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Family opinions on resuscitation and participation in end-of-life care in the emergency department: A cross-sectional study

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Abstract:

OBJECTIVE: The study looked into emergency department family members' (FMs) views on being present during resuscitation and contributing to end-of-life care.

METHODS: A cross-sectional study with 467 FM volunteers of mildly injured or ill patients was conducted at a research hospital between October 2021 and May 2022. Data were collected using a questionnaire administered by a clinical psychologist. The analysis employed SPSS 22.0 with a significance threshold of $P < 0.05$. The study was conducted according to the STROBE criteria. Statistical significance was set at $P < 0.05$.

RESULTS: The mean FMs' age was 34.3 ± 10.43; 64.2% were male, 62.1% were married, and 76.9% had nuclear families. About 61% wanted the option of being present during resuscitation, with 47.5% desiring participation in both resuscitation and end-of-life care. Significant differences were observed in opinions based on education, work status, and resuscitation training ($P = 0.015$, $P = 0.001$, $P = 0.002$).

CONCLUSION: Many FMs sought the choice to be present during resuscitation, and nearly half preferred participation in both resuscitation and end-of-life care.

Keywords:

End-of-life, emergency nursing, family presence during resuscitation, family-centered care, nursing

Introduction

Family presence during resuscitation (FPDR) is when a family member (FM) is present during resuscitation to offer psychosocial support,[1-3] aligning with family-centered care theory.[1-4] This theory promotes active involvement of FMs, not just observation.[5] The present FM also supports patient autonomy.[3,4] The American Association of Critical Care Nurses (AACN) notes that FPDR helps with medical decisions and enhances care quality.[6]

Patient and family preferences in nursing, with a focus on FPDR, gained significance around 40 years ago.[7] Doyle *et al.*'s initial study found that 72% wanted to be present during resuscitation.[7] The Emergency Nurses Association in the US advocated FPDR since 1995.[8] The European Resuscitation Council guidelines in 2015 and 2021 recommend offering FPDR as an option.[9,10] Despite these recommendations, fewer than half of the 32 implemented European countries permit FPDR.[9] The AACN guidelines advise having representative FMs during resuscitation with established procedures.

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Box-ED section

What is already known on the study topic?

- Despite the increasing evidence of its benefits, family presence during resuscitation (FPDR) is not yet a routine practice in emergency departments.

What is the conflict on the issue? Has it importance for readers?

- While family members desire the implementation of FPDR, health-care professionals are opposed to this practice.

How is this study structured?

- This study was conducted as a descriptive cross-sectional study.

What does this study tell us?

- The study examines how family presence and involvement in end-of-life care during emergency patient resuscitation influence their perspectives. Findings indicate mixed supportive and concerned views. Prioritizing patient and family preferences in health care is highlighted, showcasing how family presence can affect patient outcomes and interactions with health-care providers.

However, published guidelines in critical care units are low in the US (5%), Canada (8%), and Europe (7%).[6]

FPDR is supported by patient and FM preferences and its potential benefits.[3,8,11-14] Studies found that FMs see FPDR as a fundamental right.[3,11] In a systematic review, FMs with FPDR experience found their presence beneficial and desired the option to be present during a loved one's resuscitation.[3] Patients should be aware that they are not among strangers.[12-14] FMs' presence within the patient's view creates a trusting and peaceful environment, benefiting the patient physically, emotionally, and spiritually.[1,12] Reports indicate that patients feel the presence of FMs and relax, even when unconscious.[12,14,15] Evidence shows FPDR benefits FMs, with studies revealing it helps them feel useful, share critical information, and cope with grief in a healthy manner.[3,8,16] Similarly, the FPDR procedure is thought to reduce stress and anxiety in FMs of patients.[1,11] In one study, witnessing resuscitation reduced posttraumatic stress disorder in FMs.[2] Not being present during resuscitation is linked to prolonged pathological grief, increased anxiety, and depression in FMs.[2,6]

Although needed, there is limited literature on FM roles during resuscitation and after death in FPDR procedures. The lack of evidence hampers the development of practical FPDR procedures. To address this, understanding FMs' perspectives and roles during resuscitation and after death is crucial. This study aimed to investigate FMs' views on FPDR and end-of-life care in the emergency department.

Methods

Study design

The research was conducted in a descriptive, cross-sectional manner at an education and research hospital located in Van between December 1, 2021, and May 1, 2022.

