UNIVERSITY OF COPENHAGEN

# FAMILY PRESENCE DURING RESUSCITATION

PhD Thesis

Herlev og Gentofte Hospital

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# PREFACE

The work presented in this thesis was carried out at the Department of Anaesthesiology, Herlev Acute, Critical and Emergency Care Science Unit (Herlev ACES). Paper I was carried out in collaboration with Cochrane Critical and Emergency care group. The Danish Society of Anaesthesiology and Intensive Care Medicine financially supported a part of the thesis.

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## Conflict of interest

Thomsen and Møller hold no conflicts of interest.
Rubin is a member of the Danish parliament with a special interest in healthcare politics.
Dieckmann holds a professorship with the University of Stavanger that was established by an unconditional grant from the Laerdal Foundation to the University, and that is now financed by the University. Dieckmann leads the EuSim group, a network of simulation centres and experts providing simulation faculty development courses.

## LIST OF PAPERS

The thesis is based on the studies described in the following four papers:

**Paper I**

Family presence during resuscitation - a Cochrane review.

Rubin MA, Svensson TLG, Herling SF, Jabre P, Møller AM.

**Paper II**

The perspectives and experiences of health care professionals with family presence during resuscitation: a synthesis of qualitative evidence

Rubin MA, Strandberg S, Thomsen T, Møller AM.

**Paper III**

Healthcare professionals' perspectives on facilitators and barriers to family presence during resuscitation in Denmark – a focus group study

Rubin MA, Frederiksen KAP, Thomsen T, Dieckmann P, Møller AM.

**Paper IV**

A survey of healthcare professionals' perspectives regarding family presence during resuscitation in Denmark

Rubin MA, Langer N, Thomsen T, Dieckmann P, Møller AM.

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# ENGLISH SUMMARY

Family presence during resuscitation (FPDR) has become standard care in some Western countries despite the sparse evidence. The extent to which FPDR is practiced in emergency care settings is not well described, and it is a practice under development in the Danish healthcare system. No national recommendations exist; however, the European Resuscitation Council (ERC) recommends FPDR. The principle of FPDR is a triangular relationship where the intervention of relatives' presence affects the healthcare professionals (HCP), the relative present, and the patient involved. All their needs and well-being must be balanced in the context of FPDR, as the actions involving one of the three can influence the other. There is a belief that FPDR provides the relatives with an opportunity for a better closure - to say goodbye – in the event of death a better grieving process. Furthermore, there is a belief that FPDR enables relatives to provide emotional support to patients. Since the first study in 1987, only three randomized controlled trials, including a qualitative survey-design, and a quasi-randomized trial reviewing the potential effect on relatives of being present, and on HCP experience, have been conducted. Because of the sparse evidence, HCP may not support FPDR, as seen in an overview of the literature, and compared to nurses, physicians are more likely to feel that the risks outweigh the benefits of FPDR.
This PhD thesis aimed to assess the evidence regarding FPDR and to investigate how FPDR affects HCP, including barriers and facilitators related to the initiative.

To investigate the evidence of FPDR, we conducted two systematic reviews. One of the existing randomized controlled trials (RCT) and one of the qualitative studies – a qualitative evidence synthesis (QES). As we found the evidence sparse, we investigated the topic 'FPDR' in a Danish context through a focus group study and a survey. Both were conducted at the emergency department (ED) at Copenhagen University Hospital, Herlev Hospital in Denmark.

In study I, we conducted a systematic review of RCT to assess the existing evidence regarding FPDR on all possible outcomes. We screened 7292 articles leading to two included studies – one much larger and of much better quality than the other. We found insufficient evidence to determine any certain effects of FPDR on relatives' psychological outcomes – or any other outcomes – but in the trial that accounts for most of the included participants (570/595), the frequency of post-traumatic stress disorder (PTSD) related symptoms was significantly higher in the group of relatives that were not invited for FPDR.

In study II, we did a QES of the existing qualitative evidence from Western countries regarding HCP perspectives on barriers and facilitating factors of FPDR as well as their experience of the

potential impact of FPDR on HCP performance. We screened 6885 articles leading to nine included studies. We identified three analytical themes, including eight descriptive subthemes, but only one was found to have High GRADE CERQual confidence: “A belief that FPDR is the right thing to do”. An engaging facilitator was the ethical principle of beneficence. Almost all included studies reported that HCP found FPDR beneficial for themselves, the patient and the family and that excluding the relatives, especially when it concerns children, might be harmful.

In study III, we conducted five focus group interviews with a total of 25 participants - 17 physicians and 8 nurses. Ages ranged from 30 to 65 years (mean 39,7 years), and the majority were female. We identified three categories and 18 themes. The two dominant categories, “facilitating factors for including relatives during resuscitation” and “barriers for including relatives during resuscitation”, included five and ten themes. Participants expressed openness and positivity towards FPDR, whilst later in the interview, they would seem more skeptical and show concern that relatives could disturb the treatment, take up space or be unsuitable bystanders. They comprehend FPDR as something supporting the relatives in coming to terms with their loss, that it humanizes the patient and allows them – the HCP - to retrieve information. Inhibitory factors included self-censorship among HCP, patient safety, lack of human resources to provide a designated support person, a lack of national guidelines, training, and education.

In study IV, we used a survey based on a previously validated survey-based risk-benefit scale of 22 items, measuring HCP perceptions of FPDR using a 5-point Likert scale to assess the perspectives of HCP on FPDR. Our primary outcome was to explore differences between nurses’ and physicians’ answers to the question, “Family members should be given the option to be present when a loved one is being resuscitated”, where we found that significantly more nurses than physicians agreed. Furthermore, more nurses believed that FPDR was a right of patients and relatives.

In conclusion, we found that despite the sparse evidence available, FPDR is somewhat implemented at Copenhagen University Hospital, Herlev Hospital in Denmark. It is, however, not implemented in a standardized way and there are both barriers and facilitators correlated to FPDR. More nurses than physicians welcome the initiative. To minimize geographical differences based on limited knowledge about the evidence and affected team collaboration in relation to FPDR implementation, a national clinical guideline adapted to Danish conditions should be considered. Future research must investigate the long-term effect on both relatives and HCP when FPDR is practiced.

# DANSK RESUMÉ

Pårørendes tilstedeværelse ved akut behandling og genoplivning er i tiltagende fokus grundet den holistiske tilgang til patientbehandlingen med involvering af både patienter og pårørende. Patienterne skal have medindflydelse på deres behandling – og når de er bevidstløse, kan man derfor argumentere for at de pårørende skal have medindflydelse. Europæisk råd for genoplivning anbefaler at invitere de pårørende med ind på akutstuen ved akut behandling og genoplivning, såfremt det er sikkert, og at der kan afsættes en støtteperson til at tage sig af den pårørende. Men da evidensen er mangelfuld, er det usikkert, hvordan pårørendeinvolvering i akutte situationer som akut behandling, traumebehandling og genoplivning påvirker det sundhedsfaglige personale og deraf patientbehandlingen samt de tilstedeværende pårørende.

Vi satte os derfor for at undersøge emnet "pårørendes tilstedeværelse ved akut behandling og genoplivning" nærmere i dette ph.d.-projekt via to systematiske oversigtartikler, et fokusgruppe studie samt en spørgeskemaundersøgelse.
Den tilgrundliggende litteratur på området viser positive resultater i særligt ét større randomiseret kontrolleret studie omhandlende pårørendeinvolvering ved genoplivning af hjertestop fra Paris. Her finder Patricia Jabre og hendes kollegaer, at det formentlig kan være gavnligt for de pårørende, når man ser på parametre som udvikling af PTSD, angst og sorgbearbejdelse samt at det ikke stresser det sundhedsfaglige personale unødigt, at de pårørende overværer genoplivningsforsøget af deres kære. Dette studie danner basis for selve ph.d.-afhandlingen.

De to oversigtartikler, som er inkluderet i ph.d.-afhandlingen, viser, at der ikke findes meget evidens af god kvalitet, når det omhandler effekten af pårørendes tilstedeværelse ved akut behandling og genoplivning, og at det er usikkert hvilke barrierer og faciliterende faktorer, der er for det sundhedsfaglige personale i forbindelse med at invitere pårørende med ind i behandlingsrummet. Vi fandt en subjektiv overbevisning om, at det er det etisk rigtige at gøre – særligt når det gælder akut syge børn.
Vi har derfor undersøgt emnet i dansk kontekst, herunder først og fremmest hvordan tiltaget påvirker det sundhedsfaglige personale, som har ansvaret for patientbehandlingen, ud fra den devise, at hvis de bliver påvirket negativt i sådan en grad at det kan gå udover patientbehandlingen, så er den eventuelle gavnlige effekt for de pårørende sekundær.
Vi genfandt i fokusgruppestudiet resultatet fra oversigtartiklen over de kvalitative studier - overbevisningen om at det er det etisk rigtige at gøre – særligt når det gælder akut syge børn. Den mest dominerende facilitator er, at det sundhedsfaglige personale oplever at de pårørendes tilstedeværelse særligt gavner dem, såfremt patienten dør, da de ser, at personalet gør alt, hvad de

kan. Det hjælper de pårørende med en afslutning. Desuden menneskeliggør den pårørendes tilstedeværelse patienten for det sundhedsfaglige personale, samt bidrager med information om patienten i behandlingssituationen. Det er dog et problem, at der ofte ikke kan afsættes ressourcer til en støtteperson til at tage sig af de pårørende samt at der ikke findes danske nationale kliniske retningslinjer for pårørendes tilstedeværelse ved akut behandling og genoplivning og herunder særligt formaliseret undervisning om det. Desuden fandt jeg via fokusgruppe og spørgeskema ligeledes, at der er forskel på, hvordan sygeplejersker og læger påvirkes af og ser på initiativet med pårørendes tilstedeværelse ved akut behandling og genoplivning på Herlev Hospital i Danmark. Sygeplejerskerne er generelt mere positivt stemt.

Vi mener, at det i en tid med et tiltagende helhedsorienteret blik på patienten er uhensigtsmæssigt, hvis ægtepar og nær familie i de sidste minutter af livet forhindres i at se hinanden. Men hvis de pårørende skal kunne tilbydes at være til stede ved akut behandling og genoplivning, må det gå hånd i hånd med en omprioritering af de personalemæssige ressourcer. Der bør være en støtteperson til stede, hvis man inviterer de pårørende med ind i behandlingsrummet. At stå helt alene for sig selv i et hjørne af en hospitalsstue med taske og frakke over armen, mens ens kære ligger livløs og man ikke ved hvad der foregår, er ikke den rigtige vej at gå. I vores verden giver det mening, at der skal være en stol at sidde på og en skulder at græde ud ved. Dét bør vi prioritere, hvis vi begynder at invitere de pårørende med indenfor.

Konklusionen på denne ph.d.-afhandling må være, at det ikke er muligt at komme med en stålsat retningslinje inkluderende en anbefaling af pårørendes tilstedeværelse ved akut behandling og genoplivning, da situationen afhænger af en triade af personer; patienten, den pårørende og det sundhedsfaglige personale. Det at invitere de pårørende med ind i behandlingssituationen må derfor primært bero sig på en klinisk vurdering.
Såfremt man fra ledelsesmæssig eller politisk side beslutter, at pårørende bør have tilbuddet om at være til stede ved akut behandling og genoplivning, bør man investere i undervisning af det sundhedsfaglige personale fx simulationsbaseret for at øge trygheden og minimere stressbelastningen samt understøtte yderlige forskning på området. Desuden bør man have en plan for debriefing af både personale og pårørende efterfølgende og der skal afsættes personalemæssige ressourcer til rollen som støtteperson for de pårørende.

# ABBREVIATIONS

| | |
|---|---|
| CPR | Cardiopulmonary resuscitation |
| ED | Emergency department |
| EMS | Emergency medical service |
| ERC | European Resuscitation Council |
| FPDR | Family presence during resuscitation |
| HCP | Health care professionals |
| PTSD | Post-traumatic stress disorder |
| QES | Qualitative evidence synthesis |

# INTRODUCTION

When relatives (e.g., siblings, parents, spouses, children or close friends) to the patient are co-present in the resuscitation room, it is described as "family presence during resuscitation" (FPDR), and when FPDR is practiced, relatives are in direct contact with both the patient and the healthcare professionals (HCP) during the resuscitation attempt rather than placed outside e.g., in a waiting room. This allows relatives to interact with the patient, like holding the patient's hand and talking to them. In both the prehospital and emergency care systems, HCP have gained increased interest in FPDR.

Whether FPDR should be encouraged is a question that remains to be answered as the certainty of the available evidence is low[1–3]. Since the earliest known case in 1983 at Foote Hospital in the United States[4] and the first study in 1987[5], only a few higher quality clinical trials have been performed regarding FPDR[6–9]. Based on this evidence and expert opinion, the European Resuscitation Council (ERC) recommends that relatives should be offered the choice of being present during cardiopulmonary resuscitation (CPR)[10].

## Family-centered care

In recent decades, countries, such as America, Australia, and European countries including England, have shifted from a paternalistic approach in the relationship between the HCP, patient, and relatives towards a principle of family-centered care and personal autonomy. Increased societal interest in family-centred care could be the reason why FPDR is growing in healthcare practice.

When talking to the relatives, it is clear that they expect to be actively involved in care decisions involving the treatment of their relatives[11,12]. Even during resuscitation[a] and acute medical care, patients often want to have their relatives nearby, and relatives want to be present if offered the choice[9,12–18].

In lieu of this, it is relevant to note that FPDR is a triangular relationship involving both the HCP, the relatives present, and the patient. The needs and well-being of all parties must be balanced in the context of FPDR as the actions of all three parties mutually influence each other. As we shall see, the opinions regarding FPDR vary greatly among professionals for this very reason. It has especially been debateable during the recent Covid-19 pandemic as FPDR could be regarded as a contributor to palliative care[19].

[a] "Resuscitation" is defined as "the action or process of reviving someone from unconsciousness or apparent death" rather than equal cardiopulmonary resuscitation (CPR), as many seem to believe.

## A triangular relationship between patients, relatives and healthcare professionals

### The patients

Qualitative studies of patients' experiences of FDPR indicate that relatives provide encouragement, comfort, and support to the patient through their presence. For example, a patient stated that he felt "aware of his wife's presence", and that this encouraged him to fight on[20]. Patients want relatives to be present and to be a part of the treatment [5,18,21–24] and their presence does not appear to compromise the patients' dignity or breach confidentiality[9]. Patients also experience that their relatives have an important role in reminding HCP of their personhood[25]. Furthermore, in the only large, randomized trial of FPDR no difference in patient mortality was found[8]. However, we must be aware that during FPDR the patient is often unconscious, and their wishes can therefore not be confirmed. This can be a threat to patient integrity and to the confidentiality between patient and HCP.

### The relatives

Some relatives believe that it is their right to be present[12] and in the event of death, there is emerging evidence indicating that FPDR may help to assure relatives that everything possible was done to save the patient[7,13]. It is believed that witnessing the procedures and communication among HCP can facilitate the understanding of the person's death and help with coping[13]. The single high-quality trial of FPDR showed positive effects on relatives' psychological outcomes[8]. The authors concluded that FDPR in the context of pre-hospital CPR facilitated relatives' acceptance of the reality of death[8,13,26]. Nevertheless, FPDR can be challenging for relatives if they are not provided with an explanation or rationale for the actions of the HCP. Furthermore, it can be a traumatic experience on its own for the relatives when a dear person is suddenly in need of critical medical care. A designated support person, which is recommended if FPDR is practiced, can therefore be seen as a part of providing family centered care as FDPR has been observed to improve psychological outcomes in relatives[1,8].

### The healthcare professionals

Attitudes towards FPDR vary among HCP [17,27–36]. It is interesting to compare FPDR to the debate regarding parent involvement in pediatrics and obstetrics, which has become the modern working model[37]. This practice has been debated amongst HCP the same way as FPDR is now[38].
Some HCP are concerned that the initiative might have potential adverse psychological effects on relatives, as well as a negative impact on the HCP performance. This could subsequently affect the quality of critical medical care, and thereby worsen patient outcome[39–41]. Narrative reviews found that physicians often perceive more barriers associated with FPDR than nurses,

but perceptions may also vary in different cultural settings[31,34,42–45]. This is highlighted by the fact that the only official FPDR clinical guideline, to our knowledge, is from the Emergency Nurse Association, providing a moderate recommendation for FPDR[46]. Hospitals with an FPDR policy have not been seen to have statistically significant differences in outcomes and processes of care, when compared to hospitals without this policy, suggesting such policies may not negatively affect resuscitation care [47]. A positive experience of FPDR can potentially influence the views and attitudes in this evolving area of practice towards a more positive mindset about FPDR [48].

The potential effects of stress inferred by FPDR on physician's performance in clinical situations is poorly understood. Elevated stress levels can impede performance on tasks that require divided attention, working memory, retrieval of information from memory, and decision making[49]. Moderate-quality evidence suggests that FPDR does not affect adult resuscitation outcomes[1]. Jabre and colleagues found no increase in stress levels of HCP[8]. Likewise, a paediatric study of FPDR found no differences in the success rate of critical interventions[6] and others did not experience a negative impact on medical care in the presence of parents[50]. Furthermore, the ability to get a patient history quickly is an advantage[36].
On the other hand, studies of student nurses' and young physicians' performance during a simulated cardiac arrest with FPDR indicate that the presence of relatives may negatively impact the quality of acute medical care[39,40]. Similarly, a simulation study, including paramedics, observed that the presence of socioemotional stress, in this case from the presence of an upset friend, increased the subjective workload and frustration of HCP[51]. This is important to acknowledge as the impact on the HCP should also be considered[52,53].
Furthermore, FPDR can take a toll on hospital resources since it is recommended that the relative has a designated support person present, as an add-on to the resuscitation team[6,17,28,33,45,54]. This helps with the aim of protecting the relative and avoiding misunderstandings that might lead to possible lawsuits.

# THE OBJECTIVES

Almost 400 adults suffer from cardiac arrest annually in the Danish emergency departments (ED)[55] and many more patients are met by the trigger teams for trauma, STEMI, stroke and medical emergency[56]. If just some of these patients have a relative by their side, it is important to explore the impact of FPDR.

This PhD thesis aimed to assess the evidence regarding FPDR and to investigate how FPDR affects HCP including barriers and facilitators related to the initiative.

We wanted to investigate the published evidence regarding the topic FPDR in both a quantitative and qualitative way on the basis of a prehospital RCT regarding FPDR in Paris in 2013[8]. In Denmark no national clinical guideline regarding FPDR exists, but it is recommended that patients and relatives should have more influence on treatment decisions in the healthcare system in general, and the use of patient satisfaction surveys should be more widespread[57].

## Preunderstanding

Firstly, we expected an evidence gap regarding FPDR. Secondly, during the two qualitative studies at the ED at Herlev Hospital, we expected that HCP would express uncertainty concerning FPDR and that their attitudes toward FPDR would be shaped by different factors: previous experience with the practice, seniority, and the fear of relatives' complaining to the Danish Board of Patient Safety. Lastly, we had a preconception regarding the hierarchies amongst the included professions, physicians and nurses, as Witz has shown in her studies[58]. Physicians are the ones with the primary responsibility regarding patient care and we therefore expected them to have more barriers to FPDR than nurses, whom we expected to be more open and therefore have a larger focus on facilitators.

We had the preunderstanding that nurses have a more holistic recovery-oriented approach to patients emphasizing the importance of addressing their physical, emotional, social, and spiritual needs and recognizing the interconnectedness of these aspects of health. They view recovery as a process of personal growth and transformation, rather than simply a return to a state of pre-illness functioning and recognize that the person is a part of a family. And the nurse is often provided the role as the contact person to the family, enhancing this holistic approach.

On the other hand, we had a preunderstanding that physicians are more oriented in a biomedical discourse emphasizing the use of diagnostic tests, medications, and other medical procedures to identify and treat health conditions. Our preunderstanding was that physicians have a focus on physiological and biochemical processes and prioritizing objective measures of health, such as laboratory tests and imaging scans, over subjective experiences and social or cultural factors that contribute to health disparities.

# METHODS AND METHODOLOGICAL CONSIDERATIONS

For this PhD project, we used different methods. First, we conducted two systematic reviews to investigate the evidence. A quantitative intervention review summarizing existing RCTs and one summarizing results from qualitative studies. As the FPDR initiative depends on the cultural settings, we narrowed the investigation to Danish emergency care HCP and which barriers and facilitating factors they perceive. These studies were conducted at Herlev Hospital, a university hospital in The Capitol Region of Denmark with a population of 1.85 million. This one of five ED in the region, participated in our research. This department has no policy for FPDR, and the inclusion of relatives depends entirely on the emergency care team.

## Rationale for choice of study design

At the beginning of the doing of this PhD project, we wanted to gain knowledge about FPDR. We therefore initiated the Cochrane review to identify gaps in the existing evidence base, highlighting areas where further research was needed. Unfortunately, we were confirmed in our preconception about the lack of high-quality evidence regarding FPDR in relation to all three participants: patients, relatives, and HCP. Therefore, we initiated the QES review of HCP experience including barriers and facilitators. This decision was made because the impact on HCP is of most importance, as a negative impact can impede patient care. In our opinion, the effect of FPDR on HCP and subsequently patient outcome is the number one top priority. It was therefore our goal to investigate the impact on HCP before going on with further studies investigating the effect on the relatives.
By doing two systematic reviews we believe that we have included all relevant studies on FPDR, ensuring that the evidence is as complete as possible. The strength of doing a systematic review lies in its rigorous methodology, comprehensive evidence synthesis, transparency, and minimization of bias, which collectively enhance the credibility, reliability, and generalizability of the findings. In both reviews, we made a GRADE evaluation (Grading of Recommendations, Assessment, Development, and Evaluation) including a risk-of-bias (RoB) assessment that is a necessity for methodological quality evaluation of the included studies and provides a structured and transparent process for assessing the certainty of evidence.

From the start we wanted to investigate how relatives and HCP were affected by FPDR quantitatively in a RCT in the ED at Herlev Hospital inspired by the study by Jabre from 2013[8]. But when the Covid-19 virus spread all over the world leading to lock downs and the exclusion of relatives at the hospital, we had to rethink the project. We believe it ended up for the better. We changed the predefined pathway and investigated the topic qualitatively instead. In this way we

were able to explore the concept of FPDR and the HCP experience, thoughts, barriers, and facilitators better. We decided to investigate the topic further in relation to Danish HCP through a focus group study and a survey at the ED in Herlev Hospital.

Qualitative research can provide rich and detailed data about participants' experiences, perspectives, and attitudes. With the focus group study, we wanted to gain an in-depth understanding of HCP experiences, and beliefs and we wanted to get an understanding of the context in which HCP work. We wanted to understand the factors that influence their experienced barriers and facilitators and generate new knowledge about FPDR that has not previously been explored or recognized.
The advantage of using the survey methodology is that it is a cost-effective way to provide standardized questions to a large group of people and thus reducing the potential for bias and increasing the reliability of the results. The answers could be given anonymously encouraging respondents to be more honest in their answers. In our study, we used a previously validated survey-based risk-benefit scale.

## Limitations in chosen study design

One of the limitations of doing a systematic review is the thoroughness, as it is very time-consuming. Furthermore, a systematic review has limitations, including potential selection bias, heterogeneity of studies, and publication bias, which may impact the validity and generalizability of findings. Methodological limitations of included studies and subjective judgments in the interpretation of findings can also affect the reliability and applicability of the conclusions.
A limitation of the survey design is that surveys often provide a limited depth of information compared to other methods, such as focus groups, as surveys are limited by the questions that are asked, which may not capture all the nuances. Respondents may not be able to fully express their thoughts or feelings on a topic, and the surveys may therefore have difficulty capturing complex emotions, attitudes, or beliefs. It was, therefore, important for us to include both the survey study design and focus group in the thesis. Another limitation of surveys is self-selection bias, which occurs when only certain types of people choose to respond to the survey. This can result in a biased sample that does not accurately reflect the views of the entire population.
Regarding both the focus group study and the survey, we must consider the risk of a sampling bias. The study participants are not representative of the whole population of HCP in Denmark as recruiting was limited to a particular hospital.
A social desirability bias, where respondents want to present themselves in a favorable light or due to misunderstanding or confusion about the questions, must be considered in both study designs.

Regarding the focus group study, a response bias could occur because of the group dynamics. Participants were sitting across each other and therefore, there was a possibility for the participants to not respond truthfully to the questions. Furthermore, focus groups typically involve a small number of participants, usually between six to ten people per group. This can limit the transferability of the findings, as the opinions and perspectives of the participants may not reflect those of the larger population.

## Outline of study methods

**Study I**

In this systematic Cochrane review we included RCTs where the intervention offered relatives the opportunity of FPDR in the ED or prehospitally. We could not do a meta-analysis as we could only include two studies with high heterogeneity.

We formulated a clear and focused clinical question by identifying the Population, Intervention, Comparison, and Outcome of interest (PICO): The population of interest in the review was all types of HCP as described in the included studies, adult relatives, and patients. These three categories of participants were important to include as FPDR affects all participating categories in a triangular relationship. Regarding the patients and HCP, the intervention was if there had been FPDR or not. We defined relatives as siblings, parents, spouses, children or close friends of the patient, or any other descriptions used by the authors. We had no limitation on age or gender regarding the patients and HCP but included only adult relatives. The intervention was offering relatives the option to be present during resuscitation and we defined the type of patients undergoing FPDR as being a patient with a critical medical, surgical, or traumatic condition, an unconscious patient, a patient in cardiac arrest, or a patient in any other way at risk of death. The comparison was not to offer the relatives the opportunity of FPDR systematically. We included all outcomes found; however, our primary outcome was the incidence of post-traumatic stress disorder (PTSD) in relatives measured on the short and long term.

We did a systematic search following Cochrane standards without language, publication year or publication status restrictions and two authors independently and in duplicate screened the search results for eligible studies and extracted relevant data. We used the program Covidence in the selection process, so we had sufficient detail to complete a PRISMA flow diagram.

We were very aware that one of the co-authors of the review was also the first author of an included primary study in this review. She was, therefore, not included in the screening, data extraction or assessment of risk of bias process in any way. For risk of bias assessment, we used Cochrane's risk of bias (RoB 2) tool and to assess the certainty of the body of evidence, we used the GRADE system.

**Study II**

In this systematic review with thematic synthesis, we included primary studies from countries in the Western Hemisphere. The studies should explore experiences of FPDR in the ED from the HCP perspective, using qualitative study designs, data collection and analysis. We conducted a systematic literature search, applying Cochrane methodology and followed the Enhancing Transparence in REporting the synthesis of Qualitative research (ENTREQ) guidelines to enhance quality[59].

The participants underwent interviews regarding their perspectives on barriers and facilitating factors of FPDR in relation to the treatment of adults. Further, the studies explored their experience and reflections on the potential impact of FPDR on HCP performance. We had no limitations on age or gender and defined the type of patient undergoing FPDR as being a patient with a critical medical, surgical or traumatic life-threatening condition, an unconscious patient, patient with cardiac arrest and in need of CPR, or a patient in any other way at risk of death.

No language, publication year or publication status restraints were applied to this search.

Two review authors screened the search results for eligible studies, and we used Rayyan for transparency to develop a PRISMA flow diagram. We imported the included studies into NVivo data analysis software[60] and followed the method for thematic synthesis described by Thomas and Harden to analyse data[61]. We extracted all relevant data about barriers and facilitators together with HCP experience of FPDR performed with line-by-line coding. Codes were then organized into categories and further interpreted in analytical themes. All the included studies underwent quality appraisal by the Critical Appraisal Skills Programme (CASP)[62] and we used GRADE CERQual (Grading of Recommendations, Assessments, Development and Evaluation Confidence in the Evidence from Reviews of Qualitative research) to assess the confidence in the qualitative synthesis findings[63].

**Study III**

In this qualitative focus group study regarding barriers and facilitators to FPDR, we recruited physicians and nurses from the ED. No prior experience with FPDR was required for participation. We decided to use focus groups rather than individual interviews, to encourage dynamic discussion about FPDR. We recruited and informed participants about the aim of the study through either lectures, by e-mail, or by personal contact. We recruited six to eight participants by purposeful sampling for five focus groups. The study was conducted in early 2022 from 7.30 – 9am on Wednesdays in a conference room at Herlev Hospital. We applied both homogenous and heterogenous group composition. We followed a semi structured interview guide, wherein the

interviewer could skip or add questions[38]. Before completing the guide, we did two pilot interviews, to sharpen the interview guide and research focus. Interviews were recorded and transcribed verbatim.

We analysed data using inductive thematic analysis[64]. We coded the interviews inductively using the software NVivo, identified themes in the transcribed data and extracted relevant quotes into a table. All themes were then sorted across interviews into codes. We looked for correlations in the codes and created overall categories which pertained to the research focus.

**Study IV**

This study was performed by survey methodology using a self-administered anonymous electronic survey. The survey was distributed by email to nurses and physicians assumed to be working in the ED including a link to the survey. Unfortunately, no email directory connected directly to the HCP employed in the ED at Herlev Hospital exists, so the email survey was sent out to more HCP than those solely of interest to the study. Experience with FPDR was not a necessity as we simply wanted to gain knowledge about FPDR in the Danish setting.

We used SurveyXact for data collection. The study was carried out between 20$^{th}$ of May and 8$^{th}$ of June 2022. Participants were given 2,5 weeks to complete the survey. A reminder was sent after one week and one day before deadline. We used a Danish version of the validated Family Presence Risk-Benefit tool by Twibell including 22 questions regarding FPDR on a 5-point Likert scale[65,66]. We translated the tool into Danish by performing the 'Forward-Backward' translation method[67,68] to facilitate better understanding and more accurate answers among participants. We tested the survey on a pilot group of four HCP. They were asked to complete the survey and to consider both content and context to reach face validity (qualitative validation)[69]. Our primary outcome was to explore differences between HCP answers to the question "Family members should be given the option to be present when a loved one is being resuscitated".

We used descriptive statistics for each measurement item. To assure, that the power of the Mann-Whitney U test was 0,8, the sample size was determined by Monte Carlo simulation [70]. To reach that power we had to include a minimum of 43 and a maximum of 129 participants in each group; nurses and physicians. We ended up including 51 nurses and 100 physicians. The Mann-Whitney U test was used to assess potential differences in answers amongst HCP who had experienced FPDR and those who had not. Additionally, we examined potential differences in answers amongst HCP according to seniority and gender. Furthermore, we assessed demographic characteristics of HCP and experiences with FPDR. At the end of the survey, it was possible for the participants to provide comments.

## Ethical considerations

Written and verbal consent from the participants was obtained before the interviews. The regional ethics committee of the capital region of Denmark (Journal 21046372) waived all studies from undergoing formal ethics review.

The interviews were recorded, transcribed verbatim and kept on a locked server, maintained by the Department of Anaesthesiology at Herlev and Gentofte University Hospital. We gave thorough thought to anonymization due to the sensitive nature of cases mentioned in focus group interviews and balanced between diminishing traceability, whilst maintaining the context [71–73]. The survey was conducted using SurveyXact and the focus group using NVivo, which entails that the data are protected and safe. Both the focus group and the survey study were reviewed by the Knowledge Centre on Data Protection Compliance and obtained permissions (P-2021-515 and P-2022-547).

## RESULTS

There is insufficient evidence to determine any specific effects of FPDR. This includes relatives' psychological outcomes, the effect on HCP in relation to stress, barriers, facilitating factors or any other influence, and patient treatment, mortality, or morbidity. However, we found an overriding belief among HCP that FPDR is the right thing to do and that an ethical principle of beneficence is dominant, especially in regard to children. Additionally, the survey indicated that nurses in Denmark are more positive regarding FPDR than physicians. The nurses were more likely to agree that "Family members should be given the option to be present when a loved one is being resuscitated" and in the focus group study, HCP mentioned that FPDR humanizes their patients and allows them to quickly retrieve relevant information about the patient. In the focus group study, we found that inhibitory factors included self-censorship among HCP, possible risks to patient safety, a lack of a designated support person, national FPDR guidelines, and training.

After removing duplicates, we went through 6794 records in the Cochrane review and 6885 in the QES review. We included two studies with 595 participants and nine studies with 134 participants in the reviews. In the focus group study, we included 25 participants and in the survey 151.
In the Cochrane review, the two studies from 1998[9] and 2013[3,8,26] were overall at high risk of bias and the evidence was of very low certainty. The participants were 19 to 78 years old. In the trial by Jabre with most of the included participants (570/595), the frequency of PTSD related symptoms in the relatives was significantly higher in the group of relatives, who were not randomized for FPDR. In their per-protocol analyses, a significant statistical difference was found in favour of FPDR when looking at PTSD, complicated grief, and depression after a year.
Most of the nine studies in the QES review from 2005-2019 lacked sufficiently rigorous data analysis and most findings were appraised to have moderate GRADE CERQual confidence. The overall age range was 24-65+, however three studies did not report the participants' age. We identified eight descriptive subthemes in three analytical themes but only the finding "A belief that FPDR is the right thing to do" was found to have High GRADE CERQual confidence. A central facilitator was the ethical principle of beneficience[74] as studies reported that HCP thought FPDR beneficial for themselves, but especially beneficial to the patient and the relatives and that it would be harmful to exclude the relatives of critically ill or dying people.

