

Family presence during resuscitation: A Canadian Critical Care Society position paper

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BACKGROUND: Recent evidence suggests that patient outcomes are not affected by the offering of family presence during resuscitation (FPDR), and that psychological outcomes are neutral or improved in family members of adult patients. The exclusion of family members from the resuscitation area should, therefore, be reassessed.

OBJECTIVE: The present Canadian Critical Care Society position paper is designed to help clinicians and institutions decide whether to incorporate FPDR as part of their routine clinical practice, and to offer strategies to implement FPDR successfully.

METHODS: The authors conducted a literature search of the perspectives of health care providers, patients and families on the topic of FPDR, and considered the relevant ethical values of beneficence, nonmaleficence, autonomy and justice in light of the clinical evidence for FPDR. They reviewed randomized controlled trials and observational studies of FPDR to determine strategies that have been used to screen family members, select appropriate chaperones and educate staff.

RESULTS: FPDR is an ethically sound practice in Canada, and may be considered for the families of adult and pediatric patients in the hospital setting. Hospitals that choose to implement FPDR should develop transparent policies regarding which family members are to be offered the opportunity to be present during the resuscitation. Experienced chaperones should accompany and support family members in the resuscitation area. Intensive educational interventions and increasing experience with FPDR are associated with increased support for the practice from health care providers.

CONCLUSIONS: FPDR should be considered to be an important component of patient and family-centred care.

Key Words: *Family; Family-centred care; Family presence; Resuscitation*

The present position statement is meant to serve as a reference for the practice of offering family presence during resuscitation (FPDR). It is designed for use by physicians, nurses, allied health staff and administrators creating institutional policy in this evolving area of health care. Several organizations have published statements in support of FPDR (1-7). In light of recent evidence regarding this important issue (see accompanying systematic review), we have developed a position paper on behalf of the Canadian Critical Care Society to guide clinicians and institutions in their decisions regarding whether to offer FPDR, and how to effectively implement this component of family-centred critical care into their clinical practice.

EVIDENCE FOR POSITION STATEMENT

FPDR has been studied in both the pediatric and adult populations. We have summarized the existing evidence for FPDR in the accompanying systematic review. Herein, we present a summary of the literature regarding patient, family and health care provider perspectives on FPDR, and an ethical assessment of the practice. We also provide suggestions regarding how to implement FPDR in the Canadian setting, including which family members should be offered the opportunity to be present; how to select chaperones to

La présence de la famille pendant la réanimation : un document de principes de la Société canadienne de soins intensifs

HISTORIQUE : Selon de récentes données, la présence de la famille pendant la réanimation (PFPR) n'influe pas sur le sort des patients, et les résultats psychologiques sont neutres ou plus positifs chez les membres de la famille des patients adultes. Il faudrait donc réévaluer la pratique d'exclure les membres de la famille de la zone de réanimation.

OBJECTIF : Le présent document de principes de la Société canadienne de soins intensifs vise à aider les cliniciens et les établissements à décider d'intégrer ou non la PFPR à leur protocole clinique habituel et à offrir des stratégies pour en réussir l'implantation.

MÉTHODOLOGIE : Les auteurs ont réalisé une analyse bibliographique sur les points de vue des dispensateurs de soins, des patients et des familles à l'égard de la PFPR et ont envisagé les valeurs éthiques pertinentes de bienfaisance, de non-maléfisance, d'autonomie et de justice à la lumière des données cliniques sur la PFPR. Ils ont examiné les essais aléatoires et contrôlés et les études d'observation sur la PFPR afin de déterminer les stratégies utilisées pour dépister les membres de la famille, sélectionner des chaperons pertinents et former le personnel.

RÉSULTATS : La PFPR est une pratique solide sur le plan éthique au Canada. On peut l'envisager en milieu hospitalier pour les familles de patients d'âge adulte ou pédiatrique. Les hôpitaux qui choisissent d'adopter la PFPR devraient établir clairement quels membres de la famille sont autorisés à assister à la réanimation. Des chaperons expérimentés devraient accompagner et soutenir les membres de la famille dans la zone de réanimation. Les dispensateurs de soins qui profitent de formations intensives et qui sont plus exposés à la PFPR soutiennent davantage cette pratique.

CONCLUSIONS : La PFPR devrait être considérée comme un aspect important des soins axés sur le patient et la famille.

accompany the family; and how to educate staff about FPDR. These recommendations are derived from the randomized controlled trials (RCTs) and observational studies identified in the systematic review because we were unable to locate any evidence-based strategies on how to implement FPDR.

