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Should Family Presence Be Allowed During Cardiopulmonary Resuscitation?

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Introduction

Robert M. Sade, MD

Cardiopulmonary arrest is a common event in hospitals, occurring most frequently in emergency departments (EDs) and intensive care units (ICUs). They always cause a great deal of stress on physicians, nurses, and others who are nearby, and they require an immediate sequence of actions designed to reverse the adverse conditions to prevent death. Resuscitations are usually well-rehearsed ballets, with each successive intervention planned in advance, departing from the routine when circumstances demand a different pathway. Anything that distracts the mayday team from their total focus on the resuscitation may pose a danger to the patient. A distraught family member in the room during a cardiopulmonary resuscitation (CPR) imposes just such a distraction. Or so most physicians have believed in the past.

Some institutions have policies that encourage family presence (FP) during CPR in EDs and ICUs. The implications and results of such policies have been studied and reported in the medical literature over more than 20 years, often concluding that the benefits of the practice outweigh the harms. Despite this evidence, most surgeons believe that allowing family members to be present during CPR is a bad idea. The following hypothetical case was the focus of the debate that follows.

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The Case of the Spouse in the ICU

John Watson is 72 years old and was recently admitted to the hospital with decompensation of his chronic obstructive pulmonary disease. During this admission, he is found to have non-small cell carcinoma of the right lower lobe. He smoked a pack of cigarettes a day since age 17 until stopping several months ago when COPD limited his daily activities. John is referred to a thoracic surgeon, Dr. Sheryl Holmes. She explains the facts about his disease, describes alternative treatments, and recommends video-assisted thoracoscopic surgery (VATS) as the best alternative.

Dr. Holmes explains to the patient and his wife Dorothy that his COPD is severe enough that he will likely be on a ventilator for some time after surgery and he could become permanently ventilator dependent, depending on how extensive an operation is required. John initially refuses any operation, but Dorothy insists that he undergo the operation, as this is his only chance to remain alive. John ultimately agrees to the operation.

At surgery, the cancer proves to be too extensive for adequate access by VATS, so the procedure is converted to an open thoracotomy. After an extensive lung resection, John cannot be extubated, but remains hemodynamically stable. His oxygen requirement increases over the next few days and he is agitated and restless, requiring high doses of sedation. On the evening of his third postoperative day, Dorothy is with him when his agitation becomes much worse. After a brief period of bradycardia, his arterial monitor and EKG show flat lines. His nurse immediately appears in the room, assesses the situation instantaneously, and calls a mayday code.

His wife sees all this and is very frightened by the turn of events. As the mayday team arrives and continues the resuscitative efforts, Dorothy doesn't know whether to stay in the room or leave. The hospital does not have a policy about family members' presence during resuscitations, and when Dr. Holmes arrives a few minutes after the resuscitation efforts begin, she is not sure whether to allow the wife to stay or to insist that she leave. Should Dr. Holmes encourage Dorothy to stay in the room?

Pro

Karen Brasel, MD

Dr. Holmes should encourage the patient's wife to stay in the room, provided that appropriately trained support staff is available to accompany her, as described below.

Since unexpected severe illness and death predispose to complicated grief, one of our jobs as we care for these patients is to understand whether we can prevent or at least mitigate against this occurrence. Some things can be done to minimize the likelihood of complicated grief. One of the ways in which we may be able to mitigate the development of complicated grief is allowing families to be present during resuscitation efforts, both in the ED and in the ICU (this clearly does not apply to the operating room). The concept, or movement, began in earnest in 1982 at Foote Memorial Hospital in Michigan. By 1993 the Emergency Nurses Association endorsed a resolution allowing the option of FP during resuscitation, acknowledging several scenarios where such presence would not be appropriate—with

obviously intoxicated family members, families exhibiting overly aggressive behavior, and those that were obviously emotionally unstable.