In the focus group interviews participants expressed openness and positivity towards FPDR whilst later in the interview they would seem more skeptical and show concern that relatives should disturb the treatment, take up space or be unsuitable bystanders. We considered whether participants experienced a dichotomy between stating that the relatives could obstruct their work

and whether they were doing their job including a holistic approach and performing family centered care. They comprehended FPDR as something supporting the relatives in coming to terms with their loss, that it humanizes the patient and allows them – the HCP - to retrieve information. Inhibitory factors included self-censorship among HCP, patient safety, a lack of a designated support person, national guidelines, and training and education. Participant's age ranged from 30 to 65 years (mean 39,7 years) and the majority were female (17/25) and 17/25 were physicians. We identified three categories and 18 themes. The two dominant categories "facilitating factors for including relatives during resuscitation" and "barriers for including relatives during resuscitation" included five and ten themes.

A total of 100 physicians and 51 nurses with a median age of 36-40 years answered our survey – some of them could be the participants from the focus group, but as the survey was anonymous, we do not know. Only 4% of the participants had not experienced FPDR and more than half (62%) had more than 6 years of clinical experience. Significantly more nurses than physicians considered "Family members should be given the option to be present when a loved one is being resuscitated" (p-value 0,0127), and that FPDR was a right of patients and relatives (corrected p-value 0,0004). The answers were not affected by either gender or seniority. The nurses also agreed more than physicians did with the statement that FPDR is a right that patients and relatives should have.

Overall, we found that even though the evidence regarding FPDR is sparse, it is implemented at some hospitals including the ED at the Copenhagen University Hospital, Herlev Hospital in Denmark. FPDR is however not implemented in a standardized way and there are both barriers and facilitating factors correlated to that. More nurses than physicians welcomed the initiative, and the primary concern was the toll on resources given that a dedicated support person to take care of the relative is recommended. The lack of education regarding the topic was also a barrier.

## GENERAL DISCUSSION

The strength of this thesis is the interdisciplinary group of supervisors and authors. A further strength is the use of multiple study designs. The group of supervisors included a nurse with specialization in qualitative studies and QES reviews, a psychologist with specialization in work- and organizational psychology and experience in qualitative studies and an anaesthesiologist with specialty in quantitative study designs and systematic reviews. The co-authors of the studies included two trainees - an anaesthesiologist and cardiologist – and a medical anthropologist. On that basis, the thesis includes four different study which offer valuable angles onto this topic.

Across the studies comprising this PhD thesis we found that among HCP there is "a belief that FPDR is the right thing to do". We believe this is especially interesting, as the evidence regarding the effect of FPDR is very low[1–3]. We found that both the quantitative and qualitative evidence regarding FPDR is overall sparse and often of low quality[75,76].
However, even though no national clinical guideline regarding FPDR exists in Denmark, the topic of FPDR was relevant to explore as it is recommended that patients and relatives should have an increased influence on the treatment in the healthcare system in general. In addition, our survey and focus group interview confirmed our assumption, that FPDR is practiced in Denmark. This is no wonder as the ERC state that *"teams should offer family members the option to be present during resuscitation in situations where it is safe, and when the family can be adequately supported"*[10]. A problem with this statement is that the words "safe" and "adequately supported" are up for interpretation. Many recommend a designated support person as an add-on to the resuscitation team[6,17,28,33,45,54]. This can take a toll on hospital resources. As we found in our focus group study, the lack of such a support person is often a barrier for FPDR.
A central facilitator in our QES review was the ethical principle of beneficience[74] as studies reported that HCP thought FPDR beneficial for themselves, but especially beneficial to the patient and the relatives and that it would be harmful to exclude the relatives of critically ill or dying people. By including the relatives, the patient's wishes and values can be taken into consideration, informed consent ensured and cultural and religious beliefs respected. In the focus group study we found that FPDR humanized the patient for the HCP which is in line with other studies where patients express that relatives have an important role in reminding HCP of the patient's personhood[25]. Furthermore, the HCP we interviewed also valued the easy and quick access to the patient's history as an advantage – in line with other studies[36].

However, the results were not black and white. Throughout the studies, and especially in the focus group, we found a feeling of dichotomy. We believe that a social desirability bias, where

respondents wanted to present themselves in a favorable light, made them more positive in regard to FPDR in the begging of the interviews, because there was “a belief that FPDR is the right thing to do”. But then later during interaction with the other participants, it became more socially acceptable to question the praxis of FPDR. This process could be because of our believe in the fact that individuals construct knowledge and meaning through their interactions with others and the world around them, and this knowledge is not purely objective or innate but is shaped by social and cultural factors. The different individuals participating FPDR construct different meanings or understandings of the phenomenon, based on their unique social and cultural backgrounds. Therefore, we believe FPDR can become self-affirming because of confirmation bias. This cognitive bias makes people selectively interpret and accept information that confirms their preexisting beliefs or attitudes while ignoring or discounting information that challenges them. If a HCP think it is good for the relatives to be involved, they have fewer barriers against FPDR and invite them in more often. But then when they start interacting with others, questioning the praxis, they become less certain.

Both in our focus group study and in the literature, we found that FPDR facilitates clinicians’ overview of the patient’s history and status, making the presence of relatives an advantage during resuscitation[36]. This may lead to better and faster diagnostics, which is helpful for both patient outcomes and hospital economics, through reduction of unnecessary diagnostic tests. Furthermore, FDPR might reduce excessive non-beneficial treatment[13]. In an unpublished prehospital survey study, the opposite was however found: the resuscitation attempts were experienced by the HCP to carry on for a longer time in regard to the relatives [77].
An important component in FPDR implementation is education of the HCP, therefore one of the important barriers found was the lack of training and education. Not receiving education is a practice barrier and trained personnel with experience who follow a written policy / guideline are more likely to support FPDR[78–80]. During our research we were told, that in Sweden (Malmø and Lund) FPDR is completely systemized: the relatives sit on a chair and there is a chair next to it, for a social and healthcare worker to supports them.

The trustworthiness in relation to the analysis of focus group data was enhanced by the fact that we were two researchers doing the analysis in both the QES review and the focus group study. It increased the credibility of the findings by allowing for different perspectives and interpretations of the data. We reduced the potential biases and subjective influences of a single researcher, leading to more robust and reliable findings. We also enhanced confirmability by critically reviewing each

other's interpretations, ensuring that the findings were grounded in the data and not influenced by individual biases.

During the focus group, we were concerned about the hierarchy amongst physicians and nurses, as Witz has shown in her studies[58], but found that a heterogeneous composition in fact stimulated verbal interaction[81]. In the focus group interviews participants expressed openness and positivity towards FPDR whilst later in the interview they would seem more skeptical and show concern that relatives should disturb the treatment, take up space or be unsuitable bystanders. This enhances our concern about a possible response bias. Because in contrast to one-on-one interviews, our participants were part of a group, and the group dynamics could have favored those more positive about FPDR. However, we built up the interview guide in a way that guided the group to reflect on barriers and facilitators in the second half of the interview, where we believed that the participants would be more comfortable.

Regarding the survey, almost twice as many physicians compared to nurses participated. We must therefore consider the risk of self-selection bias. Were participants all the positive-minded nurses and the more negative-minded physicians?

## Clinical implications and future perspectives

This project sheds light on current evidence for the impact of FDPR on psychological outcomes in relatives' and HCP's experiences of barriers, facilitators and perspectives regarding the potential for implementing FDPR. This knowledge can be incorporated into a future large RCT investigating the patient-important clinical outcome of FDPR, psychological outcomes in relatives and the effect on HCP stress. We need to explore how patient treatment and relatives' and HCP's psychological outcomes are affected. Future research must investigate the long-term effect on both relatives and HCP when FPDR is practiced.

Hypothetically, FPDR may improve outcomes for patients and relatives and thereby reduce socioeconomic costs by improving patient care because relatives contribute knowledge about the patient. FPDR may also reduce sick leave among relatives related to anxiety, depression, and PTSD. The inferred economic consequences on the individual and societal level may also be reduced.

Regarding organ donation, FPDR may also be relevant[82]. FPDR facilitates a closer relationship between HCP and the relatives, making it potentially easier to talk about organ donation. It has been decided by legislation in Denmark that everyone who can and wants to donate his or her organs should have the opportunity to do so. You can almost call it a patient right. However, it can be difficult for the relatives to make this decision – especially if the patient has not decided on organ donation. In addition, the presence of relatives can also be seen from a palliative point of view, also

in the acute situation[19]. The patient and the relative can be scared and nervous, and being together relieves each other.

This PhD thesis provides evidence on FPDR and how the initiative is seen among Danish HCP, making it easier for decision-makers to understand the state of the evidence and make informed decisions.
However, while resuscitation is intended to save a person's life, it can also present several ethical challenges[83]. This requires careful consideration of the patient's medical history, prognosis, wishes, values, cultural and religious beliefs, and potential benefits and harms, which is why HCP should work collaboratively with the patient and their relatives to make informed and ethical resuscitation decisions. To minimize geographical differences based on limited knowledge about the evidence and affected team collaboration in relation to FPDR implementation, it is believed that a national policy addressing FPDR could be an advantage[84,85].
If it is decided from a managerial or political point of view that relatives should have the offer to be present during resuscitation one should invest in training of HCP, e.g. simulation-based, to increase safety and minimize stress. In addition, there should be a plan for debriefing of both staff and relatives afterwards, and staff resources must be allocated to fulfil the recommendation of having a designated support person for the relative present.

The principle of FPDR is a triangular relationship where the intervention of relatives' presence affects the HCP, the relative present, and the patient's care. All their needs and well-being must be balanced in the context of FPDR, as the actions involving one of the three can impact on the other. Furthermore, the whole organization surrounding the persons, should also be taken into consideration.

# CONCLUSION

This PhD project has contributed to the evidence base regarding FPDR and generated new knowledge about HCP perspectives on barriers and facilitating factors of FPDR. The overall evidence regarding HCP is sparse, and there is a feeling of dichotomy about the praxis.
The results can be used as an information base for future interventional studies investigating especially the long-term effect on both relatives and HCP when FPDR is practiced and subsequently inform the content of educational programs by giving focus points for the reflection of the FPDR praxis.

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# ATTACHMENTS

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|---|---|
| Study I | Family presence during resuscitation - a Cochrane review |
| Study II | The perspectives and experiences of health care professionals with family presence during resuscitation: a synthesis of qualitative evidence |
| Study III | Healthcare professionals' perspectives on facilitators and barriers to family presence during resuscitation in Denmark – a focus group study |
| Study IV | A survey of healthcare professionals' perspectives regarding family presence during resuscitation in Denmark |

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# Family presence during resuscitation

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# Abstract

## Background

Patients and their relatives often expect to be actively involved in decisions of treatment. Even during resuscitation and acute medical care, patients may want to have their relatives nearby, and relatives may want to be present if offered the possibility. The principle of family presence during resuscitation (FPDR) is a triangular relationship where the intervention of family presence affects the healthcare professionals, the relatives present, and the care of the patient involved. All needs and well-being must be balanced in the context of FPDR as the actions involving all three groups can impact the others.

## Objectives

The primary aim of this review was to investigate how offering relatives the option to be present during resuscitation of patients affects the occurrence of post-traumatic stress disorder (PTSD)-related symptoms in the relatives.

The secondary aim was to investigate how offering relatives the option to be present during resuscitation of patients affects the occurrence of other psychological outcomes in the relatives and what effect family presence compared to no family presence during resuscitation of patients has on patient morbidity and mortality.

We also wanted to investigate the effect of FPDR on medical treatment and care during resuscitation. Furthermore, we wanted to investigate and report the personal stress seen in healthcare professionals and if possible describe their attitudes toward the FPDR initiative.

## Search methods

We searched CENTRAL, MEDLINE, Embase, PsycINFO, and CINAHL from inception to 22 March 2022 without any language limits. We also checked references and citations of eligible studies using Scopus, and searched for relevant systematic reviews using Epistomonikos. Furthermore, we searched ClinicalTrials.gov, WHO ICTRP, and ISRCTN registry for ongoing trials; OpenGrey for grey literature; and Google Scholar for additional trials (all on 22 March 2022).

## Selection criteria

We included randomized controlled trials of adults who have witnessed a resuscitation attempt of a patient (who was their relative) at the emergency department or in the pre-hospital emergency medical service.

The participants of this review included relatives, patients, and healthcare professionals during resuscitation.

We included relatives aged 18 years or older who have witnessed a resuscitation attempt of a patient (who is their relative) in the emergency department or pre-hospital. We defined relatives as siblings, parents, spouses, children, or close friends of the patient, or any other descriptions used by the study authors. There were no limitations on adult age or gender.

We defined patient as a patient with cardiac arrest in need of cardiopulmonary resuscitation (CPR), a patient with a critical medical or traumatic life-threatening condition, an unconscious patient, or a patient in any other way at risk of sudden death. We included all types of healthcare professionals as described in the included studies. There were no limitations on age or gender.

## Data collection and analysis

We checked titles and abstracts of studies identified by the search, and obtained the full reports of those studies deemed potentially relevant. Two review authors independently extracted data. As it was not possible to conduct meta-analyses, we synthesized data narratively.

## Main results

The electronic searches yielded a total of 7292 records after deduplication. We included 2 trials (3 papers) involving a total of 595 participants: a cluster-randomized trial from 2013 involving pre-hospital emergency medical services units in France, comparing systematic offer for a relative to witness CPR with the traditional practice, and its 1-year assessment; and a small pilot study from 1998 of FPDR in an emergency department in the UK.

Participants were 19 to 78 years old, and between 56% and 64% were women. PTSD was measured with the Impact of Event Scale, and the median score ranged from 0 to 21 (range 0 to 75; higher scores correspond to more severe disease). In the trial that accounted for most of the included participants (570/595), the frequency of PTSD-related symptoms was significantly higher in the control group after 3 and 12 months, and in the per-protocol analyses a significant statistical difference was found in favor of FPDR when looking at PTSD, anxiety and depression, and complicated grief after 1 year.  One of the included studies also measured duration of patient resuscitation and personal stress in healthcare professionals during FPDR and found no difference between groups. Both studies had high risk of bias, and the evidence for all outcomes except one was assessed as very low certainty.

## Authors' conclusions

There was insufficient evidence to draw any firm conclusions on the effects of FPDR on relatives' psychological outcomes.

Sufficiently powered and well-designed randomized controlled trials may change the conclusions of the review in future.

# Plain language summary

# Family presence during resuscitation

**Why is this question important?**

Patients and their relatives increasingly expect to be actively involved in the decisions of treatment. However, there are concerns that family presence during resuscitation (FPDR) can lead to post-traumatic stress disorder (PTSD)-related symptoms in relatives, or have a negative impact on the performance of healthcare professionals, thereby hampering the quality of critical care. There are also concerns that patient confidentiality can be violated, as the patient's thoughts and preferences in the situation are unspoken. The needs of all participating individuals must be balanced, as the actions involving patients, relatives, and healthcare professionals is seen as a triangular relationship that may impact one another.

**What did we want to find out?**

We wanted to examine the existing evidence for the effect of FPDR, including cardiac arrest, trauma, and acute medical care.

The primary aim of this review was to investigate how offering relatives the option to be present during cardiac arrest, trauma, or acute medical care of their loved ones affects the occurrence of PTSD-related symptoms in the relatives.

The secondary aim was to investigate how offering FPDR affects the occurrence of depression, anxiety, and grief in the relatives, and what effect FPDR has on the length of

time the medical care is performed, how healthcare professionals are affected, the quality of medical care, and patient's chance of survival.

### What did we do?

We searched medical databases on 22 March 2022 without any language limits. We checked references and contacted study authors to identify additional studies. We included randomized controlled trials (a type of study where participants are randomly assigned to one of two or more treatment groups) of adults who were present during resuscitation of their relative.

### What we found

We included 2 trials (3 papers) involving a total of 595 participants who were between the ages of 19 and 78. One trial involved 15 pre-hospital emergency medical services units in France, investigating FPDR in patients with cardiac arrest. This trial had a one-year evaluation that we included in the review. The other included trial was a small pilot study of FPDR in patients with cardiac arrest or trauma in an emergency department in the UK.

### Key results

There was not enough evidence to draw any firm conclusions on the effects of FPDR on any of the outcomes studied. Overall, it appeared that FPDR decreased PTSD, anxiety and depression, and grief; however, as the studies are very few and were at high risk of bias, this effect is very uncertain. One of the included studies also measured duration of patient resuscitation and personal stress in healthcare professionals during FPDR and found no difference between study groups.

### How reliable are the results?

Our confidence (certainty) in the evidence is very low. There is too little evidence to draw any firm conclusions on the effects of FPDR on psychological outcomes of relatives or any other of the outcomes studied.

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**Summary of findings**

**Summary of findings 1**

## Family presence during resuscitation

**Population:** relatives, patients, and healthcare professionals during resucitation

**Settings:** emergency department or pre-hospital setting

**Intervention:** to offer relatives the opportunity of FPDR

**Comparison:** not to offer relatives the opportunity of FPDR systematically in a standardized way

Note: In both included studies outcomes were calculated as median and interquartile range (IQR) or presented as numbers and %.

| Outcomes, Time point of assessment | Illustrative comparative risks* | | Relative effect (95% CI) | No. of participants (studies) | Certainty of the evidence (GRADE)[a,b] | Comments |
|---|---|---|---|---|---|---|
| | Assumed risk with intervention | Corresponding risk without intervention | | | | |
| PTSD in the relatives<br><br>IES (0 to 75; > 30 = presence of PTSD) measured at 3 months and > 3 months | Both studies found median scores in the range of 8 to 15.5 for both IES subscores at 3 months, and in the range of 0 to 17.5 after more than 3 months. See Table 1. | Both studies found median scores in the range of 8 to 16.5 for both IES subscores at 3 months, and in the range of 5 to 21 after more than 3 months. See Table 1. | NA | 493 or 426<br>(2 RCTs)** | ⊕⊖⊖⊖<br>VERY LOW [c] | The difference between the 2 groups was found to be statistically significant in favor of the intervention when measured at 12 months in Jabre 2014. |
| Anxiety and depression in the relatives | Both studies found median scores in the range of 2.5 to 7 for both | Both studies found median scores in the range of 5 to 8 for both HADS subscores at 3 | NA | 493 or 426<br>(2 RCTs)** | ⊕⊖⊖⊖<br>VERY LOW [c] | The frequency of people with symptoms of anxiety was significantly higher |

| | | | | | | |
|---|---|---|---|---|---|---|
| HADS (0 to 42; subscale score > 10 (range, 0 to 21) = presence of anxiety or depression) measured at 3 months and > 3 months | HADS subscores at 3 months, and in the range of 0 to 7 after more than 3 months. See Table 1. | months, and in the range of 4 to 8.5 after more than 3 months. See Table 1. | | | | in the control group at 3 months in Jabre 2013, and the frequency of people with symptoms of depression was significantly higher in the control group at 12 months in Jabre 2014. However, this was not clinically relevant, as the subscale scores are < 10 at both short- and long-term follow-up. |
| Grief in the relatives<br><br>ICG (0 to 95; > 25 = presence of complicated grief) measured at 12 months<br><br>TRIG (21 to 105; lower scores indicate higher levels of grief) measured at 3 and 9 months | ICG score measured at 12 months: 16 (9 to 23)<br><br>TRIG score measured at 3 months: 46.5 (37.8 to 57.8)<br><br>TRIG score measured at 9 months: 38.5 (33.5 to 52.5) | ICG score measured at 12 months: 19 (9 to 28)<br><br>TRIG score measured at 3 months: 46 (36.3 to 57.8)<br><br>TRIG score measured at 9 months: 57 (38 to 64.0) | NA | 426 (2 RCTs) | ⊕⊖⊖⊖<br>VERY LOW [c] | The difference between the 2 groups was found to be statistically significant in favor of the intervention when measured by ICG at 12 months. |
| | **Family member present** | **Family member absent** | | | | |
| Survival of patients | In the Jabre 2013 trial, "survival to hospital admission" was 18% and "survival to day 28" was 3% in their per-protocol analysis.<br><br>In the Robinson 1998 trial, 3 patients "survived to hospital discharge". | In the Jabre 2013 trial, "survival to hospital admission" was 16% and "survival to day 28" was 4% in their per-protocol analysis.<br><br>In the Robinson 1998 trial, no patients "survived to hospital discharge". | NA | 493 (2 RCTs) | ⊕⊖⊖⊖<br>VERY LOW [c] | No statistical difference in either "survival to hospital admission" or "survival to day 28" was found.<br><br>Robinson 1998 did not make a statistical calculation. |
| Duration of resuscitation in minutes | 30 (23 to 40) | 30 (20 to 40) | NA | 475 (1 RCT) | ⊕⊕⊖⊖<br>LOW [d] | No statistical difference in duration of advanced resuscitation was found in the per-protocol analysis. |
| Stress intensity in the medical team members | Emergency physician: 8.5 (0 to 20) | Emergency physician: 10 (0 to 20) | NA | 1710 (1 RCT) | ⊕⊖⊖⊖<br>VERY LOW [d,e] | No statistical difference in stress intensity |

| | | | | | | |
|---|---|---|---|---|---|---|
| VAS (0 to 100; 0 = no stress; 100 = maximum stress) | Nurse: 5 (0 to 15)<br>Ambulance driver: 0 (0 to 15) | Nurse: 5 (0 to 15)<br>Ambulance driver: 0 (0 to 10) | | | | was found in the per-protocol analysis.<br>Numbers regarding how many physicians, nurses, and ambulance drivers were asked to fill out the VAS score were obtained after contact with the trial author. |

*The basis for the **assumed risk** is provided in footnotes. The **corresponding risk** (and its 95% confidence interval) is based on the assumed risk in the intervention group and the **relative effect** of the intervention (and its 95% CI).
**Short-term outcomes for the Jabre trial in Jabre 2013 and for the long-term outcomes in Jabre 2014. Both articles are from the same RCT. 493 participants were included for IES and HADS score measurement at 3 months, and 426 after > 9 months.

**CI:** confidence interval; **HADS**: Hospital Anxiety and Depression Scale; **ICG**: Inventory of Complicated Grief; **IES**: Impact of Event Scale; **NA**: not applicable; **PTSD**: post-traumatic stress disorder; **RCT:** randomized controlled trial; **TRIG**: Texas Revised Inventory of Grief; **VAS:** visual analogue scale.

**GRADE Working Group grades of evidence**
**High certainty**: we are very confident that the true effect lies close to that of the estimate of the effect.
**Moderate certainty**: we are moderately confident in the effect estimate: the true effect is likely to be close to the estimate of the effect, but there is a possibility that it is substantially different.
**Low certainty**: our confidence in the effect estimate is limited: the true effect may be substantially different from the estimate of the effect.
**Very low certainty**: we have very little confidence in the effect estimate: the true effect is likely to be substantially different from the estimate of effect.

[a]Study limitations rated as very serious for all outcomes, as overall high risk of bias was found in both studies in crucial domains.

[b]Imprecision rated as very serious for all outcomes, as the small number of heterogeneic studies precluded meta-analysis.

[c]Inconsistency rated as very serious due to clinical heterogeneity.

[d]As only a single study investigated this outcome, it is not possible to downgrade for inconsistency and publication bias.

[e]Indirectness of evidence rated as serious due to the self-assessed measurement on the VAS instead of measurement of cortisol level in saliva or heart rate variability.

# Background

Family members often expect to be actively involved in care decisions involving the treatment of their relatives (Lederman 2014). Even during resuscitation, patients may prefer to have their relatives nearby, and many relatives want to be present when given the choice (Benjamin 2004; Bradley 2017; Chew 2014; De Stefano 2016; Dwyer 2015; Meyers 2000; Robinson 1998). This could be why family presence during resuscitation (FPDR) is a growing healthcare practice, even though the majority of the evidence is of low quality and lacking investigation of the relatives' perceptions and psychological outcomes, and the impact on patient morbidity and mortality (Oczkowski 2015).

## Description of the condition

Resuscitation can be described in general as a process of correcting the physiological disorders in a patient suffering from critical illness or reviving someone from unconsciousness or apparent death. The term 'resuscitation' in this review is therefore used as a description of either cardiopulmonary resuscitation (CPR), resuscitation after trauma, or critical care of acutely ill patients. In the USA, more than 200,000 adults undergo CPR annually in hospitals, and in Germany more than 2000 in the emergency room (ER) (Mallikethi-Reddy 2017; Merchant 2011; Zwingmann 2016). Furthermore, in

the USA, 2.2 million emergency department visits result in admission to critical care out of a total of 145.6 million visits (1.5%) (National Center for Health Statistics 2016).

## Description of the intervention

When relatives (e.g. siblings, parents, spouses, children, or close friends) of the patient are present in the resuscitation room with the patient, it is described as FPDR. The family member should preferably be accompanied by a designated support person (Mentzelopoulos 2021).

There are concerns that FPDR can lead to post-traumatic stress disorder (PTSD) in the relatives (Compton 2011); have a negative impact on the quality of critical care (Fernandez 2009); and that patient confidentiality can be violated as the patient's thoughts and preferences in the situation are unknown (Benjamin 2004; Lederman 2014). When FPDR is practiced, the relatives are in direct contact with both the patient and the healthcare professionals during the resuscitation attempt and not placed outside (e.g. in a special waiting room). This means that they can interact with the patient (e.g. hold the patient's hand if they want to and talk to or with them) whenever needed.

## How the intervention might work

Some clinicians believe that family members being present during resuscitation may have more advantages than disadvantages, as it allows the relatives to feel both needed and of use in the care and comfort of the patient (Holzhauser 2008). Especially in the event of death, it may help the relatives to acknowledge that all possible measures were taken to save the patient (De Stefano 2016; Holzhauser 2006). Watching the procedures and the communication—both verbal and non-verbal—among the healthcare professionals can play a role in supporting the understanding of the circumstances of the patient's death and help the relatives to cope with the patient's death in the context of the critical care performed (De Stefano 2016). A quasi-experimental historical study and a large pre-hospital cluster-randomized controlled trial (RCT) indicated that FPDR may have positive effects on relatives' psychological outcomes (Jabre 2013; Soleimanpour 2017). The communication between relatives and the emergency care team is considered very important, and a qualitative analysis of the pre-hospital cluster-RCT by Jabre and colleagues concluded that the emergency care team could facilitate the relatives' acceptance of the reality of death (Jabre 2014). A designated support person focusing on the relatives, as a part of the resuscitation team, therefore became recommended (Downar 2013; Dudley 2009; Mentzelopoulos 2021; Meyers 2000).

It is important to investigate how family presence might influence the patient. A patient who had survived cardiac arrest felt “aware of his wife’s presence”, and also felt that this had encouraged him to fight on (Belanger 1997). Three other patients who survived resuscitation reported that they felt supported by their relatives' presence and did not feel their confidentiality or dignity had been compromised (Robinson 1998). A qualitative study of nine surviving patients found several themes concerning the positive effects that family presence during invasive procedures, or CPR, had on patients: “it comforted them, provided help, and served, the patients believed, to remind providers of a patient’s “personhood”—he wasn’t just a patient; he was a person and had a family” (Eichhorn 2001).

A relevant concern is whether FPDR negatively affects the members of the resuscitation team, and whether the relatives get in the way of the work of the healthcare professionals. Jabre and colleagues found no increase in the level of stress of the healthcare providers or difference in patient mortality and stated that "survival, the duration of advanced resuscitation, the type or dose of infused medications, and the number of electric shocks delivered to the heart were not affected by the presence or absence of the family member" (Jabre 2013). A study of physicians' performance during a simulated cardiac arrest with relatives in different states of mind indicated that relatives may have a negative impact on the quality of acute medical care, especially if the relatives are agitated (Fernandez 2009). In contrast, a pediatric study of FPDR found no differences in the success rate of the critical interventions, and the healthcare providers

surveyed believed there was a minimal negative effect of FPDR on resuscitation (Dudley 2009). Mangurten and colleagues believe a protocol for FPDR of pediatric patients was effective, and the providers in their study reported that the presence of parents did not negatively affect medical care (Mangurten 2006).

## Why it is important to do this review

We believe that much of the evidence concerning FPDR is qualitative. When investigating this literature, different themes emerge concerning relatives' perceptions, and knowledge about the effect of and how to best involve relatives is scarce. Danish researcher Camilla Bernild reports that even though nurses in an orthopedic ward had the best intention to involve the patients' relatives, they often found it difficult to implement involvement, and this resulted in an individual and random effort to achieve the goal. Many patients and relatives thus experienced that the involvement was tokenism, and that their opinions and wishes were not actually taken into account (Bernild 2018).

In 2018, Shadia Alshahrani explored how relatives' involvement was experienced in Saudi Arabia and Australia, finding that "In both fields, relatives and nurses faced ongoing ambiguity about the role relatives should play in the hospital environment. Nurses were challenged by the unpredictability of relatives' participation in patient care. The nurses' fear of taking responsibility and uncertainty about the relatives' role led them to take varied and individualized approaches to the involvement of relatives in patient care. Relatives were unclear about how to behave in the role; what was the preferences and needs of patients; and whether they were contributing positively to care; all this resulted in frustration" (Alshahrani 2018).

Since the first known case of FPDR in 1983 (Hanson 1992), and the first published study in 1987 (Doyle 1987), to our knowledge only three RCTs have focused on relatives' perspectives concerning FPDR (Holzhauser 2006; Jabre 2013; Robinson 1998). Two studies found psychological benefit for the relatives present in the ER during resuscitation in general, and not only during CPR (Holzhauser 2006; Robinson 1998). A cluster-RCT and its one-year follow-up assessment, and a qualitative analysis of this RCT, showed positive effects of FPDR on relatives' psychological outcomes, including improved clinical indicators related to PTSD, better anxiety and depression scale scores, less complicated grieving as a result of pre-hospital CPR, and no negative effects on mortality (De Stefano 2016; Jabre 2013; Jabre 2014). However, a retrospective study suggests that family members who witness ER resuscitations may be at increased risk of PTSD symptoms after one month (Erogul 2020), as the experience can be too traumatic for some to experience.

Whether family members should be offered the opportunity to be present during resuscitation or not is an important question to answer. This is because their presence during the resuscitation attempt may impact the relatives psychologically, the patient receiving care, and the performance of the healthcare professionals. The European Resuscitation Council (ERC) recommends that relatives be offered the choice of being present during CPR (Mentzelopoulos 2021). The American Heart Association (AHA) does not offer a recommendation, although they do encourage FPDR (Mancini 2015). This lack of a clear recommendation leads to disagreements among clinicians regarding FPDR, because the evidence is sparse (Bossaert 2016; Downar 2013; Lederman 2016; Meyers 2000; Porter 2013; Sak-Dankosky 2014; Youngson 2016). The disagreements are perhaps caused by fear of legal consequences, or as noted in the reasons described by relatives for whether or not to engage in FPDR, "The anticipated fear of negative or positive reactions was often mentioned as a reason for their choice about being present for the resuscitation" (De Stefano 2016). However, the feeling of exclusion when relatives are not offered FPDR is a relevant factor to be aware of (De Stefano 2016).

To our knowledge, no studies in the pre-hospital environment have been conducted covering FPDR in general, other than during CPR (Jabre 2013; Oczkowski 2015). Robinson and colleagues looked at FPDR including CPR, trauma, and critical care in the ER, but they had to terminate their trial prematurely, as the clinical team considered it unethical not to offer FPDR, even though the preliminary results were not convincing (Robinson 1998). Holzhauser and colleagues also looked at FPDR during both CPR and

critical care in the ER, but excluded trauma patients (Holzhauser 2006). Dudley and colleagues investigated FPDR of pediatric patients (Dudley 2009).

We hypothesize that FPDR may positively impact relatives' psychological outcomes, including PTSD symptoms. It is also possible that FPDR affects the performance of healthcare professionals and influences patient morbidity and mortality. Considering the public health perspective, it may also be possible that family presence leads to overtreatment. As a relative stated, "When I saw that they were being so aggressive [with the treatment], I felt it as an aggression, an assault on my husband" (De Stefano 2016). If such a tendency is discovered to be associated with FPDR, its identification can lead to the development of policies to decrease this risk.

These factors suggest the necessity of a high-quality systematic review to evaluate the evidence.

# Objectives

The primary aim of this review was to investigate how offering relatives the option to be present during resuscitation of patients affects the occurrence of PTSD-related symptoms in the relatives.

The secondary aim was to investigate how offering relatives the option to be present during resuscitation of patients affects the occurrence of other psychological outcomes in the relatives and what effect family presence compared to no family presence during resuscitation of patients has on patient morbidity and mortality.