Research setting

The study was conducted with a focus on the adult emergency department of an educational and research hospital in Van, Turkey. It examined the perspectives of patients with green zone triage codes and their FMs. The hospital's emergency department typically receives 150–200 patients per day, and 70%–80% of them are assigned green zone triage codes. These codes are defined by the Turkish Ministry of Health as patients seeking outpatient care, generally in stable health, and experiencing simple health problems caused by nonlife-threatening acute symptoms. Surveys were not administered to FMs with yellow and red zone triage codes, as it was believed that families of critically ill patients could be psychologically affected.

Participants

The study included FMs who were over 18 years old, capable of reading and writing in Turkish, had no hearing/communication or mental disabilities, had a blood or marital relationship with the patient, and who volunteered to participate in the study. FMs of critically ill patients and those who wished to withdraw from the study at any stage were excluded.

Variables

The opinions of FMs regarding participation in resuscitation and end-of-life care in the emergency department constitute the dependent variables in the study, while the sociodemographic characteristics of FMs form the independent variables of the research.

Data sources/measurement

The researcher developed data collection forms based on a literature review.[1,2,8,11,16-19] Content validity was ensured by consulting five experts, including three emergency physicians and two nursing faculty members. The form, consisting of "Introductory Information" and "FMs' Views on FPDR" reached a content validity index of 0.98 (>0.80 thresholds), confirming its suitability.[20] Data were collected in the hospital's emergency unit, where volunteering FMs, individually briefed about the research, completed a questionnaire with the assistance of a clinical psychologist.

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Sample size

The sample size was determined using G*Power 3.1.9.7 software(Düsseldorf, Germany) based on Cohen's (d) effect size for the Chi-square goodness-of-fit test.[21] With an effect size of 0.2, α error: 0.05, β error: 0.10, and 90% power, 412 participants were required. To account for data loss, 10% more participants were included.

Initially, 931 eligible FMs were considered. Excluding withdrawals (192 FMs), incomplete forms (230 FMs), and critical relative conditions (38 FMs), the final sample was 467 FMs.

Statistical methods

The SPSS software on Windows (version 22.0; IBM Inc., Canada) was used for data analysis. Descriptive statistics included n (%), mean ± standard deviation for categorical and numerical variables. The Pearson Chi-square test compared categorical variables. Significance was $P < 0.05$. A research report was prepared according to the STROBE criteria.[22]

Ethical considerations

The study covers the adult emergency department of a hospital from December 1, 2021, to May 1, 2022. It includes FMs of patients with the "green zone" code. Ethical approval for this study was obtained from the Hasan Kalyoncu University Non-Interventional Research Ethics Committee on November 16, 2021 (Approval Number: 2021/5318). FMs provided confidential verbal and written consent in accordance with international regulations and the Helsinki Declaration. FMs spent 10–15 min on research questions.[23]

Results

The descriptive characteristics of the patients are presented in Table 1.

Table 1: Descriptive characteristics of family members (*n*=467)

Descriptive characteristics	*n* (%)
Age (mean±SD: 34.36±10.43, Youngest 18 – Oldest 79)	
18–29	174 (37.3)
30–44	212 (45.5)
≥45	81 (17.2)
Gender	
Female	167 (35.8)
Male	300 (64.2)
Educational status	
Primary school	52 (11.1)
Secondary school	197 (42.2)
Undergraduate and higher	218 (46.7)
Employment status	
Health-care professional	74 (15.8)
Other professions	270 (57.8)
Unemployed, retired, and homemaker	123 (26.4)
Marital status	
Married	290 (62.1)
Single	177 (37.9)
Family type	
Extended family	71 (15.2)
Nuclear family	359 (76.9)
Single	37 (7.9)
Status of receiving resuscitation training	
Yes	212 (45.4)
No	255 (54.6)
Death of a relative (1st degree) of the family member in the past	
Yes	42 (13.7)
No	302 (86.3)
Witnessing the death of a relative (1st degree) by the family member in the past	
Yes	13 (4.2)
No	373 (95.8)
Witnessing the resuscitation of a relative (1st degree) by the family member in the past	
Yes	6 (1.9)
No	429 (98.1)
The place where the relative wants to spend his/her last moments	
Hospital	140 (30.0)
Houses	327 (70.0)
Presence of family members during resuscitation of relatives	
Should be included	237 (50.7)
There should not be any	230 (49.3)
Providing the option of being present during the resuscitation of a relative to the family members	
Or COC whichever is applicable	285 (61.0)
Should not be presented	182 (39.0)
Requesting to be present during resuscitation of relatives and active participation in end-of-life care	
I'd like to	222 (47.5)
I do not want to	245 (52.5)

