* = 39 family members; Large urban hospital	Descriptive Survey 37-item questionnaire investigator created	• 98% of family members felt they had a right to present during CPR and would do it again • 95% of family members felt that being present helped them to comprehend the seriousness of the situation and that every intervention had been done. • 95% believed it helped the patient even though the patient was unconscious • Family members described providing comfort and protection through physical acts: touching, kissing, holding, praying, calming preventing aloneness, decreasing fear, giving permission to die • Family members felt they were helpers for staff; signing consents, and knowers of the patient and informing other family members what happened. • Family members felt they reminded HCPs of the patients personhood, in which HCPs went the extra mile • Being able to say good bye during the last minutes • FMs found it a spiritual experience	Good (29) • Possibility of recall error
Tinsley et al. (2008) U.S.	Determine parents' perceptions of the effects of their presence during their resuscitation efforts of their child and whether they would recommend their experience to other families	*N* = 33 families resulting in 41 interviews of parents or guardians of deceased pediatric patients in a pediatric ICU in a university children's hospital	Interview with closed and open questions	• 71% FMs believed that their presence comforted their child • Everybody worked together as a team • They did everything they could for him • I could touch him and he was not surrounded by all strangers • cited frequent updates and staff's attitudes helped the most	Good (34) • Inability to locate a significant number of families • Recall bias
Wagner (2004) U.S.	Describe the experiences, thoughts, and perceptions of family members of critically ill patients during CPR in the ICU	*N* = 6 family members of adult patients Coronary Care Unit (CCU) at a urban community hospital in Northeastern Ohio	Qualitative study Van Manen; thematic analysis interviews	One theme: • Should we stay or should we go? • Sub themes: • What is going on? • You [healthcare team] do your job	Good (35) • Small sample size • Single research site

(Continues)

TABLE 2 (Continued)

Authors, date, country	Aim/purpose	Sample/setting	Method/design	Results/findings	Quality appraisal score/ limitations
Weslien et al. (2006) Sweden	Illuminate family members' experiences and views about being present in the resuscitation room with a relative receiving resuscitation	N = 17 family members of adult patients in Emergency Rooms of two university hospitals in Southern Sweden	Qualitative descriptive using content analysis	• Two out of 17 members were present. The two present just walked into room and thought it was their right • Members not present felt it was difficult to have an opinion • Family members present felt they were able to communicate helpful information • Trust and hope increased by witnessing HCPs competence • Being afraid of disturbing resuscitation efforts • Family members had different thoughts about presence. Differences explained as depending upon relationship, knowledge of CPR, and the strength to cope with such stressful events	Good (35) • Convenience sample • Interview guide pilot tested

3.2 | Question 1: What are the family members' perceptions of FPDR?

Family members' perceptions of FPDR were gleaned from disparate literature to answer question one (Champ-Gibson et al., 2016; Duran et al., 2007; Leske et al., 2013; Leung & Chow, 2012; Maxton, 2008; McGahey-Oakland et al., 2007; Meyers et al., 1998, 2000; Mortelmans et al., 2010; Tinsley et al., 2008; Weslien et al., 2006). Moreover, data came from family members who may or may not have been directly involved in a FPDR event.

3.2.1 | Fundamental right

A prevalent theme noted was that family members viewed it as a fundamental right to witness their loved one's resuscitation and they would like to be given the option to participate (Champ-Gibson et al., 2016; Duran et al., 2007; Leske et al., 2013; Leung & Chow, 2012; Maxton, 2008; McGahey-Oakland et al., 2007; Meyers et al., 1998, 2000). Meyers et al. (1998) reported family members voiced "patients are not hospital property and that families need to be given an option to and a choice to participate." (p. 403). Furthermore, two studies reported that family members felt it was their obligation to their family member to be present during their resuscitation (McGahey-Oakland et al., 2007; Meyers et al., 2000). Duran et al. (2007) reported that 31% of the family members had participated in resuscitation/invasive procedures and 95% of these respondents would participate again in a similar situation.