We also wanted to investigate the effect of FPDR on medical treatment and care during resuscitation. Furthermore, we wanted to investigate and report the personal stress seen in healthcare professionals and if possible describe their attitudes toward the FPDR initiative.

# Methods

## Criteria for considering studies for this review

### Types of studies

We included randomized controlled trials (RCTs) and cluster-RCTs.

### Types of participants

The participants of this review included relatives, patients, and healthcare professionals during resuscitation.

We included relatives aged 18 years or older who have witnessed a resuscitation attempt of a patient (who is their relative) in the ER or pre-hospital. We defined relatives as siblings, parents, spouses, children, or close friends of the patient, or any other descriptions used by the study authors. There were no limitations on adult age or gender.

We defined patient as a patient with cardiac arrest in need of CPR, a patient with a critical medical or traumatic life-threatening condition, an unconscious patient, or a patient in any other way at risk of sudden death. We included all types of healthcare professionals as described in the included studies. There were no limitations on age or gender.

### Types of interventions

The intervention was to offer the relatives the opportunity of FPDR in the ER or in the pre-hospital setting.

The control was not to offer the relatives the opportunity of FPDR systematically in a standardized way, but instead to offer any other intervention including following standard practice (e.g. waiting in a special room with no opportunity of witnessing the resuscitation) or no intervention at all.

Regarding the patients and the healthcare professionals, the intervention was if there had been FPDR or not.

## Types of outcome measures

We reported on any outcome specified in the included studies.

### Primary outcomes

- PTSD evaluation of the relatives measured short term (at 0 to 3 months) and long term (more than 3 months).

### Secondary outcomes

- Depression, anxiety, or complicated grief in the relatives according to ICD-11 measured short term (at 0 to 3 months) and long term (more than 3 months).
- Patient morbidity: readmission to hospital within 30 days, number of intensive care unit (ICU) admissions within 30 days.
- Patient mortality as measured in the included studies. If a study included several time points, we used the one closest to 30 days.
- Adverse events in the patient population: number of adverse cardiac and pulmonary events or other adverse events described in the included studies and total number of adverse events.
- Personal stress in healthcare professionals during resuscitation as measured by the included studies.
- Duration of patient resuscitation as reported in the included studies.
- Healthcare professionals' attitudes towards FPDR as measured in the included studies.

# Search methods for identification of studies

## Electronic searches

We searched for studies as described in Chapter 4 of the *Cochrane Handbook for Systematic Reviews of Interventions* (Lefebvre 2019). There were no language, publication year, or publication status restrictions.

We searched the following databases for relevant trials:

- Cochrane Central Register of Controlled Trials (CENTRAL; 2022, Issue 3 of 12) in the Cochrane Library (searched 22 March 2022)
- MEDLINE (Ovid, 1946 to 22 March 2022);
- Embase (Ovid, 1974 to 22 March 2022);
- CINAHL (Cumulative Index to Nursing and Allied Health Literature) (EBSCO, 1980 to 22 March 2022);
- PsycINFO (EBSCO, 1806 to 22 March 2022).

We developed a search strategy for MEDLINE and modified it as appropriate for the other databases. The search strategies can be found in Appendix 1.

## Searching other resources

We scanned the reference lists and citations of included trials using Scopus online database, and checked relevant systematic reviews identified in Epistomonikos online database for references to additional trials. We also scanned the abstracts of conference proceedings of the AHA and the European Resuscitation Council.

When necessary, we contacted trial authors for additional information. This was relevant regarding in both included studies.

We also searched ClinicalTrials.gov (clinicaltrials.gov), the WHO International Clinical Trials Registry Platform (trialsearch.who.int/), and the ISRCTN registry (www.isrctn.com) for unpublished and ongoing studies; OpenGrey (opengrey.eu) for grey literature; and Google Scholar for additional trials.

We searched for errata and retractions of included studies in PubMed and Retraction Watch Database (retractiondatabase.org/).

The search strategy was developed by the Cochrane Emergency and Critical Care Information Specialist. The search date was 22 March 2022.

# Data collection and analysis

## Selection of studies

Two review authors (MAR and TS) independently and in duplicate screened the search results for eligible studies by scanning titles and abstracts. We used Covidence for transparency (Covidence). We obtained the full-text records of all presumably eligible studies, and evaluated them before final inclusion. Any disagreements were resolved by discussion, or by consulting a third review author (AMM) when needed. We recorded the selection process in sufficient detail to complete a PRISMA flow diagram (Figure 1) (Moher 2009).

## Data extraction and management

One of the review authors (PJ) is the first author of an included primary study in this review (Jabre 2013). She did not extract data from any included studies.

Two review authors (MAR and TS) independently and in duplicate extracted relevant data using pre-designed data extraction forms (Appendix 2). Given that we only included two studies, we did not perform a pilot run to evaluate the data extraction form as mentioned in our protocol (Afzali 2020), but refined it during the data extraction. After data extraction, we compared data, resolving any disagreements by discussion, aided by a third review author (AMM) when necessary. We contacted study authors for clarification during data extraction as needed. This was relevant once (Jabre 2013).

## Assessment of risk of bias in included studies

One of the review authors (PJ) is the first author of an included primary study in this review (Jabre 2013). She did not assess the risk of bias of any included study.

For each study, two review authors (MAR and TS) independently used Cochrane's risk of bias tool RoB 2 to evaluate risk of bias (Sterne 2019). We used the RoB 2 tool including the cribsheet tools (10 November 2020 version) to assess bias for intention-to-treat (ITT) effects for the included primary and secondary outcomes. We judged each item as having low, high, or some concerns regarding risk of bias in the following domains.

- Bias arising from the randomization process
- Bias due to deviations from intended interventions
- Bias due to missing outcome data
- Bias in measurement of the outcome
- Bias in selection of the reported result

We also assessed the following domain for the included cluster-randomized trial.

- Bias arising from the timing of identification or recruitment of participants in a cluster-randomized trial

Any disagreements were resolved by discussion, aided by a third review author (AMM) when needed. A visual representation of the risk of bias assessment was made using robvis (McGuinness 2020).

As part of the risk of bias assessment, we looked for protocols within the online study databases to assess selective reporting, and contacted the trial authors of both included studies.

## Measures of treatment effect

### Dichotomous outcomes

Concerning the presence of PTSD and other psychological outcomes, mortality, morbidity, and adverse events, we originally planned to convert the effect of treatment to risk ratios (RR) if presented, and use meta-analysis to summarize treatment effects as such. However, a meta-analysis was not possible.

### Continuous outcomes

We planned to present and analyze the severity of PTSD, anxiety and depression, and duration of resuscitation as mean difference (MD) with 95% confidence intervals (CIs). We originally planned that if continuous outcomes were measured on different scales but considered to be measuring the same outcome, we would use standardized mean difference (SMD) for analysis and presentation. However, this was not relevant as the two included studies were too heterogeneous to be compared.

## Unit of analysis issues

Analysis issues could be present given that we included a cluster-RCT (Jabre 2013); however, as the included trial takes the clustering into account (Higgins 2019), we were able to use the results as they are. As the authors state for psychological-assessment analyses, Generalised Estimating Equations (GEE) were used for categorical outcomes and mixed models of ANOVA were used for quantitative outcomes, using center as a random effect and adjusting for the relative's relationship to the patient. When necessary, normalizing transformation was performed (De Stefano 2016).

## Dealing with missing data

To ensure completeness of data, we planned to contact trial authors in order to obtain and incorporate any relevant missing data. Both included trials performed ITT analysis. We planned that if trials had more that 20% dropout, we would explore the impact of missing data on the overall effect. However, this was not relevant.

Where individual studies did not account appropriately for missing data, or did not report how these data were handled, we considered whether data were likely to be missing at random, or not affecting the risk of bias assessment. We planned that where outcome data were missing, and could be recovered, we would adopt the approach suggested in Chapter 10 of the *Cochrane Handbook for Systematic Reviews of Interventions* (Higgins 2019), and use available-case analysis. We included data only for those participants whose results were known, and addressed the potential impact of missing data using the risk of bias tool. Ultimately, we considered the potential impact of including such studies in the overall assessment of intervention effect.

## Assessment of heterogeneity

We considered clinical, methodological, and statistical diversity (Higgins 2019).

The included studies were neither clinically nor statistically comparable. We have therefore presented and summarized the results narratively.

However, we assessed methodological diversity using the Cochrane risk of bias tool RoB 2 (Sterne 2019).

## Assessment of reporting biases

We did not create a funnel plot, as the number of included trials was fewer than 10.

## Data synthesis

We did not perform meta-analysis. The designs of the included studies were too diverse, therefore statistical combination would have been inappropriate. We have therefore presented the findings in a narrative fashion using the Synthesis Without Meta-analysis (SWiM) guideline (Campbell 2020).

A selection of extracted data describing the included studies is presented in a study characteristics table (Table 2), as recommended in the *Cochrane Handbook for Systematic Reviews of Interventions*, with four distinct categories: methods; participants; interventions; and outcomes (Higgins 2019).

### Subgroup analysis and investigation of heterogeneity

We originally planned to perform an adult/pediatric subgroup analysis to examine if the effects are modified by the age of patients; subgroup analyses concerning cardiac arrest/other critical situations and trauma/medical; and a subgroup analysis to explore if location of resuscitation (i.e. in or out of hospital) has significance. However, these analyses were precluded by too few studies.

### Sensitivity analysis

In the case of unavailable data, we planned to assess whether the data were missing at random, or if the missing data might be a source of bias. We planned to omit randomly missing data from analysis, while non-randomly missing data would be imputed as sensitivity analyses, as deemed appropriate by the review authors, according to the cause of their omission. In addition, we planned to challenge analyses that included imputed data by sensitivity analyses to ensure the robustness of the findings when assumptions were changed.

For dichotomous outcomes, we planned to impute missing values as experiencing or not experiencing the event. For continuous outcomes, we planned to impute missing values using different fixed values for all missing values.

We planned to perform sensitivity analyses by excluding trials we judged to be at high risk of bias.

However, all of these analyses were precluded by too few studies.

### Summary of findings and assessment of the certainty of the evidence

We used the principles of the GRADE system to assess the certainty of the body of evidence associated with specific outcomes in our review, and constructed a summary of findings table including all mentioned outcomes in the included studies. In the protocol, we stated that we would use GRADEpro GDT software (GRADEpro GDT; Guyatt 2008); however, given our narrative presentation of outcomes, we decided to do the evaluation by hand instead.

We evaluated the certainty of evidence according to the GRADE domains as described in Chapter 12 of the *Cochrane Handbook for Systematic Reviews of Interventions* (Higgins 2019). Two review authors (MAR and AMM) independently undertook the GRADE assessments. We have reported agreement reached by consensus in Summary of findings table 1 and all reasons for downgrading.

The overall RoB 2 judgement was used to feed into the GRADE assessment.

# Results

## Description of studies

See Included studies and Excluded studies.

### Results of the search

Our electronic search yielded a total of 7292 records after deduplication (see Figure 1). Handsearching of reference lists revealed no additional potentially relevant studies.

Two review authors (MAR and TS) independently performed title and abstract screening. After excluding obviously irrelevant records, we retrieved 95 potentially relevant records for full-text assessment. Following full-text reading, we excluded a total of 92 records and included 2 trials (3 papers) with 595 participants.

When screening for systematic reviews in Epistemonikos, we found a recently published umbrella review including systematic reviews between 1 January 2009 and 31 December 2018 (Tíscar-González 2021). However, this umbrella review did not include the review we found in Scopus (Barreto 2019). We found no further relevant studies when handsearching the reference lists of either review.

### Included studies

We included 2 studies (3 papers) in the review: a prospective, cluster-RCT involving 15 pre-hospital emergency medical services units in France, comparing systematic offer for a relative to witness CPR with the traditional practice (Jabre 2013), its 1-year assessment (Jabre 2014), and a small pilot study of FPDR in a single ER in the UK (Robinson 1998).

The two studies were conducted in 1998 and 2013. The more recent study included 570 family members of patients receiving CPR (Jabre 2013). The older study was a pilot study that was ended prematurely due to the risk of altered randomization (Robinson 1998); this study included 25 relatives. The age of participants across studies ranged from mean 19 to 78 years, and between 56% and 64% of participants were women. For study-specific outcomes and overall risk of bias, see Table 2. Only Jabre 2013 mentioned funding: "Funded by Programme Hospitalier de Recherche Clinique 2008 of the French Ministry of Health"; this was also the only study to declare possible conflict of interest.

### Excluded studies

We excluded 92 studies. Reasons for their exclusion are provided in Characteristics of excluded studies tables. However, a few studies are worth mentioning in particular. We excluded one study due to lack of randomization, as it was a historical trial (Soleimanpour 2017), and one study because they evaluated the wrong intervention, that is whether training of relatives before their presence in the resuscitation room could lower their anxiety (Alireza 2019). We excluded two studies due to wrong study design, as they had only asked the participants in a qualitative way about their experience without measuring it on any scale (Holzhauser 2006; Holzhauser 2008). Finally, we excluded one study due to lack of randomization, as it was a quasi-randomized study including participants related to odd and even days (Dudley 2009).

## Risk of bias in included studies

We used RoB 2 to assess risk of bias and followed the RoB 2 cribsheets (10 November 2020 version), which can be accessed in the supplementary material (Rubin 2021). We found both studies to have an overall high risk of bias for all domains. Summaries of risk of bias assessments within and across studies are provided in Figure 2.

### 1. Bias arising from the randomization process

We initially assessed both studies as being at low risk of bias arising from the randomization process for all outcomes as we believed the allocation sequence to be random and concealed. Baseline characteristics of the participants did not appear to differ. However, due to the low number of participants it was not possible to evaluate baseline characteristics in Robinson 1998. Furthermore, we decided to overturn our judgement of low risk of bias to some concerns in Robinson 1998 because the study was stopped prematurely. To quote from the trial, “They decided to stop the study early because the randomisation process was at risk of being altered by staff who had become convinced of the benefits of allowing relatives to witness resuscitation”.

#### 1b. Bias arising from the timing of identification or recruitment of participants in a cluster-randomized trial

This domain was relevant to the assessment of the Jabre 2013; Jabre 2014 trial, which was a cluster-randomized trial. All participants were identified or recruited after randomization: the pre-hospital care units were randomized in clusters at the beginning of the study, and when they arrived at the scene, they offered relatives to be present during resuscitation or the traditional practice (relatives were asked to wait in a special room or perhaps allowed to witness CPR - but the process was not standardized), respectively to the cluster to which they had been randomized. As the included outcomes were related to relatives, patients, and healthcare professionals, some signaling questions in this domain were assessed differently according to outcome. We assessed this domain as low risk of bias for all outcomes but healthcare professional stress, which we judged to be some concerns due to the fact that there were no baseline data and no information on whether the selection of individual participants could have been affected by knowledge of the intervention assigned to the cluster. There was no information in the article on how the healthcare professional participants were chosen, but after contact with the authors we learned that healthcare professional participants were the medical team that arrived on the scene. The choice was random; no specific team was allocated to this study. There was only one physician, one ambulance driver, and one nurse at the resuscitation scene each time.

## 2. Bias due to deviations from intended interventions

We assessed this domain as some concerns in the Jabre 2013; Jabre 2014 trial related to the psychological outcomes, and high risk of bias related to healthcare professional stress and resuscitation time. Overall, the trial followed a very thorough protocol, which was published beforehand, but it was not possible to assess if there were deviations from the intended intervention arising from the trial context, and it was not possible to blind the healthcare professionals delivering the intervention. Participants were not aware that they were participants in a trial before randomization.

We assessed this domain as high risk of bias for all the psychological outcomes in Robinson 1998 as they did not publish a protocol prior to the study and stopped the study prematurely due to risk of altered randomization. This resulted in selection bias and a deviation from the intended intervention.

## 3. Bias due to missing outcome data

We assessed this domain as high risk of bias for our primary outcome, PTSD, and the secondary psychological outcomes in the Jabre 2013; Jabre 2014 trial. The proportion of missing outcome data was large; however, the missing numbers were similar in both control and intervention groups. Figure 1 in Jabre 2014 shows that out of the 570 participants, there were missing data for 6% in the intervention group and 11% in the control group after 3 months, but after 12 months missing data amounted to 28% in total for all psychological outcomes. Withdrawal from the study could have been related to participants' health status, as we assume that someone affected deeply by grief might not want to attend for a repeated psychological assessment. It is therefore possible that missingness in the outcome was influenced by its true value. As mentioned in the footnote of Table 2, the inclusion of participants from each of the 15 clusters varied between 8 and 104. This information was obtained by contacting the study author, and we were informed that the deviation was because some clusters consisted of five pre-hospital units and others only one, resulting in some clusters including fewer participants than others. The authors did not state that any clusters dropped out.

As the outcome resuscitation time was related to the patient and hence the clusters of units, no outcome data were missing, resulting in a judgement of low risk of bias for this domain for this outcome. We also assessed this domain as low risk of bias for the outcome healthcare professional stress, as the authors did not state that any clusters had dropped out, and most outcome data were available (Table 2: the total missing outcome data are 44/1710 = 2.57%).

We assessed the Robinson 1998 trial as at high risk of bias due to missing outcome data for all included outcomes, as 38% of participants were missing in the intervention group and 17% in the control group, and we were not provided with the missing outcome data.

In the protocol we stated that "if trials have more that 20% dropout we will explore the impact of missing data on the overall effect"; however, given that we did not perform a meta-analysis, this was not relevant.

### 4. Bias in measurement of the outcome

We assessed this domain as some concerns for our primary outcome, PTSD, the secondary psychological outcomes, and resuscitation time in the Jabre 2013; Jabre 2014 trial. Outcome assessors were aware of the intervention received by study participants, as blinding of personnel performing CPR was not possible, and the relatives knew whether they had been present or not when reporting their outcomes in an interview. We assessed this domain for healthcare professional stress as high risk of bias because it was measured with a self-assessment questionnaire the healthcare professionals completed themselves. Additional or alternative tools completed by others may conflict with or validate this questionnaire. Furthermore, outcome assessors were aware that a trial was taking place, and, therefore, assessment of the outcome could have been influenced by knowledge of intervention received.

We also assessed bias in measurement of the outcome as some concerns for all of the included outcomes in the Robinson 1998 trial. This was mostly because the relatives could not be blinded to the intervention. It is also unclear how the relatives were interviewed, making it possible that the relatives, who were the outcome assessors, could be influenced psychologically by the interviewer.

### 5. Bias in selection of the reported result

We assessed this domain to be low risk of bias for all outcomes in the Jabre 2013; Jabre 2014 trial, as the measurement of stress in the healthcare professional was detached from the randomization, and this was in accordance to a prespecified protocol and analysis plan. Furthermore, the Impact of Event Scale (IES) and Hospital Anxiety and Depression Scale (HADS) subscale scores where obtained after contact with the author and hence not published in the article. It is also important to note that as these results are a part of the overall score, this did not add to the bias devaluation. Regarding the outcome of stress, we were also interested in the types of healthcare professionals participating in this trial, and their frequencies; these numbers are mentioned in the footnotes of Table 2.

We assessed the Robinson 1998 trial as some concerns related to bias in selection of the reported result for all outcomes because the study lacked a published study protocol.

## Effects of interventions

Table 1 summarizes the effect estimates using the descriptive statistics of median and interquartile range (IQR) from the included trials.

Overall, there is an indication that FPDR decreases PTSD, anxiety and depression, and complicated grief, but as the studies were few and at high risk of bias, this effect is very uncertain.

Only a few of our outcomes were measured in the included studies, and are all mentioned in Summary of findings table 1. For our primary outcome, PTSD, evaluation of the relatives was measured at 0 to 3 months and after more than 3 months in both studies. PTSD was evaluated by the IES scale, which is composed of two subscales, "the IESI is the intrusion subscale and consists of seven statements on intrusive thoughts and images of the event, dreams, and repetitive behaviour. The avoidance subscale, IESA, consists of eight statements about ideational constriction, denial of the meaning and consequence of the event, blunted sensation, behavioural inhibition, counterphobic activity, and emotional numbness" (quote from Robinson 1998) (Horowitz 1979). Overall, the results were in favor of FPDR.

Regarding our secondary outcomes, both studies measured depression and anxiety at 0 to 3 months and after more than 3 months using the HADS (Zigmond 1983), as well as mortality, but only Jabre 2014 measured complicated grief at 12 months, which was in

favor of FPDR. Furthermore, Jabre 2013 measured duration of patient resuscitation and personal stress in healthcare professionals during resuscitation. None of the studies assessed our other secondary outcomes (i.e. patient morbidity, adverse events, and healthcare professionals' attitude toward FPDR).

The median stress level measured on the visual analogue scale (VAS) was 5 out of 100 (IQR, 0 to 15), evaluated by 1710 healthcare professionals. After contacting the author of Jabre 2013, we received data on how many healthcare professionals completed the VAS stress evaluation: physicians: n = 567 (3 missing), nurses: n = 556 (14 missing), ambulance drivers: n = 543 (27 missing).

### Certainty of the evidence

Overall, there is not much evidence regarding FPDR. One of the included trials was large, but it was cluster-randomized. The other included trial was a very small pilot study that was ended prematurely due to the risk of tampered randomization. Both studies had high risk of bias, and based on the GRADE approach, we assessed the certainty of the evidence for all outcomes except one as very low. It was not possible to downgrade for publication bias due to the overall lack of trials.

# Discussion

Considine 2022The aim of this review was to investigate the evidence for the effect of offering relatives the option to be present during resuscitation, measured by the occurrence of PTSD-related symptoms in the relatives. We conducted a broad search that retrieved a substantial number of studies, suggesting that there is considerable interest in FPDR and family-centered care in acute settings. We included two studies (three papers) and found insufficient evidence to draw any firm conclusions on the effects of family presence during resuscitation on any outcome. Overall, there is an indication that FPDR decreases PTSD, anxiety and depression, and complicated grief, but as the studies were few and at high risk of bias, this effect is very uncertain.

The two studies (three papers) included in the review had comparable participants. However, both the size and design of the studies were different: one study was a prospective, cluster-randomized, controlled trial from 2013 involving 15 pre-hospital emergency medical services units in France including 570 participants, comparing the systematic offer for a relative to witness CPR with the traditional practice (Jabre 2013), and its 1-year assessment (Jabre 2014); the other study was a small pilot study from 1998 of FPDR in the ER including 25 participants (Robinson 1998). The Robinson study was ended prematurely due to the risk of altered randomization by staff who had become convinced of the benefits of FPDR.

When we look at emergency medicine and intensive care therapy, the available evidence is very scarce. Hypothetically, patients and their relatives would benefit from a greater involvement of close relatives in critical situations like cardiac arrest and other life-threatening situations, as well as during treatment in intensive care wards. Jabre found some evidence that relatives experienced less anxiety and PTSD if they had witnessed the resuscitation—whether successful or not—of their loved ones (Jabre 2014).

The principle of FPDR is a *triangular relationship*, where the intervention of family presence affects both the healthcare professional, the relatives present, and the care of the patient involved. The needs and well-being of all of these individuals must be balanced in the context of FPDR, as the actions of all three groups may impact one another.

There is a lack of high-quality research on the effect on any part of this *triangular relationship*, and it is controversial that the procedure is being so strongly recommended by some. The European Resuscitation Council recommends, based on very few trials but strong expert opinion, that relatives should be offered the choice of being present during CPR (Bossaert 2015), and the Emergency Nurse Association has made an official guideline with a moderate recommendation policy for FPDR (ENA 2009). This recommending of interventions before they are fully investigated can lead to

misunderstandings regarding the true effect. Once the interventions are implemented, the opportunity to test the effects is hampered, either because it is believed the effects are already known—in this particular situation that the effect of FPDR is positive—or because there is too much resistance from the control group (Freedman 1987). Another possibility is that this context is very complex and the effects, both positive and negative, are difficult to measure. We have seen FPDR become the modern working model in pediatrics and obstetrics (Vincent 2017). The practice has been widely debated in much the same way as FPDR is now (Bauchner 1996), but the evidence from high-quality RCTs is still sparse (Dainty 2021). It is possible that in this area we have to look at other study designs to evaluate the complex impact of FPDR. In 2022, the International Liaison Committee on Resuscitation (ILCOR) conducted a systematic review of family presence during adult resuscitation from cardiac arrest that included the 2 RCT we have included, 16 other quantitative studies, 12 qualitative studies and one mixed methods study (Considine 2022). This review also showed that there was variability in the effect of family presence during resuscitation on patient outcomes, family and provider outcomes with very low or low certainty evidence.

Reviews have shown that physicians often perceive more barriers associated with FPDR than nurses (De Robertis 2017; Sak-Dankosky 2014; Tíscar-González 2021), which may be enhanced by the higher risk for legal actions against physicians.

## Summary of main results

Our electronic search yielded a total of 7292 records. We included two trials involving a total of 595 randomized patients and their relatives undergoing critical care including CPR: a cluster-randomized trial from 2013 involving pre-hospital emergency medical services units in France, comparing the systematic offer for a relative to witness CPR with the traditional practice (Jabre 2013), and its one-year assessment (Jabre 2014); and a small pilot study from 1998 of FPDR in an emergency department in the UK (Robinson 1998). The two included studies (three papers) had comparable participants. However, the Jabre study was much larger than the Robinson study, which furthermore was ended prematurely due to the risk of altered randomization by staff who had become convinced of the benefits of FPDR.

The included participants were 19 to 78 years old, and between 56% and 64% were women. PTSD was measured with the IES; the median score ranged from 0 to 21 (range 0 to 75; higher scores correspond to more severe disease). The presence of PTSD is estimated as IES > 30, which was not found as a median score in either groups in any of the ITT analyses. However, in the French trial (Jabre 2013; Jabre 2014), which accounts for most of the included participants (570/595), the frequency of PTSD-related symptoms was significantly higher in the control group after both 3 and 12 months, and in the per-protocol analyses a significant statistical difference was found in favor of FPDR for PTSD, depression, and complicated grief after 1 year. However, the included studies were at overall high risk of bias, and most of the evidence was of very low certainty.

In both included studies there was a large amount of missing outcome data.

## Overall completeness and applicability of evidence

Unfortunately, the results of this systematic review show that we still have too little knowledge about the effect of FPDR on any part of the triangular relationship consisting of healthcare professionals, patients, and relatives. The included studies appeared to be in favor of FPDR with respect to our review aims; however, we could not perform a meta-analysis, and both the risk of bias assessment and the GRADE evaluation were remarkably low.

The effects of stress due to the presence of family on physician’s performance in clinical situations with FPDR is poorly understood, but it is known that elevated stress levels can impede performance on tasks that require divided attention, working memory, retrieval of information from memory, and decision-making (Leblanc 2009). Before investigating the effect of FPDR on relatives' psychological outcomes further, we believe that the effect on healthcare professionals and patient care should be investigated with high-quality trials.

This could be done at first in a controlled simulated environment following the Simulation-Based Research Extensions for the CONSORT Statement (Cheng 2016), where healthcare professionals could be randomized according to FPDR or not, and healthcare professional stress could be measured by heart rate variability during the simulation, looking at the effect of FPDR. Patient care could be monitored as time to critical event throughout the scenario. Afterwards, a similar design randomizing the offering of FPDR to the relatives, measuring healthcare professionals heart rate variability, could be implemented in an ER including follow up of patient outcomes, and finally the measurement of psychological outcomes in relatives (similar to Jabre 2013). It could also be of interest to ask healthcare professionals, in a questionnaire, about the effect of FPDR on their self-considered performance right after a resuscitation event.

## Quality of the evidence

In both included studies, the same scales to measure PTSD, anxiety, and depression were used. To measure PTSD, the Impact of Event Scale (IES) and its subscales were used (Horowitz 1979), and the Hospital Anxiety and Depression Scale (HADS) was used for measuring the level of anxiety in relatives (Zigmond 1983). Neither of these scales is validated for these specific kinds of participants, but to our knowledge no scales are. The IES was previously found to be relevant for use in this context (Sundin 2003). Jabre 2014 used the Inventory of Complicated Grief (ICG) score to measure complicated grief, which seems more relevant when exploring the literature compared to the Texas Revised Inventory of Grief (TRIG) score used in Robinson 1998, as the grief-related symptoms investigated with the TRIG score "seem more likely to reflect greater difficulty accepting the death and to predispose the bereaved to enduring complications in the adjustment to bereavement" and "may also be under-inclusive with respect to symptoms of complicated grief" (Prigerson 1995). Furthermore, we have not been able to locate a cut-off value for the TRIG score.

We assessed the overall risk of bias as high in both included studies, and the GRADE assessment indicated very little confidence in the effect estimates. We believe the true effect is likely to be substantially different from the estimate of effect. Only the outcome resuscitation time was graded as low certainty.

To account for the high risk of bias, we recommend that future studies include enough participants, ideally in an emergency department, including both relatives to patients undergoing CPR but also trauma and critical care, and the trials must be truly randomized to eliminate confounders. It is also important to be aware of the possible selection bias when proposing FPDR, and why it is important to have prespecified eligible participants, for instance as Jabre did (i.e. spouse, parent, offspring, sibling). However, this is a highly sensitive area to conduct research in. We suggest that there should be an exclusion criterion where healthcare professionals are given the opportunity to exclude relatives from the study due to ethical reasons, as it may be presumed harmful for some relatives to participate and for others to stay outside the patient room.

It is imperative that trials concerning FPDR be conducted in settings that are true to the RCT design and on the premise that true equipoise exists. If we do not know what is best, we should test it (Freedman 1987). Bias could, perhaps, be explored by investigating healthcare professionals attitudes qualitatively toward the initiative in advance and including the information in the statistics. Personal communication with authors of the Jabre 2013 trial revealed that before inclusion phase started in each center, medical teams that preferred not to participate in the study were allowed not to participate, which may have led to selection bias.

## Potential biases in the review process

A very important potential bias in this review process is that one of the review authors (PJ) is the first author of an included primary study in this review (Jabre 2013). However, PJ did not extract data from any included studies and was not included in the risk of bias assessment or the GRADE evaluation. Another potential bias is that two review authors

(MAR and AMM) are included in other research project regarding FPDR, including a PhD project; however, none of these projects are pre- or in-hospital clinical trials.

A potential bias could be that indexing of studies in the area is poor, but as we searched many other resources, we believe this bias in our review to be minimal.

## Agreements and disagreements with other studies or reviews

We found an umbrella review of the evidence including all systematic reviews completed (Tíscar-González 2021). The only systematic review we found of RCTs, Oczkowski 2015, included both our included studies, but also included two studies we excluded (Dudley 2009; Holzhauser 2006), and on this basis completed meta-analyses which seemed to be in favor of FPDR. Most meta-analyses, however, were based on just one study (Jabre 2013), which is not recommended practice. In addition, in one of its meta-analyses, the Oczkowski 2015 systematic review reported unpublished data about mortality outcomes from the Holzhauser 2006 study, which were obtained after personal contact with the study authors. The mortality data provided by Holzhauser 2006 to Oczkowski 2015 were the number of survived and deceased from resuscitation, as in-hospital mortality at 28 or 30 days was outside the scope of the Holzhauser 2006 paper.

# Authors' conclusions

### Implications for practice

There was insufficient evidence to draw any firm conclusions on the effects of family presence during resuscitation on relatives' psychological outcomes.

Sufficiently powered and well-designed randomized controlled trials may change the conclusions of the review in future.

### Implications for research

This review highlights the lack of evidence for the effect of family presence during resuscitation (FPDR).

Several reasons can account for the lack of comparative research in this field, as follows.

- Evaluation of FPDR often takes place in difficult conditions and a hostile environment.
- Many confounding factors (e.g. the degree of trauma, the success/failure of the resuscitation, the length of time the patient had chronic disease, the skill or sympathy of the staff, the way the staff are affected) must be considered.
- The important clinical, cultural, and personal heterogeneity between relatives requires large-scale studies allowing specific subgroup analyses.
- From a practical point of view, cluster-controlled trials seem to be the most reasonable study design for assessing the psychological effects of FPDR. However, with this type of design, other outcomes such as patient mortality and healthcare professional performance and stress could be biased.
- The main trial included in this review was at risk of attrition bias; future studies should ensure that they take the necessary actions to reduce dropout and loss to follow-up.

The area of FPDR should also be investigated more by qualitative research, which could elaborate on the phenomenon in relation to the whole triangular relationship of patient, relative, and healthcare professional.

# Acknowledgements

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We would like to thank Tobias Wirenfeldt Klausen for statistical advice during the review process.

The first draft of this review was screened by: Andrew Smith (Co-ordinating Editor, Cochrane Anaesthesia); Ann Møller, Jasmin Arrich, and Lars Lundstrøm (Content Editors); Cathal Walsh, Marialena Trivella, and Nathan Pace (Statistical Editors); Vernon Hedge (Managing Editor); and Janne Vendt (Cochrane Information Specialist).