PERSPECTIVES ON FPDR

Health care providers

Many studies have investigated the perspectives of health care providers on FPDR in adult patients. In general, physicians tend to be more reluctant to support FPDR than nurses (8,9). In studies in which physicians opposed the practice, the most commonly cited concerns were that the presence of family members would affect the quality of resuscitation; that family members may experience psychological trauma; and the possibility of medicolegal repercussions (8,10-12). However, in many studies, physicians were supportive (13-18), especially with rising seniority (19,20) or experience with FPDR (9,21,22). Support for FPDR may be, in part, culturally based, with marked variation among studies from different regions of the world (11,23,24).

The majority of studies examining nursing perspectives found nurses to be in favour of having families present during resuscitation,

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often regarding it an issue of patient advocacy (13,14,16,18,20,25-33). The few studies in which nurses have been reluctant to implement FPDR have been conducted outside the North American setting (10,11,34,35). Emergency medical services workers, the only allied health group investigated, were found in a single study to be critical about FPDR, citing concerns about family interference and feeling “threatened” by their presence (36).

In the pediatric setting, physicians were generally more supportive of FPDR and invasive procedures (37-44). FPDR has been a well-established practice in Canada and the United States in the pediatric realm and, thus, most studies in which physicians were opposed to family presence were conducted outside of North America (45-50). Almost all studies investigating nursing attitudes toward FPDR in pediatrics were supportive of the practice, especially in the intensive care unit (38,39,42,43,51,52). All pediatric studies finding nurses to be against the procedure were conducted outside of North America (46,50).

Family members

Overall, family members are supportive of FPDR in adult and pediatric patients (11,16,20,48,53-66). Even families who would not want to be present often believe they should at least be given the option (20,54,61). A common theme was that it was a ‘right’ for family members to be present, especially during pediatric resuscitations (47,54,63). We were unable to locate studies in which family members did not support the practice. Studies conducted outside of North America similarly found broad support from family members for FPDR. This suggests families of different cultural backgrounds also often want to be offered this opportunity. Two studies found that families understand the need for physician and nurse discretion to ensure quality resuscitation for the patient (57,65). One study highlighted that family members would want guidance from a health care provider while present during resuscitation (67).

Patients

Studies in which survivors of resuscitation were asked what their preferences regarding FPDR would be all found that survivors were generally supportive (9,14,20,68-71). One study that included inpatients who had not undergone resuscitation also found this group to be generally supportive. However, approximately one in five patients did not want a family member present, and preferred to have only certain close family members nearby (69,70). There is, thus, a need for discretion in who participates in FPDR and for advanced directives, where possible (69). Patients were also aware that health care teams may need to exercise discretion in which, if any, family members may be present (71).

ETHICAL CONSIDERATIONS

Resuscitation is a critical time in the lives of patients and families. There are important ethical considerations in the decision to include or exclude families from a resuscitation. We have used the four overarching ethical principles described by Beauchamps and Childress (72) to analyze the ethics of FPDR from the point of view of the patient, family and health care team.

Nonmaleficence (do no harm)

Given the high acuity and mortality of patients undergoing resuscitation, and that the fiduciary responsibility of the physician and nurse is first toward the patient, a prerequisite for FPDR is that it causes no harm to the patient. Any significant benefits to the family, the care providers or the institutions as a result of FPDR must be secondary to any risks it poses to the patient undergoing resuscitation. Risks to the patient can include the early termination of resuscitation due to family member distress or direct interference by the family with the health care team’s resuscitation efforts. As noted above, these are the usual concerns voiced by health care providers who are wary of introducing a family member to an already chaotic environment (8,10,12,73). Although one RCT investigating simulated cardiac arrest showed increased time until the first shock is delivered with

family member presence (74), a recent meta-analysis of several trials shows no evidence that family presence affects patient mortality or resuscitation quality (75-79). Other studies have, similarly, not been able to demonstrate any detrimental effects of parental presence during invasive procedures in the pediatric setting (38,80). There are instances in which the health care team should exercise discretion in allowing family presence, for instance if family members are intoxicated, physically abusive, or have other signs that their presence will be disruptive and harmful (81). However, because such instances are infrequent, they are not sufficient to justify exclusion of family members as the default option during resuscitation.