Respondents recognised that not all family members want to be present during resuscitation (McGahey-Oakland et al., 2007; Meyers et al., 1998). Some family members expressed concern that their presence may be detrimental to the patient's resuscitation efforts or that they would physically be in the way (McGahey-Oakland et al., 2007; Meyers et al., 1998). Our oldest study described 20% of family members not wanting to witness the resuscitation or death of their family member (Meyers et al., 1998), but 96% of these family members felt families should be able to be with their family members before their death if they desire to be present.

Weslien et al.'s (2006) study included 17 participants with a family member who required resuscitation. Only two of these 17 participants witnessed their family member's resuscitation efforts because both entered the room without invitation; they believed they had the right to participate in the event. In contrast, the remaining 15 family members were escorted into a private room during the resuscitation. Some of these family members voiced concern that their presence may interfere with the resuscitation efforts if they were allowed to be present and that it would depend on a family member's ability to cope with a stressful event.

3.2.2 | Psychological impact

Studies demonstrated that a majority of family members are not concerned about the potential for an adverse psychological effect after being present during resuscitation of a family member (Duran

et al., 2007; Meyers et al., 1998; Mortelmans et al., 2010). Several studies reported that family members who were not present during resuscitation of a loved one believed if they were present, it would have facilitated acceptance of their family member's death and their own emotional healing (Duran et al., 2007; McGahey-Oakland et al., 2007; Meyers et al., 1998). In contrast, Tinsley et al.'s (2008) study had only 35% of participants who felt if they were present during CPR, it would have helped facilitate acceptance of their child's death.

3.3 | Question 2: How do family members describe their FPDR experiences?

In contrast to the focus of question one, related to family members' perceptions, question two considered how family members described their experiences when they witnessed resuscitation of a close family member (Champ-Gibson et al., 2016; Leske et al., 2013; Maxton, 2008; McGahey-Oakland et al., 2007; Meyers et al., 2000; Tinsley et al., 2008; Wagner, 2004; Weslien et al., 2006). Several commonalities emerged from the studies.

3.3.1 | Being there for the patient

A theme that emerged from the research was that being present benefited the patient in various ways. This has two sub-themes: sharing information and providing physical, emotional and spiritual comfort.

3.3.2 | Sharing information

The family member felt that the information that they were able to provide to the healthcare team was valuable in relationship to the care the team provided (Champ-Gibson et al., 2016; Leske et al., 2013; McGahey-Oakland et al., 2007; Meyers et al., 2000; : Weslien et al., 2006). Signing consents and advocating for the patient were also benefits of being included during the resuscitation (Champ-Gibson et al., 2016); in addition, being able to provide information to other family members was a benefit (Leske et al., 2013). One participant in this study said, "It was extremely helpful to other family members in the waiting room because I was able to tell them what was going on in lay terms" (p. 82).

3.3.3 | Providing physical, emotional and spiritual comfort to the patient

Several studies found that the family members felt that the patient was comforted by their presence, even though the patient was unconscious (Leske et al., 2013; Maxton, 2008; Meyers et al., 2000). McGahey-Oakland et al. (2007) described family members telling a child that they loved them and giving permission to the child to die. Knowing that the patient was not surrounded only by strangers was important. Family members indicated that they were able to touch the patient, and in cases where the patient died, being able to sit and talk to them and assist in post mortem care. The experience of being present throughout the resuscitation efforts allowed the family member to have a sense that they had provided comfort to the patient during the traumatic event as well as at the conclusion, no matter the outcome. Champ-Gibson et al. (2016) describe participants in her study as experiencing "being 'ushered in', 'guided through', 'praying for' and 'hoping for' when they experienced a loved one's resuscitation" (p. 72). This was supported by Meyers et al. (2000) whose participants described the experience to be spiritual.