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# History

Protocol first published: Issue 5, 2020

# Contributions of authors

Monika Afzali Rubin (MAR), Tintin Svensson (TS), Suzanne Forsyth Herling (SFH), Patricia Jabre (PJ), Ann Merete Møller (AMM).

AMM is the guarantor. AMM and MAR contributed to the conception of the review. MAR developed the search strategy together with Janne Vendt, Information Specialist of the Cochrane Anaesthesia and Cochrane Critical and Emergency Care Group. AMM, PJ, and SFH provide expertise on family presence during resuscitation (FPDR). All authors, except PJ, contributed to the selection criteria, strategy for assessment of the quality of the evidence, and data extraction forms. MAR drafted, and all other authors have contributed to and approved, the final review.

Co-ordinating the review: MAR

Undertaking manual searches: MAR

Screening search results: MAR, TS

Organizing retrieval of papers: MAR

Screening retrieved papers against inclusion criteria: MAR, TS

Assessing risk of bias: MAR, TS, AMM

Appraising quality of papers: MAR, TS, AMM

Abstracting data from papers: MAR, TS

Writing to authors of papers for additional information: MAR

Providing additional data about papers: MAR

Data management for the review: MAR

Entering data into Review Manager Web software: MAR

Interpretation of data: MAR, TS, PJ, SFH, AMM

Writing the review: MAR

Performing previous work that was the foundation of the present study: PJ

Guarantor for the review (one author): AMM

Person responsible for reading and checking review before submission: MAR

# Declarations of interest

Monika Afzali Rubin: is a member of the Danish parliament with a special interest in healthcare politics.

Tintin Svensson: nothing to declare.

Suzanne Forsyth Herling: nothing to declare.

Patricia Jabre is the first author of a primary study (which she has conducted) included in this review (Jabre 2013; Jabre 2014). She did not extract data from her own study. Instead, review authors MAR, TS, and AMM extracted these data, and checked the interpretation against the study report and any available study registration details or protocol.

Ann Merete Møller: nothing to declare.

# Sources of support

## Internal sources

- No sources of funding, Other

## External sources

- No sources of funding, Other

# Differences between protocol and review

In the protocol we stated that we would include quasi-randomized trials. However, as this is not recommended by Cochrane, we decided not to include quasi-randomized trials in the final review.

In the protocol we stated that we would use RoB 1, but decided instead to use RoB 2 in the final review, which is a more up-to-date method for assessing risk of bias.

In the protocol we stated that we would include the outcomes for the comparison in three summary of findings tables: one including the post-traumatic stress disorder (PTSD) evaluation of relatives and their depression, anxiety, or complicated grief evaluation; one including patient mortality, length of hospital stay, and adverse events; and one including the personal stress of healthcare professionals as measured by the included studies and duration of patient resuscitation. However, during the review process we decided to include all outcomes in one summary of findings table, as the number of outcomes measured in the included studies was less than expected.

We have refined and finalized the data extraction form, including deleting the phrase to extract "methods of blinding", as this is not possible, and "duration of resuscitation", as this has no clinical relevance. It is not possible to detect whether a long or short resuscitation time is positive or negative.

Since the publication of the protocol, Monika Rubin as become a member of the Danish parliament. The conflicts of interest section has been updated.

# Characteristics of studies

## Characteristics of included studies [ordered by study ID]

## Jabre 2013

| *Study characteristics* | |
|---|---|
| Methods | Prospective, cluster-randomized controlled trial<br>**Setting:** Pre-hospital emergency medical service units*<br>**Country:** France<br>**Groups:** Family presence offered versus no family presence offered<br>**Period:** November 2009 to October 2011 |
| Participants | **Sample size:** 15 clusters randomized (8/7) resulting in 266/304 relatives in each group<br>**Included:** Adult family members of adult patients in cardiac arrest occurring at home.<br>Only 1 first-degree relative per patient. The relative was chosen in accordance with the legislation on hospitalization at the request of a third party in the following order of preference: spouse, parent, offspring, sibling.<br>**Excluded:** Communication barriers with the relative and cardiac arrest cases in which resuscitation was not attempted<br>**Missing:** None; all are accounted for in the flowchart |
| Interventions | Clusters were assigned in a 1:1 manner. A blinded statistician used a simple randomization method employing SAS software.<br>**Intervention:** Relatives offered to witness resuscitation of patients in cardiac arrest occurring at home<br>**Control:** traditional practice (Relatives asked to wait in a special room or allowed to witness CPR) |
| Outcomes | **Primary:** PTSD evaluation of the relatives measured at 3 months<br>**Secondary:**<br>• Depression and anxiety in the relatives measured at 3 months<br>• Duration of resuscitation<br>**Measured by:** IES and HADS |
| Notes | ***The units are ambulance base stations equipped with 1 or more mobile intensive care units, consisting of an ambulance driver, a nurse, and a senior emergency physician as the minimum team.<br>**Published protocol:** ClinicalTrials.gov number NCT01009606. NEJM final protocol.<br>**Funding:** Programme Hospitalier de Recherche Clinique 2008 of the French Ministry of Health<br>**Conflict of interest:** The following authors have conflict of interests (not related to this publication): Azoulay E. has received payment from Pfizer and Gilead. Borron S. has received funding from Vidacare for a study of EZ-IO in resuscitation. Tazarourte K. has received payment from LFB, France for a VKA study. Vivien B. has received accommodations costs from Hutchinson Technology Inc. related to a meeting on StO2.<br>**Contact with authors:** Author emailed (patricia.jabre@aphp.fr) in January 2020 for more information regarding the randomization process and receiving the HADS and IES subscales. |

## Jabre 2014

| *Study characteristics* | |
|---|---|
| Methods | |
| Participants | |
| Interventions | |
| Outcomes | **Primary:** PTSD evaluation of the relatives measured at 12 months<br>**Secondary:**<br>• Depression and anxiety in the relatives measured at 12 months<br>• Complicated grief<br>**Measured by:** IES, HADS, Inventory of Complicated Grief (ICG), and the structured diagnosis of a major depressive episode (MINI) |
| Notes | This is the long-term follow-up of the Jabre 2013.<br>The relative was deemed unreachable after 15 calls went unanswered. |

### Robinson 1998

| *Study characteristics* | |
|---|---|
| Methods | Prospective, randomized controlled trial<br>**Setting:** Emergency department, single center<br>**Country:** UK<br>**Groups:** Family presence offered versus no family presence offered<br>**Period:** November 1995 to February 1997 |
| Participants | **Sample size:** 25 randomized (13/12)<br>**Included:** Eligible resuscitations were those in which the patient was accompanied by a relative and 1 of 3 specific senior staff members were present. The person most closely related to each patient was chosen. Random selection was used if assigned relatives were equally close to the patient.<br>**Excluded:**<br>• Successful resuscitation of patient<br>• Relative refusal or lost to follow-up<br>**Missing:** None; all are accounted for in the flowchart. |
| Interventions | The unit of randomization was the patient and not the relative. Patients were assigned in a 1:1 manner by sealed envelope.<br>**Intervention:** Relatives offered to witness resuscitation of patients who required resuscitation for cardiac arrest or multiple trauma<br>**Control:** Relatives not offered to witness resuscitation |
| Outcomes | **Primary:** PTSD evaluation of the relatives measured at 3 and 9 months<br>**Secondary:** Depression and anxiety in the relatives measured at 3 and 9 months<br>**Measured by:** IES and HADS |
| Notes | No published protocol, preliminary pilot study.<br>**Conclusion**: They recommend that relatives should be offered the choice to remain with the patient during resuscitation, but no pressure should be applied to those who are reluctant. If the family choose to remain in the resuscitation room, they must be continuously accompanied and supported by an experienced member of staff.<br>**Funding:** Not stated<br>**Conflict of interest:** Not declared, however the study was stopped early because the randomization process was at risk of being altered by staff who had become convinced of the benefits of allowing relatives to witness resuscitation. |

HADS: Hospital Anxiety and Depression Scale
IES: Impact of Event Scale
PTSD: post-traumatic stress disorder

# Characteristics of excluded studies [ordered by study ID]

| Study | Reason for exclusion |
|---|---|
| Albarran 2009 | Wrong study design |
| Albarran 2009a | Personal opinion |
| Aldridge 2005 | Wrong study design |
| Alireza 2019 | Wrong intervention |
| Anon 2000a | Personal opinion |
| Anon 2000b | Wrong study design |
| Anon 2001 | Personal opinion |
| Anon 2007 | Personal opinion |
| Anon 2008a | Personal opinion |
| Anon 2008b | Personal opinion |
| Barrat 1998 | Personal opinion |
| Blättler 2014 | Wrong study design |
| Boie 2007 | Personal opinion |
| Boschini 2007 | Wrong patient population |

| Study | Reason for exclusion |
|---|---|
| Boucher 2010 | Wrong study design |
| Bredahl 2011 | Wrong study design |
| Broome 2000 | Personal opinion |
| Broyles 2016 | Wrong study design |
| Carter 2008 | Wrong study design |
| Cavlovich 2011 | Wrong study design |
| Clark 2005 | Wrong study design |
| Compton 2009 | Wrong study design |
| Compton 2010 | Abstract to a screened study |
| Compton 2011 | Wrong study design |
| Davidson 2011 | Wrong study design |
| Day 2011 | Wrong study design |
| De Stefano 2016 | Wrong study design |
| Decker 2012 | Personal opinion |
| DelVecchio Gilbert 2013 | Personal opinion |
| Dill 2006 | Wrong study design |
| Dolan 1997 | Personal opinion |
| Dudley 2009 | Wrong study design |
| Dwyer 2016 | Wrong study design |
| Edwards 2012 | Wrong study design |
| Egging 2011 | Wrong study design |
| Ellison 1997 | Wrong study design |
| Fromm 2016 | Wrong study design |
| Fulbrook 2008 | Personal opinion |
| Gaucher 2012 | Wrong intervention |
| Goldberger 2015 | Wrong study design |
| Gomez 2016 | Wrong study design |
| Hagan 2008 | Wrong study design |
| Hardin Fanning 2014 | Wrong study design |
| Herrera 2016 | Wrong study design |
| Hodge 2009 | Wrong study design |
| Holzhauser 2006 | Wrong study design |
| Holzhauser 2007 | Wrong study design |
| Holzhauser 2008 | Wrong study design |
| Islekdemir 2016 | Wrong intervention |
| Itzhaki 2012 | Wrong study design |
| Jabre 2012 | Duplicate |
| Jabre 2013a | Duplicate |
| Jabre 2014a | Personal opinion |
| Jaques 2014 | Personal opinion |
| JeongLim 2013 | Wrong study design |
| Jermark 2017 | Wrong study design |
| Kenny 2017 | Wrong study design |
| KurtogluCelik 2013 | Wrong study design |
| Leske 2010 | Wrong study design |
| Leske 2012 | Wrong study design |
| Leske 2017 | Wrong study design |
| Lomas 2007 | Personal opinion |
| Loyacono 2001 | Personal opinion |
| Lynch 2008 | Wrong study design |
| Mangurten 2005 | Wrong study design |
| Mangurten 2006 | Wrong study design |
| Mangurten 2006a | Abstract to a screened study |
| Maxton 2008 | Wrong study design |
| McClement 2008 | Wrong study design |
| McClement 2010 | Abstract to a screened study |
| Mian 2007 | Personal opinion |
| Mitchell 2008 | Wrong study design |

| Study | Reason for exclusion |
|---|---|
| Moon 2008 | Personal opinion |
| Morris 1998 | Personal opinion |
| NCT01009606 | Protocol of a screened study |
| Ong 2004 | Wrong study design |
| Parra 2018 | Wrong study design |
| Pasquale 2010 | Wrong study design |
| Petterson 1999 | Personal opinion |
| Piiparinen 2020 | Abstract.<br>Unfortunately, the whole study has not been published as a full article. Contact with the author said it was not an RCT. |
| Powers 2017 | Wrong study design |
| Pye 2010 | Wrong study design |
| Sacchetti 2005 | Wrong study design |
| Selos 2010 | Personal opinion |
| Shirazi 2009 | Wrong study design |
| Soleimanpour 2017 | Wrong study design |
| Stauffer 2012 | Wrong study design |
| Tosh 2015 | Wrong study design |
| Weslien 2006 | Wrong study design |
| Wolfram 1996 | Wrong patient population |
| Wolfram 1997 | Duplicate |
| Yanfang 2012 | Wrong study design |

RCT: randomized controlled trial

# Appendices

## Appendix 1. Search strategy

**MEDLINE (MedAll, Ovid)**

1. *Family/px [Psychology]
2. *Parents/px [Psychology]
3. *Professional-Family Relations/
4. ((famil* or next of kin* or kinship or relativ* or significant other* or spouse* or husband* or wife* or partner* or parent* or sibling* or friend* or companion* or brother* or sister* or father* or mother* or bereave*) adj5 (presen* or attend* or observ* or witness* or perception* or participat*)).mp.
5. (family cent?red adj2 care).mp.
6. 1 or 2 or 3 or 4 or 5
7. exp emergency medical services/
8. emergency medicine/
9. exp resuscitation/
10. exp Emergency Treatment/
11. exp heart arrest/
12. ((Emergen* or acute) adj3 (servic* or medicine or treat* or room*)).mp.
13. (resuscitat* or CPR).mp.
14. (prehospital* or pre-hospital* or out of hospital or trauma*).mp.
15. ((cardiac or heart or cardiopulmonary) adj2 arrest*).mp.
16. 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15

17. 6 and 16
18. (FPDR or FWR).mp.
19. 17 or 18
20. ((randomized controlled trial or controlled clinical trial).pt. or randomi?ed.ab. or placebo.ab. or drug therapy.fs. or randomly.ab. or trial.ab. or groups.ab.) not (exp animals/ not humans.sh.)
21. 19 and 20

**Embase (Ovid)**

1. exp family/ and (outcome assessment/ or exp psychologic assessment/ or psychological aspect/)
2. ((famil* or next of kin* or kinship or relativ* or significant other* or spouse* or husband* or wife* or partner* or parent* or sibling* or friend* or companion* or brother* or sister* or father* or mother* or bereave*) adj5 (presen* or attend* or observ* or witness* or perception* or participat*)).mp.
3. (family cent?red adj2 care).mp.
4. 1 or 2 or 3
5. exp emergency health service/
6. exp emergency medicine/
7. exp resuscitation/
8. exp heart arrest/
9. exp emergency treatment/
10. emergency ward/
11. ((emergen* or acute) adj3 (servic* or medicine or treat* or room*)).mp.
12. (resuscitat* or CPR).mp.
13. (prehospital* or pre-hospital* or out of hospital or trauma*).mp.
14. ((cardiac or heart or cardiopulmonary) adj2 arrest*).mp.
15. 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14
16. 4 and 15
17. (FPDR or FWR).mp.
18. 16 or 17
19. (randomized controlled trial/ or controlled clinical study/ or random$.ti,ab. or trial.ab. or randomization/ or intermethod comparison/ or placebo.ti,ab. or (compare or compared or comparison).ti. or ((evaluated or evaluate or evaluating or assessed or assess) and (compare or compared or comparing or comparison)).ab. or (open adj label).ti,ab. or ((double or single or doubly or singly) adj (blind or blinded or blindly)).ti,ab. or double blind procedure/ or parallel group$1.ti,ab. or (crossover or cross over).ti,ab. or ((assign$ or match or matched or allocation) adj5 (alternate or group$1 or intervention$1 or patient$1 or subject$1 or participant$1)).ti,ab. or (assigned or allocated).ti,ab. or (controlled adj7 (study or design or trial)).ti,ab. or (volunteer or volunteers).ti,ab. or human experiment/ or trial.ti.) not (((random$ adj sampl$ adj7 (cross section$ or questionnaire$1 or survey$ or database$1)).ti,ab. not (comparative study/ or controlled study/ or randomi?ed controlled.ti,ab. or randomly assigned.ti,ab.)) or (cross-sectional study/ not (randomized controlled trial/ or controlled clinical study/ or controlled study/ or randomi?ed controlled.ti,ab. or control group$1.ti,ab.)) or (((case adj control$) and random$) not randomi?ed controlled).ti,ab. or (Systematic review not (trial or study)).ti. or (nonrandom$ not random$).ti,ab. or Random field$.ti,ab. or (random cluster adj3 sampl$).ti,ab. or ((review.ab. and review.pt.) not trial.ti.) or (we searched.ab. and (review.ti. or review.pt.)) or update review.ab. or (databases adj4 searched).ab. or ((rat or rats or

mouse or mice or swine or porcine or murine or sheep or lambs or pigs or piglets or rabbit or rabbits or cat or cats or dog or dogs or cattle or bovine or monkey or monkeys or trout or marmoset$1).ti. and animal experiment/) or (Animal experiment/ not (human experiment/ or human/)))

20. 18 and 19

**PsycInfo (Ebsco)**

S1 ( DE "Family" OR DE "Family Members" ) AND ( DE "Perception" or DE "Witnesses" or DE "Health Personnel Attitudes" or DE "Attitudes" )

S2 TX ((famil* or next of kin* or kinship or relativ* or significant other* or spouse* or husband* or wife* or partner* or parent* or sibling* or friend* or companion* or brother* or sister* or bereave*) N5 (presen* or attend* or observ* or witness* or perception* or participat*))

S3 TX (family cent*red N2 care)

S4 S1 OR S2 OR S3

S5 DE "CPR" OR DE "Emergency Services" OR DE "Crisis Intervention Services" OR DE "Heart Disorders"

S6 TX ((emergen* or acute) N3 (servic* or medicine or treat* or room*))

S7 TX (resuscitat* or CPR)

S8 TX (prehospital* or pre-hospital* or pre hospital or out of hospital or trauma*)

S9 TX ((cardiac or heart or cardiopulmonary) N2 arrest*)

S10 S5 OR S6 OR S7 OR S8 OR S9

S11 S4 AND S10

S12 TX (FPDR or FWR)

S13 S11 OR S12

S14 ( DE "Randomized Controlled Trials" OR DE "Randomized Clinical Trials" ) OR ( TX (random* OR trial) OR AB (groups OR placebo) OR AB (control W5 group) OR AB (cluster W3 RCT) )

S15 S13 AND S14

**Cinahl (Ebsco)**

S1 (MH "Family+/PF")

S2 (MH "Parents+/PF")

S3 (MH "Professional-Family Relations")

S4 TX ((famil* or next of kin* or kinship or relativ* or significant other* or spouse* or husband* or wife* or partner* or parent* or sibling* or friend* or companion* or brother* or sister* or mother* or father* or bereave*) N5 (presen* or attend* or observ* or witness* or perception* or participat*)) or TX (family cent*red N2 care)

S5 S1 OR S2 OR S3 OR S4

S6 (MH "Emergency Medical Services+")

S7 (MH "Emergency Medicine")

S8 (MH "Emergency Treatment+")

S9 (MH "Resuscitation+")

S10 (MH "Heart Arrest+")

S11 TX ((emergen* or acute) N3 (servic* or medicine or treat* or room*))

S12 TX (resuscitat* or CPR)

S13 TX (prehospital* or pre-hospital* or pre hospital or out of hospital or trauma*)

S14 TX ((cardiac or heart or cardiopulmonary) N2 arrest*)

S15 S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14

S16 S5 AND S15

S17 TX (FPDR or FWR)

S18 S16 OR S17

S19 (MH (randomized controlled trials) OR MH (double-blind studies) OR MH (single-blind studies) OR MH (random assignment) OR MH (pretest-posttest design) OR MH (cluster sample) OR TI (randomised OR randomized) OR AB (random*) OR TI (trial) OR (MH (sample size) AND AB (assigned OR allocated OR control)) OR MH (placebos) OR PT (randomized controlled trial) OR AB (control W5 group) OR MH (crossover design) OR MH (comparative studies) OR AB (cluster W3 RCT)) NOT ((MH (animals+) OR MH (animal studies) OR TI (animal model*)) NOT MH (human))

S20 S18 AND S19

**Central (Cochrane Library)**

#1 MeSH descriptor: [Family] explode all trees and with qualifier(s): [psychology - PX]

#2 MeSH descriptor: [Parents] explode all trees and with qualifier(s): [psychology - PX]

#3 MeSH descriptor: [Professional-Family Relations] explode all trees

#4 ((famil* or "next of kin" or kinship or relativ* or (significant next other*) or spouse* or husband* or wife* or partner* or parent* or sibling* or friend* or companion* or brother* or sister* or mother or father* or bereave*) near (presen* or attend* or observ* or witness* or perception* or participat*)):ti,ab,kw

#5 (family NEAR (centred or centered) NEAR care):ti,ab,kw

#6 #1 or #2 or #3 or #4 or #5

#7 MeSH descriptor: [Emergency Medical Services] explode all trees

#8 MeSH descriptor: [Emergency Medicine] explode all trees

#9 MeSH descriptor: [Emergency Treatment] explode all trees

#10 MeSH descriptor: [Resuscitation] explode all trees

#11 MeSH descriptor: [Heart Arrest] explode all trees

#12 ((emergen* or acute) near/3 (servic* or medicine or treat*)):ti,ab,kw

#13 (resuscitat* or CPR):ti,ab,kw

#14 (prehospital* or (pre next hospital*) or (out next of next hospital) or trauma*):ti,ab,kw

#15 ((cardiac or heart or cardiopulmonary) near/2 arrest*):ti,ab,kw

#16 #7 or #8 or #9 or #10 or #11 or #12 or #13 or #14 or #15

#17 #6 and #16

#18 (FPDR or FWR):ti,ab,kw

#19 #17 or #18

#20 #19 in Trials

**ClinicalTrials.gov**
Advanced search
(family OR relative) AND (presence OR witness OR witnessed) AND (resuscitation OR emergency OR arrest)

**ISRCTN**
Advanced search
(family OR relative) AND (presence OR witness OR witnessed) AND (resuscitation OR emergency OR arrest)

**WHO ICTRP**
Basic search
family AND presence AND resuscitation
family AND presence AND emergency
family AND presence AND arrest
relative AND presence AND resuscitation
relative AND presence AND emergency
relative AND presence AND arrest
family AND witness AND resuscitation
family AND witness AND emergency
family AND witness AND arrest
relative AND witness AND resuscitation
relative AND witness AND emergency
relative AND witness AND arrest

# Appendix 2. Data extraction form

We extracted the following information where possible.

- Bibliographic data, including date of completion/publication.
- Study settings:
- Study design
- Methods of randomization
- Study length
- Setting
    - Single- or multicenter study
    - Number of centers if multi-center
    - Emergency department or other
- Length of follow-up
- Country of origin
- Source of funding
- Participants:
    - Method for selection of participants
    - Total number
- Number randomized to each group
- Number of exclusions and reasons for exclusions
- Missing
- Age
- Gender distribution

- Inclusion criteria
- Exclusion criteria
- Interventions

Participants being offered to observe

- Resuscitation in the emergency department
  - Both cardiac arrest and
  - Treatment of critical conditions including trauma
- Resuscitation pre-hospital
  - Both cardiac arrest and
  - Treatment of critical conditions including trauma
- Comparators:
  - Participants not offered the opportunity of observation but instead following standard practice of placement in, for instance, a special room, any other intervention, or no intervention at all
- Outcomes:

Primary:

PTSD evaluation of the relatives measured at 0 to 3 months and more than 3 months

Secondary:

- Depression, anxiety, or complicated grief in the relatives according to ICD-11 measured at 0 to 3 months and more than 3 months
- Patient morbidity: readmissions within 30 days, number of ICU admissions within 30 days
- Patient mortality as measured in the included studies. If a study has several time points included, the one closest to 30 days will be used.
- Adverse events in the patient population: number of adverse cardiac and pulmonary events or other adverse events described in the included studies and total number of adverse events
- Personal stress in healthcare professionals during resuscitation as measured by included studies
- Healthcare professionals' attitudes towards FPDR as measured in the included studies
- Duration of patient resuscitation as measured in the included studies
- Number of withdrawals (by group) and number of withdrawals (by group) due to adverse events

# References

## References to studies included in this review

### Jabre 2013 {published data only}

16954760

Jabre P, Belpomme V, Azoulay E, Jacob L, Bertrand L, Lapostolle F, et al. Family presence during cardiopulmonary resuscitation. New England Journal of Medicine 2013;368(11):1008-18. 16954761 [PMID: 23484827]

### Jabre 2014 {published data only}

17944679

Jabre P, Tazarourte K, Azoulay E, Borron S W, Belpomme V, Jacob L, et al. Offering the opportunity for family to be present during cardiopulmonary resuscitation: 1-year assessment. Intensive Care Medicine 2014;40(7):981-7. 17944680 [PMID: 24852952]

### Robinson 1998 {published data only}

16954762

Robinson SM, Mackenzie-Ross S, Campbell Hewson GL, Egleston CV, Prevost AT. Psychological effect of witnessed resuscitation on bereaved relatives. Lancet 1998;352(9128):614-7. 16954763 [PMID: 9746023]

## References to studies excluded from this review

### Albarran 2009 {published data only}

16954764

Albarran J. Seeking experiences of family witnessed resuscitation. Nursing Standard 2009;23(32):33. 16954765

### Albarran 2009a {published data only}

16954766

Albarran J. Call to readership. Family witnessed resuscitation: an invitation to share your experiences. Journal of Advanced Perioperative Care 2009;4(1):55. 16954767

### Aldridge 2005 {published data only}

16954768

Aldridge MD, Clark AP. Making the right choice: family presence and the CNS. Clinical Nurse Specialist: The Journal for Advanced Nursing Practice 2005;19(3):113-6. 16954769 [PMID: 15897763]

### Alireza 2019 {published data only}

16954770

Alireza ZF, Ali AJ, Tayebeh NB. Comparison the effect of trained and untrained family presence on their anxiety during invasive procedures in an emergency department: A randomized controlled trial. Turkish Journal of Emergency Medicine 2019;19(3):100-5. 16954771 [PMID: 31321342]

### Anon 2000a {published data only}

16954774

Relatives' choice to witness resus. Nursing Times 2000;96(15):10. 16954775

### Anon 2000b {published data only}

16954776

Hospital changes policy to allow benefit of family presence during invasive procedures and resuscitation. Report on Medical Guidelines and Outcomes Research 13 of April 2000;11(8):1-2, 5-6. 16954777 [PMID: 11794340]

### Anon 2001 {published data only}

16954778

Support for relatives witnessing attempts to resuscitate patients. Emergency Nurse 2001;9(8):2. 16954779 [PMID: 27237555]

## Anon 2007 {published data only}

22898366

Is family presence a factor in lawsuits? ED Management 2007;19(8):93-4. 22898367

## Anon 2008a {published data only}

16954786

Resuscitation efforts: how do you feel about family presence? Nursing 2008;38(7):25. 16954787

## Anon 2008b {published data only}

16954788

Allow parents to attend child CPR. Nursing Times 2008;104(47):8. 16954789

## Barrat 1998 {published data only}

22898368

Barrat F, Wallis DN. Relatives want the option to attend CPR. Nursing Times 1998;94(20):47. 22898369

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# Additional tables

**Table 1**

**Summarized effect estimates**

Median and interquartile range (IQR) for the Impact of Event Scale (IES) and Hospital Anxiety and Depression Scale (HADS) including their subscales in the 2 included studies when comparing the effect estimates of the relatives that were offered to witness resuscitation compared to those who were offered the traditional practice (relatives asked to wait in a special room or allowed to witness CPR)

| | | IES* | IESI | IESA | HADA | HADD | HADS** | | IES | IESI | IESA | HADA | HADD | HADS |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| **Study ID** | **Intervention: offering relatives the opportunity of FPDR** | | | | | | | | | | | | | |
| Jabre 2013<br>Jabre 2014 | 3 months | 22 (12 to 33) | 14 (8 to 21) | 8 (3 to 13) | 5 (3 to 8) | 4 (2 to 8) | 10 (6 to 16) | 12 months | 19 (7 to 28) | 2 (0 to 13) | 0 (0 to 8) | 4 (2 to 8) | 3 (1 to 5) | 8 (4 to 13) |
| Robinson 1998 | 3 months | - | 15.5 (11.5 | 8 (3.3 to 18) | 7 (5 to 8.8) | 2.5 (1 to 5) | - | 9 months | - | 17.5 (3 to | 7 (0.8 | 6.5 (2.3 to | 6.5 (0.8 to | - |

| | | | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | | to 24.8) | | | | | | | 27.8) | to 18.3) | 10.3) | 9.3) | |
| | **Comparison:not offering relatives the opportunity of FPDR** | | | | | | | | | | | | | |
| Jabre 2013<br>Jabre 2014 | 3 months | 24 (13 to 35) | 15 (8 to 21.75) | 8 (4 to 15.75) | 6 (3 to 10) | 5 (2 to 9) | 11 (6 to 19) | 12 months | 20 (11 to 35) | 9 (0.25 to 17.75) | 5 (0 to 12) | 5 (2 to 9) | 4 (1 to 8) | 10 (5 to 16) |
| Robinson 1998 | 3 months | - | 16.5 (11.5 to 21.8) | 10 (5.8 to 13.3) | 8 (5 to 12) | 5 (3 to 6.5) | - | 9 months | - | 21 (10 to 25) | 18 (9 to 20) | 8.5 (3.3 to 11.3) | 4.5 (1.6 to 6.8) | - |

Abbreviations: CPR: cardiopulmonary resuscitation; FPDR: family presence during resuscitation; HADA: HADS anxiety subscale; HADD: HADS depression subscale; HADS: Hospital Anxiety and Depression Scale; IES: Impact of Event Scale; IESA: IES avoidance subscale; IESI: IES intrusion subscale; PTSD: post-traumatic stress disorder

*Scores on IES range from 0 (no PTSD-related symptoms) to 75 (severe PTSD-related symptoms). The IESI subscale ranges from 0 to 35, and the IESA from 0 to 40. The presence of PTSD is defined by an IES score > 30.
**Scores on HADS range from 0 to 42, with higher scores indicating greater anxiety and depression. The presence of anxiety or depression is defined by a HADS subscale score higher than 10 (range, 0 to 21).

