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10.1177/0969733020968171
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Family witnessed resuscitation and invasive procedures: Patient and family opinions

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Abstract

Background: Family presence during invasive procedures and cardiopulmonary resuscitation (FPDR) is a highly controversial issue, with divergence of opinion among health professionals, with clinical evidence in favor, and with barriers to its implementation in comprehensive patient care. Many international organizations support health policies for its implementation, but it is not a widespread practice. Little research has been conducted on this subject from the perspective of patients and families.[AQ3]
Objective: To learn opinions, perceptions, and desires of family members and patients in terms of family presence during invasive procedures and cardiopulmonary resuscitation.
Method: Qualitative descriptive study, using semi-structured interviews with relatives and patients regarding their experiences and perceptions about FPDR (n = 18) from 8 October 2017 to 8 March 2018. The interviews were recorded and transcribed verbatim for later analysis using the method of content analysis.
Ethical considerations: This study has the approval of the Clinical Research Ethics ~~Comittee~~ of the Fundació Unió Catalana d'Hospitals and ethical considerations were carefully regarded throughout the study.[AQ4]
Results: Three significant categories were identified: knowledge, respect for rights, and accompaniment of the patient, relating FPDR to courage, emotional support, and trust in professionals.
Conclusion: FPDR is an unusual practice; it is not offered to patients or their families, and it is not considered a patient's right, although most of the interviewees support it. The desire for accompaniment is conditioned by the courage and knowledge of the accompanying persons, as well as the degree of invasiveness of the procedures. The results of this study provide information for a change of vision in patient-centered care.[AQ5]

Keywords

Accompaniment, bioethics, family presence invasive procedures, family witnessed resuscitation, qualitative research, resuscitation

Introduction[AQ6]

Internationally, since the 1980s, family presence during resuscitation and invasive procedures (FPDR) has been a subject for controversial research, as it carries a high emotional burden for all the participants of the intervention and has ethical and moral implications.[1,2] FPDR is part of a new paradigm that focuses on

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respect for the patient's autonomy and on involving family in the decision-making process and the determination of care options, leaving aside the paternalistic approach, keeping the family in the patient's care area, where there can be eye or physical contact with the patient.[3] Family is understood as two or more people who are biologically, legally, or emotionally related.

Some studies on FPDR expose benefits and harms, assessing the approach of health professionals, patients, and families.[4–7] As positive aspects, the following can be highlighted: enabling a faster decision-making process, knowing at all times what is happening,[8,9] that the patient receives humane treatment,[10] that they have the right to presence during the interventions carried out on the patient,[2,8] while the disadvantages that were identified are that the medical team feels the pressure of the family; they feel observed and analyzed by the family members~~9,~~[11]~~,12~~; the interventions can turn out to be traumatic for the family, both physically and emotionally; ignorance and wrong interpretation of the invasive procedures (IPs) (blood, chaos, tubes, etc.)[8–10]; and a legal gap, there are no guidelines or implemented protocols.[2,12] In most of the conclusions of these studies, they recommend designing guidelines and protocols in this regard.[11–14] In their recommendations, the studies state that the guidelines should be individual for every hospital[15] but two important FPDR conditions must be fulfilled: the first one is that a family support person should be present to control the family reactions, act as a link between the healthcare staff and the family, translate the medical jargon, and explain the procedures.~~10,~~[16] It is noteworthy that the publications on the FPDR can vary widely depending on the culture, the religion, and the customs of the countries they come from.

There is a strong support for family accompaniment by healthcare teams in pediatrics, but not in adults.[17]

Numerous official medical and nursing organizations advocate the endorsement of FPDR, that is, the European Nursing Organization, the American Heart Association, and the European Resuscitation Council.[18–20] The World Health Organization (WHO) supports the integration of the family into the care of the patient, including it in the shared decision-making process.[21]

When IPs are performed, family members, due to custom or tradition, usually do not have the option of staying by the patient's side, especially in hospital care: they wait in a separate room to be told the results of these procedures. The family and patients, through the media, where different health procedures are shown, recognize these techniques, believing themselves to be familiar with them, although, as it appears in television series, they are not completely faithful to reality and may create false expectations in this regard.[22]

From an ethical point of view, hospital policies restricting FPDR should be rectified, and new protocols should be developed to enable admitting the family to these procedures, as the principle of patient's autonomy supports this.

