Family Presence During Resuscitation: Attitudes of Yale-New Haven Hospital Staff

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Introduction: A novel paradigm of patient- and family-centered care has been promoted and adopted by many parties in the United States. This new attitude emphasizes the role of the family in the care of the patient. One topic that should be affected by the new paradigm is family presence during resuscitation, which continues to be a highly debatable topic with no widespread implementation. The objective of this study was to assess the attitudes of Yale Emergency Department (ED\textsuperscript{†}) health care personnel toward Family Presence during Resuscitation (FPDR).

Materials and Methods: In 2012, we surveyed 100 health care professionals in the Yale-New Haven Hospital ED, including physicians, nurses, technicians, social workers, and chaplains. One researcher analyzed the qualitative data, and both researchers reviewed the results to increase internal validity.

Results: Seventy-seven percent of staff members favored allowing the option of FPDR. Seventy-six percent of staff members believed that family members would want to be present during their loved one’s resuscitation.

Conclusion: Given scientific evidence to support FPDR and the staff’s wide acceptance of it, we recommend drafting and implementing a protocol for allowing FPDR. The protocol should be individualized to the Yale-New Haven Hospital ED setting.

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\textsuperscript{†}Abbreviations: FPDR, Family Presence During Resuscitation; ED, Emergency Department.

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INTRODUCTION

In recent years, a novel health care paradigm has been put forward in the United States by various parties [1,2], including President Obama [3]. This paradigm has been designated patient- and family-centered care, to express the extent to which health care professionals should recognize the key role that patients’ families play in the care of patients. In a sense, this new paradigm makes the Hippocratic Oath, which considers neither the patient’s autonomy nor the patient’s family, obsolete [4].

A recent report by The Joint Commission lays out general principles that American hospitals should follow in order to provide the most optimal health care according to the new paradigm. Even though the report does not mention the issue of Family Presence During Resuscitation (FPDR), among its recommendations is to “[a]llow family to participate in end-of-life care by providing comfort during the dying process by touching, talking, playing favorite music, or participating in care activities such as washing” and “[a]llow the patient access to the support person at all times” [1]. Similarly, both Kovacs et al. and Meeker and Jezewski review the literature on palliative care and advocate for a family-centered care approach in acute care as well as palliative care [2,5].

At Yale-New Haven Children’s Hospital, patient- and family-centered care has been adopted, advocating for concepts such as dignity and respect, information sharing, collaboration, and, most importantly, participation of family members in rounds, decision making, and advisory councils [6]. However, in the Yale-New Haven Emergency Department (ED), it seems that such an approach has not been adopted yet, at least regarding family presence during resuscitation, since there is no protocol for allowing FPDR and it is not to a common practice.

FPDR in adults as an ethical dilemma and a practical guideline has been much explored and debated over the last 2 decades, spanning various professions and societies around the globe [7-19]. Many organizations advocate for allowing the option of FPDR, including the American Heart Association [20], the UK Resuscitation Council [21,22], The Royal College of Nursing [23], the American Association of Critical Care Nurses [24], the Emergency Nurses Association [25], the European Federation of Critical Care Nursing Association, the European Society of Paediatric and Neonatal Intensive Care, and the European Society of Cardiology Council on Cardiovascular Nursing [26]. Most of the arguments against allowing the option of FPDR have not been substantiated by the scientific literature. For instance, one such argument warns that FPDR might cause increased emotional stress to the medical staff. While one recent study demonstrated that FPDR negatively affected the number of electrical shocks given by residents during medical simulation [27], most studies rebutted that claim [20,28-30]. Despite the recent publication of a large randomized controlled study that concluded in favor of FPDR [31], many claim that a scarcity of double-blinded randomized controlled studies renders the debate still open for discussion [32]. In the current study, we sought to assess the attitudes of health care professionals working in the Yale New Haven Hospital ED toward FPDR.