**Table 2**

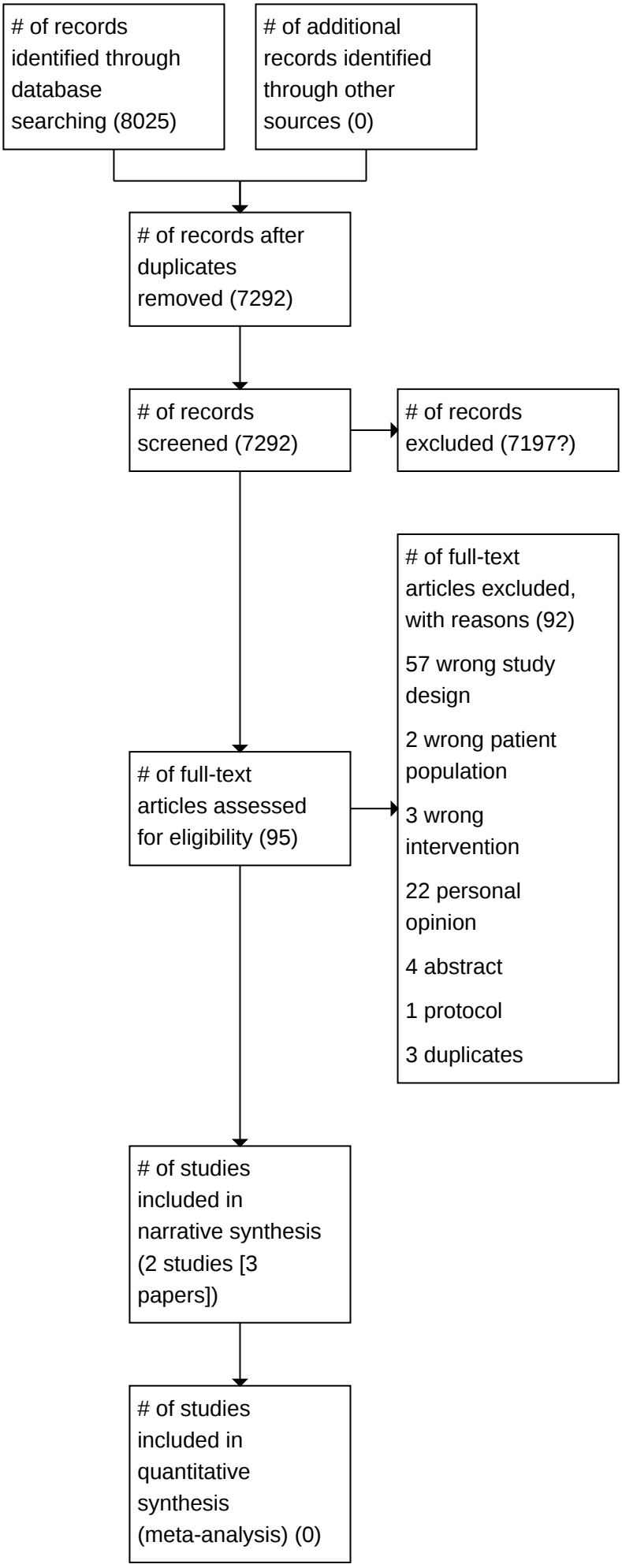
**Characteristics of included studies**

| Study[a] | Country | Setting | Methods | Outcomes | Sample size | Age range | % women | Participants | Risk of bias |
|---|---|---|---|---|---|---|---|---|---|
| Jabre 2013 | France | Pre-hospital emergency medical service units | cluster-RCT | Primary: PTSD evaluation<br>Secondary: anxiety and depression, resuscitation time,<br>healthcare professional stress evaluation | 570[b] | 41 to 73<br>52 to 84[c] | 63, 68<br>33, 33[c] | 475<br>1666[d] | High |
| Jabre 2014 | - | - | - | Primary: PTSD evaluation<br>Secondary: anxiety, depression and complicated grief | - | - | - | 408 | - |
| Robinson 1998 | UK | Emergency department | RCT | Primary: PTSD evaluation<br>Secondary: anxiety and depression | 25 | 19 to 78 | 55, 56 | 18 | High |

Abbreviations: PTSD: post-traumatic stress disorder; RCT: randomized controlled trial; VAS: visual analogue scale

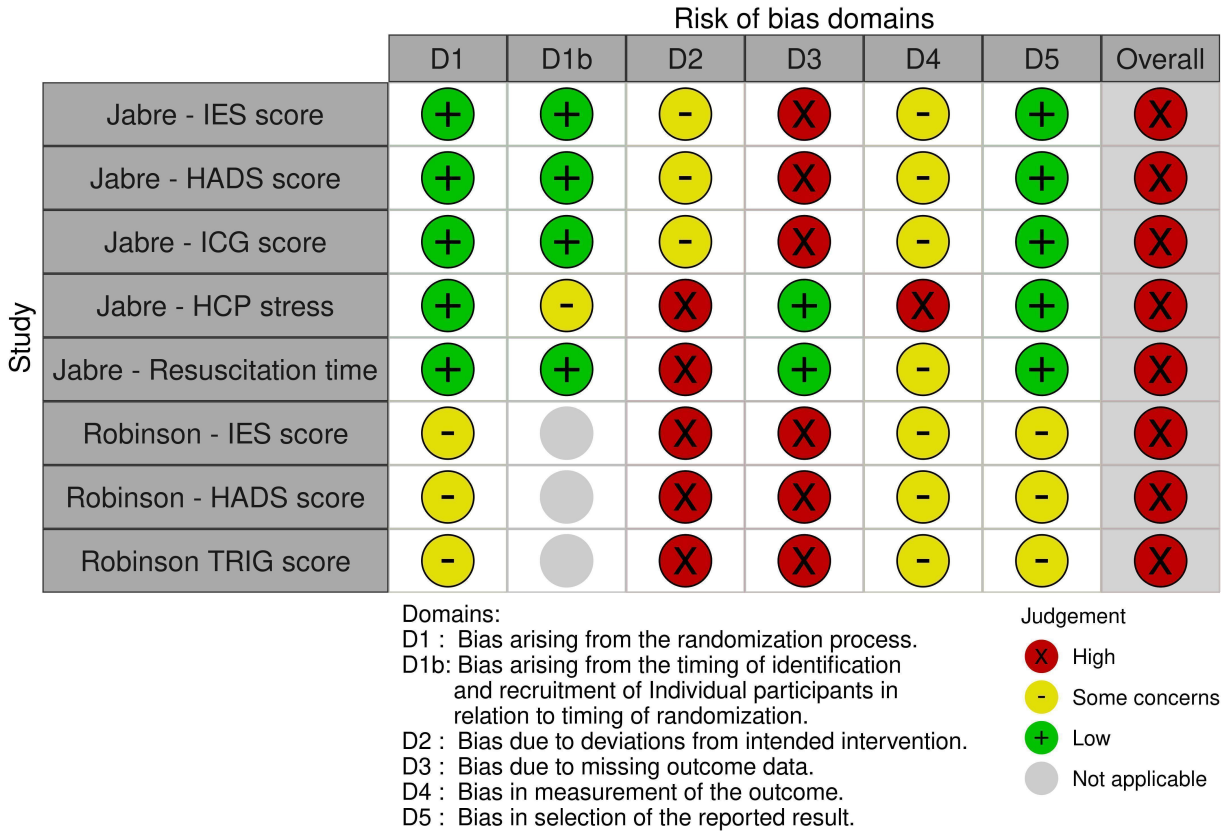
[a]The two first studies are part of the same trial with short- and long-term effect measured.
[b]15 clusters included: n = 104, 16, 17, 29, 56, 64, 15, 32, 35, 88, 45, 14, 8, 26, 21.
[c]Patient demographic.
[d]Through communication with the trial author, we obtained the following numbers of healthcare professional participants by profession, from those who completed the VAS stress evaluation: physicians: n = 567 (3 missing); nurses: n = 556 (14 missing); ambulance drivers: n = 543 (27 missing).

**Figure 1**


# of records identified through database searching (8025)
# of additional records identified through other sources (0)
# of records after duplicates removed (7292)
# of records screened (7292)
# of records excluded (7197?)
# of full-text articles excluded, with reasons (92)
57 wrong study design
2 wrong patient population
3 wrong intervention
22 personal opinion
4 abstract
1 protocol
3 duplicates
# of full-text articles assessed for eligibility (95)
# of studies included in narrative synthesis (2 studies [3 papers])
# of studies included in quantitative synthesis (meta-analysis) (0)

Study flow diagram.

**Figure 2**




Risk of bias.

# The healthcare professionals' perspectives and experiences with family presence during resuscitation: a qualitative evidence synthesis

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## TABLE OF CONTENT

# ABSTRACT

**Introduction**

Family presence during resuscitation (FPDR) is a growing hospital praxis despite lack of high-quality evidence. The aim of this qualitative evidence synthesis (QES) review was to synthesize current evidence regarding healthcare professionals (HCP) perspectives on barriers and facilitating factors of FPDR in western hospital setting. Additionally, the potential impact of FPDR on HCP performance, during resuscitation in the emergency department.

**Methods**

We conducted a systematic literature search from 1980 to 22nd of March 2022 and included primary studies with qualitative study designs. We applied NVivo for data analysis and extracted all relevant data concerning HCP experiences, barriers and facilitators regarding FPDR. Data was coded and organized into themes and categories. All the included studies underwent quality appraisal by Critical Appraisal Skills Program (CASP).

**Results**

We identified 6885 articles suitable for screening, 136 articles were selected for full-text screening and 9 studies included from Australia, UK and USA. In total, 134 HCP participated in the included studies, between 2005-2019. Most included studies lacked sufficiently rigorous data analysis and their findings were appraised to have moderate GRADE CERQual confidence.

We identified three analytical themes with eight descriptive subthemes. One finding was found to have high GRADE CERQual confidence: A belief that FPDR is “the right thing to do”. Included studies reported that HCP found FPDR beneficial for themselves, and especially beneficial for the patient and the relatives and that it would be harmful to exclude the relatives of critically ill and dying loved ones. Situations involving resuscitation of a child nearly always facilitated FPDR.

**Conclusion**

The evidence on HCP perspectives on barriers and facilitating factors is of low to moderate confidence. There is a consensus across the included articles, that FPDR is the “right thing to do”, and an ethical principle of beneficence is dominant, especially regarding children.

## BACKGROUND

"Family Presence During Resuscitation" (FDPR) refers to the presence of relatives in a location allowing observation of or physical contact with the patient during resuscitation. The aim of FPDR is to meet the emotional needs of patients and their relatives, as a means to integrate holistic care in nursing and medical practice[1–3]. The relatives may interact with the patient: hold their hand or speak with them during a resuscitation attempt or they can be present in a passive manner.
It has been found that if offered the opportunity, relatives prefer to be present in the case of resuscitation[1,4–10]. Since the first reports of FDPR in the early 1980's[11], there is an increasingly more open-minded attitude toward FPDR in the context of western biomedicine [9,12,13]. Accordingly, family centred care and involvement of the parents is common in paediatrics and obstetrics[14–17]. In this same thread, FPDR can be understood as a triangular relationship between the healthcare professional (HCP), the patient and the relatives. The principle of FPDR relies on the collaboration around the intervention of FPDR meeting all needs and everyone's well-being in a balanced way. This could explain the differing attitudes towards the praxis amongst HCP[1,16,18–24].

As for now, the European Resuscitation Council recommends FPDR[25] and it is recommended that a support person should be designated to the relatives during FPDR, however this can take a toll on hospital resources [26–31]. For that reason, FPDR is subject to controversy and remains inconsistently implemented. There is a belief that FPDR facilitates closure for the relatives and offers an opportunity to say goodbye. In turn, the relative can provide emotional support to the patient [32,33]. But since 1987 only three randomized controlled trials (RCT) [34], including a qualitative survey-design [35], and a quasi-randomized trial [29] which reviewed the potential effect on relatives of being present, and on HCP experiences, have been conducted. Conversely, an overview of the literature on FPDR shows that HCP do not unanimously support the practice. In fact their attitudes vary significantly [1,9,16,20,22,31,36–38.] Some HCP are concerned that FPDR can have potential psychological adverse effects on relatives, as well as impact the performance of the HCP [21,23,44,26,28,30,39–43]. This could subsequently affect the quality of acute medical care[32,45,46]. Published guidelines encourage educational programs that train support persons for FPDR[9].

## OBJECTIVES

The primary aim of this qualitative evidence synthesis review was to synthesize current qualitative evidence regarding HCP perspectives on factors which influence FPDR, as well as how they experience the potential impact of FPDR on work performance in the emergency department setting.

# METHODS

This was a systematic review with thematic synthesis of the findings of qualitative studies. The protocol was published before data extraction[12]. We conducted a systematic literature search, applying Cochrane methodology and followed the Enhancing Transparency in REporting the synthesis of Qualitative research (ENTREQ) guidelines to enhance quality[47].

## *Criteria for considering studies for this review*

We included primary studies with qualitative study designs, data collection and analysis, from Europe, The UK, Canada, Australia, and USA, in relation to the treatment of adults in the emergency department.
We excluded studies which gathered data with qualitative methods that did not apply qualitative methods in the analysis. We also excluded mixed method studies. Lastly, descriptive papers, editorials and opinion papers were excluded, along with quantitative and qualitative open-ended surveys.

We included studies using the SPICE acronym for a stepwise approach to the review question, meaning:
SPI: Setting, Perspective and phenomenon of Interest. Studies that focus on FPDR in the ED as seen from the HCP perspective, was included. The definition of HCP in this review included all categories of HCP as described in the included studies.
C: There was no Comparison.
E: Evaluation. The participants included underwent interviews regarding their perspectives on barriers and facilitating factors of FPDR in relation to the treatment of adults. Further, regarding their experience and reflections on the potential impact of FPDR on HCP performance. We had no limitations on adult age or gender and defined the type of patient, undergoing FPDR, as being one with cardiac arrest and in need of CPR, a patient with a critical medical, surgical or traumatic life-threatening condition, an unconscious patient or a patient in any other way at risk of death.

## *Identification of studies*

No language, publication year or publication status restraints were applied to this search. We included a methodological filter for qualitative studies and searched the following databases for relevant trials:

- MEDLINE (Ovid, from 1946)
- Embase (Ovid, from 1974)
- Cinahl (EBSCO, from 1980)
- PsycINFO (EBSCO, from 1806)

We developed a draft search strategy for MEDLINE. The search strategy can be found in Appendix 1 and was modified for the other databases. An information specialist developed the search strategy in consultation with the review authors.

We also browsed the reference lists of included trials and conducted a cited reference search for all

included studies in Scopus and Google Scholar. Furthermore, we searched Epistemonikos for related reviews in order to identify suitable studies for inclusion.

Two review authors (MAR and SS) screened the search results for eligible studies by examining titles and abstracts independently and in duplicate. We used Rayyan for transparency and retrieved the full texts of all the papers detected as potentially relevant. We consulted with a third author (TT) when needed. We developed a PRISMA flow diagram (figure 1) to show our search results and the process of screening [48]. All the included studies underwent quality appraisal, made by three reviewers (MAR, KF and SS) independently by the Critical Appraisal Skills Programme (CASP)[49]. Any disagreements were solved by discussion, aided by a fourth author (TT). See the CASP assessments in Table 2.

## *Data management, analysis and synthesis*

We imported the included studies into NVivo data analysis software[50] and followed the method for thematic synthesis described by Thomas and Harden to analyse data[,51]. We extracted all relevant data regarding barriers and facilitators from the included studies, together with HCP experiences with FPDR from both results, discussion and conclusion section of the papers. This was performed with line-by-line coding. Codes were then organized into categories and data was further interpreted to develop analytical themes. See the summary of the review findings in figure 2.

We used GRADE CERQual (Grading of Recommendations, Assessments, Development and Evaluation Confidence in the Evidence from Reviews of Qualitative research) to assess the confidence in the qualitative synthesis findings[52]. Three authors (MAR, TT, AMM) made an evaluation of the overall confidence in the evidence supporting the review finding in which we marked the judgement of confidence as high, moderate, low, or very low. The final assessment was based on the agreement of the review authors. See the summary of the
GRADE CERQual assessments in table 3 and 4.

# RESULTS

We identified 6885 articles suitable for screening after duplicates were removed, leading to 137 articles for full-text screening. We included 9 studies in the final review as we found it necessary to exclude one before data extraction due to low methodological quality of the study[53]. See the PRISMA flowchart in figure 1.

## *Description of the studies*

In total, 134 HCP participated in the included studies which were published between 2005-2019. The studies originated from Australia, USA, and the UK. Data were collected using face-to-face interviews, (6 studies), interviews via telephone (3 studies), and observational/individual interviews in combination (1 study). Sample sizes ranged from 10-29 HCP and the overall age range was 24-65+, however three studies did not report the participants' age. For a full overview of the study characteristics see table 1.

All studies were assessed to have methodological limitations, most of them due to a lack of rigorous description of the data analysis. For a full overview of CASP assessment see table 2.

## *Review findings*

We identified three analytical themes with eight descriptive subthemes.

1. "Facilitating factors for FPDR", with the subthemes "Knowledge about the patient and helping decision-making", "Emotionally satisfying for the HCP" and "A belief that FPDR is the right thing to do".
2. "Barriers for FPDR", with the subthemes "Lack of physical space and emotional support", "Fear of imposing psychological trauma and misunderstanding" and "Clinical experience – friend or foe".
3. "How staff are affected by FPDR", with the subthemes "A feeling of "being scrutinized"" and "The communication in the team changes".

For an overview of review findings see figure 2. For a full overview of GRADE CERQual assessment in relation to the review findings see table 3 and 4.

### ***Facilitating factors for FPDR***

Facilitating factors for engaging in FPDR were both practical and ethical. The most predominant facilitating factors found, was an understanding of FPDR as advantageous for the relatives and HCP, ethically and psychologically. Furthermore, that FPDR allowed HCP quick access to the patient's medical history and wishes for treatment and resuscitation.

**"Knowledge about the patient and helping decision-making"** (Moderate GRADE CERQual confidence): Relatives who are present in the emergency room may have relevant information regarding their loved one's recent symptoms, activities or their wishes for medical care and resuscitation. This can be a powerful tool in situations where the patient is incapable of expressing their own needs or medical history. The relatives can even be included in decision-making in relation to the continuation or discontinuation of the resuscitation efforts.

Another advantage is the relative's unique knowledge about the patient, especially in stressful situations with limited time and human resources:

> *"NO! He will go into anaphylax if you give him that," and in fact when we checked the records, the child had anaphylaxed at least three times before, and so if mom hadn't been there, we would have made a really horrible situation worse"* [54]

Vital information can be obtained from the relatives which makes them an important resource, in one interview called a "key informant".

"**Emotionally satisficing for the HCP**" (Low GRADE CERQual confidence):

It was found that numerous HCP across the articles, described how they believed that the presence of relatives could make the HCP feel validated and appreciated for the care their loved ones were receiving. Some HCP described an interaction and a connection to the relatives that had a large role in making the experience positive for the HCP. Some HCP had even received hugs, thank you notes and public acknowledgement.

A feeling of making a difference and letting the relatives witness the HCP efforts was mentioned in several studies. The HCP who was in support of FPDR felt that the relatives could witness, even accept, that everything that could be done, had been done for their loved one. This in turn created a realistic picture of the situation:

> *".... Feel satisfaction also that I did my best for the relatives and for that patient also, that they've seen everything was done at that time"* [55]

This was in some studies linked to initiating the grieving process in case the resuscitation efforts were hopeless. Some HCP came to that conclusion it could spare the HCP for an unpleasant conversation when breaking the news of someone's passing.

> *"I didn't have the usual anxiety, frustration, or dread of going out and talking to the family because I knew that the family was there and they could ask questions while the process was going on. It just seemed like a calmer situation."* [54]

Lastly FPDR can facilitate a closure afterwards, in case of unsuccessful resuscitation and FPDR can lead the way towards emotional defusing with the relatives:

> *"Helps the staff get a little closure as well if the family, hey you see we tried, and you know that way there's a little emotional exchange between the family and the staff and I think that's a very important thing for staff to have."* [56]

**"A belief that FPDR is the right thing to do"** (High GRADE CERQual confidence):

This topic was characterized by considerations of an ethical nature and personal preference amongst the HCP. The belief that FPDR was beneficial for both the patient and the relatives, was reported in almost all the included studies and thus, FPDR was prioritized by HCP in efforts to support family centred care. Some clinicians mentioned that an exclusion of families could be directly harmful to both the relatives of critically ill and dying loved ones:

> *"These clinicians believed forced separation of family from their critical ill and dying loved ones could be emotionally harmful. For example, Darren (NP/RN) stressed that clinicians are "just passing briefly though these people's lives and it's the person that's been with them all their life who has far more rights .. . we don't want to leave any more debris than we have to [by denying FPDR]."* [57]

And:

> *'I think certainly he knew she (wife) was there … Why separate them when they've been together that long … Why separate them in the last few minutes of their lives?'* [58]

Other studies described that the opinions of the HCP, was a factor in including or excluding the praxis of FPDR. These studies showed that HCP mirror themselves in the situation and emphasize the patient's culture and family, which lead to “what if it was me” contemplations which ultimately guided their decision-making.
The HCP also reported a greater sense of closure amongst relatives when resuscitation efforts were futile. To be with their loved ones in their last moments, to say their goodbyes and witness the efforts of the HCP seemed to help relatives come to terms with the outcome.

> *FPDR demystified the resuscitation, allowed family to see everything possible was done, prepared them for death, allowed them to say goodbye and facilitated grieving and closure.* [57]

Most HCP continued to practice FPDR repeatedly due to no disadvantageous situations with FPDR during critical care. A positive experience with FPDR was a facilitative factor in future decision making about whether to practice FPDR.
There were sparse examples of hospital policies for FPDR, however, numerous HCP relied on scientific research that recommended FPDR to guide their decision. Some HCP also found that the culture towards FPDR was changing towards a more inclusive culture and wanted to embrace the “new” standard.

Another aspect brought to life in the articles, was a time perspective and the suddenness of events. It is mentioned, that if the patient has gone through a long period of illness, the relatives are more mentally prepared, making the decision of FPDR easy for the HCP. In chronic illness or long-term hospitalization, it is possible to get a deeper connection to the relatives which is unobtainable in the ED and other acute settings. This connection seems important to many HCP and can be strengthened by FPDR. It could also help humanise the patient, and to amplify empathy.
Lastly, a strong facilitator for having relatives present was critical paediatric situations, where there is consensus about including parents:

> *“All clinicians in the study agreed FPDR should be allowed (and even expected) if the patient was a child. Clinicians stressed the nurturing nature of the parent–child relationship and spoke about parental presence during resuscitation as an inherent right”* [57]

### *Barriers for FPDR*

Two major themes emerged from the studies in the discussion revolving barriers to FPDR. Firstly, many HCP were concerned with practical issues regarding such as physical space in the resuscitation room, the behaviour of the relatives and the lack of a designated support person. Secondly, some HCP mentioned that ethical issues on a professional and personal level, weighed against their support of FPDR.

**“Lack of physical space and emotional support”** (Moderate GRADE CERQual confidence):
The practical issues range widely. Not enough physical space at the bedside and too many people in the resuscitation room was mentioned as some of the most basic impractical challenges to not engage FPDR. Some also denied FPDR to protect families from safety hazards and dangerous equipment.
Another barrier for FPDR which was stressed in nearly all the studies, was the lack of a support person to comfort and explain the situation to the relatives.

> *“Health professionals also stressed the need for a dedicated support person to offer choices about the type and level of FPDR, to adequately prepare family, to explain that happening and support them as the resuscitation progressed. Some healthcare settings in this study provided a dedicated family support person as part of their standard (yet informal) practice.”*

Other barriers were of more emotional, yet practical character. Relatives that interfered with the patient at were highly emotional, hysterical or out of control, either by disturbing physical or emotional behaviour would, was not feasable for inclusion in resuscitation room. The HCP feared they would lose focus and concentration from the patient because of a distracting relative:

> *"A primary concern for the nurses was family behavior at the bedside and the potential interference that a grieving family might present during resuscitation."*

**"Fear of imposing psychological trauma and misunderstanding"** (Moderate GRADE CERQual confidence):
Almost every included study had a mention of the ethical challenge of FPDR, as HCP feared that it to be emotionally harmful for the relatives to witness resuscitation, which could lead to psychological trauma to the relatives. This posed a significant ethical issue and was a barrier to many HCP.
Another barrier was the HCP fear that misunderstandings could arise leading to legal persecutions. Relatives generally lack the medical knowledge to interpret and understand procedures during resuscitation attempts. This could lead the relatives to question the acute medical treatment, to misunderstanding certain treatments elements and trigger strong reactions in them.

> *"These nurses recognize that relatives may misinterpret medical therapy because they do not understand pathophysiology. Relatives' misunderstanding of procedures may impact their behaviour, and to include them at the resuscitation may not be in the best interest of the relatives or the staff."* [59]

Other articles mentioned barriers related to inexperience among the HCP, e.g. during difficult procedures where HCP might fear professional inadequacy and experience performance anxiety.

> *"The presence of relatives was seen as an additional pressure on the resuscitation team making them conscious of their actions, with concerns that relatives would be critical"* [60]

Some also believe that FPDR can conflict with the patient's privacy to invite relatives in without the patients accept.

**"Clinical experience – friend or foe"** (Very low GRADE CERQual confidence):
When HCP had to decide whether to invite the relative in, staff competence and confidence often was taken into consideration by the team leader, usually a doctor of high seniority. If including the relative was decided against, the decision often went unchallenged to avoid disruption of the resuscitation process. Thus, the role, seniority and maturity of the HCP was important factors for engaging in FPDR:

> *"The participants stated that life experience and maturity were essential elements to successfully interaction with relatives, especially in the CC role. The notion of being more mature, experienced and professionally comfortable was emphasised with participants noting that they avoided interactions with relatives in their early career years."*

### *How staff are affected by FPDR*

**"A feeling of "being scrutinized ""** (Moderate GRADE CERQual confidence):
A theme identified was the feeling of being watched when relatives were present. Some HCP described this it as emotionally draining as they felt an additional pressure on the resuscitation team. The HCP described being overly self-conscious and experiencing a higher level of anxiety during FPDR. As one nurse described, it feels like you are focusing on two people instead of one. This supervisory sensation during FPDR also depended on the knowledge and skills of the HCP, which in turn added stress to the new staff and less to the more experienced staff.

> *"But you do feel like you're on stage, like somebody's watching your performance."* [59]

The presence of relatives can also function as a reminder for the staff, that the patient is a human, important to others. This can make the situation even harder to deal with for the HCP, because they would like to avoid feeling the same pain as the relatives and maintain a barrier. A nurse also indicated that FPDR could make the resuscitation event continue slightly longer. However, some HCP did seem to value the closeness which may develop with families during resuscitation. A relationship that was both rewarding and emotionally draining.

**"The communication in the team changes"** (Moderate GRADE CERQual confidence):
The presence of relatives was found to alter the way the resuscitation team worked. Some believe that the code itself was much more respectful and that it enhanced staff professionalism, effectivity and efficiently. FPDR would increase the team's awareness on the communication and physical actions. A few nurses described how an informal tone functioned as a stress relief among team members during tense situations, yet this might appear unprofessional, even disrespectful, to the present relatives.

# DISCUSSION

The aim of this review was to synthesize current qualitative evidence regarding HCP perspectives on factors influencing FPDR, as well as their experience of the potential impact of FPDR on HCP performance, during resuscitation in the emergency department setting. We identified three main themes “Facilitating factors for FPDR”, “Barriers for FPDR” and “How staff are affected by FPDR”.

Solely one finding in the main theme “facilitating factors for FPDR” was found to have High GRADE CERQual confidence: “A belief that FPDR is the right thing to do”. We find this especially interesting, as the evidence regarding the effect of FPDR is quite low [34]. If HCP operate outside of clinical guidelines and policies, the risk of inconsistent and ad hoc practices based on individual and subjective preferences is of concern and an important facilitative factor found in this review was the ethical principle of beneficence [57]. HCP seemed to be driven by the desire to do "what's best" for patients and relatives when they had to contemplate whether to permit or forbid FPDR. Almost all included studies reported that HCP found FPDR beneficial for both the patient and the relatives. However, each person's view of "what's best" is unique and do not necessarily align with family preferences or with recent research that reflects the effects of FPDR. The HCP considered it harmful to exclude the relatives of critically ill and dying loved ones. Situations where the patients were a child was a significant facilitative factor for FPDR. We believe that the notion of FPDR as “the right thing to do” is rooted in HCP observations that relatives feel their presence comforts the patient, even if unconscious. Additionally, that it comforts the relatives to witness the measures that are taken to save the patient, especially in the event of death[9,38]. Some relatives even feel it is their right to be present and consider their own presence to be both helpful and useful to HCP [1,11,4].
However, even though, some clinicians believe that FPDR may have more advantages than disadvantages, as it allows the relatives to feel both needed, involved and of use in the care and comfort of the patient[61]. Another facilitative factor was that relatives could contribute with “Knowledge about the patient and helping decision-making” (Moderate GRADE CERQual confidence). The ability to rapidly get a patient’s history is construed as advantageous[62]. Nevertheless, one should bear in mind that the information given by the relatives is never objective and not always beneficial to the patient, due to possible complexities in the family.

A barrier for FPDR was “lack of physical space and emotional support” (Moderate GRADE CERQual confidence). This is important to bear in mind should FPDR be implemented. The need of a designated physical space for the relative such as a chair, specific markings on the floor or a specific area in the emergency room for relatives. It could also be taken into consideration when allocating staff and organizing the medical team physically in the emergency room. The allocation of a support person is in particular relevant to address leading to the need of further education of HCP to fulfil this position. The practical circumstances regarding physical space for relatives and the role of the support person could be trained during simulation to make the staff prepared for FPDR.
Other barriers that affected the FPDR was “A feeling of "being scrutinized"” and that “The communication in the team changes” (both with moderate GRADE CERQual confidence). This is relevant to address and explore further as the studies included found that the communication changed to a more positive tone, but it could be imagined withholding of information from one’s colleagues during critical care, to project the feeling of a relative. This would be unsafe for patient treatment together with potentially stress due to FPDR, which is poorly understood. Elevated stress levels may impede performance on tasks which requires divided attention, working memory, retrieval of information from memory, and decision making[63]. It seems

that FPDR does not affect adult resuscitation outcomes or increase stress levels of HCP during FPDR[64,65]. However, simulation studies of student nurses and young physicians indicate that FPDR may negatively impact the quality of acute medical care[46,66]. In a simulation study with paramedics, it was observed that the presence of socioemotional stress, in this case from the presence of an upset friend, increased the subjective workload and frustration of HCP[67]. In pediatric studies no differences in the success rate of critical interventions was found with FPDR[29] and neither a negative impact on medical care in the presence of parents[68].
Although the theme "Clinical experience- friend or foe" was graded very low with GRADE CERQual, it is important to acknowledge it. An overview of the literature available on FPDR show that HCP do not entirely support the practice[1,9,16,20,22,31,36–38]. However, the literature does indicate a tendency that openness toward FPDR grows exponentially with seniority and experience. Further, it increases susceptibility toward FPDR that FPDR protocols are available at the hospital [23,69]. In turn this suggest that uncertainties related to the praxis of FPDR is an important issue. Compared to nurses, physicians are more likely to feel that the risks outweigh the benefits of FPDR[9,16,20,22,31,36–38]. Likewise, the majority of FPDR related literature is published in nursing-journals which may be an indicator that it has yet to find its way into the mindset of physicians. This theory is enhanced when one considers that the only official set of FPDR guidelines known to the authors, is produced by the Emergency Nurse Association[70].
We believe that FPDR should be prioritised in multidisciplined teams during the education of young HCP if FPDR is to be implemented.

Educational and cultural backgrounds seem to influence the openness and attitude towards FPDR[20,71]. It is therefore a limitation to this QES that only studies from the Western hemisphere are included. A potential bias is that three of the authors (MAR, TT, AMM) are included in other research project regarding FPDR, including a PhD project with a focus group study included - however this study is not yet published and therefore not included in this QES. Another potential bias could be that indexing of studies in the area is poor, but as we searched many other resources, we believe this bias in our review is minimal.
The results of the included studies could be biased by the authors preconceptions, as none of the authors of the included studies has mentioned their relationship between the researchers and the participants adequately (see table 2. CASP checklist). There is a risk that the answers to the interviews could be affected by the way the questions are asked, and through the included studies, we are left with a feeling, that the authors are somewhat very positive regarding FPDR. This concerns is enhanced by the fact that most of the included studies lacked rigorous description of the data analysis, leading to a collection of the participants answers instead. However, it is a known limitation of systematic reviews, that results of the review is affected by the included studies. We have been transparent and systematic in both the search process and how we appraise the quality and methodological limitations of the included studies by using Rayyan and creating a PRISMA flow diagram, CASP and GRADE CERQual checklists.

## AUTHORS' CONCLUSIONS

This systematic QES review showed the evidence on HCP perspectives on barriers and facilitating factors is of low to moderate confidence. There is a belief that FPDR is the "right thing to do", and an ethical principle of beneficence is dominant, especially in regarding to children. FPDR is regarded as a praxis which supports the relatives in coming to terms with the loss of a love done. However, one noteworthy barrier was that FPDR was perceived as having a negative impact on the HCP. Future research must investigate the long-term effect on both relatives and HCP when FPDR is practiced.
Findings may contribute to and qualify discussions among healthcare professionals in ED and other hospital settings about FPDR and to further advance family centred hospital care.


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We would like to thank Janne Vendt (former Cochrane Information Specialist) for her assistance in developing the search strategy and searching for eligible studies.
When preparing the protocol for the review, we used EPOC's Protocol and Review Template for Qualitative Evidence Synthesis[72].


## CONTRIBUTIONS OF AUTHORS

Monika Afzali Rubin (MAR), Sandra Strandberg (SS), Katja Anna Poulsen Frederiksen (KF), Thordis Thomsen (TT), Ann Merete Møller (AMM).
AMM is the guarantor. AMM and MAR contributed to the conception of the review. MAR developed the search strategy together with Janne Vendt, the information specialist of Cochrane Anaesthesia and Cochrane Critical and Emergency Care. TT is the guarantor of the
analyses. AMM provide expertise on FPDR. All authors contributed to the selection criteria, quality of evidence assessment strategy and data extraction forms. MAR drafted, and all other authors have contributed to, and have approved, the final protocol manuscript.
Co-ordinating the review: MAR
Undertaking manual searches: MAR
Screening search results: MAR, SS
Organizing retrieval of papers: MAR
Screening retrieved papers against inclusion criteria: MAR, SS
Appraising quality of papers: MAR, SS, KF, TT
Abstracting data from papers: MAR, SS
Writing to authors of papers for additional information: MAR
Providing additional data about papers: MAR
Obtaining and screening data on unpublished studies: MAR, SS
Data management for the review: MAR
Entering data into NVivo: MAR, SS
NVivo analyses: MAR, SS, AMM, TT
Interpretation of data: MAR, SS, TT, AMM

Writing the review: MAR, SS
Performing previous work that was the foundation of the present study: MAR, AMM
Guarantor for the review (one author): TT
Person responsible for reading and checking review before submission: MAR

## DECLARATIONS OF INTEREST

Rubin is a member of the parliament in Denmark with a special interest in healthcare politics. None of the other authors had any conflict of interests.