In literature reviews, most of the studies found recommend FPDR, highlighting aspects that need to be addressed: the patient's own view, recommendations to carry out qualitative methodology studies related to the views of patients and families, and also education and training of healthcare professionals so that they can understand and adequately advise the accompanying family members.[5,23,24]

In this research, we explore the perceptions, opinions, and desires regarding family presence during cardiopulmonary resuscitation and/or IPs of patients and their families in our context.

Methodology

Study design

The study was carried out using an analytic qualitative design.

Population and sample

The participants were patients admitted to different care units of the Consorci Sanitari de l'Alt Penedès i Garraf, more specifically the Consorci Sanitari del Garraf,[25] who have been submitted to invasive

Table 1. Demographic characteristics of the participants.

Interview	Relationship	Gender	Age	Marital status	Children	Education	Job
1	Family	Woman	46–55	Married	No	Basic	Unemployed
2	Family	Man	46–65	Married	No	Medium	Employed
3	Family	Man	46–65	Married	Yes	Medium	Employed
4	Patient	Woman	>65	Married	Yes	Basic	Pensioner
5	Family	Man	46–55	Married	Yes	Higher	Unemployed
6	Patient	Man	>65	Others	No	Basic	Pensioner
7	Family	Woman	46–55	Others	No	Basic	Housework
8	Patient	Woman	>65	Widower	Yes	Basic	Pensioner
9	Patient	Man	>65	Married	Yes	Basic	Pensioner
10	Patient	Man	56–65	Married	No	Medium	Pensioner
11	Family	Man	56–65	Single	No	Higher	Employed
12	Family	Woman	56–65	Married	Yes	Basic	Housework
13	Family	Man	56–65	Married	No	Medium	Self-employed
14	Family	Woman	46–55	Married	Yes	Medium	Employed
15	Patient	Woman	>65	Sep./Div.	Yes	Higher	Self-employed
16	Family	Woman	>65	Married	Yes	Basic	Housework
17	Patient	Man	>65	Married	Yes	Basic	Pensioner
18	Patient	Man	56–65	Married	No	Medium	Self-employed

techniques or survived cardiopulmonary resuscitation (CPR) and their most direct relatives, between 8 October 2017 and 8 March 2018. Participants (n = 18) were recruited using purposive sampling; they participated voluntarily and anonymously. The care context of the participants was in sub-acute, convalescent, and long-stay units of the Hospital Sant Antoni Abat. Nineteen people were invited to participate in the study, of whom one refused.

The inclusion criteria consisted of the following: the subjects to be interviewed had to be autonomous in decision making at the time of participation in the study, over 18, and for patients over 65 years of age, a score of less than or equal to 2 errors is required on the Pfeiffer SPMSQ Scale (Short Portable Mental State Questionnaire).[26] This scale measures the cognitive impairment in patients older than 65 and it was adapted and validated for the Spanish language in 2001.

Eighteen people were interviewed, 8 of whom were women, 10 were family members and 8 were patients; 13 were married and 10 had children. The socio-demographic characteristics are shown in Table 1.

Data collection

The data collection tool was the semi-structured interview with open-ended questions, since this methodology is the most suitable for carrying out an in-depth analysis of the data, as well as for describing and interpreting the opinions, experiences, and feelings of the subjects to be interviewed.[27]

After an extensive bibliographic review, a set of questions for the interview was formulated ad hoc (or expressly) as no existing script was found to allow achieving the specific goals of the study. A script of 12 open questions for the semi-structured interviews was generated (Table 2), along with an ad hoc created questionnaire in which the socio-demographic data of the interviewees are collected.