3.4 | Seeing is believing

Witnessing the efforts of the healthcare team allowed family members to feel confident that everything was done to assist their loved one (Champ-Gibson et al., 2016; Leske et al., 2013; Maxton, 2008; McGahey-Oakland et al., 2007; Meyers et al., 2000; Tinsley et al., 2008; Wagner, 2004). Observing the professionalism and teamwork was noted as an important aspect of being present during the resuscitation efforts (Leske et al., 2013; McGahey-Oakland et al., 2007; Tinsley et al., 2008). The sheer number of HCPs involved added to the sense that everything was being done to revive the patient. Observing the patient being treated with respect also impressed some family members (Leske et al., 2013). In addition, Leske et al. (2013) found that family members felt that their presence helped to ensure that the team was doing its job. Moreover, being present during the resuscitation allowed family members to comprehend the seriousness of the situation (Maxton, 2008; Meyers et al., 2000). For some families, being present gave them an opportunity to say goodbye and provided closure (Champ-Gibson et al., 2016; McGahey-Oakland et al., 2007; Meyers et al., 2000). In addition, some family members felt it helped to facilitate their acceptance of their loved one's death and their own emotional healing (McGahey-Oakland et al., 2007; Meyers et al., 2000).

4 | DISCUSSION

To our knowledge, this is the first integrative review to comprehensively explore not only family members' perspectives and perceptions, but also their personal experiences of FPDR. Our review findings extend existing knowledge about FPDR. Although the literature reveals many HCPs are divided in their opinions about FPDR, most family members surveyed in our review favoured FPDR practice. It is clear that some family members want to be included when a loved one is being resuscitated. While they may be overwhelmed, family members have indicated that they feel it is their fundamental right to be present. This is consistent with a recent study's finding in which interviewed family members stated that they would like to have the option to be present if CPR is initiated on their family member (Sak-Dankosky, Andruszkiewcz, Sherwood, & Kvist, 2018). In contrast to some HCPs concern about the potential for psychological harm among family members during FPDR, participants in this

review did not share that same worry. In fact, some family members indicated that it helped them to heal after the death because they were aware that everything had been done for their relative.

4.1 | Policy implications

Our healthcare culture has moved to more patient-centred care, with an emphasis on family involvement. However, healthcare systems do not automatically default to allowing FPDR (Strasen, Van Sell, & Sheriff, 2015; Twibell, Siela, Riwitis, Neal, & Waters, 2018). Instead, patients' family members are all too often ushered into a waiting room to await being updated about the outcome of the resuscitation efforts of their family member as reported by Weslien et al. (2006). To address this issue, clear policies that support the option, not mandate, of FPDR as a patient-centred practice, and trained HCPs are needed for the implementation of FPDR.

This would help to alleviate the disparities that are caused by different staff members' opinion as to what is right in a code situation. This hospital-based policy initiative is supported by professional organisations such as the Emergency Nurses Association for more than 20 years (Emergency Nurses Association, 2010). Developing FPDR policy based on evidence and guided by family-centred principles will help to reduce the mistaken belief that family members are too fragile to witness such a traumatic event. The International Emergency Cardiovascular Care (ECC) and Cardiopulmonary Resuscitation (CPR) Guidelines (Cummins & Hazinski, 2000) state support and specific attention to family members are needed during resuscitation. Maxton (2008) found that family members handled the situation best when they received support by a designated staff person, a role some family members concluded was best provided by an experienced nurse. Hospitals need to develop role descriptions and trainings for FPDR facilitators who are specifically assigned to support families during FPDR.

4.2 | Education implications

Based on our findings, family members desire for FPDR; however, it is well documented in the literature that HCPs do not always embrace the practice of FPDR (Al Mutair et al., 2013; Sak-Dankosky et al., 2017). Therefore, education is needed for nurses and other HCPs. When designing FPDR educational training for nurses, the affective domain of learning should be targeted. If the affective learning domain is not addressed, more often than not the desired behaviour change of the learner will be temporary at best (Chen et al., 2017). Assessing nurses' perceptions of FPDR is a recommended first step. Nurse professional development specialists are encouraged to consider inclusion of consensus-building teaching strategies into their educational plans, realising that there may be objectors to FPDR among the targeted audience.