So what do we know about FP during resuscitation, from institutions with a fair amount of experience? First, it is important to recognize that many of the studies are small, and that the issue is extremely emotional. Second, the majority of the data come from experiences in the ED or out of hospital resuscitation events, not the ICU. Although different environments, the likelihood is that patients, families and resuscitation events are more similar than different in these environments.

The Foote Memorial experience began with a survey of 18 families, 13 of which would have chosen to be present during resuscitation. A similar survey at Parkland Memorial Hospital found that 76% would have made the same choice if they had had the option. An overwhelming number believe that they should be allowed to make the decision, regardless of whether they would choose to be present or not. In a follow-up study from Foote Memorial, 94% of those families that chose to be present would make the same choice again. Everyone surveyed believed that the team responsible for care had done everything possible for their family member. This is extremely important to remember when addressing the concerns of healthcare workers considering a FP option^{1,2}.

During a resuscitation event, our primary concern is the patient. Given that resuscitation is often unsuccessful, the opinion of the patient can be difficult to ascertain. However, the limited information that is available from patients that had family members present during either invasive procedures or resuscitation attempts suggests that patients feel comforted, feel that healthcare workers are reminded of “personhood”, that their connection with their family was enhanced, and that their care was positively impacted. Of some concern is that patients who have been surveyed are unclear about which family member of loved one they would allow to be present. From an ethical decision-making standpoint, it is disingenuous to disallow families from being present because the patient has not made a determination about who they might want to be present, but to then immediately ask one of those same people to make surrogate decisions on behalf of that same patient after a partially successful resuscitation event.

In terms of tangible benefit, the Parkland survey, in which families had NOT been given the option to be present, found that 64% of families believed that if they had been present it would have eased their grief. 76% of families at Foote that WERE present did believe that it eased their grief. 60% of families at Parkland believed that their presence would have aided their dying family member; 64% of families at Foote believed their presence did aid their dying family member. These survey data come after implementation of a formal program, and should be weighed much more heavily than survey data that exist when the question about FP is asked in isolation or outside of a formal program; navigating a scenario such as a resuscitation event without a family facilitator would be daunting for even the most informed^{1,2}.

In addition to subjective survey data, we have objective data. Families randomized to be present at resuscitation at an institution in the UK had lower bereavement scores, using the

Texas Inventory of Grief, both 3 and perhaps more importantly 9 months after the resuscitation event. This evidence was felt to be so compelling to the clinicians that they no longer felt equipoise in not allowing FP, so the trial was stopped at the institution and the practice of FP adopted³. Furthermore, it has been adopted as a standard by the Emergency Nurses Association⁴, the American Academy of Pediatrics⁵, and the American Heart Association⁶.

More recently, Jabre et al randomized 570 relatives of patients undergoing CPR to FP or standard practice during out of hospital resuscitation. Standard practice, by EMS unit, was that the family member would be taken outside the home or to another room. Ninety days after resuscitation, a trained psychologist administered a structured questionnaire by phone. The intervention group had significantly fewer symptoms of PTSD (37 vs 27%, $p=0.01$) and anxiety (23 vs 15%, $p<0.001$) than the control group⁷. Follow-up at one year demonstrated that the control group had a higher rate of complicated grief (36 vs 21%, $p = 0.005$) and more major depressive episodes (31 vs 23%, $p = 0.02$)⁸.

After implementation of the FP program at Parkland the healthcare staff was surveyed about how comfortable they felt during FP and whether the program should continue. There was overwhelming support for continuation of the FP program. Importantly, 97% agreed that family behavior was appropriate. Equally important are the facts that no litigation has resulted from the implementation of a FP program, and that 100% of the families surveyed believed that everything appropriate was done for their family member.^{1,2}