The sample consisted of 18 semi-structured interviews, with question format allowing for a more in-depth discussion of the FPDR meaning and life experiences. The interviews were recorded by means of the Recorder&Smart apps version 5 (40.0) processed by computer and transcribed literally for later reading and analysis.

Table 2. Questions asked to the persons interviewed.

1. Do you know what an IP is? What about cardiopulmonary resuscitation?
2. Could you tell me about your experience with CPR/IP?
3. What is your relationship to the person who had CPR/IP? (for family members).
4. If your family members had the opportunity to be with you during resuscitation, do you think it would be beneficial or harming for them? And for you? Could it be traumatic? What if they were waiting in a room nearby?
5. If you were offered the possibility of accompanying your loved one during the CPR or IP, would you accompany her/him? Have you been offered such possibility?
6. If you were to be submitted to an IP, would you want to be accompanied by a relative of yours? What if it was a resuscitation?
7. Have you had any experience of being accompanied by a relative while a CPR or an IP was performed on you?
8. Do you consider that doctors and nurses are prepared to accept the presence of a family member witnessing the CPR or IPs?
9. Do you think the family is ready for such accompaniment?
10. Do you think that the accompanying person would disturb?
11. Do you think that witnessing the resuscitation of a loved one would be traumatic for you?
12. Would you like to have a person who would explain the procedures and decisions as they are carried out during the resuscitation or IP?

CPR: cardiopulmonary resuscitation; IP: invasive procedure.

Data analysis

Content analysis has been used as a descriptive approach to the results obtained in order to carry out a process of analysis of the phenomenon under study.[28] Codes were assigned through constant comparison for the organization and grouping into categories and subcategories, using the method proposed by Verd and Lozares.[27] Literal transcription permitted systematic text analysis, using a coding system, isolating categories and subcategories. No program was used for data analysis. For the validation of the study, a triangulation was carried out among the researchers, reading and analyzing the transcriptions separately and agreeing on the codification of the units of meaning, the final categories being coincidental.

Ethical considerations

This study has the approval of the Clinical Research Ethics Committee (CREC) of the Fundació Unió Catalana d'Hospitals (CEIC15/31). All participants were previously informed of the characteristics of the study and the confidentiality of their data, and signed the informed consent documents, accompanied by an information sheet detailing all relevant aspects of the study. The information provided in the demographic chart does not allow the identification of the interviewees.

Results

For a better understanding of the experiences lived by the interviewed, it should be noted that only in 1 case out of 18 did the health professional offer the FDPR, while the people who had experience of accompaniment were 5. In terms of the family members' and patients' opinion on the acceptance of family presence by health professionals, this view is associated with the rules, the fear that the family member might be disturbing, and the training and knowledge of the team; five perceived that they would not agree because "they would disturb the doctors" (E13f), while four would accept it because they are considered "to be good doctors" (E9p), and the remaining nine believe that it is up to the doctor's will of being exposed to be watched or not "if you like having someone watching you while you are working" (E7p).

Three significant categories were identified: knowledge, respect for patient rights and patient accompaniment. To interpret the interlocutions, each direct quotation is accompanied by a reference to the interview: (E + interview number + f (family member)/p (patient)).

Knowledge

CPR is better known than IPs. Knowledge of IPs (including cures) depends on one's own lived experience and also on what is perceived through filmography: "But from what you see in the movies, that the doctors go . . . do this, do that . . . " (E12f). This lack of knowledge can generate misinterpretation of what they see "if it was done right or wrong, they would not be able to tell at the moment" (E5f), although the accompaniment gives them peace of mind because they witness what is being done to their loved ones.

The majority of the respondents consider that accompaniment would not be traumatic, although they value the presence of a health professional explaining the techniques to their relatives in such a way that they can understand them, and adjusting to the emotional situation of those involved: "many do not know how to treat a person in distress" (E5f), "being a spectator without knowing what is happening or seeing some screens and not understanding what they say" (E9p).