The teaching method to use when delivering FPDR training will depend on the resources the organisation can provide. The literature reveals that there are many ways to educate nurses about FPDR. The use of simulation, standardised patients, role-play, case studies, online asynchronous modules and traditional face to face lecture methods have all demonstrated significant gains in knowledge, skills and attitudes among nurses after FPDR trainings (Powers, 2017; Powers & Candela, 2016).

Education of nurses about FPDR needs to begin early in undergraduate nursing programs (Bray, Kenny, Pontin, Williams, & Albarran, 2016; Johnson, 2017; Sak-Dankosky et al., 2017, 2018). Faculty can target the perceptions of nursing students related to FPDR through learning activities that encourage thoughtful reflection, discussion and deliberation about FPDR practice. Kantrowitz-Gordon, Bennett, Wise Stauffer, Champ-Gibson, and Corbett (2013) created a FPDR student toolkit for faculty to consider using when addressing this potentially controversial topic with students. The toolkit includes several open access video vignettes that can be viewed by students in the classroom setting. The vignettes provide a platform that will encourage dialogue among students and faculty about the barriers and facilitators encountered with the practice of FPDR.

Nurses are part of an inter-professional team when providing resuscitation to patients. Decisions to invite, or permit, family to be present are often driven by the needs of the resuscitation team or leader as opposed to being patient-centred (Dwyer & Friel, 2016).

Inter-professional learning experiences are warranted to ensure effective FPDR practice. If a healthcare organisation or school has access to simulation, the inclusion of other disciplines (doctors, social workers, chaplains, etc.) in simulated FPDR scenarios will help to encourage FPDR practice in the workplace. This educational approach may lessen HCPs concern about performance anxiety (Johnson, 2017; Strasen et al., 2015).

4.3 | Research implications

Most of the studies in our review were surveys. Few authors of the included studies addressed survey development, content validity and pilot testing of instruments. Psychometrics should be reported in future studies to help build the science. Research using an experimental design is needed to study the short- and long-term effects of FPDR on families. Cultural implications should be considered when researching the effects of FPDR on family members (Masuda, 2017). Additional research with any particular group of patients or in a particular setting will benefit our understanding of the differences that are present. Research that explores patients' perspectives of FPDR will help add to HCPs understanding of FPDR. Moreover, there is a need to identify best practices for FPDR educational trainings with nurses and other HCPs.

4.4 | Limitations

This review has several limitations. While many countries were represented in this review, only one study was conducted in an Eastern country. It is plausible that family perspectives from Eastern countries may differ, thus supporting a need to explore the extent findings from this review are similar to, or different from family perspectives of FPDR in Western countries.

While there may be pertinent studies that were not accessed, the use of comprehensive databases and ancestry searches provided a thorough review of the research that has been done related to family perception of and experience with FPDR during CPR. As new studies are published, the integrative review should be updated.

Limitations to the studies included have been previously described (See Table 1). Although all of the cited research was rated as good using the Hawker et al. (2002) criteria, the studies were often not comparable because they studied different age groups (such as paediatrics and adults), in different settings (such as Emergency Departments and ICUs) and with different methodologies.

5 | CONCLUSION

As findings revealed family members support for FPDR while the literature shows it is controversial among nurses, this review supports the need for educational preparation of nurses and nursing students related to the practice of FPDR. Moreover, lack of policy related to FPDR leads to inconsistent patient-centred care. The establishment of policies with adequate training and resources should promote the success of including families in resuscitation of family members.

6 | RELEVANCE TO CLINICAL PRACTICE

The findings of this review are relevant for a clinical practice that promotes a more family-centred approach to allowing FPDR. Creating FPDR policy and providing FPDR education to nurses based on evidence will ensure more consistency in clinical practice and help to eliminate the moral distress experienced by clinical nurses forced to make difficult decisions during a stressful event. Clear FPDR policy and effective educational training of HCPs should help mitigate dissension among the healthcare team members.

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