There are several important steps in a FP program, including only the program itself, not all the preparation, education, and culture change necessary in many institutions before implementation. Successful programs require a designated support staff available at all times. This support staff can be a medical social worker, chaplain, or nurse, but must be specifically trained both about the amount of medical information to relay and to recognize the family response to the resuscitation events. This person first assesses the family to determine whether they would be appropriate candidates for FP. Sometimes this involves an independent decision, sometimes the family is asked. The providers are then asked whether FP is appropriate; a “no” decision is absolute. If family, support staff, and provider are in agreement the family is prepared for what they might see, are told where to stand, what to do if they feel faint, that they might be asked to leave at any time. During the resuscitation the role of the support staff is to explain interventions, interpret jargon, provide information about expected outcomes, supply comfort measures, give an opportunity to ask questions, and grant an opportunity to see, touch, and speak to the patient. Given the medical background of the support staff they might or might not be able to fulfill all of these responsibilities. Once the resuscitation is over, the support person remains with the family, providing support and an opportunity to ask questions. If appropriate, a bereavement protocol is implemented.

Given the proven benefits of FP programs, the stated desires of those who have been surveyed after participation in such a program, it is clear that greater efforts to allow the option of FP during resuscitation events should continue.

Con

John Entwistle, III, MD, PhD

Dr. Holmes should ask Mrs. Watson to leave the room out of respect for, and safety of, the patient.

When discussing FP, the setting is critical. Much of the FP literature concerns FP during procedures, in pediatric patients, or during pre-hospital/ED resuscitation. While FP may be beneficial in these settings, our scenario is very different. Likewise, any potential benefit from FP during withdrawal of care or a natural death is not applicable. In the scenario above, Mr. Watson is elderly with a chronic illness and suffers an arrest in the ICU. The discussion on family presence during resuscitation (FPDR) in a chronically ill ICU patient needs to focus on this type of patient, using literature specific to this scenario when possible.

Our first and foremost responsibility is to the patient, even in this era of family-centered care. This is so paramount that, except for specific circumstances, we cannot discuss the care of our patient with family members without permission. This responsibility begins at first contact with the patient or their protected information, and extends beyond death. The FPDR movement has focused on the potential benefits to the family, but has largely ignored the wishes and safety of the patient. In fact, position statements by the Emergency Nurses Association⁴ and America Heart Association⁶ promoting FPDR do not address the wishes or consent of the patient.

FPDR has been touted as “evidence-based medicine”. However, there is very little strong data to support FPDR, especially outside of the ED setting, and much of the evidence used does not focus on the patient population treated by most cardiothoracic surgeons – elderly patients with chronic disease. Three of the often-quoted studies are examples of how studies with significant methodological weaknesses have been used to promote FPDR. In the seminal study by Doyle et al.⁹, they conclude that 94% of family members who witnessed an arrest would wish to be present again. However, this was based on only 47 returned, completed surveys and does not include surveys returned blank (3) or not returned (23). Further, 11% of the respondents felt that too much was done in the efforts to resuscitate the patient. This point is not addressed by proponents of FPDR. The study by Robinson et al.¹⁰ looked at the psychological impact on those offered an opportunity for FPDR compared to those who were not. This under-powered, pilot study showed no difference in psychological outcome to family members (contradicting the putative benefits of FPDR), and the conclusions were based on only 13 family members who were studied at the 9-month follow-up point. In addition, the study was halted prematurely due to biases in the staff favoring FP which threatened to interfere with the randomization process. Finally, Eichhorn et al.¹¹ reported on interviews following FP. Despite being widely quoted in the FPDR literature, this study focused on patients undergoing invasive procedures, and included only one patient who had survived resuscitation. Interestingly, this patient did not remember that his wife was present during the code, underscoring that FPDR offers no benefit to the patient. These three studies, which are frequently cited to support FPDR throughout all areas of the hospital, are small, have significant limitations, and looked only at resuscitations in

the ED. In total, they involved fewer than 70 family members, and only included one patient, yet have been used by proponents of FPDR to espouse the benefits in all situations.

More recent literature on FPDR is not significantly better. Much of the data focuses on patients in the ED. There remains very little data that is specific to adult ICU patients with chronic illness. The literature that does look at this population is often obtained by surveying health care providers, and relatively little looks at the views of the patient. Yet, it is precisely this view that we need if we are to respect the needs of our patients. Finally, hospitals that permit FPDR require the presence of a family facilitator, a person trained to shepherd the family through the resuscitation process. Yet, no study has looked to see if the benefits the family may perceive from FPDR are due to the family facilitator alone or the FPDR itself.