MATERIALS AND METHODS

A questionnaire was adapted from Wacht [33,34] and modified by the authors after review of the literature. The questionnaire is anonymous and consists of open-ended questions, multiple-choice questions, and statements that need to be confirmed or negated by a Likert Scale of 1 (“completely disagree”) to 5 (“completely agree”). A pilot study of n = 5 was conducted at the Pittsburgh Presbyterian Hospital in order to assess face validity, meaning the extent to which participants deemed the survey appropriate for its proclaimed purpose. Face validity was 100 percent. In 2012, once the study was approved by the Yale Human Investigation Committee, the questionnaire was sent via email to all 42 Yale ED faculty members, 37 of whom responded (88 per-
cent response rate). Then the nursing team at the ED was asked by team leaders to fill out the computer-based questionnaire during their shifts. One social worker, one chaplain, one physician assistant, and 60 nurses were asked to participate in the survey (100 percent response rate). Overall, the study includes 100 participants (n = 100).

Here we provide and analyze the qualitative responses. There were four open-ended items:

1. If you believe that family members should be present during their loved one’s CPR, could you specify why? Leaving this space blank means that you believe that family members should not be present.
2. If you believe that family members would want to be present during their loved one’s CPR, could you specify why? Leaving this space blank means that you believe that family members would not want to be present.
3. Please elaborate on one or more of the questions/statements above.
4. Please share any of your personal experiences relevant to the issue at hand.

As Bradley et al. [35] and Folkestad [36] maintain, there is no single appropriate way to conduct qualitative data analysis. Following their discussion, we assigned one researcher for data analysis, while both researchers reviewed the analysis in order to increase internal (inter-observer) validity. We place our study within the Naturalistic/Positivistic paradigm with the goal of identifying recurrent themes explicit in the participants’ replies. The analysis was conducted according to the following steps:

1. Reading for overall understanding.
2. Coding qualitative data. In the first two questions, data were coded first into four categories: in opposition to FPDR, in favor of FPDR, undecided, and no response (which, in this specific case, meant opposing FPDR). Consequently, an integrated approach (i.e., both inductive and deductive) was used to identify themes within each category. Where we felt it appropriate, quotes were often used either to describe or exemplify a theme.
3. Applying the finalized code structure. After review of the analysis by the two researchers, both convened to resolve any discrepancies and arrive to a consensus.

RESULTS

First item: If you believe that family members should be present during their loved one’s CPR, could you specify why? Leaving this space blank means that you believe that family members should not be present.

Fifteen subjects did not reply to this question, suggesting that they opposed the option of FPDR. Of the 85 who responded, four were undecided, four argued against allowing the option, and 77 were in favor of allowing the option of FPDR. Table 1 summarizes the replies to the first item.

Second item: If you believe that family members would want to be present during their loved one’s CPR, could you specify why? Leaving this space blank means that you believe that family members would not want to be present.

Fourteen participants did not respond, suggesting that they believed family members would not want to be present. Of the 86 who responded, seven maintained that it depends on the family or did not give a direct reply, three argued that family members would not want to be present, and 76 believed that family members would wish to be present. Table 2 summarizes the responses to the second item.

Third item: Please elaborate on one or more of the question/statements above.

The following themes arise:

1. One question in the survey asked whether the participants believe that FPDR will motivate the staff to view and treat the patient in a more humane manner. Some participants disagreed with the implication, claiming that they do not require motivation: “[p]hysicians don’t need motivation. It is already present.” One participant claimed that
Table 1. Replies to first item: If you believe that family members should be present during their loved one’s CPR, could you specify why?