Respect for the rights of the patient

From the ethical point of view, FPDR is considered a right. In this study, the patients and families standardize the demand of the health workers to leave the IP/CPR site, not generating expectations of accompaniment in this respect

The subcategories include right to FPDR and paternalism.

Right to FPDR. In our study, without having determined if it was out of habit, or due to the will of fulfilling the requests of health professionals, the interviewees refer not to refuse to leave the premises when asked to do so, normalizing the fact that "he was holding our hands tight (. . .) then he had to let go of our hand because they threw us out" (E1f); or leave the room before the health professional demands it, "what happens is that before they throw me out, I leave" (E7f); "many times I have left by myself, as if for good manners or whatever . . . " (E10p). Thus, generating helplessness because "I don't see it right that she should be left alone even if they don't do anything to her" (E6p). Two patients have never considered family presence: "it's just that these are questions that . . . a little bit like . . . it's hard to consider, isn't it?" (E4p) or they take it for granted that they won't be able to be there: "because as they don't let you . . . I think they already think that I won't be there" (E13f). Others asked to stay with their loved one and the health professionals did not let them: "this is the first thing I asked for, if I could stay . . . a simple drip, I ask to stay and even so they made me leave" (E5f), relating professional insecurity with not allowing accompaniment during IP: "because the person who is putting the drip is not sure of what they are doing" (E5f).

Paternalism (patients and doctors). The idea that the doctors do it for our own good, that they know what is convenient for us and that the FPDR could be traumatic for the relatives, represents a paternalistic attitude of health professionals, an attitude that is contrasted with the experience and opinions of the people interviewed in this study, since the majority do not consider it traumatic, while the family presence conditioned to the invasiveness of the IP would have less support: the more invasive, the less desire for accompaniment: "I prefer to step back and let them work, they are the ones who can save lives" (E7p) or "I would just be there, in the corner, doing nothing" (E8p) while "what is important is the result" (E11f).

Patient accompaniment

The reasons for patient accompaniment are emotional support—in order to learn about the care of the patient “I want to see too! (. . .) how they do the tests (. . .) and learn things” (E10p); transparency—“It is reassuring for me to witness it and see that things have been done correctly, witnessing is for me very beneficial” (E5f); and the tranquility of the companion and the patient, although there are people who prefer medical effectiveness to accompaniment:

> what is important in the end is the result and all that can be done so that the result is positive (. . .) the important thing is that the doctor feels uncomfortable with somebody’s presence there and this can make it . . . more difficult to carry out an intervention or to do what’s necessary at that moment . . . (E12f)

The subcategories are emotional support, courage, and trust.

Emotional support. Emotional support consists of providing peace of mind and reducing anxiety both for the patient “when she is alone and with strangers (. . .) we have already seen that she gets very nervous” (E1f), and for the family members, “because if you don’t see her, and then you get there and see that she complains . . . damn, what have you done to her” (E18p). It also provides security and transparency “I felt that they were doing everything they knew and everything they could have done to get him back” (E3f), and makes patients feel loved: “to feel that people are caring for you, that you are not a person who has been left there abandoned” (E11f), although in our study there is a protective approach of mothers toward their children, to spare them suffering: “That they accompany me . . . well . . . I don’t know . . . if I see that I am in such a bad condition, I don’t want them to suffer either . . . ” (E16f) or “I would like to be accompanied by someone who can calm me down and whom I don’t have to worry about” (E14f).

Courage and fortitude. Courage and fortitude are related to the family presence since they condition it. “(Family presence) would not traumatize me, one would need a lot of courage” (E17p). Personal experience provides the necessary courage for accompaniment “Me, I have had so many injections that I don’t care if I see it done to me or to someone else” (E15p), “[I would like to be there while they are pricking and stuff] because I have a different kind of strength” (E17p) and others relate the opposite: “I love him very much . . . but I couldn’t see him being done all those things, I don’t have the courage” (E16f); “even though they love you very much, they can’t watch it because it affects them very much . . . ” (E3f).