Beneficence (do good)

The principle of beneficence directs health care providers to do as much good as possible. Traditionally, a physician’s fiduciary responsibility is toward the patient; however, as a health care provider, the goal should be to do the most good as possible for patients and their families. In the absence of harm to the patient, the principle of beneficence states we should support family members if possible. Some ethicists have argued that the chances for survival during cardiopulmonary resuscitation are so low that the well-being of family members should be a priority during the resuscitation (82). Thus, family members witnessing resuscitation should be properly supported if they exercise the option to be present, to avoid excessive shock, and to allow them to focus on their loved one and during what may be their last moments together as a family. These interventions constitute beneficent, family-centred care (83,84).

Respect for persons (autonomy)

Birth and death are poignant and personal life events. Patients and families should, therefore, have as much autonomy as possible in matters concerning them. Denying a family member the right to see their loved one in the moments before death, or allowing a patient to die without a loved one nearby if that was their wish, contravenes the principle of autonomy. Debates similar to those raised by FPDR were made in the past about paternal presence during childbirth, now a common accepted practice (85). Although evidence suggests that for many families, FPDR may be beneficial, there are published anecdotes of traumatic recollections (86). Therefore, as with any medical intervention in which there are potential risks and benefits, the autonomy of those affected – in this case, the patient’s family – should be respected. FPDR may be offered, but should never be mandated for families irrespective of any demonstrated benefits.

Justice (fair distribution of resources)

The principle of justice encourages us to ensure that all people have equal, reasonable access to health care and social resources. Justice suggests that we should strive for equal access to interventions such as FPDR. Studies investigating FPDR indicate more family members would accept the offer to be present than currently request it (75-78). Currently, only family members with the confidence to ask health care providers if they can be present during resuscitation will have the opportunity to be present. By systematically offering FPDR, health care providers can help to correct this inequity.

A major concern of some practitioners is that FPDR could lead to increased litigation because families may misinterpret resuscitation efforts as being substandard. This has not been demonstrated in the largest RCT to date, which included >500 patients (75). The legal risks to health care providers of FPDR, although a regular source of worry, are small, and should lessen as FPDR becomes routine practice (1-3,7,87,88).

Should FPDR be offered to families of adult patients?

We suggest that it is reasonable for clinicians to offer families the option to be present during resuscitation of adult patients in the emergency department, ward or intensive care unit (ICU) setting. Our suggestion is based on weighing the risks and benefits of FPDR, potential costs, as well the ethical principles of autonomy and justice.

The systematic offering of FPDR is consistent with the principle of autonomy, and improves the equity of patient care by empowering family members to be present during a critical moment in the life of their loved one. Furthermore, there is moderate quality evidence that offering family presence results in no harm to patients undergoing resuscitation, and may result in a modest reduction of symptoms of anxiety and post-traumatic stress disorder in family members. In summary, FPDR may be used safely and effectively to provide family-centered care in the emergency room, ward or ICU setting.

Should FPDR be offered to families of pediatric patients?

We suggest that it is reasonable for clinicians to offer families the option to be present during resuscitation of pediatric patients in the emergency department, ward or ICU setting. Our suggestion is based on weighing the risks and benefits of FPDR, potential costs, as well as ethical consideration of the principles of autonomy and justice. The systematic offering of FPDR is consistent with the principle of autonomy, and improves the equity of patient care by empowering family members to be present during a critical moment in the life of a child. Our suggestion is based on the low-quality evidence of minimal harm of family presence to children undergoing resuscitation. Although no studies quantitatively assessed long-term benefits to parents or children of FPDR, multiple observational studies suggest that parents who have witnessed resuscitation have found it to be beneficial and would recommend it to other parents. In the absence of demonstrated risk to patients, and clear, nearly universal preferences of parents to be present, the exclusion of family members cannot be justified as the default option during resuscitation. Such concerns are even more important in the pediatric than the adult setting because parents are usually the substitute decision makers on behalf of their children and closer access can facilitate more informed decision making. Thus, despite the weaker evidence to support the practice than in the adult population, we still suggest FPDR in pediatrics can be a valuable element of patient-centred care.

Selection of appropriate family members for FPDR

A common concern of health care providers is that family members may interfere with resuscitation efforts. Some family members also share this concern (20,59). All of the major trials in adult and pediatric populations involved screening to detect disruptive family members. With such screening efforts, the presence of disruptive family members is rare, occurring in <1% of resuscitations (75,77,79).