| Arguments articulated by those undecided | Arguments articulated by participants who opposed FPDR | Arguments articulated by those who favored FPDR |
|------------------------------------------|-----------------------------------------------------|-----------------------------------------------|
| Lack of personal experience required to make a decision. | Witnessing CPR will be an emotional burden on the family: “…seeing and hearing the compression being performed will stay with them, forever.” | For the well-being of the family. As long as it does not impede care, and as long some staff member accompanies the family, it facilitates acceptance, helps with the grieving process, and provides emotional closure. Family members see that everything possible was done for their loved one. FPDR might improve relationships of family members with providers and among themselves. By including family in decision-making, “[i]t is a more family centered approach.” |
| Whether to allow FPDR should be family dependent: “Some families can handle the sights and sounds while other cannot.” | Family members may get in the way and ask questions during inappropriate times. | While it should be emphasized that it is not the family’s obligation, it is the family’s right: “…health care providers would need an affirmative justification for excluding family members.” |
| “May be more difficult if you are just going to call the code without having done much in a case of someone brought to the ED w/o signs of life.” | | FPDR is recommended and supported by the medical literature and official guidelines. |
| Provider related: Might hurt trainees. Inhibits providers from openly discussing their thoughts and “decompress stress with frank remarks or humor.” Might negatively affect care of other patients, “the entire ED will suffer if someone is pulled from another assignment …” | | Personal experience has shown FPDR is beneficial for both staff and family members. |
| | | The Golden Rule: “[w]e should treat everyone as we would want to be treated if we were the patient or family member.” |
| | | For the good of the patient: ”[s]eeing a loved one at the bedside or hearing them will let the patient know that someone they know is there with them, rather than having 20 strangers in the room.” Witnessing CPR, family members might be inclined to request to cease CPR, thus ensuring their loved one is not suffering. |
| | | Improves care: “… helps staff to be more professional and see that this is someone’s loved one.” |
| | | For religious/spiritual reasons: ”[i]t is human nature for family members to be attached to one another … the moments leading up to death should be as peaceful as possible, without invasive procedures, CPR, etc.” |

“[h]umanizing the patient during CPR may not be helpful if it interferes with clear decision-making by staff.” Conversely, some participants noted that FPDR will increase empathy and improve care: “… I feel motivated while family is present during CPR efforts. I think it is natural for us to want the best outcome and survival for all of our patients, but just seeing a family member gives me the extra drive.”

2. Some participants elaborated against allowing the option of FPDR, arguing that it may hamper communications, prevent staff members from speaking freely, and delay invasive procedures. One participant claimed that lack of physical space is a potential limitation, although there is always room for up to two family members. Some participants noted that family members might faint, suffer from panic attacks and post traumatic stress...
disorder, and verbally attack the staff, but most emphasized that this rarely happens and could be managed. One participant predicted that even though FPDR currently decreases legal liability, this trend will eventually reverse when people “will find that they can cash in by claiming to have witnessed or heard things during the resuscitation.”

3. Some participants elaborated in favor of allowing FPDR, arguing that it will reduce legal liability and allow complete transparency. Some suggested that FPDR will decrease the use of black humor, which is also beneficial to the patient undergoing CPR who might still be able to hear. Some participants also noted that FPDR will enhance the family’s trust in the medical staff.

4. Some participants emphasized that black humor, as a way for staff members to unwind during CPR, is not a valid argument to deny FPDR.

5. Many participants emphasized that having an accompanying staff member is essential for FPDR.

Table 2. Replies to the second item: If you believe that family members would want to be present during their loved one’s CPR, could you specify why?

| Arguments articulated by the participants who argued that family members would not want to be present | Arguments articulated by the participants who believed family members would want to be present |
|--------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------|
| “... it would be too traumatic to witness.”                                                     | So family members could see that everything possible was done in order to save their loved one and in order not to leave any questions unanswered. |
| “... it could be the last view the family member remembers of their loved one.”                 | To share last moments with loved ones, to have closure and say goodbye, and to facilitate acceptance of death. |
|                                                                                                 | It has been demonstrated by the literature or personal experience: “I have been present during resuscitation with family members in the room … I took the role of filling the family in with what was going on. Each time they told me that they were glad to have been there.” |
|                                                                                                 | To negate any feelings of guilt as a consequence of not being with the loved one during last moments. |
|                                                                                                 | It is considerate toward the patient: “I don’t believe that there are many people in the world who would want to die alone.” |
|                                                                                                 | Family members might feel that they make a difference by just being in the room. |
|                                                                                                 | It is a natural for relatives to be with their loved ones when they die. |
|                                                                                                 | So family members could provide valuable information regarding the patient and participate in decision-making. |
|                                                                                                 | To allow continuity of family and life. |

Fourth item: Please share any of your personal experiences relevant to the issue at hand.

1. “Witnessed CPR on a patient in ED last year. A nurse stood by the patient’s wife and explained what was happening. When appropriate, they brought her to the bedside and let her speak to her husband. She yelled at him not to leave her. The patient survived.”

2. “I do not have personal experience; however, the more we seek to make patients into customers and yield to their needs, the less academic medicine becomes. We be-
come a business, the business of medicine, in which patients dictate their care and direct us as to what is good for them and their families. The trouble is, patients don’t know what is good for them. We do, that is what we are trained for.”