Trust in professionals. Competence and experience are factors that determine the predisposition of health professionals to allow FPDR according to the opinions of patients and relatives, especially the ones who are against FPDR: “we should trust health professionals, they know what they have to do . . . ” (E2f); “I guess the doctors are doing it right, aren’t they? Cause they are trying to save your life” (E7f), and value the professionalism of the team: “when they are working I think they ignore completely what’s around them, I think they are focused on their work” as opposed to others who would like to be present “because they are paying more attention, because they are . . . because at least they are paying a lot of attention to all these things” (E15p), to reassure the patient.

Table 3 shows examples of the categories and subcategories found in the interviews.

There is a majority acceptance of the benefits of family presence, but the more invasive the procedure is, the more the interviewees have doubts about the accompaniment. The general reasoning for not allowing family presence would be the protection by the patient in terms of the sight of painful procedures witnessed by the relatives, this being the case of the totality of the interviews to mothers “my daughters would have a very hard time” (E16f) or “thinking about my daughter, I would prefer her not to be there” (E12f).

Table 3. [AQ7] Results of categories and subcategories.

Category	Subcategory	Literal quotation examples
Knowledge		Not being able to accompany her seemed to me: "Awful, absolutely wrong, wrong, she has full confidence in me, I have enough knowledge to be able to stay by her side" (E5f). "Well, the good thing is that I saw what they were doing to him, mmm . . . I saw it. I also saw and felt calmer about . . . what you've done to him . . . you see?" (E18p)
Respect of the patient's rights	Right to the ~~FPDRI~~	"I asked if I could stay . . . a simple drip, I ask to stay and even so they made me leave." (E5f)
	Paternalism of the patient	"If it's something serious I think you would be disturbing them." (E12f)
	Paternalism of the doctor	"Because they wouldn't let anyone inside." (E17p) "They haven't let them in, they told them to leave the room." (E10p)
Patient accompaniment	Emotional support	"I would give them my full support if that's somebody who knows me . . . the fact of being there, and me being there especially for them." (E5f)
	Courage and fortitude	" . . . my daughter in law, maybe she could bear it, if it's my son, he prefers not to be in the room." (E15f) "I don't see him capable of withstanding that, he would have a very hard time." (E4p)
	Trust in professionals	"I guess the doctors are doing it right, aren't they? Cause they are trying to save your life." (E7f) "What is important in the end is the result and all that can be done so that the result is positive." (E11f) "If the doctors were prepared . . . They would give you the chance to stay . . . wouldn't they?" (E1f)

Most of the interviewees considered it positive that a health professional joins them and explains the procedures to be carried out at all times and their outcome: "being a spectator without knowing what is happening" (E4p), taking into account the emotional state of the accompanying person: "many do not know how to treat a person in distress" (E5f).

Discussion

Most respondents felt that family presence would be beneficial, but patients being more supportive than family members. Family presence depends on the procedure and on the degree of invasiveness, an aspect that coincides with the Bashayreh and Saifan[29] study, and with the Perez-Alonso~~[28]~~ study but differs from Tíscar-González et al.~~[30]~~ where the patients and their relatives refer to be afraid and reluctant to presence during a CPR.[AQ8] Another conditioning factor would be the state of the patient, where no point is seen in accompanying patients in a state of unconsciousness. Those who would not accompany are the people who identified themselves as apprehensive if the procedure is very invasive. In terms of preparation for accompaniment, most of the relatives report not being prepared, whereas the patients trust in the preparation of the relatives who have stayed beside them during their hospitalization, a subject that differs from some studies in the bibliographical review of Paplanus et al.~~[31]~~

On the contrary, all the interviewees consider it beneficial to have a member of the team explaining the applied treatments and attending to the companion, an approach that coincides with Parra et al.'s~~[32]~~ study and Puigblanqué Reyes~~[33]~~ study which concludes with the need for accompaniment and information for parents in family presence.