Prime time television has a large impact on the public perception of resuscitation, where most resuscitations are in young trauma patients, and have a high rate of survival¹². With this positive view, and the normalization of being a bystander during aggressive medical treatment that television provides, it is not surprising that the public perceives FPDR as a right. However, patients are much less likely to desire FP than their family members, and only 29% of patients undergoing cardiac or major vascular surgery desire FPDR¹³. In preparing for this debate, I did a small informal poll of medical professionals on this topic. When asked “Would you want your family present if you were being coded?”, the answer was uniformly “no”. The few studies that have asked this question have returned similar results. When health care providers are asked what they would want if they were the patient or the family member, most do not want FPDR^{14,15}. This speaks volumes when those familiar with real world codes would not put their family members in that situation. Remembering that our duty is to the patient, we are violating the trust of the patient by permitting FPDR without prior patient approval.

The potential for harm to the patient is real. Helmer et al.¹⁶ argue that the resuscitation room should be treated like the cockpit of an airliner – there should be minimum chance for interruption during a life-or-death situation. FPDR leads to increased stress of the health care providers, inhibits the opportunity for teaching and limits open communication during the resuscitation. In a study of simulated codes, the presence of a disruptive family member led to a delay in delivering the first shock and fewer total shocks delivered¹⁷. This is critical since disruption cannot be accurately predicted and defibrillation is a cornerstone of successful resuscitation. In a study of nearly 42,000 in-hospital arrests, patients in hospitals with a FPDR policy had greater delays in obtaining vascular and airway access, more medication errors and more frequent severe delays in defibrillation¹⁸. The evidence of potential harm to the patient from FPDR is real and needs to be studied further before touting FPDR is safe.

There are several ethical issues that have not been addressed in the FPDR literature that further bring in to doubt the appropriateness of this movement. Given that a physician’s responsibility is to the patient, and that most cardiovascular patients do not want FPDR, it seems questionable to assume the opposite and encourage FPDR without prior evidence of patient agreement. Presuming consent violates the patient’s right to autonomy. Patient confidentiality is also a potential issue. Surveys that have looked at this issue have been very

small and minimize the concern. However, when dealing with larger numbers of patients, we will be faced with a situation where the family members do not know about a malignancy, infectious disease, drug habit or other potentially devastating medical or social issue that our patients trust us to keep confidential. The inappropriate release of information is even bigger if the family member is estranged, or is not even a true relative – difficult issues to try to sort out during a code.

Screening families quickly for FPDR has the potential for bias. Some families will be screened out due to misconceptions or biases of the screener. To date, no study has rigorously looked at why some families are felt to be appropriate for FPDR while others are not. Some FPDR policies expressly prohibit families who do not speak English. While this may avoid interruption of the code and misinterpretation of information, it is not ethically sound to exclude one group based on their native language.

Finally, what are the legal or ethical implications if a family member is injured or exposed to blood-borne pathogens during FPDR? Code situations are often chaotic and involve many people working simultaneously, often with sharp objects. There is potential for a needle to be left in the bed or on the floor, or for bodily fluids to be scattered. Health care providers accept this risk, but family members have not been adequately informed of potential risks, do not have the requisite knowledge to protect themselves, and may be at higher risk for exposure as a result. Despite this, some FPDR policies allow for the family member to come to the bedside and talk to or touch the patient during the resuscitation. In the unlikely event of exposure or injury, we would bear some ethical responsibility for the outcome.

For this case, we can assume that Mr. Holmes would not agree to FPDR if asked before his unfortunate event — he only agreed to surgery at the urging of his wife, and he fits into the demographic that is less likely to desire FPDR. Further, our duty is to the patient, and the evidence on the effectiveness of resuscitation with FP suggests that there is increased potential for harm or significant delays. The only responsible action is for Dr. Holmes to ask Mrs. Watson to leave the room.