SD: Standard deviation, COC: Certificate of conformity

Common reasons for FPDR include: staying informed about relatives (91.4%), being present in final moments (88.7%), feeling safe (85.6%), understanding medical decisions (82.0%), and communicating with health-care professionals (81.5%). Additional factors are saying goodbye (78.8%), offering support (77.9%), participating in decisions (66.2%), and ensuring medical care (65.3%). Less common are alignment with preferences/beliefs (55.9%), aiding health-care

professionals (55.0%), cultural practices (50.0%), and privacy respect (49.1%). Furthermore, 68.5% consider it a fundamental right to be present during a relative's resuscitation [Table 2].

Major reasons against FPDR are: not witnessing relatives' distress (84.6%), concerns about health-care tasks (82.9%), and preserving positive memories (74.8%). Others include avoiding patient distress (67.9%), infection fears (63.4%), conflicts with health-care professionals (58.9%), and causing harm (58.1%). Less common concerns involve task inadequacy, patient privacy (47.2%, 35.4%), and personal health (17.8%) [Table 2].

Perceiving inadequate health care prompts common reactions: seeking explanations (86.5%), verbal reminders (66.4%), legal action (65.3%), and patient transfers (52.7%). Less frequent responses include restricting physical contact (17.1%), trying to assist (12.8%), leaving it to fate (10.3%), and physical intervention (7.5%) [Table 2].

Comparing desired last moments' location with family type showed significance for large families favoring home ($P = 0.012$, $P < 0.05$). Views on family presence during patient resuscitation significantly differed by age, education, work status, and resuscitation training ($P = 0.024$, $P = 0.011$, $P = 0.000$, $P = 0.012$, respectively, $P < 0.05$). The desire for presence during relative resuscitation and end-of-life care varied significantly by education, work status, and resuscitation training ($P = 0.015$, $P = 0.001$, $P = 0.002$, respectively, $P < 0.05$) [Table 3].

Table 2: Reasons for family members to want/unwant to be present during resuscitation and reactions of family members when health professionals are considered not doing their jobs well

	n (%)
Reasons for request (*n*=222)	
Being informed about the situation of the relative at any time	203 (91.4)
To be with the relative in the last moments	197 (88.7)
Being close to the relative, making him/her feel safe	190 (85.6)
To know all the medical decisions to be taken about the relative	182 (82.0)
To convey important information about the relative to health professionals	181 (81.5)
Saying goodbye/writing off each other's debts	175 (78.8)
Supporting and helping relatives	173 (77.9)
Being present during the resuscitation of the relative is a fundamental right	152 (68.5)
I would like to participate in all decisions to be made about my relative	147 (66.2)
Ensure that health-care professionals perform adequate intervention	145 (65.3)
To ensure that the relatives receive care in line with their preferences and beliefs	124 (55.9)
Assisting health-care professionals	122 (55.0)
In case of the death of a relative, to carry out religious and cultural practices in line with the preferences and beliefs of the relative	111 (50.0)
Protecting the privacy of relatives	109 (49.1)
Reasons for not requesting (*n*=245)	
I cannot bear to see my relatives like this	209 (84.6)
I'm afraid of complicating the work of health professionals	204 (82.9)
I would like to remember my relatives (in case of death) with good memories	184 (74.8)
I do not want my relative to see me crying or feeling sorry for him/her	167 (67.9)
I'm afraid of my relative getting infected	156 (63.4)
I do not want to have a conflict with health professionals	145 (58.9)
I am afraid of doing something wrong and hurting my relative	143 (58.1)
I am afraid of not being able to do the tasks assigned to me and not being able to help enough	116 (47.2)
My relative's privacy is compromised	87 (35.4)
I'm afraid of getting sick myself	44 (17.8)
Reactions considering that health professionals do not do their jobs well (*n*=467)	
I ask the health professionals about the situation, listen to their explanations	404 (86.5)
I remind them that they should do their job well, and I intervene verbally	310 (66.4)
I take legal action and sue the health professionals	305 (65.3)
I transfer the patient to another health institution	246 (52.7)
I do not allow health-care professionals to touch the patient	80 (17.1)
I make the right application myself	60 (12.8)
I do not do anything (I refer to Allah)	48 (10.3)
I physically interfere with health-care professionals	35 (7.5)