3. “It has only been since the development of CPR and medical technology that we move more patients from the home and into a hospital setting away from their loved ones in their final moments. We need to provide better patient and family support and make it more like home.”

4. “I had a patient who was 40 years old and coded in the ER. We brought her husband back, and he kept telling her that he loved her and that she needed to stay for their children. She went to the cath lab and made a full recovery. She stated that she remembers most of the code and her husband being there, and I believe that is what helped keep her alive.”

5. “My mother passed away from metastatic breast cancer in 2008. I was able to be present with my two sisters during my mother’s passing and share in her care prior to her death. At the time, I did not understand or appreciate the magnitude of the experience. My sisters and I were able to begin our grieving process immediately, because we appreciated how truly sick our mother was and were involved with the hospice staff daily in caring for her. Though that experience was incredibly emotional, I would never want to take it away. It truly helped everyone to be able to say goodbye to my mother and be with her in her last moments. I am sure it was also a comfort to my mother to have us by her side.”

6. “I had a positive experience with family presence when there was a nurse that stayed with the patient’s wife for explanation. I believe that this was helpful for the wife.”

7. “During nursing school, I worked in a level 1 trauma center as a ‘patient representative.’ It was my responsibility to be at every adult and pediatric trauma and medical resuscitation to provide family support … whether that meant calling family to inform them their loved one was receiving treatment at our facility or to stand and hold their hand at the bedside. I frequently was called on my nursing staff to facilitate the family being at the bedside. Nursing staff was comfortable with the family being present, knowing there was someone tending to them. The hospital I currently work at does not provide a staff member with such a job description.”

8. “I often wish that I was present when I lost my brother traumatically. It’s been over 25 years, and I still have mixed feelings about it.”

9. “Again, most families are hysterical, and I find do not want to be there. In rare cases, they may and should be allowed. Many people have told me that they have been involved in end of life scenes and they wished they did not and could get those memories out of their mind.”

10. “I have experienced unrealistic expectations from family members during CPR. Specifically, I declared someone dead after 15 minutes of unsuccessful CPR, and the daughter insisted we continue and ‘bring him back like they do on TV.’”

11. “I have never had a bad experience by inviting or having the family members present at a code. In fact, I have had many family members thank me for involving them.”

DISCUSSION

The present study has several strengths and novelties. First, it offers a qualitative analysis of professionals’ attitudes toward FPDR. Most similar studies to date have mainly focused on quantitative data [11,18,37], and the few other qualitative studies have included far fewer subjects [34,37-39]. Some commentators have called for further qualitative research to enhance our understanding of health care providers’ dispositions toward FPDR [11,15,18,39,40]. According to a recent report commissioned by the National Institutes of Health, “[q]ualitative data help researchers understand processes … provide detailed information about setting or context, and emphasize the voices of participants through quotes” [41]. Further, the report’s authors claim that
“qualitative methods allow for identification of previously unknown processes, explanations of why and how phenomena occur, and the range of their effects” [41]. Accordingly, we believe that the qualitative data presented here might further elucidate the motives for supporting or opposing FPDR in a way that quantitative data could not. Such data might prove more useful than quantitative data in addressing concerns and producing solutions to problems that arise from a complex, multi-party dilemma such as FPDR. A telling example is the second response to the fourth item, in which the practitioner claims that accommodating patients’ needs contributes to the commodification of medicine. This is one argument against FPDR that we have not encountered before, and it requires further deliberation.

Second, the method used in this study has been more effective compared to others. While a major problem in paper-based quantitative surveys had been a relatively low response rate (roughly 42 to 80 percent), our response rate equals interview-based qualitative surveys (roughly 89 to 100 percent) [18,33,40] but with a greater number of subjects. Third, this study places the dilemma of FPDR within the context of the Family-Centered Care paradigm; to our knowledge, only few have done so previously [8,15,25,42-44]. Wide national and international adoption of such a paradigm is essential to improving health care in general and to facilitate acceptance of the practice of FPDR in particular. Fourth, the study focuses on adult FPDR in the ED. Other studies have compounded the data by including family presence during invasive procedures and in pediatric resuscitation and/or including other departments such as the intensive care unit [15,39,44,45].