Before admitting a family to the trauma bay, Dudley et al (77) screened family members and excluded those who exhibited "disruptive behaviour," defined as "...violent behavior, loss of self-control, extremely loud voices, concern for influence of alcohol or drugs, or inability to comply with the [institutional policies for] family presence." Only two family members were permitted at a time. Similarly, in the study by O'Connell et al (79), screening was performed in family members of a pediatric trauma population.

Screening procedures were also used in the only available three adult FPDR trials. Jabre et al (75) allowed only a "reasonable number" of family members into the resuscitation, to be escorted out if they displayed "aggressive or agitated behaviour". Family members were only allowed in once endotracheal intubation and central venous catheter insertion had been performed. Holzhauser et al (78) had specific inclusion criteria for FPDR: participants must be immediate family/significant other, >18 years of age and nondisruptive to the resuscitation. Robinson et al (76) selected one family member who had accompanied the patient to the emergency room, but did otherwise not specify any inclusion/exclusion criteria.

The role of a trained support person

All three of the RCTs evaluating FPDR in adults, as well as both the RCT and observational study evaluating FPDR in pediatrics, integrated a trained support worker: a nurse (20,76,78,79), physician (76), social worker (77,79) or spiritual care provider (20,76,79). Most FPDR programs described in the literature had a similar policy

(20,76,78,79,89). Retrospective studies of family members are also supportive of having a chaperone (59). Identifying a dedicated chaperone may also increase staff comfort with FPDR (9).

Education of staff members

For FPDR to be safe and effective, the studies included in our review suggested that all staff members involved in the resuscitation efforts were aware of the practice. Feagan and Fisher (90) found that an educational intervention consisting of a 40 min presentation followed by discussion was effective at increasing both nurses' and physicians' support for FPDR. Pye et al (91) found that simulation training was effective at improving pediatric ICU nurse comfort with FPDR as well as crisis communication. Finally, Mian et al (92) conducted an intensive educational program, which improved staff attitudes toward FPDR. The intervention included a 1 h presentation reviewing the literature supporting FPDR, open discussion and a script that could be used to support families during the resuscitation. In the studies by both Pye et al (91) and Mian et al (92), the factor most associated with a favourable clinicians' attitude with FPDR was previous experience with FPDR. This suggests that following an educational intervention, routine rather than sporadic offering of FPDR can enhance clinician comfort with the practice.

Suggestions for the implementation of FPDR

Although no studies have directly compared strategies for implementing FPDR in the adult or pediatric settings, the studies that have evaluated FPDR versus usual care have systematically screened family members and provided them with trained chaperones for support. Based on this limited evidence, we make the following suggestions for how FPDR can be implemented. More research is still needed to clarify how FPDR can most effectively be implemented.

To facilitate the safe and effective implementation of FPDR, hospitals should develop policies regarding the practice in the emergency room, ward and ICU settings to provide consistent practice within institutions. Policies should outline which family members are eligible for FPDR (eg, spouse, first-degree relatives) and criteria to not offer FPDR (eg, aggressive behaviour, intoxication, etc). It is prudent to initiate such screening before bringing families to the resuscitation area while initial assessment and critical care interventions (eg, intubation) take place.

Departments in which FPDR is to be implemented should designate a skilled, senior member of the health care team (eg, physician, nurse or social worker) to screen for potentially disruptive family members and to act as a chaperone for the family. The chaperone should be able to brief family members, explain events during the resuscitation, provide comfort and escort the family member out if they show signs of distress. If an appropriate chaperone cannot be provided, or there are specific concerns that a family may interfere with resuscitation efforts in a way harmful to the patient or health care providers, family presence should not be offered.

There is no evidence to suggest that any one health professional is best suited to act as a family chaperone. However, all such personnel should have the experience and training to guide families through the resuscitation, including introducing the team, explaining the appearance of the patient (intubated, unconscious, etc), describing the medical procedures, translating basic medical terms and answering questions. They should also be able to provide comfort, recognize family distress and participate with the rest of the caregiving team in debriefing sessions following the resuscitation. For pediatric resuscitations, a child life specialist can be helpful to provide support for families, including young siblings who may be present.

Education interventions for health care workers should be in place to introduce the concept of FPDR because observational studies have shown that education and experience with FPDR is associated with increased support among care providers. A postresuscitation debrief with the health care staff can be an important part of the process to help deal with emotions and moral distress, and address any conflicts that may have occurred during the resuscitation.

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