**n* is folded because more than one option is marked[20]

Table 3: Comparison of family members' opinions about being present during the resuscitation of their relatives with their descriptive characteristics (*n*=467)

Features	Should be present, *n* (%)	Should not be present, *n* (%)	Test (χ^2, *P*)
Age (mean±SD*: 34.36±10.43, youngest 18–oldest 79)			
18–29	90 (19.3)	84 (18.0)	7.435, 0.024
30–44	96 (20.6)	116 (24.8)	
≥45	68 (14.6)	13 (2.7)	
Gender			
Female	87 (18.6)	80 (17.1)	0.189, 0.664
Male	150 (32.1)	150 (32.1)	
Educational status			
Primary school	35 (7.5)	17 (3.6)	8.962, 0.011
Secondary school	104 (22.3)	93 (19.9)	
Undergraduate and higher	98 (21.0)	120 (25.7)	
Employment status			
Health-care professional	20 (4.3)	54 (11.6)	25.615, 0.001
Other professions	138 (29.6)	132 (48.9)	
Unemployed, retired, and homemaker	79 (16.9)	44 (9.4)	
Marital status			
Married	144 (30.8)	146 (31.3)	0367, 0.545
Single	93 (19.9)	84 (18.0)	
Family type			
Extended family	37 (7.9)	34 (7.3)	0.074, 0.964
Nuclear family	181 (38.8)	178 (38.1)	
Single	19 (4.1)	18 (3.9)	
Status of receiving resuscitation training			
Yes	143 (30.6)	112 (24.0)	6.382, 0.012
No	94 (20.1)	118 (25.3)	
Death of a relative (1st degree) of the family member in the past			
Yes	81 (17.3)	84 (18.0)	0.281, 0.596
No	156 (33.4)	146 (31.3)	
Witnessing the death of a relative (1st degree) by the family member in the past			
Yes	50 (10.7)	44 (9.4)	0.281, 0.596
No	187 (40.7)	186 (39.8)	
Witnessing the resuscitation of a relative (1st degree) by the family member in the past			
Yes	21 (4.5)	17 (3.6)	0.337, 0.561
No	216 (46.3)	213 (45.6)	

SD: Standard deviation

Discussion

The study aimed to understand FMs' views on their involvement in resuscitation and end-of-life care at an emergency department. Results revealed mixed opinions, possibly due to the uncommon practice of FPDR in Turkey, indicating low awareness. Niemczyk *et al.*'s study with 500 patients and 500 FMs showed limited knowledge of FPDR rights, as patients and FMs supported FPDR at 24.2% and 29.2%, respectively.[17] Qualitative research demonstrated stronger FM support for FPDR, aligned with Mortelmans *et al.*'s 2010 report of 75% of FMs desiring involvement during resuscitation.[18] Twibell *et al.*, in 2015, found that over 90% of FPDR-experienced patients favored family presence, with 52% of initially opposed individuals wanting to contribute when their own FMs were involved.[19]

In the study, it was observed that individuals aged 45 and above preferred to be present during their loved one's resuscitation, possibly due to their higher exposure to the loss of loved ones. Similarly, those with a primary education degree expressed a preference for presence, potentially indicating lower trust in health-care professionals or a limited understanding of their explanations. In contrast, individuals who were not employed or homemakers also favored being present, likely because they had more available time to care for their loved ones.