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# APPENDIX 1, search strategy

MEDLINE

1946 to March 22, 2022

1 *Family/px [Psychology]
2 *Parents/px [Psychology]
3 *Professional-Family Relations/
4 ((famil* or next of kin* or kinship or relativ* or significant other* or spouse* or husband* or wife* or partner* or parent* or sibling* or friend* or companion* or brother* or sister* or father* or mother* or bereave*) adj5 (presen* or attend* or observ* or witness* or perception* or participat*)).mp.
5 (family cent?red adj2 care).mp.
6 1 or 2 or 3 or 4 or 5
7 exp emergency medical services/
8 emergency medicine/
9 exp resuscitation/
10 exp Emergency Treatment/
11 exp heart arrest/
12 ((Emergen* or acute) adj3 (servic* or medicine or treat* or room*)).mp.
13 (resuscitat* or CPR).mp.
14 (prehospital* or pre-hospital* or out of hospital or trauma*).mp.
15 ((cardiac or heart or cardiopulmonary) adj2 arrest*).mp.
16 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15
17 6 and 16
18 (FPDR or FWR).mp.
19 17 or 18
20 exp medical staff/ or exp nurses/ or exp nursing staff/ or exp physicians/ or Personnel, Hospital/ or Health Personnel/ or Attitude of Health Personnel/ or emergency responders/ or emergency medical technicians/
21 (staff* or clinician* or nurse* or nursing or physician* or doctor* or professional* or personnel or paramedic* or para medic* or (emergency adj2 (responder? or technician?))).mp.
22 20 or 21
23 Perception/ or Attitude/ or Attitude of Health Personnel/ 216378
24 (experience* or view* or opinion* or perception* or perceiv* or attitude* or consideration* or preference*).mp.
25 23 or 24
26 19 and 22 and 25

# TABLES

## Table 1. Characteristics of studies table

| *Author* | *Year* | *Question or objective* | *Study setting* | *Funding* | *Methodo-logical framework* | *Sample collection* | *Methods of data collection* | *Analysis method* | *Study period* | *Participants (n)* | *Healthcare profession* | *Age range* | *Gender (female /male)* |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| *Davidson 2011* | 2011 | Explore inhibitors and enhancing factors surrounding the practice of allowing family presence in at resuscitation from the perspectives of emergency departments of nurses and physicians | USA | NA | Grounded theory | theoretical | Loosely structured individual interviews and observations | constant comparative | NA | 12 | RN and physicians in ED at a level 1 trauma | NA | NA |
| ** Giles 2016* | 2016 | Examine factors that impact family presence during resuscitation practices in the acute care setting | Australia | None | Grounded theory | purposive and snowball | In depht, face-to-face and phone semi-structured interviews | constant comparative | Oct 2013 - Nov 2014 | 20 | RN, doctors, paramedics | 25 - 63 | 5 / 20 |
| ** Giles 2018* | 2018 | examine how clinicians practice the principles of beneficence | same as Giles 2016 | same as Giles 2016 | same as Giles 2016 | same as Giles 2016 | same as Giles 2016 | deductive content analysis | same as Giles 2016 | same as Giles 2016 | same as Giles 2016 | same as Giles 2016 | same as Giles 2016 |

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| | | in deciding whether to allow or deny family presence during resuscitation | | | | | | | | | | | |
| *Gluck 2015* | 2015 | determine the lived experiences of emergency department nurses involved in family presence during resuscitation events. | USA, Phoenix | NA | Phenomenological | convenience sample | In-depth, face-to-face, semi structured interviews | thematic | Not mentioned | 20 | RN practicing in emergency departments | 24 - 65+ | 17 / 3 |
| *Knott & Kee 2005* | 2005 | Explore beliefs and experiences of registered nurses abut family presence during CPR | USA | Not mentioned | Descriptive | maximum variation | Semi-structured interviews | constant comparative | Not mentioned | 10 (2 from ED) | RN | 31-53 | 9 / 1 |
| *Lowry 2012* | 2012 | describe the benefit and harm of being present during resuscitation to relatives, | USA, Chicago | Not mentioned | Descriptive | Voluntary Response Sampling | open-ended, semi-structured questions from an interview | Conceptual content analysis | Not mentioned | 14 | RN | 18-56 (mean 39,75) | 13 / 1 |

| | | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | using perceptions of nurses who work in an emergency department with a well-established family presence protocol and (2) define family presence using perceptions of nurse participants. | | | | | | | | | | | |
| *Miller & Stiles 2009* | 2009 | understand the experiences of nurses who participate with families during resuscitation and invasive procedures in-hospital | USA | None | Phenome-nological | purposive | semi structured interviews (face-to-face and telephone) using a interview guide | thematic | Not mentioned | 17 | RN who had participated in FPDR or invasive procedures, from ED, ICU and transport teams or POA and coordination nurse from OR | 38-57 | 15 / 17 |
| *Porter 2019* | 2019 | explore the experiences and attitudes of | Australia | None | Descriptive | convenience sample | face-to-face interviews | thematic | April to July 2013** | 29 | RN, medical personnel, employed in ED, active | Not mentioned | 20 /9 |

| | | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | emergency personnel towards FPDR immediately post resuscitation events | | | | | | | | | member of resuscitation team | | |
| *Walker 2014* | 2014 | Explore lived experience of lay presence during CPR attempt in primary out-of-hospital secondary in-hospital environments of care | UK | Not mentioned | Hermeneutical phenomenological | purposive | Individual interviews, face-to-face | thematic | June 2005 - May 2006<br><br>July 2007 - June 2008 | 12 + 8 | RN from ED | Not mentioned | 10/2 + 3/5 |

* Two studies based on the same data material

** Study period not mentioned in the article, but found in the article they refer to: "Family Presence During Resuscitation (FPDR): Observational case studies of emergency personnel in Victoria, Australia"

## Table 2 - Critical Appraisal Skills Programme (CASP) Checklist

| *Author(s) and year* | *Was there a clear statement of the aims of the research?* | *Is a qualitative methodology appropriate?* | *Was the research design appropriate to address the aims of the research?* | *Was the recruitment strategy appropriate to the aims of the research?* | *Was the data collected in a way that addressed the research issue?* | *Has the relationship between researcher and participants been adequately considered?* | *Have ethical issues been taken into consideration?* | *Was the data analysis sufficiently rigorous?* | *Is there a clear statement of findings?* |
|---|---|---|---|---|---|---|---|---|---|
| *Davidson et al. 2011* | Yes | Yes | No. Grounded theory isn't to be applied loosely. Theory must come from it. Besides that, it is not enough grounds to state that a method is appropriate. There should be an in-depth consideration as to what method to apply according to your subject. They write "the goal of the study was to identify barriers and enhancing factors - not to develop a substantive theory." | Can't tell. They state the use of purposive sampling in relation to include both "positive and negative opinions", but they do not state the definition of these categories. | Yes | No | Can't tell. We do not know how they were informed of the study. However, they write "This study was conducted in partial completion for the requirements of the San Diego Consortium for Evidence-Based Practice and the Evidence-Based Practice Institute for support throughout the conduct of this study." | Can't tell. They did not develop a grounded theory. | No |
| *Giles et al. 2016* | Yes | Yes | Yes, they created a theory, however they don't really tie it all together. Instead, they discuss their findings but don't tie it up on their theory. | Yes, snowball sampling and through professional contacts. | Yes, although they did not assess how the different interview settings (face to face and phone | No | Yes | Can't tell. The analysis work is okay, but it is not sufficient for grounded theory. | Yes |

| | | | | | | | | | |
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| | | | | | interviews) impacted data. | | | | |
| *Giles et al. 2018* | Yes | Yes | Yes, however, they examined data taken from a study design that did not have the same purpose as their secondary analysis. An article is one thing, but to analyze a whole dataset that was gathered from a design different from one's current purpose is shaky. | Can't tell, as they do not mention it. | No, they data was collected in regard to another study and research issue. | No, they only mention that participants contacted the researcher because the researcher was in a radio interview. | Can't tell. There is uncertainty whether they have informed participants of their altered research focus - bordering on unethical if not. | Can't tell. It is not clear what kind of data analysis they made (Mayrings deductive category application of content analysis?), as their analysis design was originally grounded theory including a constant comparative analysis. | Yes |
| *Gluck 2015* | Yes | Yes | Yes | Yes | Can't tell. As the author is the one to point out that phenomenology is best applied to long term study, it would have been more appropriate to conduct a follow up | No | Yes | Can't tell. What we are left with from the analysis are opinions - we do not know much about the grounds. What cultural aspects or experiences | Can't tell |

| | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | | | | | interview (interview series). | | | influence their stance? | |
| *Knott & Kee 2005* | Yes, in their intro but they forget to mention FPDR in their later statement. | Yes, it is, as it explores beliefs and experiences, which require in depth answers and background knowledge. | Yes. Qualitative description, as a 'light' version of analytics does match this small study. Generalizing from a sample of 10 nurses would seem a bit far-fetched. | No. They briefly mentioned participants were contacted personally by the primary investigator, whom they knew personally. | Can't tell. Because this issue pertains to their work, the interview setting should have been a work setting. It seems odd to interview a participant in their home regarding a work situation/praxis. It's a different story if you're interviewing a person regarding i.e., their own health, family life or how they handle unsettling work experiences. | No. The researcher knows all of the participants personally - that is a bias. There aren't any other statements from non-acquaintances to compare to. | Yes, they were asked to sign an informed consent agreement and an approval to conduct the study was obtained. | Yes, however there could have been a better backing of external literature and a discussion of not only similarities but differences. | Can't tell |
| *Lowry 2012* | Yes | Yes, both since they are examining perceptions rather than "fact" and | No. Why they analyze perception via content analysis is hard to understand. Content analysis is for identifying patterns in behavior or communication. It doesn't | Can't tell. Criteria wasn't disclosed or researchers weren't critical regarding who | Yes. Interviews with open ended questions are a great way to examine not | No. The researcher did not let the reader know about their own background or how they were situated. | Yes. There was no ethical discussion, but they did live up to the criteria of ethical qualitative research. | No. Limitations were ok. But the analysis seems more like a | Yes, but rather lacking analysis of the findings. |

| | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | | because their participant group is so small. | answer research question, but rather describes tendencies in participants answers. | should participate other than their experience with FPDR, out of the 19 nurses that responded to their letters. No selection procedure. They didn't actively exclude anyone. | only their life worlds and perceptions, but to get a feel of their background that shaped the perceptions, and separate interviews (when the group is so small) allowed for more in-depth information. | No info on researcher positioning. | | summing up than an in-depth discussion applying relevant literature and studies. | |
| *Miller & Stiles 2009* | Yes | Yes | Can't tell. They describe the use of a phenomenological methodology, but we believe they may have applied thematic analysis instead. | Yes | Can't tell. The interviews are too thin a foundation to talk about life worlds, phenomenology, but for a thematic analysis it is fine. | No | No | Can't tell. There is something lacking in making it clear so we understand how the nurses are situated, how this pertains to their life worlds so that it isn't just opinions. | Yes |
| *Porter 2019* | Yes | Yes, it makes sense to analyze experiences and attitudes | Yes, but it would have been nice if they explained why the period of the interviews varied so much. | Yes, the participants are relevant and have a "fresh" memory of the | Yes | No, we do not know of the researcher's relation to the participants. | Yes, however the study was unethical. Even though they obtain ethical approval, | Yes, they analyze instead of summing up. | No |

| | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | | qualitatively, also strengthens the study, that they observed the events. | | events. However, a bit info is lacking regarding how many were interviewed after each resuscitation event. | | | they purposely misinform participants about the study focus. That is unethical. | | |
| *Walker 2014* | Yes | Yes | Can't tell. Phenomenology and hermeneutics are contradictions. It seems they made a hermeneutical study. | Yes | Can't tell. You can't gain an understanding of someone's life world and lived experience through one interview. It takes a series of interviews and perhaps observation. | No | No | No. We only get a summary of their experiences, but if we're to understand the research method the author should have elaborated on how this pertained to the particular person, context, their deliberations etc. otherwise it's simply descriptive. | Can't tell |

## Table 3 - Overall GRADE CERQual assessment of confidence

| # | Summarised review finding | GRADE-CERQual Assessment of confidence | Explanation of GRADE-CERQual Assessment | References |
|---|---|---|---|---|
| 1 | Facilitating factors: Knowledge about the patient and helping decision-making | Moderate confidence | Moderate concerns regarding methodological limitations, No/Very minor concerns regarding coherence, Minor concerns regarding adequacy, and Minor concerns regarding relevance | Giles et al. 2018; Walker 2014; Miller & Stiles 2009; Lowry 2012; Giles et al. 2016; Knott & Kee 2005; |
| 2 | Facilitating factors: Emotionally satisfying for the HCP | Low confidence | Moderate concerns regarding methodological limitations, No/Very minor concerns regarding coherence, Moderate concerns regarding adequacy, and Minor concerns regarding relevance | Davidson et al. 2011; Miller & Stiles 2009; Gluck 2015; |
| 3 | Facilitating factors: A belief that FPDR is the right thing to do | High confidence | Moderate concerns regarding methodological limitations, No/Very minor concerns regarding coherence, No/Very minor concerns regarding adequacy, and No/Very minor concerns regarding relevance | Davidson et al. 2011; Giles et al. 2018; Walker 2014; Miller & Stiles 2009; Lowry 2012; Giles et al. 2016; Gluck 2015; Knott & Kee 2005; Porter 2019; |
| 4 | Barriers: Lack of physical space and emotional support | Moderate confidence | Moderate concerns regarding methodological limitations, Minor concerns regarding coherence, No/Very minor concerns regarding adequacy, and No/Very minor concerns regarding relevance | Davidson et al. 2011; Giles et al. 2018; Walker 2014; Miller & Stiles 2009; Lowry 2012; Giles et al. 2016; Gluck 2015; Knott & Kee 2005; Porter 2019; |
| 5 | Barriers: Fear of imposing psychological trauma and misunderstanding | Moderate confidence | Moderate concerns regarding methodological limitations, Minor concerns regarding coherence, No/Very minor concerns regarding adequacy, and No/Very minor concerns regarding relevance | Davidson et al. 2011; Giles et al. 2018; Walker 2014; Miller & Stiles 2009; Lowry 2012; Giles et al. 2016; Gluck 2015; Knott & Kee 2005; Porter 2019; |
| 6 | Barriers: Clinical experience – friend or foe | Very low confidence | Moderate concerns regarding methodological limitations, Serious concerns regarding coherence, Serious concerns regarding | Giles et al. 2018; Giles et al. 2016; Porter 2019; |

| # | Summarised review finding | GRADE-CERQual Assessment of confidence | Explanation of GRADE-CERQual Assessment | References |
|---|---|---|---|---|
| | | | adequacy, and Moderate concerns regarding relevance | |
| 7 | How staff are affected: A feeling of "being scrutinized" | Moderate confidence | Minor concerns regarding methodological limitations, Minor concerns regarding coherence, Minor concerns regarding adequacy, and No/Very minor concerns regarding relevance | Davidson et al. 2011; Giles et al. 2018; Walker 2014; Miller & Stiles 2009; Gluck 2015; Knott & Kee 2005; Porter 2019; |
| 8 | How staff are affected: The communication in the team changes | Moderate confidence | Moderate concerns regarding methodological limitations, No/Very minor concerns regarding coherence, Moderate concerns regarding adequacy, and No/Very minor concerns regarding relevance | Giles et al. 2018; Walker 2014; Miller & Stiles 2009; Gluck 2015; Knott & Kee 2005; |

## Table 4 - Detailed Evidence Profile Table

| # | Summarised review finding | Methodological limitations | Coherence | Adequacy | Relevance | GRADE-CERQual assessment of confidence | References |
|---|---|---|---|---|---|---|---|
| 1 | Facilitating factors: Knowledge about the patient and helping decision-making | Moderate concerns<br><br>**Explanation:** Moderate concerns regarding methodological limitations because all included studies include methodological concerns, and one study is a secondary analysis of an originally study where data was collected with another aim. | No/Very minor concerns<br><br>**Explanation:** The underlying data and the review finding matches. | Minor concerns<br><br>**Explanation:** Minor concerns regarding adequacy because findings are based on few studies. However, the number of participants in the included studies and the data includes a sufficiently thick description of the phenomenon of interest. | Minor concerns<br><br>**Explanation:** Minor concerns regarding relevance because three of the studies (Giles x 2 and Miller&Stiles) includes healthcare professionals from settings that are not the ED. | Moderate confidence<br><br>**Explanation:** Moderate concerns regarding methodological limitations, No/Very minor concerns regarding coherence, Minor concerns regarding adequacy, and Minor concerns regarding relevance | Giles et al. 2016; Giles et al. 2018; Knott & Kee 2005; Lowry 2012; Miller & Stiles 2009; Walker 2014; |
| 2 | Facilitating factors: Emotionally satisfying for the HCP | Moderate concerns<br><br>**Explanation:** Moderate concerns regarding methodological limitations because all | No/Very minor concerns<br><br>**Explanation:** The few included studies support the review | Moderate concerns<br><br>**Explanation:** Moderate concerns regarding adequacy because findings are | Minor concerns<br><br>**Explanation:** Minor concerns regarding relevance because the studies did | Low confidence<br><br>**Explanation:** Moderate concerns regarding methodological limitations, No/Very minor | Davidson et al. 2011; Gluck 2015; Miller & Stiles 2009; |

| # | Summarised review finding | Methodological limitations | Coherence | Adequacy | Relevance | GRADE-CERQual assessment of confidence | References |
|---|---|---|---|---|---|---|---|
| | | included studies include methodological concerns. | finding with data. | based on very few studies. However, the number of participants in the included studies and the data includes a sufficiently thick description of the phenomenon of interest. | not exclusively include HCP from the ED. | concerns regarding coherence, Moderate concerns regarding adequacy, and Minor concerns regarding relevance | |
| 3 | Facilitating factors: A belief that FPDR is the right thing to do | Moderate concerns<br><br>**Explanation:** Moderate concerns regarding methodological limitations because all included studies include methodological concerns, and one study is a secondary analysis of an originally study where data was collected with another aim. | No/Very minor concerns<br><br>**Explanation:** The data from the included studies are in line with the review finding. | No/Very minor concerns<br><br>**Explanation:** No concerns regarding adequacy because findings are based on many studies with sufficiently thick description of the phenomenon of interest. | No/Very minor concerns<br><br>**Explanation:** | High confidence<br><br>**Explanation:** Moderate concerns regarding methodological limitations, No/Very minor concerns regarding coherence, No/Very minor concerns regarding adequacy, and No/Very minor concerns regarding relevance | Davidson et al. 2011; Giles et al. 2016; Giles et al. 2018; Gluck 2015; Knott & Kee 2005; Lowry 2012; Miller & Stiles 2009; Porter 2019; Walker 2014; |

| # | Summarised review finding | Methodological limitations | Coherence | Adequacy | Relevance | GRADE-CERQual assessment of confidence | References |
|---|---|---|---|---|---|---|---|
| 4 | Barriers: Lack of physical space and emotional support | Moderate concerns<br><br>**Explanation:** Moderate concerns regarding methodological limitations because all included studies include methodological concerns, and one study is a secondary analysis of an originally study where data was collected with another aim. | Minor concerns<br><br>**Explanation:** Minor concerns regarding coherence because the review finding includes the importance of having a designated support person, which we have interpreted as the need for emotional space (in the team). | No/Very minor concerns<br><br>**Explanation:** No concerns as data are based on many studies and the data are sufficiently thick. | No/Very minor concerns<br><br>**Explanation:** No concerns. | Moderate confidence<br><br>**Explanation:** Moderate concerns regarding methodological limitations, Minor concerns regarding coherence, No/Very minor concerns regarding adequacy, and No/Very minor concerns regarding relevance | Davidson et al. 2011; Giles et al. 2016; Giles et al. 2018; Gluck 2015; Knott & Kee 2005; Lowry 2012; Miller & Stiles 2009; Porter 2019; Walker 2014; |
| 5 | Barriers: Fear of imposing psychological trauma and misunderstanding | Moderate concerns<br><br>**Explanation:** Moderate concerns regarding methodological limitations because all included studies include methodological concerns, and one study is a secondary analysis of an | Minor concerns<br><br>**Explanation:** Minor concerns regarding coherence because the review finding is our interpretation of data. | No/Very minor concerns<br><br>**Explanation:** No concerns regarding adequacy because findings are based on many studies with a sufficiently thick description of the | No/Very minor concerns<br><br>**Explanation:** No concerns. | Moderate confidence<br><br>**Explanation:** Moderate concerns regarding methodological limitations, Minor concerns regarding coherence, No/Very minor concerns regarding adequacy, and | Davidson et al. 2011; Giles et al. 2016; Giles et al. 2018; Gluck 2015; Knott & Kee 2005; Lowry 2012; Miller & Stiles 2009; Porter 2019; Walker 2014; |

| # | Summarised review finding | Methodological limitations | Coherence | Adequacy | Relevance | GRADE-CERQual assessment of confidence | References |
|---|---|---|---|---|---|---|---|
| | | originally study where data was collected with another aim. | | phenomenon of interest. | | No/Very minor concerns regarding relevance | |
| 6 | Barriers: Clinical experience – friend or foe | Moderate concerns<br><br>**Explanation:** Moderate concerns regarding methodological limitations because one study is a secondary analysis of an originally study collected with another aim. | Serious concerns<br><br>**Explanation:** Serious concerns regarding coherence because the impact of clinical experience is not included in the data directly, but it is our interpretation that less clinical experience is a barrier to FPDR decision-making. | Serious concerns<br><br>**Explanation:** Serious concerns regarding adequacy because findings are based on few studies and the few studies have thin description of the phenomenon of interest. | Moderate concerns<br><br>**Explanation:** Moderate concerns regarding relevance because it is unclear whether the underlying data is relevant. | Very low confidence<br><br>**Explanation:** Moderate concerns regarding methodological limitations, Serious concerns regarding coherence, Serious concerns regarding adequacy, and Moderate concerns regarding relevance | Giles et al. 2016; Giles et al. 2018; Porter 2019; |
| 7 | How staff are affected: A feeling of "being scrutinized" | Moderate concerns<br><br>**Explanation:** Moderate concerns regarding methodological limitations because all included studies include | Minor concerns<br><br>**Explanation:** Minor concerns regarding coherence because some of the data explaining the | Minor concerns<br><br>**Explanation:** Minor concerns regarding adequacy because findings are based on many of the | No/Very minor concerns<br><br>**Explanation:** No concerns. | Moderate confidence<br><br>**Explanation:** Minor concerns regarding methodological limitations, Minor concerns regarding | Davidson et al. 2011; Giles et al. 2018; Gluck 2015; Knott & Kee 2005; Miller & Stiles 2009; Porter 2019; Walker 2014; |

| # | Summarised review finding | Methodological limitations | Coherence | Adequacy | Relevance | GRADE-CERQual assessment of confidence | References |
|---|---|---|---|---|---|---|---|
| | | methodological concerns, and one study is a secondary analysis of an originally study where data was collected with another aim. | emotional impact, is our interpretation into the review finding. | included studies, but the richness of data is not sufficient. | | coherence, Minor concerns regarding adequacy, and No/Very minor concerns regarding relevance | |
| 8 | How staff are affected: The communication in the team changes | Moderate concerns<br><br>**Explanation:** Moderate concerns regarding methodological limitations because all included studies include methodological concerns, and one study is a secondary analysis of an originally study where data was collected with another aim. | No/Very minor concerns<br><br>**Explanation:** No concerns. Our review finding is in line with the data. | Moderate concerns<br><br>**Explanation:** Moderate concerns regarding adequacy because findings are based on few studies that do not have a sufficiently thick description of the phenomenon of interest. | No/Very minor concerns<br><br>**Explanation:** No concerns. | Moderate confidence<br><br>**Explanation:** Moderate concerns regarding methodological limitations, No/Very minor concerns regarding coherence, Moderate concerns regarding adequacy, and No/Very minor concerns regarding relevance | Giles et al. 2018; Gluck 2015; Knott & Kee 2005; Miller & Stiles 2009; Walker 2014; |

# FIGURES

## Figure 1 - PRISMA 2009 Flow Diagram

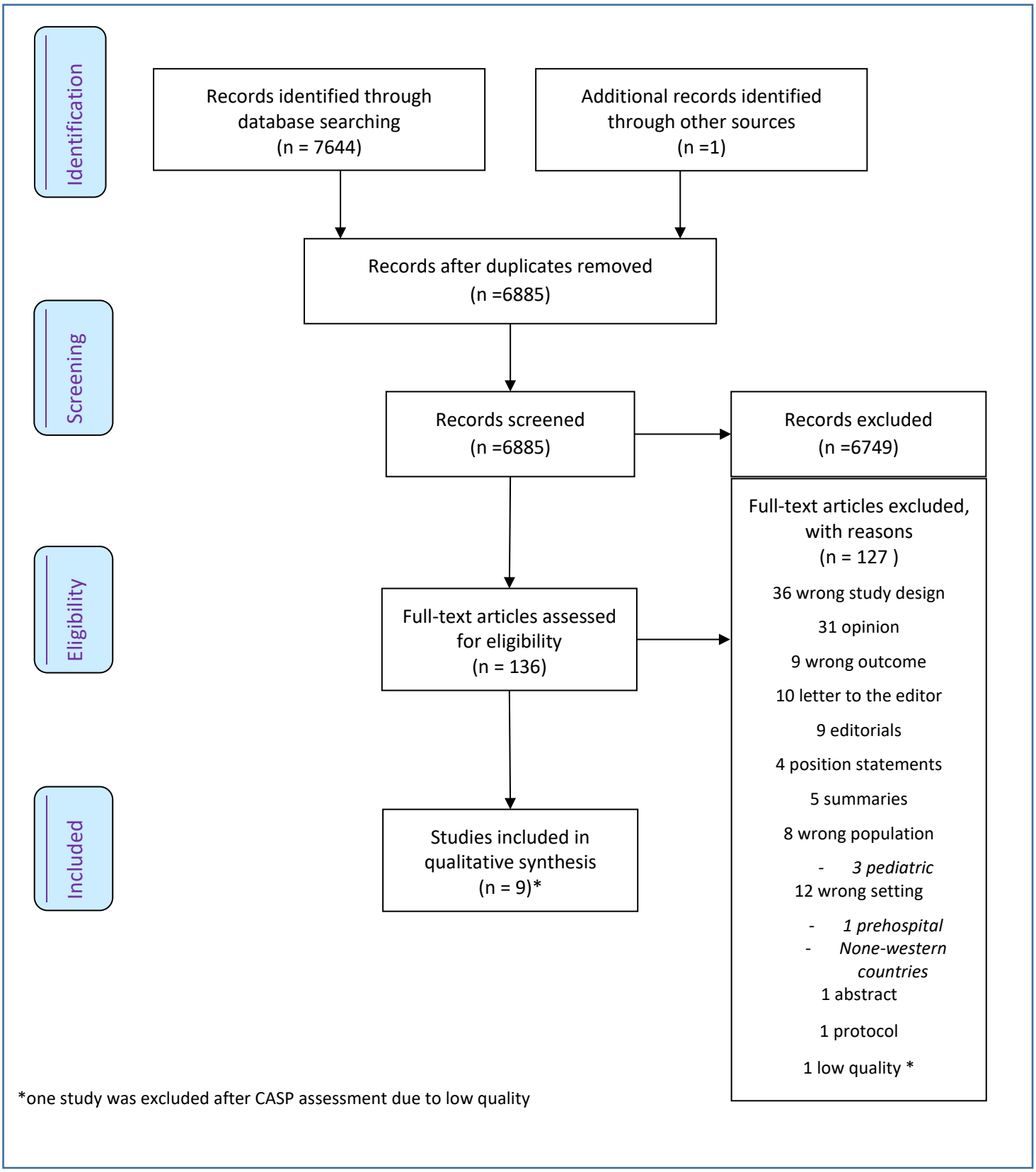
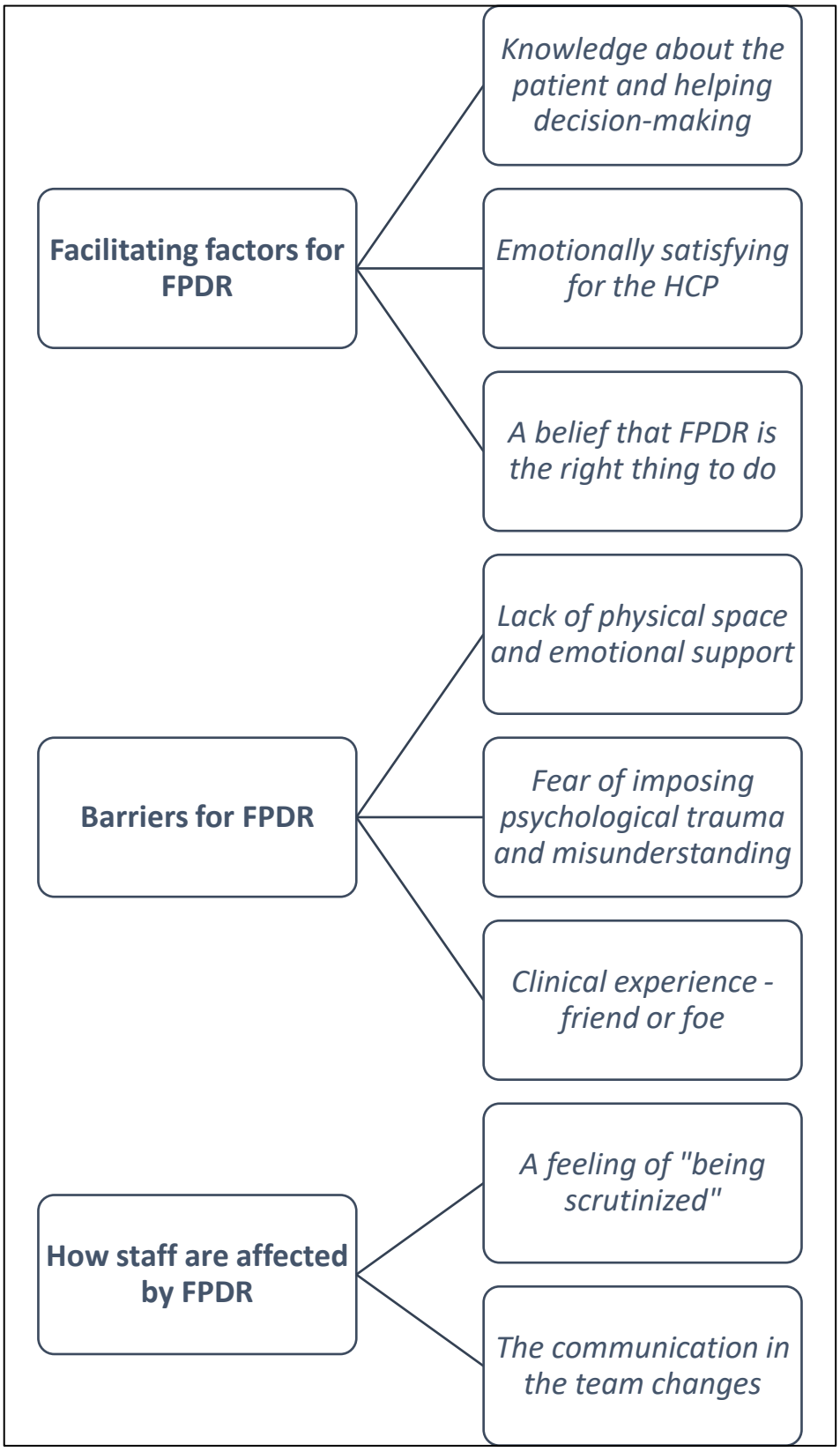


Figure 2 - Review findings



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# Healthcare professionals' perspectives on facilitators and barriers to family presence during resuscitation in Denmark – a focus group study

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## ABSTRACT

Background:

Family presence during resuscitation (FPDR) is evolving. However, we have limited knowledge of the impact. The praxis can take a toll on resources due to a lack of a designated support person and may impede the performance of healthcare professionals (HCP).

The aim was to gain an understanding of the barriers and facilitative factors that shape HCP deliberations and decision-making regarding FPDR.

Method:

This qualitative study was conducted with focus groups at the Department of Emergency Care at Copenhagen University Hospital, Herlev, Denmark. A purposeful sample of physicians and nurses were recruited. We collected data through semi-structured focus group interviews and analyzed data using inductive thematic analysis.

Findings:

We conducted five focus group interviews with a total of 25 participants - 17 physicians and 8 nurses. Ages ranged from 30-65 years (mean 39,7 years) and the majority were female (17/25). We identified three categories and 18 themes. The two categories were “facilitating factors for including relatives during resuscitation” and “barriers for including relatives during resuscitation”. Participants expressed openness and positivity towards FPDR whilst later in the interview they seemed more skeptical and concerned that FPDR might disturb treatment. Participants seemingly experienced an inner conflict between fearing that their work could be obstructed by present relatives and doing their job well.

Conclusion:

The most prominent facilitative factor for FPDR in Denmark was that HCP see FPDR as helpful for relatives in coming to terms with the loss of a loved one. Additionally, FPDR humanizes and allows HCP to retrieve information about the patient. Inhibitory factors included self-censorship among HCP, perceived possible risks to patient safety, a lack of FPDR guidelines, a designated support person, and training.