Concluding Remarks

Robert M. Sade, MD

Most surgeons would shrink in horror from the idea of family members being present in the operating room during a surgical procedure on their loved one. That attitude extends to most other situations in which bodily invasion occurs, such as CPR in ICUs. Yet, evidence is accumulating that suggests it may be time to reconsider this attitude.

Brasel has presented a persuasive case that family presence during resuscitations should be permitted. Entwistle has argued convincingly that family presence should not be allowed. Both essayists have access to the same literature, and, as might be expected, both chose to cite studies that support their respective positions or criticize those that oppose them. Both admit that the evidence is not of high quality, but, using the evidentiary standard of preponderance of evidence, Brasel finds that the quality of evidence is reliable enough and

its consistency is good enough to support a permissive FPDR policy, while for Entwistle, the evidence is very weak and the reasons to oppose the policy outweigh those that support it.

Much of the evidence regarding this practice is derived from opinion surveys of patients, their families, and health professionals. Surveys are notoriously unreliable in predicting what people actually will do when confronted with the hypothesized situation in reality. Entwistle correctly, in my opinion, points out that in health care, population or group statistics have little bearing on what should be done for an individual patient whose voice alone should determine what is done. Very few patients are asked in advance whether they would like family members to be present in case of a cardiopulmonary arrest. During resuscitation, a great deal of private information and bodily exposure may be revealed to those present in the room. Whether the patient wants all or any particular family member to be privy to that information and exposure is rarely known at the time of the event.

Federal regulations protect patients' privacy by prohibiting release of private information without the patient's agreement. The regulations provide an exception, however, in emergency situations: any or all of the patient's private information can be disclosed if it is "in the individual's best interest as determined by the covered health care provider, in the exercise of professional judgment."¹⁹ Whether a particular patient benefits from a family member's presence is difficult to discern, yet the criterion in law is the patient's best interest. A family member's presence might be good for the family, but whether it serves the best interest of the patient will be an extremely difficult judgment to make.

Ethically, confidentiality and privacy have always been crucially important and even more restrictive than federal regulations, from Hippocratic antiquity ("*What I may see or hear in the course of the treatment or even outside of the treatment in regard to the life of men, which on no account one must spread abroad, I will keep to myself, holding such things shameful to be spoken about*")²⁰ to the contemporary era ("*The physician should not reveal confidential communications or information without the consent of the patient, unless provided for by law or by the need to protect the welfare of the individual or the public interest*").²¹ Exceptions to the obligation to protect confidentiality and privacy — beyond protection of the patient or others — are rare in ethical discourse.

Thus, we have circled back at the original problem: should FPDR be allowed? If it is permitted, specific guidelines should be documented in a written policy that provides several constraints, as Brasel has enumerated. Trained support staff designated to accompany family members must be available and present at all times during the resuscitation, and must be available to continue to provide support and answer questions after the event. The patient's caregivers must have absolute veto power on family presence. In addition to those constraints, however, the most difficult requirement is that the person responsible for making the decision about whether to offer the option of FPDR to the family must know the patient well enough to be able to judge with reasonable accuracy whether the patient would want family presence or not. Given the importance of confidentiality and privacy, the principles of ethics and the requirements of law suggest that any FPDR policy should state explicitly that when such a subtle and delicate judgment cannot be made with confidence, the default decision should be not to offer FPDR.

If a policy to allow FPDR is adopted, these requirements should be strictly observed, given the paramount importance of confidentiality and privacy protection. It seems likely to me that if these constraints are observed, few circumstances will permit a family member to be present during resuscitation. The question at the outset of this debate was whether family members should be allowed to observe resuscitations. The weight of evidence does not help very much, as the point-counterpoint of Brasel and Entwistle attests. When deliberating on whether to pursue such a policy, hospital policy makers should consider both sides of this argument with care; there is much to weigh in the balance.

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