The study shows differing FM views on FPDR availability. Some support it, while others are concerned due to health-care professionals' worries about complexity. FMs' opinions could change with direct experience. Qualitative research suggests that FMs

participating in resuscitation wish to actively assist both relatives and health-care professionals.[24] Recent reviews confirm FPDR acceptance as a fundamental right. FM presence during resuscitation benefits both patients and health-care pros.[25]

In this study, numerous FMs prefer their relatives' final moments at home, aiming for support and togetherness. Youngson *et al*. found that FMs with resuscitated relatives sought info, gave support, and offered comfort.[26] In this study, families had equally important reasons for wanting to be present during relative resuscitation, aligning with literature sources.[19,24] Most notably, the top reason was accessing real-time information about the relative's condition (91.4%).[26]

Witnessing the resuscitation process comforts FMs psychologically.[27] In this study, another key reason for FMs desiring presence during resuscitation is sharing vital medical history and medication details with health-care professionals (81.5%). FMs' input affects interventions. De Stefano *et al*.'s[24] 2016 study found that FMs shared patient medical history. FMs also find reassurance in observing health-care efforts. Twibell *et al*.'s 2015 study noted FPDR benefits, including updates and comprehensive care.[19] Farewells (78.8%) hold cultural significance. FMs provide support (77.9%), emphasizing their active role. The study underscores FMs actively contributing during critical moments, not just observing.

In this study, 68% of FMs viewed being present during relative resuscitation as a fundamental right, marking a shift toward patient and FM preferences. FMs' desire to participate (65.3%) reflects the commitment to relatives' autonomy. Around 55.9% aligned care with preferences, 50.0% followed cultural practices, and 49.1% valued privacy. These practices arise from beliefs, fulfilling obligations for relatives' final moments. Preserving autonomy and privacy becomes crucial as patients lose consciousness, aligning with cultural and religious emphasis on privacy protection.

Common FM reasons for hesitancy during resuscitation include avoiding distress witnessing (84.6%), fearing professional disruption (82.9%), and preserving positive memories (74.8%). De Stefano *et al*.'s 2016 study emphasized distress as key.[24] Twibell *et al*. found FPDR could complicate work,[19] aligning with this study. FM nonparticipation also involves not showing upset (67.9%), fearing infection (63.4%), and noninterference (58.9%). If relatives desire participation (63%), FMs fear disrupting professionals. Concerns about harm (58.1%) contribute to hesitation. Studies highlight limited professional FPDR support.[28,29] Demir reported that 82.6% of professionals found FM presence during resuscitation unsuitable, with 56.3% observing FM disruption and 43.6% considering it traumatic.[28] Kosowan and Jensen identified FPDR barriers, including lack of FM support, procedure misunderstandings, and staff stress concerns.[29]

Health-care professionals' hesitation to support FPDR can stem from FM reactions.[28] The study explores FM responses to perceived inadequate care. Common reactions include questioning professionals (86.5%) and verbal reminders (66.4%). A dedicated professional for FM communication and stress management is vital. FMs taking legal action (65.3%) is a reported risk.[30] Patient transfer (52.7%) risks misunderstanding. Clear communication is crucial. Rare responses include no touching (17.1%), self-intervention (12.8%), fate acceptance (10.3%), and physical intervention (7.5%). Despite the low rate (7.5%), it is significant. FPDR has benefits but violence risks. Aljohani *et al*.'s meta-analysis indicated that 52% of health-care violence is from FMs.[27] Anti-violence measures are essential for FPDR implementation.

Conclusion

This study underscores the significance of patient and family preferences in emergency nursing. Extending FPDR to FMs in emergencies is vital. Despite hospital progress, many prefer patients' final moments at home for comfort. FMs' willingness to engage in resuscitation is shaped by patient benefit, emphasizing the importance of their involvement. Improving security and patient-FM participation can reduce incidents stemming from perceived inadequate care. Preferences should be assessed beforehand, and FMs informed about resuscitation and FPDR.

Limitations

The study is limited by uncertainty about patients' health status in the emergency setting, including only FMs of patients in better health (green area). A significant drawback is the omission of FMs with critically ill relatives (yellow and red areas). Awareness of the right to FPDR among FMs is also lacking, presenting a constraint. Nonetheless, surveying FMs in the hospital's emergency department and the study's unique contribution to a limited research area enhance its value.

Author contributions credit statement

- UA: Conceptualization, methodology, investigation, software, resources, data curation, visualization, and writing.
- AK: Conceptualization, methodology, investigation, software, resources, data curation, visualization, writing – review and editing, supervision, and project administration.
- All authors read and approved the final manuscript. We have no conflicts of interest to disclose.

Conflicts of interest

None Declared.

Ethical approval

Ethical approval for this study was obtained from the Hasan Kalyoncu

University, Non-Interventional Research Ethics Board. Ethics Committee on November 16, 2021 (Approval Number: 2021/5318).

Consent to participate
Approval received.

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