## INTRODUCTION

Family presence during resuscitation[a] (FPDR) is recommended by the European Resuscitation Council (ERC) during cardiopulmonary resuscitation[1] and entails that healthcare professionals (HCP) invite relatives to stay during treatment. Relatives' presence can be beneficial for psychological outcomes[2–4] as FPDR may alleviate anxiety and fear in the patient, help relatives come to terms with their loss and even aid HCP in obtaining the patient's medical history quickly [5]. As the praxis has expanded, the HCP is met with patients and relatives who wish to decide for themselves whether to be present. This presents a dilemma for HCP who do not necessarily agree on the matter[4,6,7]. Thus, FPDR is debated within the field of healthcare, yet research on the topic is sparse[8–11].

FPDR is a triangular relationship involving the patient, the relatives, and the HCP. The needs and well-being of all parties must be balanced in the context of FPDR as the actions of all three parties mutually impact each other[7]. In a narrow timeframe, the HCP must decide whether to invite a relative to be present during resuscitation.

Opinions regarding FPDR vary greatly among HCP[7,12,21,22,13–20]. While some HCP are positive, others find the risks to be manyfold. They are afraid that FPDR can affect the quality of emergency medical care, and worsen patient outcome[23–25] by disrupting the working process of the HCP[26]. There is also a concern that the proceedings may incite psychological trauma in participating relatives[7]. Moreover that their limited knowledge of medical procedures might lead to misunderstandings in the onlooker[27]. Narrative reviews report that physicians often perceive more barriers associated with FPDR than nurses, but perceptions may also vary in different cultural settings[16,22,28–31]. FPDR can take a toll on hospital resources since it is recommended that the relative has a designated support person present, additional to the resuscitation team[1,7,12,20,31–33]. This to protect both the relative, avoid misunderstandings and suffering in relatives and minimize the risk of legal persecutions.

## AIM

The aim of this study was to explore HCP perspectives on facilitators and barriers to FPDR in Denmark.

[a] According to the Oxford dictionary "Resuscitation" means "the action or process of reviving someone from unconsciousness or apparent death" and not as many thinks, only equal cardiopulmonary resuscitation (CPR).

## METHODS AND MATERIALS

This was a qualitative study using focus group interviews for data collection. Data were analyzed using inductive thematic analysis[34].

### Preunderstanding

The backgrounds of the researchers varied from nursing, anthropology, psychology, and medicine. Authors AMM, MR, and TT all have experience in emergency care including resuscitation, but only AMM with FPDR. Two of the authors (AMM, MR) have written a Cochrane review on the topic FPDR [35]. Aware of an evidence gap, we expected that HCP would express uncertainty regarding FPDR during interviews. Further, that the attitudes of the HCP toward FPDR was shaped by factors such as previous experience with the praxis, seniority, and profession. Additionally, that risk-based considerations were tied to the notion of FPDR among HCP, such as a risk to their professional safety should the relatives complain. Lastly, the two authors who conducted the interviews and analysis (MR, KF) had a preconception regarding the hierarchies amongst physicians and nurses, as Witz has shown in her studies[36].

### Participant recruitment and sampling

Physicians and nurses were recruited from the emergency department (ED) including department of surgery, cardiology, intensive care, anesthesiology, and the medical and orthopedic departments– 417 HCP in total. No prior experience with FPDR was required. We decided to recruit physicians and nurses as they have responsibility for the treatment. Participants were informed about the aim of the study by the first author, approached through lectures, by e-mail and personal contact. See figure 1 for a flow diagram of participants. Eighty volunteered and, after purposeful sampling, six to eight participants were recruited for five focus groups. Twenty-five participants were interviewed.

### Setting

The study was conducted at Herlev Hospital, a university hospital in The Capitol Region of Denmark with a population of 1.85 million. One of the five EDs in the region participated in this research. This department has no policy for FPDR, and the inclusion of relatives depends entirely on the emergency care team.

### Data collection

The study was conducted in January to March 2022 from 7.30 – 9 am on Wednesdays in a conference room at Herlev Hospital. Focus groups were applied as a method to facilitate dynamic

discussion about FPDR. The groups were composed both heterogeneously and homogenously to observe group dynamics. We found that a heterogeneous composition stimulated verbal interaction[37]. The interviewers followed a semi structured interview guide (Table 1), wherein the interviewer could skip or add questions[38]. Two pilot interviews were performed with anaesthesiologists, who are most often in charge during resuscitation in the ED, to sharpen the guide and research focus. The guide was designed to examine subjective meaning attributed to FPDR and widen the researcher's understanding of the contextual backdrop[39]. A physician (MR) was selected as interviewer. She took the role of an *examiner* - an interviewer who seeks beyond opinions to uncover the social tapestry of the participants' reasoning[38]. Interviews were recorded and transcribed verbatim.

### Data analysis

We conducted an explorative descriptive study using inductive thematic analysis. We coded the interviews inductively, identified themes in the transcribed interviews and extracted relevant quotes into a table. We looked for connections across the codes and created overall themes and categories (figure 2) which pertained to the research focus using the software NVivo[40].

### Ethics

All participants signed an informed consent form and permission for the study was obtained from the Knowledge Centre on Data Protection Compliance (P-2021-515). No formal review by the Danish Ethics Committee was required (Journal 21046372). We gave thorough thought to anonymization due to the sensitive nature of cases mentioned in interviews and balanced between diminishing traceability, whilst maintaining the context [38,41,42].

## RESULTS

### Participants

We conducted five focus group interviews with a total of 25 participants - 17 physicians and 8 nurses. Ages ranged from 30 to 65 years (mean 39,7 years) and the majority were female (17). See table 2 for socio-demographic characteristics of the participants and figure 1 for flow of participants. The interviews lasted between 60 to 80 minutes and the recorder was turned on until the last participant left the room.

## Categories

Three analytical categories were identified: barriers, facilitators, and developmental areas. The categories and themes are illustrated in figure 2.

### *Category 1: Facilitating factors for including relatives during resuscitation*

This category included five themes and referred to the participants' experiences and preunderstanding of FPDR as an inevitable development and in some situations a necessity.

#### *Referring to evidence as a facilitative factor*

Participants considered FDPR to be beneficial to relatives based on recent articles, argueing that FDPR helped relatives grieve their loss. There seemed to be a narrative at play that deemed the praxis as beneficial, with reference to evidence supporting this stance. Conversely, some participants had FDPR experiences which caused them to contemplate whether this was in fact always the case.

#### *The relatives as a resource*

Participants regarded relatives as a potential resource, especially when treating children, adolescents, or cognitively impaired patients. If the patient was unconscious, relatives could assist in decision-making and if the patient was awake, relatives could calm the patient.

*''(...) it can prove a great advantage [for a relative to be present], because you can ask them how this all came about. Right? You might ask >How were things on the way in? < or >Why did you make the phone call? < ''*

#### *Enabling closure*

FPDR allowed relatives to witness the resuscitation process with their own eyes, and this was portrayed as helpful for relatives' grieving process. Participants described that FPDR offered relatives an opportunity to be included in the process and the possibility of a last goodbye.

*"I do not believe it will make a difference to a completely unconscious patient, about to pass away, whether anyone [relatives] attends to them. However, it might make a difference to the relative".*

*The patient is humanized*

Several participants indicated that FPDR seemed to humanize the patient thus conferring an additional dimension of meaningfulness to their work.

*"I recall all cardiac arrests I have attended, where relatives were present, as the experience just sticks with you, whilst other cardiac arrests are more, let us say >trivial <. You forget [them] rather easily because they are so impersonal. And, well, more mechanical."*

Participants were more inclined to remember cases in which relatives were present. One participant mentioned that they remembered every case where a relative was present and largely forgot cases where no relatives were present. The presence of a relative humanized the patient, but also etched the screams or sobs of the relatives into participants' memory. Those sounds and images stayed with them.

*"(...) my recollection of them [FPDR cases] (...) are their screams, their prayers > Fight, please, you can do it, come back to us < "*

*"(...) I am not always sure we are doing them a favor, in letting them observe the procedures that we perform. We produce images, lasting images, that will stay with them. And they might prefer a lasting image of > The last time I saw him, he was in that chair in the garden <, however, now suddenly they must deal with quite a different image."*

*Seniority of the HCP*

Seniority was portrayed as a facilitative factor across all interviews. Most participants expressed that professional confidence made it easier to include or exclude relatives, and to shut out possible distractions caused by their presence.

*"I believe, I have a greater focus on it [FPDR] now, than earlier. The focus increases with time"*

*Category 2: Barriers for including relatives during resuscitation*

This category includes 10 themes referring to participants' experiences and feelings regarding the mental impact of FPDR during resuscitation, where the patient naturally has highest priority.

*The quantity of present relatives is a matter of space and relevance rather than preference*

When researchers enquired as to what the maximum number of relatives present should be, conversation among participants often turned to what was possible rather than what was ideal.

In all interviews, the participants described that emergency care, including resuscitation, requires many HCP, often up to twelve, and that physical space therefore frequently became a challenge in these situations. Often, they had to get rid of unnecessary furnishings and move other patients to make room for ECG machinery, medical equipment and drop stands.

*"In my opinion, we are often short of space. You lose sight of things because of it."*

Only one participant, a senior anesthesiologist, expressed that space was not an issue if you were an experienced clinician. A young cardiologist in training argued that the need for space also depended on one's profession, in terms of instruments and tasks. On another note, some participants emphasized the importance of how present relatives were related to the patient.

"*If a bunch of relatives and friends from the neighborhood start showing up, their presence starts to become irrelevant"*

*The needs of the patient have first priority*

The participants overall stressed that saving the life of the patient remained their top priority in treatment situations. They seldom had time to consider how present relatives were coping or remember to invite them in from the waiting room if not present. This troubled their conscience. Ideally, they wanted to tend to the relatives and to let them be present or say their goodbyes.

*Compromised patient safety*

Patient safety was a prerequisite in all interviews. Participants mentioned that the presence of a relative could become problematic if they displayed signs of agitation, were too vocal, or sought physical contact with the patient. Such behavior could disturb the focus of the staff and the communication between them, leading to breaches in patient safety.

These scenarios were referred to as cases in which the relative would be asked to leave the room.

Some participants also mentioned that the presence of a relative censured communication between HCP.

Younger physicians mentioned that they sometimes hesitated to pose questions or exchange reflections with their colleagues regarding treatment and diagnosis. They feared it could be misconstrued as insecurity by relatives. However, participants emphasized that this form of staff communication is vital in treatment situations and important considerations may be lost due to self-censorship. The more senior the participants however, the less this was a concern.
Participants also mentioned that in situations where criminal activity was suspected, they chose to deny relatives access to protect the patient.

*An invasion of privacy*

Participants shared concerns regarding the integrity and privacy of unconscious patients, because treatment procedures could leave them quite exposed. Particularly procedures involving the genital area or procedures that required staff to undress the patient. When possible, staff asked relatives to wait outside, but exposure was an afterthought in life-or-death situations.
The presence of a relative could also compromise the privacy of the physicians and nurses, for example if filmed or photographed by relatives without consent. As participants were focused on the treatment, they often failed to notice if they were filmed or photographed.

*"As the delegation calmed and I was completely covered in blood, which looked quite horrifying, right? The patient's wife was standing there, filming it all with her iPad (…) and I have wondered since why she did that. Whether they had agreed upon it before hand, so that he could document it in case they were to make a complaint or whether it was to help her process his death. He was very ill with cancer."*

*The trauma of witnessing resuscitation of a loved one*

Participants expressed doubt about whether relatives were in fact equipped to cope with the sometimes quite violent scenes in the emergency room. Blood, severe injuries, and invasive procedures could likely appear quite brutal to relatives. The main concern was whether these images might traumatize the relative and distort the last living memories they had of their loved one.

*Minors are not eligible for FPDR*

Participants overall agreed that children were not suitable for FPDR. This out of concern as to whether minors could handle the scenes that might play out during resuscitation and fear of them being left with traumatizing memories relatives' last moments. More importantly, the participants felt a responsibility to protect minors from the brutal reality. On the other hand, some participants deemed it appropriate for minors to be present if they were accompanied by an adult. If accompanied, they believed that the minor could potentially even benefit from the experience and be aided in coming to terms with their parent's death.

*"I think it is worth considering how old they [the relatives] ought to be, before inviting them into that universe"*

*"(...) If it is someone who passes away in the end, I should think most children would benefit from witnessing it. Just so that mom did not simply vanish into a black box, never to return (...)"*

*Lacking professional insight might distort the relatives' experience*

Some participants voiced a concern that relative's deficient insight into health care procedures could lead to misinterpretation of the open communication and deliberations between them. Participants emphasized that open communication regarding treatment was important for team collaboration but feared it might be misconceived as professional insecurity. Just as a relative might misinterpret their fast-paced activity as chaotic and unstructured. Yet as one participant explained, this activity can be likened to an anthill: All team members fulfill their task in a precise and rapid symphony of movements.

*"(...) everyone is occupied with something, and it resembles an anthill, but there is a purpose to it."*

*Low seniority and the discomfort of being watched*

It was not always a matter of age, state of mind or potential traumatization, whether relatives were welcomed in the emergency room. Physicians mentioned that in the presence of relatives, treatment procedures that were essentially learning situations for them, could result in discomfort or fear of making mistakes. Relatives present with a non-health care worker perspective and may fail to understand that young physicians need to ask questions. Participants who were young physicians expressed that they were yet to achieve unshakable trust in their own abilities. Being observed by relatives could generate professional insecurity even when they were performing well.

*"If you are in the midst of performing a task that you are uncertain of how to perform, then it is uncomfortable that someone should stand there and watch. However, if you have performed it numerous times and you are comfortable in your [professional] role and you know what to do, the distraction of someone watching you is lessened"*

*Disruptive and unfamiliar sounds*

Participants agreed that emergency care situations involved a great number of audible impressions, such as verbal exchanges between staff and beeps and buzzing from machinery. Some of these sounds were necessary for their work tasks, such as information from a colleague or a machine. However, some sounds where coined as "irrelevant sound" and thus interruptive, such as outbursts, sobbing and questions from relatives. These were harder for HCP to block out as the sound was less familiar - one they were not trained to deal with.

*"We have developed an ability to filter out the noise and [sound of the] oxygen mask, that is running at full throttle, and the people that talk over it (...)"*

*" Cardiac arrest, trauma calls, a lot of people are called to them, which in turn causes there to be if not disturbance, then at least a buzzing (...) apart from the buzz of conversation, medicine is ordained, stuff is beeping, utensils are unpacked. (...) However, I believe it all falls under, what should we call it? A background noise (...)*

*How team behavior is affected by relatives' presence*

FPDR affected the team's behavior, not only through censuring of interprofessional deliberation but also the tone became more professional and polite when a relative was present. They were very much aware that a non-member of the team was present and how their behavior might be perceived, thus adjusting their behavior slightly.

Some participants described cases in which the team chose to continue futile treatment simply due to the presence of a relative. Out of pure consideration for the relative the team gave it "one more try". Participants considered this a means to helping relatives come to terms with the pending death of their loved one.

*"(…) you are considering whether to discontinue the cardiac arrest treatment, and you have been at it for a while, and then you go > Ok, we are going to go on for a little while longer. Let us get the relatives in here so that they can see for themselves, that we are doing everything we can about this situation (…) so that they are informed about the process and see, that we have not just been chatting away, but have actually put everything into motion."*

### *Category 3: Areas of development for implementation of FPDR*

This category includes three themes and refers to the participants views on implementation of FPDR, and which areas management should focus on.

#### *Disoriented relatives*

Participants mentioned that relatives often followed the ambulance to the hospital in their own car. When a relative accompanied the patient in the ambulance, they were usually placed in a waiting room until the team leader deemed it appropriate for them to be present. Relatives were often described as disoriented, with bags and jackets under their arms, and if in the middle of the night, a bit disheveled. They would hardly know where to place themselves in the hospital room, which led some participants to propose that a chair should be placed for relatives. Although participants harbored concern that agitated relatives could obstruct treatment, they mostly described relatives as calm bystanders who adhered to staff instructions.

*"(…) they often just stand there holding overcoats and bags (…) Often it is as simple as having a chair [for them]. Whether they want to sit down or not, well… > You can unload your stuff here < and such. Something physical. >Where am I to place myself? < (…) I believe that is quite important".*"

#### *Lack of national clinical guidelines*

The lack of national clinical guidelines coupled with a lack of designated support persons for relatives was a main barrier for implementation of FPDR. Currently, t FPDR practice hinges on the experience and preferences of individual HCP. Ensuring physical space for relatives in the emergency room and designating a team member to care for relatives were mentioned as concrete initiatives that decision makers should prioritize: The support person should be an HCP aware of the standard of care and able to inform the relative, thus becoming a resource for both the relative and the resuscitation team.

*"I would like there to be a mark on the floor (…) That we had a designated spot for the relatives, in order to increase the focus on it and for all of us to remember to invite them [the relatives] in and such."*

Or who has the responsibility:

*" Sometimes, too much time passes before someone says > Who is tending to the relatives? < Really, we are not nearly good enough at tending to them, I believe".*

Furthermore, participants stressed that national clinical guidelines should not be too rigorous:

*"Because I believe it is the worst thing we can possibly do for some relatives, and the best for others. It depends on the sort of relationship that exists between the relative and the person who is lying there, ill, and the personal experiences of both the relative and the patient."*

*A support person is essential*

The participants found it essential that a designated support person should be allocated for the relatives during FPDR. However, they found the notion to be unattainable in a time where the Danish health care system is already feeling understaffed.

*"I believe it is nearly always a prerequisite that someone should be there to take care of them. Because if no one is, the experience will not be a good one for the relative and there is a risk that will affect our work negatively".*

*"Well, they cannot just walk into the room and stand there and watch. Someone has to inform them of what has occurred and why we are handling things the way we are, with the patient."*

## DISCUSSION

Participants expressed openness and positivity towards the presence of relatives whilst at the same time voicing skepticism concern that relatives could disturb treatment, take up space or become disruptive.

We deliberated whether due to the current ERC guidelines, HCP were more open toward the inclusion of relatives despite having concerns. These were mainly expressed later in the interviews, such as whether the procedures would traumatize relatives or that relatives would obstruct treatment. However, a positive experience of FPDR can potentially influence the views and attitudes in this evolving area of praxis towards a more positive mindset about FPDR[43].

We also considered whether participants experienced a dichotomy between stating that their work could be obstructed by relatives and whether they were fulfilling their job. Physicians and nurses are trained from the onset of their education to handle necessary tasks under pressure. Participants mentioned having developed a kind of tunnel vision during emergency treatment and therefore they were not disturbed by irrelevant noise from colleagues or machinery. Conversely, some participants would claim that noise from agitated relatives fell under this category of irrelevant noise, however later in the interviews the same participants coined this noise as unfamiliar and intrusive to their work. This made us aware of a dynamic, in which some participants struggled with the fact that they were trained to block of certain distractions yet could not always maintain their focus when the distraction came from relatives. We consider whether this is due to some distraction being somewhat familiar and those from relatives continuously unfamiliar. A large part of their training prepared them to sort out irrelevant noise such as communication between other colleagues, however, outbursts and questions from relatives is not a part of that training.

Moderate-quality evidence suggests that FPDR does not affect adult resuscitation outcomes[44] and a pre-hospital study of FPDR found no increase in stress levels among HCP[3]. Likewise, a pediatric study of FPDR found no differences in the success rate of emergency interventions[32] and another study found no negative impact on medical care[45]. Furthermore, the ability to get a patient history quickly is an advantage[13]. On the other hand, performance studies of student nurses and young physicians, during a simulated cardiac arrest with FPDR, indicate that the presence of relatives may negatively impact the quality of acute medical care[23,25]. Similarly, in a simulation study with paramedics, it was observed that the presence of socioemotional stress, in this case from the presence of an upset friend, increased the subjective workload and frustration of the HCP[46].

Resuscitation in ED is characterized by the participants having very little information beforehand. Most of them are called by a beeper and the information is not attained before entering the emergency room, either from the ambulance personnel, patients, colleagues, medical records, or relatives. They proceed to gain information through the initial ABCDE assessment. Thus, although HCP staff are highly trained in working under pressure and in their use of algorithms and initial assessments, emergency care was characterized by a sense of unpreparedness. It is the HCP job to fill in the gaps as fast as possible.

The effects of stress on physician's performance in clinical situations with FPDR is poorly understood. HCP are not unphased by the grievous reactions of relatives and their presence often created an additional mental load. Elevated stress levels may impede performance on tasks that require divided attention, working memory, retrieval of information from memory, and decision making[47].

The European Resuscitation Council recommends, albeit based on a limited number of trials, that relatives should be offered the choice to be present during cardiopulmonary resuscitation (CPR) if supported by a designated support person[1]. However, we found that the participants could not always allocate this resource - preferably a nurse. However, some did mention allied health professionals as possible candidates. The need for a national clinical guideline regarding FPDR in Denmark is evident from this study. Guidelines could raise focus on education practise regarding FPDR, training designated support persons and allowing relatives to be prioritized in the physical space. E.g., a designated chair or markings on the floor. Hospitals with an FPDR policy have not been seen to have statistically significant differences in outcomes and processes of care, when compared to hospitals without this policy. This suggests such policies do not negatively affect resuscitation care[48].

### Trustworthiness and limitations of findings

The semi structured open-ended interview schedule allowed participants to voice their feelings and experiences.

The composition of the groups was given much thought. Researchers are normally advised to avoid great differences in groups, but in this particular case, heterogeneity in experience and professional backgrounds gave rise to lively discussion[37]. Thus, it served the purpose of applying the format of focus interviews well, as it extracted diverse opinions and considerations around the research topic.

We wished to include both HCP with and without prior experience with FPDR, as studies have shown that experienced nurses hold more positive views of FPDR than inexperienced nurses[49]. Additionally, a positive experience with FPDR could influence their attitudes towards the praxis and produce a more positive mindset about FPDR overall [43]. As this study showed, Danish HCP were predominantly positive towards FPDR, whilst simultaneously revealing an experienced dichotomy between their intentions to include relatives and their concerns. We consider the possible bias that those who signed up for the study held a more positive attitude regarding FPDR, than those who declined.

### Perspectives

There is a lack of awareness and material available regarding FPDR in Denmark, perhaps due to the novelty of the praxis. For the same reason, we were not able to find any quality assurance evaluations by relevant Danish health authorities. As an example, The Unit of Evaluation and User Inclusion in Denmark has no mention of FPDR in their patient evaluations of critical care reports[50,51]. We seek to rectify this and contribute a knowledge base on in-hospital FPDR in Denmark. This study can be used as a conceptual base for future study designs on FPDR, as well as contribution to considerations underlying official hospital guidelines on FPDR. This qualitative study is a part of a larger ongoing Ph.D. study on FPDR at the Department of Anaesthesiology Copenhagen University Hospital Herlev, DK.

## CONCLUSION

This study showed that the most prominent facilitative factor for FPDR in Danish hospitals was that HCP see FPDR as beneficial for relatives in coming to terms with the loss of a loved one. Additionally, FPDR contributes to humanizing the patients and allows HCP quick access to information about the patient. Conversely, inhibitory factors included self-censorship among HCP, possible risks to patient safety, a lack of FPDR guidelines and training. Future research must investigate the long-term effect on both relatives and HCP when FPDR is practiced.

## DECLARATIONS

a) Ethics approval and consent to participate

All participants signed an informed consent form and permission for the study was obtained from the Knowledge Centre on Data Protection Compliance in the Capitol Region of Denmark (P-2021-515). No formal review by the Danish Ethics Committee was required (Journal 21046372).

b) Consent for publication

Consent for publication has been given by all authors.

c) Availability of data and materials

The datasets generated and analysed during the current study are not publicly available due to the to the sensitive nature of cases mentioned in interviews but are available from the corresponding author on reasonable request.

d) Competing interests

Rubin is a member of the parliament in Denmark with a special interest in healthcare politics. Dieckmann holds a professorship with the University of Stavanger that was established by an unconditional grant from the Laerdal Foundation to the University and that is now financed by the University. Dieckmann leads the EuSim group, a network of simulation centers and experts providing simulation faculty development courses.
None of the other authors had any conflict of interests.

e) Funding

Copenhagen Academy of Medical Education and Simulation has sponsored the conference room for the completing of focus groups and lent us a recorder.
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f) Authors' contributions

All authors have made substantial contributions to all of the following: (1) the conception and design of the study, or acquisition of data, or analysis and interpretation of data, (2) drafting the article or revising it critically for important intellectual content, (3) final approval of the version to be submitted and (4) agreement to be accountable for all aspects of the work.
**MR:** Project administration, Conceptualization, Methodology, Validation, Software, Visualization, Investigation, Data curation, Formal analysis, Writing- Original draft preparation **KF**: Conceptualization, Methodology, Validation, Software, Visualization, Investigation, Data curation, Formal analysis, Writing- Original draft preparation, Reviewing and Editing. **TT**: Conceptualization, Methodology, Validation, Reviewing and Editing **PD***:* Conceptualization, Methodology, Reviewing and Editing **AMM:** Funding acquisition, Conceptualization, Methodology, Supervision, Reviewing and Editing.

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# TABLES

## Table 1: Interview Guide

| **Introducing the theme of the interview** | | |
|---|---|---|
| **Themes** | **Notes for the interviewer** | **Manuscript** |
| **Presentation of the interviewer** | Division of roles | **Interviewer:** My name is Monika, and I am a physician and a Ph.D. student, with a specialisation in anaesthesiology. I will be your interview coordinator.<br><br>**Notetaker:** Across from me, we have anthropologist and my research assistant, Katja. She will take notes during the interview to add context to the sound recording. |
| **The purpose of the project and subsequent interview** | Subject matter and participants | This interview is a part a qualitative study in which attitudes of physicians and nurses toward family presence during in-hospital resuscitation and emergency treatment, are examined. |
| **Written consent** | | You have either signed and brought along the written consent form that was emailed to you before the interview, or you can sign a copy here.<br>This consent form allows the researchers to use the content of the anonymized interview for the research project and future publications.<br>You may withdraw your consent any time. |
| **Practical information** | Time frame | The interview will last approximately 1 hour. We will finish 5-10 minutes before 9 o'clock. |
| | Recording | We will record the interview to ensure you are quoted correctly. The recording is also used for later analysis. The data is kept solely on Herlev Hospital servers, safeguarded by the Regional Capital cyber and data security. |
| **Method** | Semi-structured interview and follow-up questions | The interview questions are similar in all focus group interviews; however, we may ask follow-up questions of a more a spontaneous nature during the interviews. Additionally, you may feel free to respond to the reflections of other participants during the interview. |
| **Introductory section: The interview begins** | | |
| **Introducing the participants** | **Thematic introduction** | We will begin with an enquiry into your experience with family presence during in-hospital resuscitation and emergency care. |
| | **Personal introduction -** Profession, name, and age. | I would like you to begin by telling me your names, ages, and professions. |
| | Seniority | **a.** How long have you worked as a_____? |
| | Level of experience with FPDR | **b1.** Do you have any experience with FPDR? Yes/No<br>**b2**. In your assessment, how widespread do you think the praxis of in-hospital FPDR is in Denmark? |

| | | |
|---|---|---|
| **Grand tour questions:** Establishing an understanding of their work environment | **Thematic introduction:** Emergency treatment | I will narrow the focus now to in-hospital emergency treatment and resuscitation, as well as your work tasks when you are called to an acute patient. |
| | Definition | **c.** How would you explain what emergency treatment is to a non-health professional? |
| | A typical scenario | **d1.** In a typical scenario, what happens when you are called to a room with an acute patient? |
| | | **d2.** How many staff members are usually present during emergency treatment and resuscitation? |
| | | **d3.** Who is the first person you speak to when you enter a hospital room with an acute patient? |
| | | **d4.** What is your knowledge of the patient based on? For instance, the medical journal, interaction with the patient or other? |
| | | **d5.** Who usually takes the role of team leader in an emergency treatment situation?<br>**Follow- up question themes:** division of roles between physicians, nurses and health care assistants. |
| | The physical space | **e1.** I will now enquire into your physical workspace and environment. Perhaps you expect me to know the answers to these questions already, since I am a physician myself. However, these questions are applied to avoid assumptions about your experiences.<br><br>**e2.** How would you describe the physical space as you enter a room of an acute patient?<br><br>**e3.** What auditive impressions stand out to you during emergency treatment e.g., from colleagues, equipment, the patient or other. |
| **Mid-interview: Reflections of the health care professional** | | |
| **Zoom in:** opinion questions | Leading question, to encourage an opinionative stand. | **f.** Is it *even* possible to imagine the presence of a relative, in the work environment that you describe during emergency treatment? |
| | Deliberating whether the relative should be present. | **g1**. How does the condition of the patient affect your decision as to whether a relative may be present during emergency treatment?<br>**Follow-up question themes:** Visible injury, the differences between resuscitation and emergency treatment. |
| | Patient status | |
| | Age of the patient | **g2.** How does the patient's age affect your decision on whether to include a relative?<br>**Follow-up question:** If there is a difference, why? |
| | The mental state of the relative | **g3.** How does the mental state of the relative affect your decision as to whether they can be present?<br>**Follow-up question:** What would cause you to decline a relatives wish to be present? |
| | Age of the relative | **g4**. How does the age of the relative affect your decision regarding whether they can be present or not?<br>**Follow-up question:** Why do you think your attitude varies as an effect of their age? |

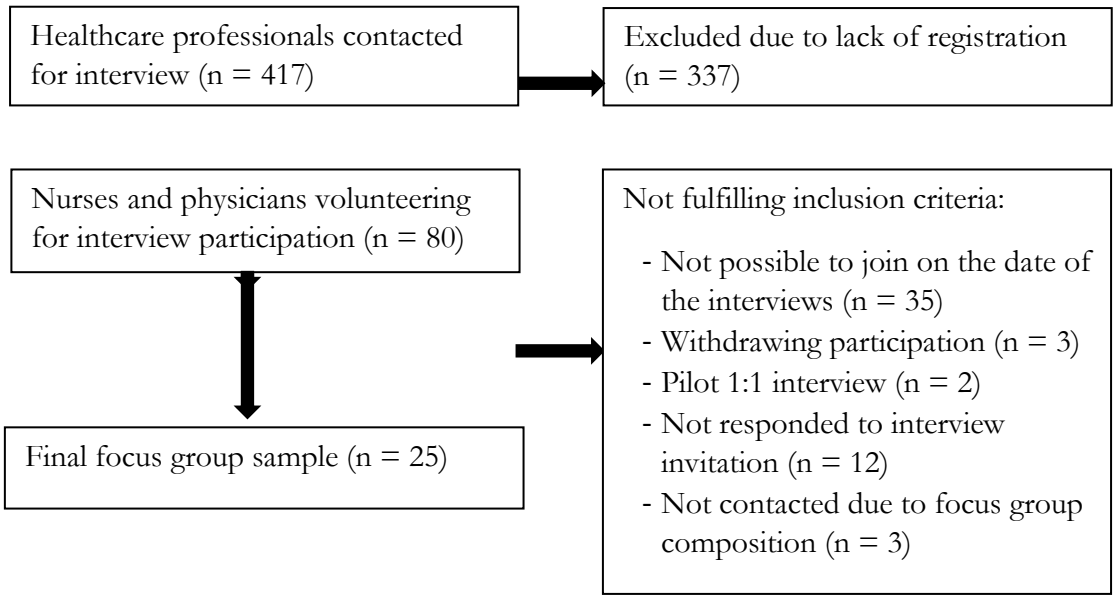
| | | |
|---|---|---|
| | Affiliation | **g5**. How does the affiliation between the relative and patient affect your stand on whether they should be present during the emergency treatment? |
| | When the relative is already present in the hospital room | So far, we have discussed factors that play into your decision making regarding whether the relative should be present during emergency treatment. I will now shift the focus to situations in which the relative has already been invited to be present. |
| | Patient safety | **h1.** How might the presence of a relative affect your work during the emergency treatment?<br>**Follow-up question themes:** Possible risks, lack of space, interruptive behaviour, noise etc. |
| | Decision making | **h2.** How might the presence of a relative affect your procedural and treatment related decisions?<br>**Follow-up question:** Are there ways in which the presence of a relative inhibits inter-collegial communication or discussion? |
| | The relative as a resource<br>(Intention: lead conversation toward resources needed in relation to FPDR, such as a support person) | **h3.** How might a relative be a resource to you during emergency treatment?<br>**Follow-up question:** Or perhaps they draw on the resources of the staff, rather than act as one? |
| | **Theme**<br>a. Research and recommendations<br>b. Support persons | **Background:** ERC recommends that a health professional should act as a support person in cases of FPDR. |
| | | **i1.** In your opinion, what type of HCP should fulfill the role of a support person? |
| | | **i2.** If in time, research shows that it is beneficial to the relative to be present during emergency treatment, how might that affect your stand on FPDR? |
| **In closing: Generalisation** | | |
| **Zoom out** | Reflection and broadening the perspective | **j.** Have you had conversations with colleagues regarding in-hospital FPDR?<br>**Follow-up question:** What have their attitude been regarding FPDR? |
| | | **k.** Do you think there is a correlation between a HCPs attitude towards FPDR, their profession and area of responsibility? |
| | | **l.** Have I overlooked any important subjects; do you think? |
| **Closing** | | |
| **Thank you** | Assure them of the importance of their contribution | Thank you all for your participation. It has greatly expanded our knowledge on the subject. |
| | Demographic data and follow-up with results | I will need to ask you for demographic data in relation to the study. Please fill out this form.<br>If you would like to receive an email regarding our findings and a link to the final publications, you may fill out the relevant area on the consent form. |