The impact of contextual and socio-cultural elements on perceptions should be highlighted, as Bashayreh and Saifan29 and Zali et al.~~[34]~~ also point out in their studies.

In our society, the attitudes toward IP differ from those described in the studies of Anglo-Saxon countries, where the population considers it a right to witness IP29,~~[31,35]~~; in contrast, in our study, the people interviewed related not refusing to leave the premises when asked to do so, normalizing the fact, or simply out of habit not considering being able to accompany their loved ones.

In relation to patient accompaniment, the reasons coincide with the ones found in the study of De Robertis et al.~~[36]~~ where the main point for family presence is to support and comfort the patient and to understand the witnessed situation, which leads to the conclusion that most patients would support the presence of family members, although not all family members would be good candidates for FPDR.

The results of this study show patients' desire for accompaniment, as it generates peace of mind and security. The same perception is highlighted by Eichhorn et al.~~[37]~~ in their article on the patient's explicit view on FPDR, in which the patients state that accompaniment provides them with security, gives them strength to endure the procedures, and makes them feel loved. However, Eichhorn et al. does not refer to the attitude of mothers, while, in our study, it is the mothers who reject accompaniment because of a protective motivation toward their children and husbands. Another study to consider is that of Işlekdemir and Kaya,~~[38]~~ where family presence does not influence the anxiety and pain of the participants of IP, differing from the opinions of the respondents in our study, who state the opposite.

Courage and fortitude are related to the ability to endure family presence, opinions that coincide with the article by Tíscar-González et al.,~~30~~ reporting that witnessing resuscitation techniques could increase the suffering of the family members.

Conclusion

This study describes the fear and resistance of family members to witness IPs, although in most cases they would accept accompaniment, considering the invasiveness of the procedure and the courage to witness it. Lack of familiarity with medical techniques causes insecurity, which would be mitigated with the support of a team member who would explain the procedures to the accompanying person. This team member is necessary to avoid misunderstandings and give emotional support to the family's member, since in all the studies found, including ours, the family's need for emotional support and an explanation of the techniques applied.

FPDR is not considered a right and it is not standardized in our clinical practice. This study reveals that there were family members who wanted to witness the IPs, but since nobody asked them, they gave up the option.

FPDR is an unusual and complex practice and each case should be assessed independently. Accompaniment is positive because decisions could be made together, and family members and patients would have emotional support.

Further research is needed on the patients' and families' point of view, with socio-cultural and geographical variations, as there are few studies on this subject.

Limitations

The recall bias and the subjective perception of the events of the subject/family under research is a limitation to consider, as well as the fact that the interviews were carried out by the principal researcher, which may generate certain subjectivity when interpreting the interviews. On the contrary, the sample is small and does not allow generalizations to other geographical areas or different age groups, and the perceptions and opinions of younger subjects cannot be considered.

Implications for clinical practice

This study collects patients' and families' desires for accompaniment during IPs or resuscitation; without considering it a right and feeling fear and ignorance related to the courage of being present. These patients' and families' view could help with the development and implementation of health policies supporting the practice of family presence, thus respecting bioethical principles. The interviews have opened for people the possibility to consider whether they want to stay by their loved one's side while he or she is being resuscitated or undergoing an invasive process.

Acknowledgements

To all the participants for their collaboration, essential for the development of this study. To the Consorci Sanitari de l'Alt Penedès i Garraf, for allowing us to select users and carry out the interviews. I would like to highlight the CSG Research Department for their help and advice, especially Dr Antonio Yuste, Dr César Gálvez, Esther Valldosera, and Dr Alejandro Rodríguez Molinero.

Conflict of interest

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) received no financial support for the research, authorship, and/or publication of this article.

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