Fifth, the present study detects significant differences between health care professionals at Yale New-Haven Hospital and elsewhere, showing much more tolerance for the practice of FPDR by the former. The majority of the Yale ED staff (77 percent) believed that family should be allowed to be present during a loved one’s resuscitation. The arguments mainly pertained to improving professionalism of staff members, care of the patient, and the well-being of the family. The right of relatives to be present was a major argument as well. Some based their opinion on the scientific literature. Those who were undecided or objected to FPDR argued that it might impede patient care, hurt trainees and other care providers, and emotionally traumatize the family. The majority (76 percent) also believed that relatives would want to be present during resuscitation. The reasons mainly pertained to the relatives’ need for closure and for feeling useful, as well as to their perceived ability to improve care by providing valuable information. These results differ greatly from other studies that report only slightly positive or even negative attitudes toward FPDR both in North America and elsewhere [12,13,15,18,34,45,46]. As a hospital affiliated with one of the leading medical schools in the country, it is important that staff members support and apply evidence-based practices and professional guidelines, setting an example for other institutions.

Considering the medical literature and various guidelines that support FPDR, as well as the Yale-New Haven ED medical team’s positive attitude toward it, we suggest drafting and implementing a protocol to allow FPDR. Helmer et al. warn that implementation of a FPDR protocol may result in conflict between trauma team members [47]. However, at least five hospitals in North America have reported their existing protocols to be efficient in yielding positive results once implemented: St. Luke Medical Center in Milwaukee, Wisconsin, [38]; St. Cloud Hospital in St. Cloud, Minnesota [8]; Parkland Hospital in Dallas, Texas [48]; Wooster Community Hospital in Ohio [29]; and Foote Hospital in Jackson, Michigan [30]. In all of these settings, health care professionals were first surveyed to assess attitudes toward FPDR. In follow-up surveys after the implementation of the protocols, both relatives and health care professionals reported greater satisfaction and more positive attitudes toward FPDR.

We believe that a protocol to allow FPDR should be individualized to the local
setting and written by local health care professionals, addressing population-specific values and needs. This will likely improve compliance by both relatives and health care professionals. Hanson et al. [30], Basol et al. [8], and the Royal College of Nursing [23] provide examples for such a protocol that could be used as a blueprint. In any case, it appears from this survey and the medical literature that two ground rules should be emphasized: 1) At least one staff member is required to accompany the family members and brief them before and during CPR about the specific care of their loved one (we would join Bradley et al. [49] and others [21] by also recommending post-event debriefing of both relatives and staff members); and 2) The option of FPDR should never be perceived and presented to relatives as their moral or social obligation, rather, it should be at their discretion [38].

Once implemented, a further study should be conducted in the Yale-New Haven ED in order to assess the success of the protocol and re-examine the staff’s attitudes toward FPDR. Other institutions around the world should conduct similar surveys to assess whether the time has come to make FPDR the default practice rather than a rare privilege of a few family members.

The study has at least two major limitations:

1. Taxonomy. Some replies with the same meaning were placed in different categories because their tone was different. For example, in responding to the first item, one subject wrote, “I think this should be individualized for each family. Some may not be able to handle the whole process and event.” Another wrote that “[d]epending on the family, I think that having family members at the bedside may be helpful. I think it’s important to have a designated staff member with the family for understandable explanations.” We included the former reply within the undecided category, while the latter was counted as being in favor of FPDR (interobserver validity was 100 percent).

2. Stratification. In this paper, we did not stratify the results according to profession, years of experience, etc. Rather, we focused solely on qualitative un-stratified data. While we lose longitudinal comparative data by this approach, we gain rich transversal data, as mentioned above.

CONCLUSION

The data suggest that most staff members in the Yale New-Haven Hospital ED favor FPDR, as long as there is a staff member to accompany the family. Given the scientific evidence in favor of FPDR and the staff’s approval of it, we recommend that a protocol for allowing FPDR be drafted and implemented in the ED. Such a protocol should be written by and individualized to the Yale-New Haven Hospital ED staff. Based on the literature, we recommend conducting similar surveys in emergency departments around the world and assessing whether individual protocols for FPDR are in order.

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