## Table 2. Socio-demographic characteristics of the participants

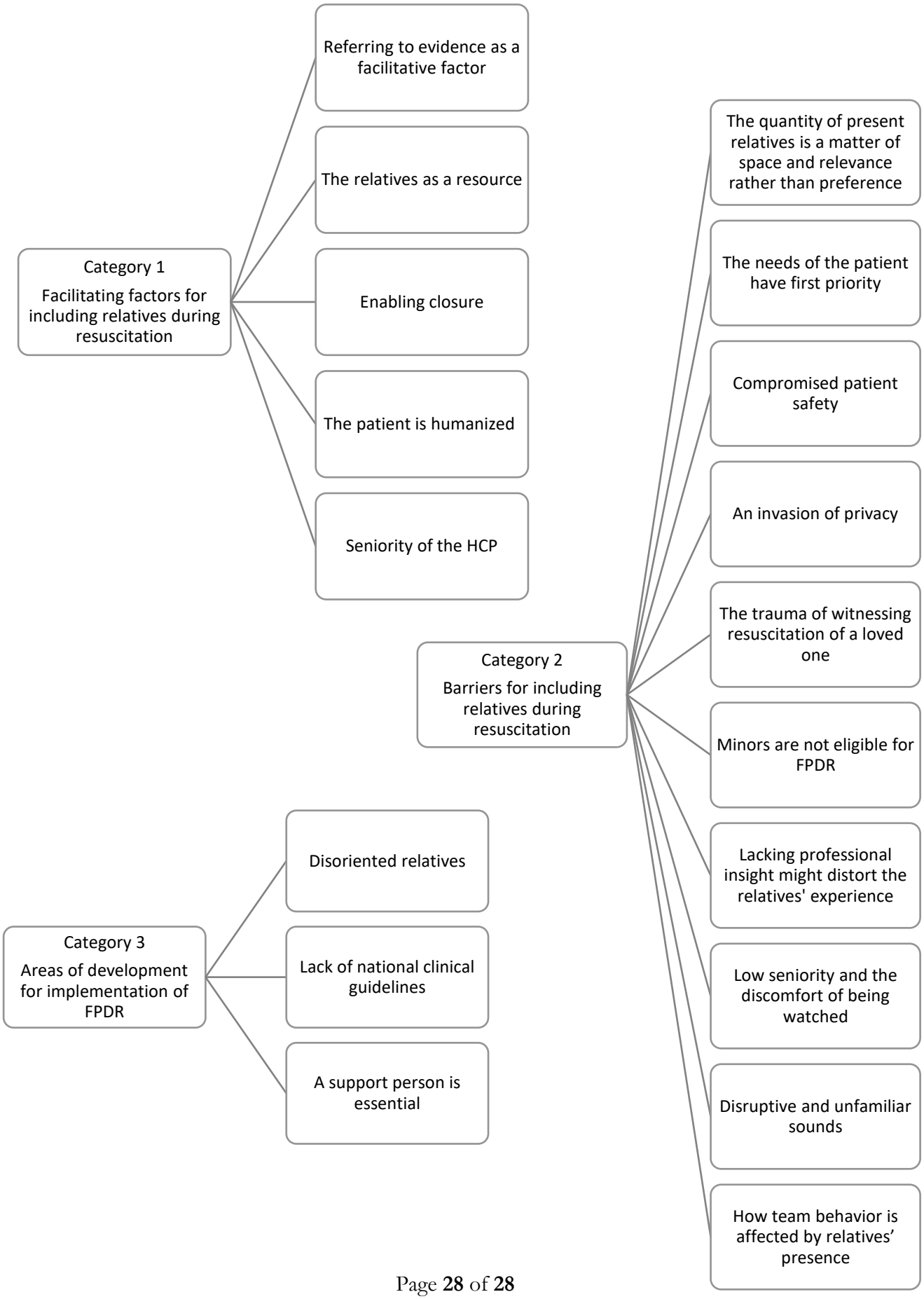
| Characteristics | Total | |
|---|---|---|
| | N | % |
| Gender | | |
| Male | 8 | 32 |
| Female | 17 | 68 |
| Age | | |
| <40 | 16 | 64 |
| >40 | 9 | 36 |
| Profession | | |
| Physician | 17 | 68 |
| Nurse | 8 | 32 |
| Post-graduation degree | | |
| Yes | 12 | 48 |
| No | 13 | 52 |
| Working period of time | | |
| >10 years | 12 | 48 |
| <10 years | 13 | 52 |
| Experience with FPDR | | |
| Yes | 25 | 100 |
| No | 0 | 0 |

# FIGURES

## Figure 1. Flow of participants



## Figure 2. Illustration of categories and themes



# A survey of healthcare professionals' perspectives regarding family presence during resuscitation in Denmark.

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ABSTRACT

**Background:** Healtchcare professionals (HCP) do not entirely support family presence during resusciation (FPDR). Compared to nurses, physicians are more likely to feel that the risks outweigh the benefits of FPDR.

The aim of this survey was to assess the perspectives of HCP on FPDR among those working in the emergency department (ED) in Denmark. Our primary outcome was to explore differences between nurses/physicians in their response to the question “Family members should be given the option to be present when a loved one is being resuscitated”.

**Methods:** An anonymous electronic survey was distributed to nurses and physicians in the ED. The survey included a previously validated survey-based risk-benefit scale of 22-items, measuring HCP perceptions of FPDR using a 5-point Likert scale together with demographic items. The original risk-benefit scale was translated and validated into Danish before use. Permission for the study was obtained from the Knowledge Centre on Data Protection Compliance (P-2022-547).

**Results:** A total of 151 clinicians answered the survey (34% nurses and 66% physicians) with a median age of 36-40 years. More than half (62%) had more than 6 years of experience. Only 4% of the participants had not experienced FPDR. Significantly more nurses than physicians considered “Family members should be given the option to be present when a loved one is being resuscitated” (p-value 0,0127), and that FPDR was a right of patients and families (corrected p-value 0,0004). The answers were not affected by either gender or seniority. The nurses also agreed more than physicians with the statement that FPDR is a right that patients and relatives should have. However, it should be noted that almost twice as many physicians compared to nurses answered the survey.

**Conclusion:** In Denmark nurses are more likely to agree that “Family members should be given the option to be present when a loved one is being resuscitated” than physicians which could lead to affected team collaboration in relation to FPDR involvement. Findings may contribute to qualifying discussions among HCP in ED and other emergency care settings about FPDR and to further advance family-centered hospital care.

## BACKGROUND

A system, where a family- and patient-centered approach, caring for the patient as well as for the family or a significant other, is central in today's modern western medicine. In relation to resuscitation, evidence indicates that patients wish for their relatives to be present during treatment and that the relatives want to be [1–7] . Some relatives believe it is their right to be present and expect to be actively involved regarding care decisions involving the treatment of their relatives [8,9]. Family presence in the resuscitation room during resuscitation, including trauma and emergency critical care (FPDR), is referred to as: "The attendance of one or more family members or significant others in a location that affords visual or physical contact with the patient during invasive procedures or [cardio-pulmonary resuscitation] CPR" [10], and is considered an essential part of patient and family-centered care[11].

The practice of offering FPDR was initially introduced in the emergency setting in 1987 [1]. Since then, FPDR has been increasingly endorsed by healthcare professionals (HCP) and lay people [12]. Guidelines by two major resuscitation councils – the American Heart Association and European Resuscitation Council have been published, encouraging family presence to be offered during resuscitation [13–15]. Furthermore, other associations have responded to the debate regarding advantages and disadvantages of FPDR by producing guidance to enhance decision-making[7,11,16].

The principle of FPDR relies on both HCP, family and the patient working together around the intervention of family presence and meeting all needs and everyone's well-being in a balanced way. FPDR can take a toll on hospital resources since it is recommended that the relative has a designated support person present, additional to the resuscitation team[8,17–21]. For that reason, FPDR remains inconsistently implemented, and is subject to controversy. There is a belief that FPDR gives relatives an opportunity to say goodbye, facilitating closure and grieving and enabling the family to provide emotional support to the patient [22,23]. But only three randomized controlled trials (RCT) [24], including a qualitative survey-design [25], and a quasi-randomized trial [20] reviewing the potential effect on relatives of being present, and on HCP experience, have been conducted since 1987. An overview of the literature available on FPDR shows that HCP do not entirely support the practice[26–34]. Their attitudes towards FPDR vary with some being concerned that FPDR might have potential psychological adverse effects on relatives, as well as impact HCP performance negatively[8,17,19,35–42].

This could subsequently affect the quality of critical medical care, and thereby worsen patient outcome[22,43,44].

The literature does indicate a tendency that as seniority and experience increases, so does openness toward FPDR[45,46]. If specific protocols related to FPDR are available at the hospital, this too contributes to an increased susceptibility toward FPDR[47,48]. In turn this suggests that uncertainties related to practicing FPDR are an important issue. Compared to nurses, physicians are more likely to feel that the risks outweigh the benefits of FPDR[26,27,29–34]. Likewise, the majority of FPDR related literature is published in nursing-journals which may be an indicator that it has yet to find its way into the mindset of physicians. This theory is enhanced when one considers that the only official FPDR guidelines known to the authors, are produced by the Emergency Nurse Association[49]. This guideline, however, only provides a moderate recommendation for FPDR.

Educational and cultural backgrounds seem to influence the openness and attitude towards FPDR[30,50]. In Denmark no national clinical guidelines exist which can lead to variation in relation to implementation of FPDR. Some studies describe that the values and beliefs of the family and HCP influence their decision to choose family presence or not[34]. In the context of Danish Healthcare, it is therefore relevant to explore how physicians and nurses working with FPDR are affected by the intervention.

The aim of this survey was to assess the perspectives of HCP working in the emergency care setting on FPDR in Denmark. Our primary outcome was to explore differences between nurses and physicians in their response to the question (Table 1) *"Family members should be given the option to be present when a loved one is being resuscitated"*.

## METHODS

**Study design and Participants**

This survey was completed at Herlev Hospital in the Capital Region of Copenhagen. A self-administered anonymous electronic survey was distributed by email to 482 HCP assumed to be working in the ED. Unfortunately, no email directory connected directly to the HCP employed in the ED existed, as many HCP working there are consultants from other departments, where they are employed. The emails were therefore sent to more HCP than those solely dedicated to the ED. The

target group was nurses and physicians working in the ED, who had experienced or could experience, having relatives present during emergency treatment or resuscitation. The study was carried out between 20th of May and 8th of June 2022. The invitation was sent out by the first author (MR) via corporate mail in a direct message including a digital written informed consent and a link to the survey (SurveyXact). Participants were given 2,5 weeks to complete the survey. An electronic survey-reminder was sent after one week and one day before deadline. We used a Danish version of the validated Family Presence Risk-Benefit tool by Twibell et al [51] with permission from the author. This included 22 questions regarding FPDR on a 5-point Likert scale (1, strongly disagree, to 5, strongly agree) (Table 1). Furthermore, we assessed demographic characteristics and experiences with FPRD. At the end of the survey, it was possible for the participants to fill in a comment.

Participants were notified of the choice to withdraw from the study at any point without any consequences, that no personal identifiers would be collected, responses would remain anonymous, and kept with the investigators for research purposes only, and that there would be no financial involvement in the study.

Since the study was conducted as an anonymous questionary survey with no interventions, there were no ethical considerations relating to the study and therefore exempt from formal ethics approval. Permission for the study was obtained from the Knowledge Centre on Data Protection Compliance (P-2022-547).

**Translation and validation**

To our knowledge, no study has translated and validated Twibells Risk-Benefit instrument[48] into Danish. Translation of the tool into Danish was performed to facilitate better understanding and more accurate answers among participants. To our knowledge no guideline for translational validation of survey exists. However, current recommendations were followed [52]. For translation, the 'Forward-Backward' method was used. Forward translation was performed independently by two bilingual persons (MR, NL). Another language expert (TT) back-translated the survey to ensure semantic equivalence [53].

The Risk-Benefit-scale was chosen, as Twibell *et al.* had already performed a quantitative validation using item-to-total correlation and Cronbach alpha reliability [51,54]. The factorial survey tool was tested on a pilot group of four staff members. They were asked to complete the survey and to consider both content and context to reach face validity (qualitative validation).

**Data management and statistical analysis**

Experience with FPDR was not a necessity as we simply wanted to gain knowledge about FPDR in the Danish setting rather than make statistical inference. Our primary outcome was to explore differences between nurses and physicians in their response to the question (Table 1) *"Family members should be given the option to be present when a loved one is being resuscitated"*.

We used SurveyXact for data collection. The program follows EU's General Data Protection Regulation (GDPR).

We used descriptive statistics for each measurement item. Sample size was determined by Monte Carlo simulation to assure, that the power of the Mann-Whitney U test, was 0,8. Our intention was to include a minimum of 43 and a maximum of 129 participants in each group; nurses and physicians. The Mann-Whitney U test was used to assess potential differences in responses amongst HCP who had experienced "Family presence during resuscitation" and those who had not and amongst HCP according to seniority and gender. Results are presented as percentages and a p-value $< 0.05$ is assumed to be significant. The statistical program "R" (version 2022) was used for statistical analysis.

## RESULTS

A total of 162 nurses and physicians participated (Flowchart, Table 2). Among these, 34 % were nurses and 66 % physicians; and the median age of participants was 36-40 years. There was an almost equal distribution of males and females (59% males and 41% females). Most were anesthesiologists or nurses working directly in the ED (56 %). Over half (62%) had more than 6 years of experience. Only 4 % had less than 1 year of experience and only 4% had not experienced FPDR. The demographic characteristics of the participants are shown in Table 3.

In general, the nurses were more positive towards FPDR than physicians (figure 1). We found a significant difference (p-value 0,0127) between nurses and physicians regarding our primary outcome: “Family members should be given the option to be present when a loved one is being resuscitated”, with more nurses agreeing than physicians. We found no statistical difference between years of clinical experience (<6< years, p-value 0,4005) or gender (p-value 0,0822). When exploring the 21 other questions for differences between nurses and physicians’ answers, after correcting for multiple analyses, we only found statistically significant differences in responses to questions 21 and 22 (p-value 0,0004) (Table 1 and figure 2). Nurses agreed more than physicians with the statements that FPDR is a right that patients and relatives should have. Our results indicate that HCP, especially nurses, perceive FPDR as most beneficial to families rather than patients and HCP as seen in their answers to the questions 14 in figure 1.

Participants commented that it was essential for them that relatives should have the option of FPDR. Furthermore, the presence of a support person was crucial for whether they agreed to the statements in the survey. They also commented on the definition of resuscitation which included emergency critical care, pointing out that cardiopulmonary resuscitation and resuscitation in general were different interventions. As the survey did not distinguish one from the other, they commented that they had responded 3 on the 5-point Likert scale to many of the questions.

## DISCUSSION

The perspectives of HCP on FPDR among those working in the emergency care setting in Denmark was investigated in this survey using a Danish translation of a validated survey[51]. We found that Danish nurses were more likely to agree that “Family members should be given the option to be present when a loved one is being resuscitated” than physicians. The answers were not affected by either gender or seniority. The nurses also agreed more than physicians with the statement that FPDR is a right that patients and relatives should have. However, it should be noted that almost twice as many physicians compared to nurses answered the survey.

Our results are in line with narrative reviews reporting that physicians often perceive more barriers associated with FPDR than nurses[38,41,55], although perceptions vary across different cultural

settings.[21,31,38,40,56,57] The difference in responses of nurses and physicians to our primary outcome is interesting, especially considering their consensus in responses to many of the other statements in the survey, and their consensus regarding the statement "If my loved one were being resuscitated, I would want to be present in the room". We believe the difference in the answers among the professions could be because of their tasks, roles and (legal) responsibility during resuscitation. We believe the difference in the answers can be caused by the fact that, ultimately, physicians are responsible for decision-making[58]. There was however no difference in the answers between the professions regarding question 10 "Family members who witness a resuscitation effort are more likely to sue".

Our hypothesis was that the answers to our primary outcome would be affected by seniority as unpublished results from a focus group study we have done, identified seniority among HCP as a facilitating factor for FPDR. The more professional confidence, the easier to include or exclude relatives in relation to FPDR. Other studies have shown that experienced nurses held more positive views of family presence during resuscitation than inexperienced nurses[45]. A positive experience of FPDR can potentially influence the views and attitudes og HCP in this evolving area of practice towards a more positive mindset about FPDR [46].

Our results that indicate that HCP perceive FPDR as beneficial to families is in line with the only good quality large RCT of FPDR that found positive effects of FPDR on relatives' psychological outcomes, including improved clinical indicators related to PTSD, better anxiety and depression scale scores, less complicated grieving because of pre-hospital CPR, and no negative effects on mortality[23,59,60]. However, we expected that participants would also agree that FPDR was equally beneficial for HCP as unpublished data on HCP views on facilitators and barriers to FPDR indicate that relatives are a resource, especially when resuscitating children, adolescents, cognitively impaired patients, or psychiatric patients.

A main limitation of this study is the survey design where self-reported measures are subject to response biases and only 4% of the participants had not experienced FPDR. The survey was distributed using extracted corporate mailing lists. However, we were not able to test if all invited participants were directly employed in the ED. Moreover, it was not possible to find and remove potential inactive mail addresses. Therefore, it was not possible to calculate a response rate. The

study was conducted at a single hospital. Thus, the sample is not representative for a cross-national opinion. Our findings cannot be generalized beyond the current survey participants.

One department was more represented in the answers as 35 % of participants were from the Department of Anaesthesiology. This could be a sampling issue, but we believe it is acceptable as anaesthesiologists and anaesthesia nurses have a large role in the treatment of emergency critical care patients, trauma, and cardiopulmonary resuscitation in Danish hospitals. Some participants were disagreeing to the definition of resuscitation including emergency critical care, which could make them negative to the survey overall.

There were no questions to evaluate cultural differences and religious beliefs, which could potentially play a part in forming opinions on FPDR[38].

Although FPDR has been studied throughout the literature it remains a controversial issue among HCP. Relatives' presence during resuscitation attempts may impact psychologically on relatives, the patient receiving care, and the performance of the involved HCP. In general, comparison of our results with previous studies is difficult because these studies used different instruments to determine HCP perceptions of FPDR. Nevertheless, we note that the participants in our survey disagreed regarding the question "Family members will become disruptive if they witness resuscitation efforts". This is in line with the evidence where it has been shown that FPDR does not disrupt patient care, cause adverse CPR outcomes, or negatively impact family member[7,11,13]. However, the effects of stress due to the presence of family on physician's performance in clinical situations with FPDR is poorly researched. Elevated stress levels can impede performance on tasks that require divided attention, working memory, retrieval of information from memory, and decision making[61]. Moderate-quality evidence suggests that FPDR does not affect adult resuscitation outcomes[62]. Jabre and colleagues found no increase in stress levels of HCP[60]. Likewise, a paediatric study of FPDR found no differences in the success rate of critical interventions[20] and others did not experience a negative impact on medical care in the presence of parents[63].

Many comments to the survey concerned the presence of a designated support person. We believe this is of importance when interpreting the results in figure 1. It is believed that the emergency care team can facilitate relatives' acceptance of the reality of death [59] and therefore a designated support person focusing on the relatives, as a part of the resuscitation team is recommended [13].

## CONCLUSION

Nurses in Denmark are more likely to agree that “Family members should be given the option to be present when a loved one is being resuscitated” than physicians. A significant percentage of the participating HCP had experienced FPDR, although no national policies regarding FPDR exist. Findings may contribute to qualifying discussions among healthcare professionals in ED and other hospital settings about family presence and to further advance family-centered hospital care.

## DECLARATIONS

*Ethics approval and consent to participate:* Since the study was conducted as an anonymous questionary survey with no interventions, there were no ethical considerations relating to the study and therefore exempt from formal ethics approval. Permission for the study was obtained from the Knowledge Centre on Data Protection Compliance (P-2022-547). Participants made consent to participate.

*Consent for publication:* Not applicable.

*Availability of data and materials:* The datasets used and analysed during the current study are available from the corresponding author on reasonable request.

*Competing interests:* Thomsen, Møller and Langer holds no conflicts of interest.

Rubin is running for the national elections in Denmark with a special interest in healthcare politics. Dieckmann holds a professorship with the University of Stavanger that was established by an unconditional grant from the Laerdal Foundation to the University and that is now financed by the University. Dieckmann leads the EuSim group, a network of simulation centers and experts providing simulation faculty development courses.

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*Authors' contributions:* Monika Rubin: Project administration, Conceptualization, Methodology, Validation, Software, Visualization, Investigation, Data curation, Formal analysis, Writing- Original draft preparation Natasha Langer: Data curation, Writing- Original draft preparation, Reviewing and Editing. Thordis Thomsen: Conceptualization, Methodology, Validation, Reviewing and Editing Peter Dieckmann: Conceptualization, Methodology, Reviewing and Editing Ann Møller: Funding acquisition, Conceptualization, Supervision, Reviewing and Editing.

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*Authors' information:* This study is a part of a larger Ph.D. project regarding FPDR.

## APPENDIX

### Table 1: Survey

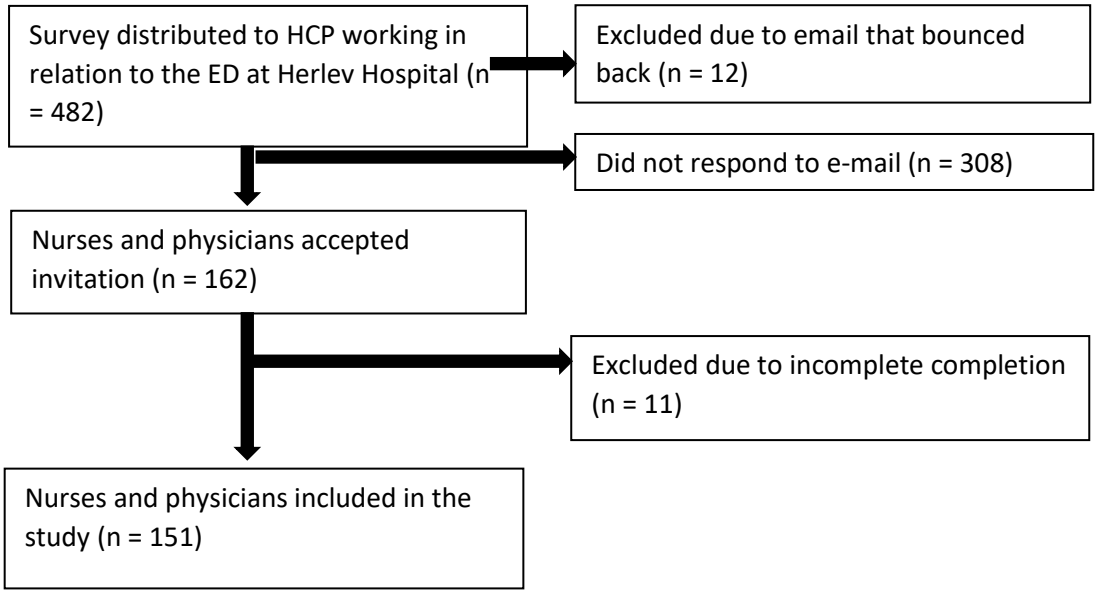
Table 1 showing the originally validated survey tool developed by Twibell et al in 2018[51].

**Questions regarding Risk-benefit scale is measured at a 5-point Likert Scale**

| Question number | Risk-Benefit Scale item |
|---|---|
| 1. | Family members should be given the option to be present when a loved one is being resuscitated. |
| 2. | Family members will panic if they witness a resuscitation effort. |
| 3. | Family members will have difficulty adjusting to the long-term emotional impact of watching a resuscitation effort. |
| 4. | The resuscitation team may develop a close relationship with family members who witness the efforts, as compared with family members who do not witness the efforts. |
| 5. | If my loved one were being resuscitated, I would want to be present in the room |
| 6. | Patients do not want family members present during a resuscitation attempt. |
| 7. | Family members who witness unsuccessful resuscitation efforts will have a better grieving process |
| 8. | If my loved one were being resuscitated, I should be allowed to be present because I am a physician |
| 9. | Family members will become disruptive if they witness resuscitation efforts. |
| 10. | Family members who witness a resuscitation effort are more likely to sue. |
| 11. | The resuscitation team will not function as well if family members are present in the room. |
| 12. | I would invite a family member to come in to most resuscitation efforts of which I was in charge. |
| 13. | Family presence during resuscitation is beneficial to patients. |
| 14. | Family presence during resuscitation is beneficial to families. |
| 15. | Family presence during resuscitation is beneficial to nurses. |
| 16. | Family presence during resuscitation is beneficial to physicians. |
| 17. | Family presence during resuscitation should be a component of family-centered care. |
| 18. | Family presence during resuscitation will have a positive effect on patient ratings of satisfaction with hospital care. |
| 19. | Family presence during resuscitation will have a positive effect on family ratings of satisfaction with hospital care. |
| 20. | Family presence during resuscitation will have a positive effect on physician ratings of satisfaction in providing optimal patient/family care. |
| 21. | Family presence during resuscitation is a right that all patients should have. |
| 22. | Family presence during resuscitation is a right that all family members should have. |

## Table 2: Flowchart (participants)

Flow of participants:



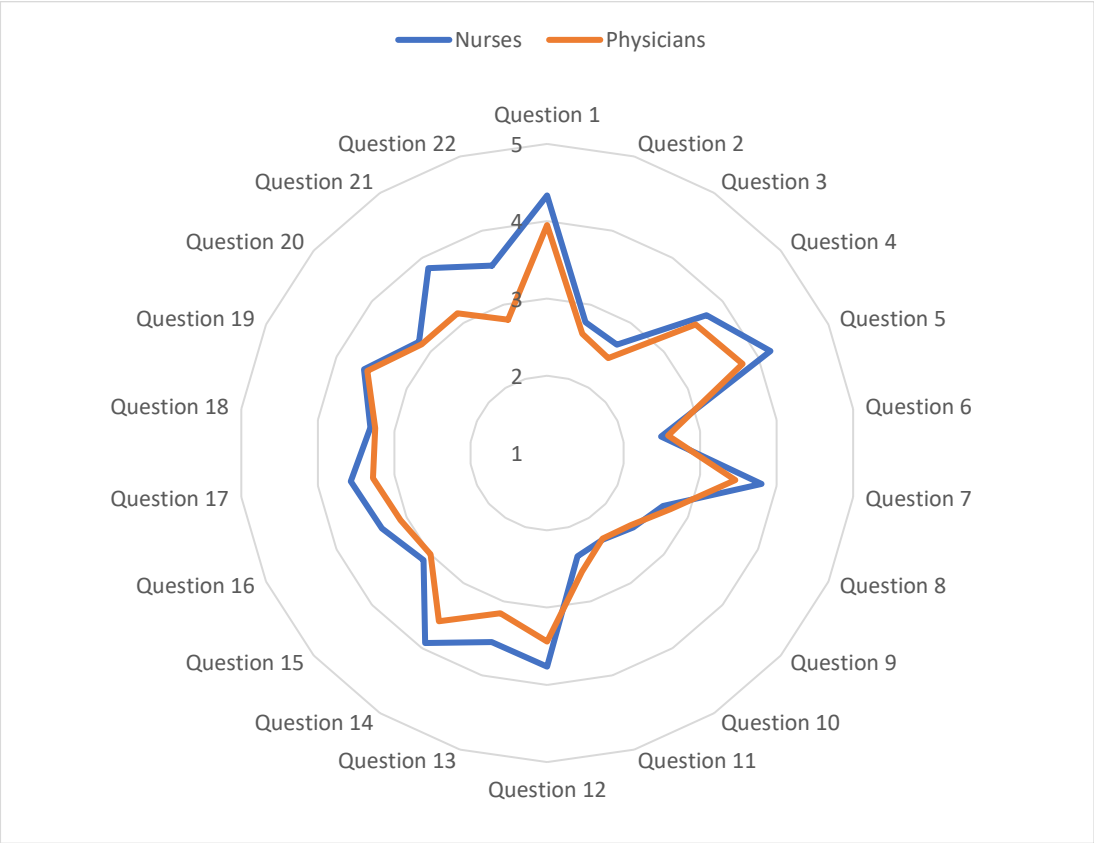
## Table 3: Demographic data

Demographic characteristics

| | Procent | Number |
|---|---|---|
| **Profession** | | |
| Nurse | 34% | 51 |
| Physician | 66% | 100 |
| **Age** | | |
| < 30 years | 13% | 20 |
| 30 - 35 years | 25% | 37 |
| 36 - 40 years | 18% | 27 |
| 41 – 45 years | 14% | 21 |
| 46 - 50 years | 13% | 19 |
| > 50 years | 18% | 27 |
| **Gender** | | |
| Woman | 58% | 88 |
| Man | 42% | 63 |
| Other | 0% | 0 |
| **Primary department employement** | | |
| Anaesthesiology | 35% | 53 |
| Surgery | 9% | 14 |
| Ortophedic surgery | 11% | 17 |
| Medical | 14% | 21 |
| Cardiology | 12% | 18 |
| I am employed directly in the Emergency Department | 21% | 31 |
| **Number of years working as a nurse/physician** | | |
| < 1 year | 4% | 6 |
| 1-5 years | 22% | 33 |
| 6-10 years | 24% | 36 |
| 11-15 years | 21% | 31 |
| > 15 years | 30% | 45 |
| **Number of times experience of FPDR** | | |
| Never | 4% | 6 |
| < 5 times | 28% | 42 |
| 5 - 10 times | 19% | 29 |
| > 10 times | 49% | 74 |

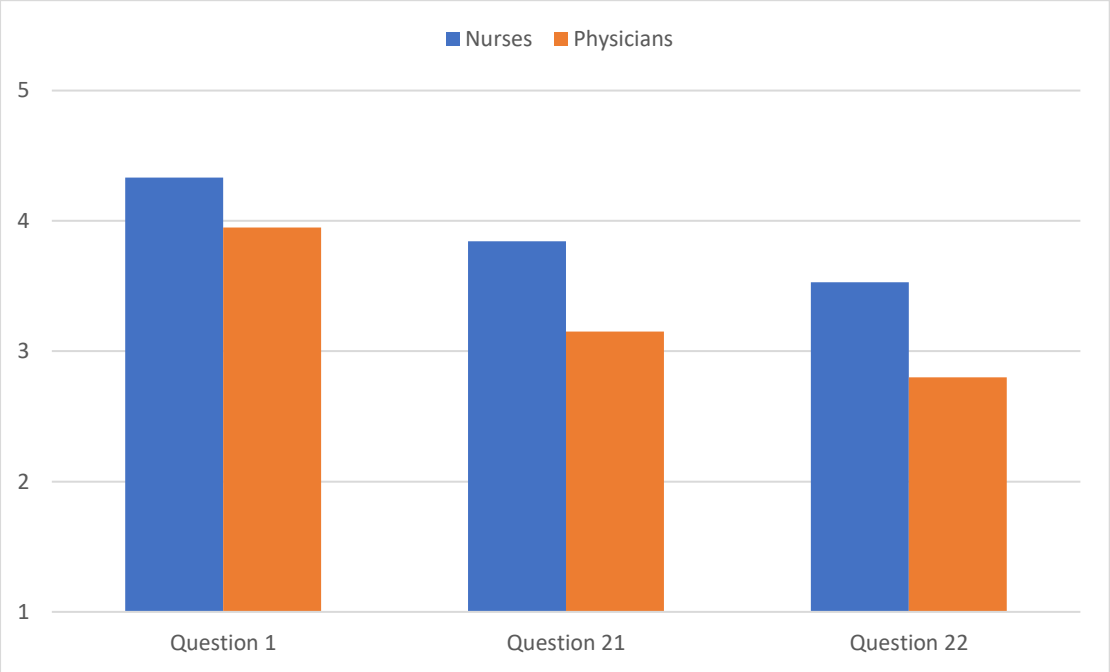
## Figure 1: visualization of all answers

The distributions of the answers amongst nurses and physicians regarding question 1-22 on a 5-point Likert scale (1, strongly disagree, to 5, strongly agree).




## Figure 2: visualization of differences in nurses and physicians' answers

The distributions of the answers amongst nurses and physicians regarding question 1, 21 and 22 on a 5-point Likert scale (1, strongly disagree, to 5, strongly agree).



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